

The ISCCM/IAPC Position Statement: Ending the Sisyphean Struggle to Practice Ethical End-of-life Care in India

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End-of-life care is an integral part of treating seriously ill patients. In most parts of the developed world, end-of-life decisions are frequently made and executed by the intensive care team, often with the ready approval of the primary care physicians. In the rare circumstances, when conflicts arise, amicable solutions are reached through in-hospital ethics consultations with very little external interference from administrators or legal professionals.

This was not the case in India from the early 1990s when the technology and treatments required for intensive care grew rapidly, unaccompanied by equivalent progress in the comprehension of moral and legal positions. In particular, there was plenty of ambiguity about what was ethical and permissible in limiting life-support treatments, especially when patients developed irretrievable illnesses. This was true in many other developing countries as well.¹ The consequences of this ethical and legal vacuum were often, unfortunately, quite abhorrent.

In those early years, intensivists in practice in India felt much like the mythological Greek Sisyphus, who was condemned to a life of unending labor and frustration, for having angered the Gods. Practicing good end-of-life care was frustrating. A lot of hard work and some progress was often undermined by some "God" pushing you back saying, "It is unethical" or "It is illegal and cannot be done in India".

The "deities" in this Indian scenario were often administrators who rode roughshod over the opinions of the practicing clinician, resetting or even annulling clinical judgment with arbitrarily passed rules and blatant misinterpretation of the existing law. This was often backed by hospital lawyers whose primary goals were more aligned to protect the hospital's broader interests than to deliver distress-free death to terminally ill patients. Even in the rare situation that these overseers agreed with the physician to limit care, one was often advised to, "Do it-but don't document it"! Despite these admonitions, limitation of futile care was being practiced by some hospitals in Mumbai in that period.²

One particularly revolting act that was promoted in this legal and ethical void was what was euphemistically called "Leaving against medical advice (LAMA)".³ As much as this was promoted as a mode of respecting patient autonomy, it was often amenable to being misused. It gave rise to a tendency not only to compel patients to comply with unilateral physician decisions to stop life-supporting treatments but squarely placed the onus of decision-making almost entirely on the patients and their families. It 'allowed' physicians to evade their fiduciary duty of taking primary responsibility for all aspects of patient care, including

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and especially the provision of palliative support when curative approaches ceased to be effective.

Many of the practices in this era, including LAMA were rooted in a misunderstanding of ethical principles: The belief that limitation of life-supportive care was in effect euthanasia. This was a perception that had traction not only with the practicing physician, but also amongst the majority of legal professionals.^{4,5}

The ISCCM took a major step in correcting these misinterpretations in 2005 by approaching the Law Commission of India. The consequential 196th report of the Law Commission was first legal recognition that limitation of life-support therapies was not the ethical or legal equivalent of euthanasia.⁵ This was strongly backed by an ISCCM position statement that provided a professional consensus on the ethics and execution of end-of-life care.⁶

Despite this ground-breaking effort, much was left in easing the implementation of end-of-life care, primarily because the judiciary built in many "protective" processes to minimize a perceived potential for abuse. The initial Law Commission report required authorization of the decision to limit life-supporting therapy by a judicial magistrate, obviously not fully recognizing the temporal restraints of such a process in making real-time decisions in day-to-day clinical practice.⁵ Likewise, it was very dismissive of advance care directives that would have maintained patient autonomy, albeit in a small minority of individuals who were fortunate enough to have had sufficient prior insight into the consequences of ineffective medical treatments.⁵

These procedural obstacles have since been diluted by recent court rulings which initially approved the use of advance directives and living wills (2018), but left us with a multi-tier execution process involving district collectors and judicial magistrates, probably because the test cases dealt with patients in long term vegetative states rather than acutely ill patients in the intensive care unit.^{7,8} Most recently (2023), under the urging of the ISCCM, many procedural obstacles have been ameliorated making physician-centered decision-making an increasing possibility.⁹ Unlike the eternally condemned Sisyphus, we have seen progress over the last few decades and the hope of practicing high quality end-of-life care is now a relatively stress free, streamlined reality in many hospitals.

To paraphrase Tennyson, "Though much (has been) taken, much abides". The steps forward in the judicial arena have been slow, but, definitely, progressive. Unfortunately, the ground reality in clinical practice has not caught up with this legislative progression. The national INDICAPs studies have shown that ICU practitioners continue to opt for 'defensive' practices like LAMA and terminal discharge in many parts of our country.^{10,11} Legal experts continue to use the term "passive euthanasia" in the context of limiting life-support technologies. Though they give legal sanction to "passive euthanasia", in contrast to "active euthanasia", the use of the term is, by itself, fraught with issues of misperception, that might impede further easing of the legal processes or in ensuring greater public acceptance.

A turning point in the delivery of good end-of-life care has been the involvement of palliative care consultants and teams in some of our hospitals. Physicians and intensivists would often talk the talk, when it came to end-of-life care and prescribing comfort measures, but would rarely walk the walk, often blaming it on time constraints or inadequate staffing. This was especially true after the patient was moved out of the ICU. The involvement of palliative care consultants and teams has addressed this issue, allowing end-of-life care to be seamlessly continued from ICU to hospital floors and even to smaller nursing homes or home care.

The comprehensiveness of the current position paper needs to be applauded. Especially relevant is the fact that it is a statement that has been developed with the wholehearted support of the Indian Association of Palliative Care. Legal processes are often built on the edifice of consensus professional standards and the cooperative work of these two professional societies will go a long way in ensuring wider acceptance and legal approval of these ethical approaches.

The current iteration of the ISCCM/IAPC end-of-life processes is debatably called a "position statement" rather than a "guideline". We feel that this description may be interpreted as a bit of reticence on the part of the societies in standing wholeheartedly behind their ethical and legal positions, but this document is more than

just a "guideline" that only aims to provide practical steps in the execution of end-of-life care. It is a much broader "statement" of the moral and ethical basis supporting these processes. The time is ripe for the ISCCM and IAPC to seek a broader buy-in from other Indian professional societies as well.

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