

# Coming together to care for the dying in India

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The two halves – palliative and critical care, mistakenly believed to be polar opposites, have come together for the better care of the dying. Protecting life, ensuring care appropriate to disease prognosis, facilitating a “good death” and alleviating pain, all form a continuum. The guiding principle of medicine has been to care always and cure if possible. We have learnt that the model of care that correlates best with patient and family satisfaction is not to approach the patient as a disease entity but as a whole person.<sup>[1]</sup> We have seen that fragmentary care can be dangerous for the living and insensitive for the dying. Hence, the twain has met toward achieving excellence in end of life care (EOLC). In a first for India, in this issue of the IJCCM, Myatra and Salins *et al* present a joint statement by the Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC) defining a policy and bedside practice for holistic care of the dying.<sup>[2]</sup> This monumental document based on the position statements of ISCCM and IAPC<sup>[3,4]</sup> comes at a time when issues relating to EOLC are in the media spotlight<sup>[5]</sup> and awaiting deliberations in the Supreme Court (Common Cause versus Government of India, C 215 of 2005). For this reason, I think this consensus document is well timed and historic.

Technologically intensive medical care should be tempered by good sense and humanity. Disproportionate interventions in the last few decades have seriously affected the quality of dying and accentuated social inequities.<sup>[6]</sup> Although in the developed world physicians have acknowledged these pitfalls and have shifted to a new paradigm of setting different goals for a dying patient,<sup>[7]</sup> in India we have been slow to change.<sup>[8]</sup> The society and healthcare professionals must together address these larger issues because law and legislation

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must follow their felt needs. Unfortunately, debate on the issues around terminal care in our country has been hijacked by opinionated discussions on euthanasia. Consequently, legal attention has been confined to a narrow frame of reference.<sup>[9]</sup> The scope of such discussion must be expanded to include all aspects that are required to facilitate quality EOLC in which shared decision making is paramount.

All this needs to be done urgently because presently India is ranked among the lowest in public awareness, prevalence and quality of EOLC in the world.<sup>[10]</sup> This is attributable to the fact we have not kept pace with the extraordinary global advances in the areas of ethics and law related to healthcare.<sup>[11]</sup> We have been quick to bridge technological and infrastructural gaps, making impressive strides in diagnostics and innovations. However, it has escaped our vision that technology cannot be judiciously applied without ethical and legal framework. The time has arrived to balance out this skewed evolution of healthcare in the country.

Medical futility has defied precise definition but in practice it is imperative that we recognize it early to avoid disproportionate treatment. The perception that EOLC improves the overall intensive care outcomes are rooted in evidence.<sup>[12]</sup> This joint statement offers pragmatic and evidence-based guidance in identifying (so far as is possible), the onset of the dying process and medical futility-vital first steps for timely shifting of the goals of

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care. Physicians may be wary of defining futility in the face of rapidly advancing technologies that have brought within the ambit of successful outcomes, disease states that were once considered unsalvageable. Extracorporeal membrane oxygenation and left ventricular assist devices have generated not only new survival possibilities for the patient, but also new ethical dilemmas when they fail.<sup>[13]</sup> It would also be necessary to have a workable approach to early EOLC if we were to establish nonheart beating organ donation in this country.<sup>[14]</sup> Physicians must find solutions to these new questions through a return to the drawing board of fundamental ethical principles.

Palliative care begins the moment any specific treatment is instituted. In critical illness, it should be integrated at all times with life supporting interventions regardless of the patient's prognostic status.<sup>[15]</sup> In Integrating the theory and "practice points" of palliative and critical care from their respective position statements, the whole has turned out to be greater than the sum of its parts! For the success of these procedures, effective communication is pivotal.<sup>[16]</sup> Standard methods to ensure the completeness and quality of communication have been comprehensively addressed in this document.

The principle of respect for the whole person must ensure that patient's individual rights are taken into account in medical decision making. This document reinterprets the four cardinal principles of medical ethics in the context of providing quality critical and palliative care. While patient's right of refusal is implicit in the principle of autonomy, physician's respect for patient's values in relation to life supporting therapies is an extension of the principles of beneficence and nonmaleficence. The right to palliation, that is, to be pain- and distress-free is likewise an inalienable right. It follows that we should engage the law makers in discussions on how these rights can be restored to our patients as citizens, rather than expend our energies in debates on the right to die.

The economics of healthcare is a part of mainstream research today.<sup>[17]</sup> A large proportion of healthcare expenditure is used up in the care of the dying. We do not have accurate data of the proportion of such expenditure in our country, where in any case central allocation for healthcare is one of the lowest in the world. As responsible professionals, we cannot afford to ignore the devastating financial consequences of reckless expenditure to the individual and society. Facing the prospects of an aging population with no corresponding rise in allocation of healthcare resources,

national policy on EOLC is needed with utmost urgency. This document draws attention to hitherto neglected aspects of professional education and training that are essential for ensuring humane care and fair allocation of resources.

The shift to "comfort care" approach in many circumstances begins well before the moment of crisis as in advanced cancer. With appropriate preparation, utilization of critical care by such patients can be reduced substantially. The term "advance care planning"<sup>[18]</sup> refers to the introduction of EOLC and palliative care that begin months before the patient's anticipated time of loss of capacity. These interventions including open discussions, counseling and opportunities to receive emotional support and to plan life closure have been shown to substantially reduce burdens to the patient and posttraumatic stress among the family. The "complete" physician must empower patients to exercise their own will and to plan the last days of life according to their cherished values. Human life is imbued with the Spirit, and death, as with life, was intended to be meaningful.

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