

Challenges in the implementation of “end-of-life care” guidelines in India: How to open the “Gordian Knot”?

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Guidelines on any topic in medicine are generally backed up by a body of evidence. The highest level of evidence has been regarded as large multicenter randomized clinical trials or meta-analyses based on such trials. Recent evidence based medicine guidelines, have recommended the GRADE system where in addition to the level of evidence that is reviewed, the panel of experts also determine the strength of their recommendations. The complex integrative skills of the end-of-life (EOL) do not lend themselves to the GRADE system of evaluation. All the standard EOL care guidelines in the world today have, therefore not used this system. The Indian Society of Critical Care Medicine (ISCCM) guidelines of 2005 likewise are based on the standard principles and practices that have evolved and have become established with time.^[1] These guidelines are highly researched and referenced and have passed through a consensus and international review process. The research that went into the making of the guidelines has been based on the foundational and relatively less measurable aspects of medicine such as comfort, needs, and satisfaction and universally adopted ethical principles.

The second iteration of the guidelines in 2012 has reviewed the developments in this field including some Indian literature on the topic and also the developments in the legal field including the law commission reports.^[2] The recent publications of Indian Association of Palliative Care (IAPC) position statement^[3] and in this issue the joint statement by ISCCM and IAPC^[4] are excellent examples of a multi-professional collaborative effort. However well

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researched and containing precise practice points, implementation in the real world remains a vexatious problem. The critical question before us is-how do we go forward and ensure that these guidelines and statements don't remain only on paper? Like the Gordian knot that Alexander the Great could not open but had to cut through, EOLC issues in India have so far defied a solution. There are many useful guides in the literature for the implementation of guidelines into practice.^[5-7]

The common impediments to implementation of the EOL guidelines in India can be summarized thus:

- Lack of clarity and consensus within the medical community and in the Indian Medical Council (Professional conduct, Etiquette and Ethics) Regulations, 2002 about our ethical position regarding EOLC^[8]
- Perceived lack of legal backing and fear of litigation among medical practitioners
- Lack of clear regulatory requirements from statutory governmental or other bodies e.g.: National Board for Accreditation of Hospitals (NABH).

The way forward could be found in the following proposed activities by the ISCCM and IAPC: To start a campaign in October 2014 to increase awareness of

these issues within the medical and legal communities, legislators and the general public. Standardized slide sets are being created for educating medical practitioners, as well as the general public all over the country. A toolkit to facilitate implementation of the EOL guidelines is also being created that will be available free of cost for use by all hospitals and practitioners. The toolkit will include algorithms for EOL decision-making and management of EOL symptoms, frameworks for application of standard principles of ethics, for surrogate decision-making in EOLC and appropriate documentation of EOLC and FLST.

Brochures are also being prepared for free distribution to the general public that will answer frequently asked questions about EOLC. The main objective is to allay the misconceptions among the general public regarding EOLC. Choices available to the patients and families, when faced with terminal illness, will be discussed. Patients and families will then be able to make patient comfort oriented decisions through discussion with caregivers. Education for families regarding death and bereavement will also be provided.

The ISCCM has intervened in the Supreme Court by filing an impleadment motion in a public interest litigation filed by the non-governmental organizations common cause versus state that all the issues around EOLC will be presented to the court.

We must lobby with the Medical Council of India (MCI) for clarifying the difference between “withholding and withdrawing therapy” and euthanasia (chapter 6 Indian Medical Council [Professional conduct, Etiquette and Ethics] Regulations, 2002), which are ethically distinct and should not be equated.^[8] A separate mention about appropriate EOLC including Foregoing of life support treatments (FLST) and palliative care as one of the paramount duties of the physician in chapter 2 of the MCI Code of Medical Ethics would increase the confidence of physicians practicing appropriate EOL care and would also encourage physicians who are currently reluctant because of the lack of legal clarity. Brain death too should be dealt with separately from the Organ Transplantation Act.

The NABH has played an important role in the implementation of standards in our country, and we

must lobby with NABH as well to ensure implementation of appropriate EOL guidelines. EOL care is an area where even most NABH accredited hospitals are not able to ensure appropriate implementation despite the presence of national and international guidelines on the topic. The toolkit for EOL care should help address this gap.

A survey questionnaire on EOL care has been planned and will soon be sent to all ISCCM members to address knowledge gaps in our understanding of current EOL practices. This survey is designed to generate data that would help us evaluate through future surveys the success of our campaigns.

The biggest challenge before us is to convince our colleagues to care enough about their patients and families and put aside their personal fears and misgivings to deliver appropriate EOLC - a truly Alexandrian solution to the Gordian knot of end-of-life care.

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