

## **Editorial**

### **End of life decisions**

This is a topic that is hardly discussed in any forum in Sri Lanka whether scientific or non scientific. Even though doctors are not under stress to take end of life decisions in this country, time and again the intensive care clinicians have to face these dilemmas. Traditionally we do not discuss and accept different modalities of end of life decisions. Understanding key ethical and legal principles are important considerations for ICU practitioners when taking treatment decisions. Medical futility, respect for autonomy, justice, non- maleficence, advance directives or “living wills”, shared decision making are some of these ethical principals. ICU clinicians should neither take over nor accept the responsibility of end-of-life decisions without having the correct understanding of these.

Nowadays in other parts of the world and to a certain degree in Sri Lanka as well, not only the physician but other stakeholders too get involved in medical decision making. But the degree of involvement, legal understanding and ethical views of stakeholders are questionable. It is well understood that improvement of technology and communication has led the general public to become more aware of futile modes of treatment. But there would still be some who believe in patients dying with considerable discomfort after facing painful and unnecessary investigations or treatments. To what extent this applies to Sri Lanka is still not very clear.

It is very important to consider the patient as the major decision making authority. The rights of a competent patient to have control over his/her own life, including decisions about how the life should end, and to refuse life-saving treatment is called respect for autonomy. This understanding warrants discussion on the conditions and consequences of end-of-life support with chronically ill and elderly

patients and their relatives, while they are still capable of understanding and making decisions. A death with dignity is valued and also the autonomy of the patient should be respected. A competent adult patient has a right to refuse medical treatment. There should be discussion regarding advance directives about foregoing life-sustaining modes of treatment. The willingness to discuss about a Do Not Resuscitate order (DNR) should not depend on whether someone asks for information or not.

The concept of distributive justice which explains whether the treatment should not be given if it deprives others of greater benefit can be of importance when a situation arises for resource allocation. This concept should have bigger usage in countries like ours that have very limited amenities.

When taking many risk-benefit decisions in the ICU, a principle of duty not to harm (non-maleficence) is of much use, which says any treatment should not be given if it is likely to cause more harm than good.

When managing a critically ill patient, all involved including doctors and nurses should understand why certain decisions are made. After coming to agreeable conclusions about the prognosis, futility and patient’s care among all attending clinicians and staff, the family members should be informed and given the opportunity to discuss matters with them. Such discussions should be very informative. Regular meetings should be held with experienced clinicians and the families from the time of intensive care unit admission to discuss all medical matters including prognosis and futility. Also in these discussions it should be informed that the patient’s own wishes are more paramount than the wishes of family members.

Compared to the South Asian countries including Sri Lanka, in the Western world, where the autonomy of the patient has been increasingly emphasized, there have been increasing discussions regarding ethical dilemmas in the recent past. In this context, most of the patients die in the intensive care unit due to withholding or withdrawal of life support. To arrive at such decisions the communication and value of facts is a critical issue. A duty to act in the patient's best interest (beneficence) is the basis for withdrawing intensive care in futile cases. In that perception treatment should only be given if it is likely to benefit the patient. It is not always easy to make such a decision considering the social, multicultural and multi religious background in this part of the world.

There is a difference between actively killing someone and refraining from an action that may save or protect the patient's life. (Withholding treatment) This will only be allowed if the patient's quality of life was so poor, and treatment would not be in the patient's best interest.

Do we as intensive care clinicians and decision makers have moral knowledge or experience on aspects of end of life issues? Do we need national guidelines which consider the diverse cultural and religious aspects of this important management issue? The advice of ethics committees and relevant professional bodies may be necessary to guide the decision making process.

Medical schools in Sri Lanka have incorporated into their curricula teaching sessions on ethical, legal and communication aspects relating to end of life decisions in medical practice which will promote the doctors to be involved in such discussions at an early stage of their career. Post graduate education too needs more emphasis on these issues.

We believe inquiry and research on this subject is definitely needed in Sri Lanka. This will promote awareness and also help formulate clinical decision making guidelines for this difficult aspect of clinical practice in a professional manner.

We also trust that these discussions are well timed or may perhaps be late already but even so they are undoubtedly most challenging.

Is it possible to start a dialogue about End of Life Decisions in Sri Lanka? If yes - how? When? and by Whom?

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