EDITORIAL

Planning for a Dignified Death with a Living Will

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End-of-life care (EOLC) is an approach to a terminally ill patient that shifts the focus of care to symptom control, comfort, dignity, quality of life, and quality of dying rather than treatments aimed at cure or prolongation of life.[1] End-of-life care is an integral aspect of intensive care. In several situations, such as in patients with catastrophic or unresponsive severe illness and organ failure, or those with poor comorbid disease states, prolonged coma or persistent vegetative state, progressive metastatic cancer with no therapeutic options, or postcardiac arrest without neurological recovery, life-sustaining treatments are futile and potentially inappropriate. In surveys concerning EOLC preferences, intensivists in India favor withholding life-support (WHLS) in such circumstances.[2,3] Position statements by the Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC) guide the practice of EOLC in the intensive care unit (ICU).[4,5] However real-world data from the Indian Intensive Care Case Mix and Practice Patterns (INDICAPS) and INDICAPS-II studies suggest that WHLS and withdrawal of life-sustaining (WDLS) are seldom practiced, and patients either receive full support, have a do-not-resuscitate order or are discharged against medical advice (DAMA).[6,7] There appear to be several barriers that may account for the dichotomy between what intensivists would like to do and what they do. Fear of the legal consequences of such a course of action is probably the most prominent.[8]

The ethical principle of patient autonomy dictates that the patient's wishes and preferences are paramount in any decision-making process. However, when an EOLC decision has to be made for a critically ill patient, the patient is often not in a condition to express his or her preferences regarding continuing or limiting life-sustaining treatments. The patient's surrogates as well as the medical team too may not have any indication of the patient's wishes, and even if they do, there is usually no supportive evidence for the same. Decisions are taken by the surrogates and the medical team in the best interest of the patient, based on the principles of beneficence and non-malfeasance. If, however, the patient had made a "living will" or executed an "advance medical directive (AMD)" before he/she was critically ill and while he/she was mentally competent, then that document would be the basis for EOLC decisions when the patient is not in a condition to participate in the decision-making process.

In a landmark judgment on March 9, 2018, the Supreme Court of India brought the right to autonomy over medical decisions under the ambit of Article 21, making it an extension of the fundamental right to life with dignity.[9] The Court declared that an adult human being, having the mental capacity to take an informed decision, has the right to refuse medical treatment including withdrawal from life-saving devices. A person of competent mental faculty is entitled to execute an AMD. The right to life with dignity, guaranteed by Article 21 of the Constitution, includes the smoothening of the process of dying when the person is in a vegetative state or is living exclusively by the administration of artificial life-support that arrests and prolongs the dignified and inevitable process of dying. As this right is a fundamental right, the right of execution of an AMD as well as WHLS or WDLS does not depend on any recognition or legislation by a State. However, the Supreme Court mandated several safeguards for making and executing an AMD as well as for making EOLC decisions in mentally non-competent patients in the ICU.[9] The procedure prescribed was extremely complex and unworkable, making any progress on the ground next to impossible. The ISCCM appealed to the Supreme Court to simplify the procedure, and in another significant judgment, a simplified procedure was outlined in January 2023.[10]

Essentially, a living will can be made when an individual is mentally competent. It will state preferences regarding medical treatment, including end-of-life care if they lose decision-making capacity. It could also specify what treatments the individual would not like to receive in case of catastrophic illness, or progressive disease (e.g., mechanical ventilation, dialysis, etc.). The living will also identify the individual/s who will make decisions when the patient is not mentally competent. It must be signed by two witnesses and notarized. In this issue of the Indian Journal of Critical Care Medicine, Damani et al. propose a 12-step pathway to implement an AMD in the Indian context.[11] The 12-step pathway focuses on three phases: Creating living wills, periodic reviews, and updates, and executing AMDs. This article deals with the nuts and bolts of creating and executing a living will. It also provides the ethical and legal background for the same. The links to sample documents designed by legal experts are tucked away in the references; readers will do well to go through the paper in detail and download the relevant documents.

The living will or AMD is an embodiment of the principle of patient autonomy. The legal standing is now crystal clear. The living will or AMD is a legally valid entity and there should be no reason not to follow a course of action dictated by the AMD. The challenge is now to disseminate this knowledge and information and lay

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down systems and mechanisms to make the AMD a smooth and satisfying experience for patients, families, caregivers, and medical teams. The discussion on living will be proactively initiated by physicians dealing with progressive diseases, including oncologists, neurologists, pulmonologists, cardiologists, family physicians, palliative care physicians, etc. This requires frank discussion about the progressive nature of the disease, its future trajectory, the need for life support, and when it may be inappropriate or futile to initiate or continue life support. It is important to spread awareness about AMDs, their legality, and the procedures to be followed. Physicians should be able to act upon a patient's request for an AMD guide them and elicit their values and preferences. This paper provides valuable guidance on these aspects. One of the stumbling blocks has been the requirement for the presence of the Chief Medical Officer or his/her nominee on the secondary medical board. There is no clarity (with a couple of exceptions) on who that person should be, among hospitals, doctors as well the state and local health authorities. State, municipal, and local government health officials and the judiciary (Judicial magistrates first class) need to be sensitized and made aware of their role in the EOLC process.

After several years, virtually all legal impediments to EOLC, AMDs, WHLS, and WDLS have been cleared. While effective implementation remains a work in progress, it is now up to us as a community to ensure that the benefits of good EOLC are made available to our patients and that facilitating a good death becomes an important element of critical care. Fear of the law is no longer a reason, but only an excuse not to provide EOLC. We must overcome our fears and inhibitions and indeed, our demons to provide good EOLC.

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