Integrated Care Plan for the Dying: Facilitating Effective and Compassionate Care as an Urgent Process Needed in India

"How people die remains in the memory of those who live on."

–Dame Cicely Saunders

Comprehensive care ensuring a seamless continuum of care is paramount for effective health care. It is very satisfying to the person and family as it is an expression of whole person care, responding appropriately and ethically to the situation with good communication and teamwork. This is necessary to meet the needs of a person progressing through an incurable illness and facing death. Palliative and end-of-life care (EOLC) is geared for it, and an integrated care plan for the dying makes sure a good death is achieved. It also continues its support to the family after death of the person and makes provision for ongoing bereavement support.

We do have a desperate situation in India. Despite good progress made by the Indian Association of Palliative Care over the past 23 years, availability of palliative care for those who need it is only <5%. In addition to this, we have obvious deficiencies in that palliative care is still not part of undergraduate health curriculum, and doctors do not learn about death and dying.[1] There is no national policy for palliative and EOLC, no clear legal support, and most training programs are achieving awareness but lack in building full capacity for providing effective palliative care. Although palliative home care is the big need, there are limited home care programs. Another reality is the ratio of population utilization of private health services is 76 in comparison to 24 for public health-care system, and a large portion of this includes those at the end of life due to an incurable and progressive illness. Many of these private hospitals are not equipped for providing palliative care. Families unable to bear the cost of futile care get discharged against medical advice with no further support or guidance to manage a dying person.[2] The final blow of commercial medicine results in unnecessary suffering for the person and the family and financial ruin pushing over 20 million into poverty every year. The Human Rights Council equates such exploitation and denial of pain relief to torture.[3]

Efforts are currently underway to rectify these various deficiencies, but all these will take time. In the meantime, there is an urgent need to help those who are actively dying. The first step in this regard has been taken with the Indian Society of Critical Care (ISCCM) and Indian Association of Palliative Care joining hands to create an EOLC Policy and Integrated Care Plan for the dying.[4] This major development is further strengthened by the International Auditing Practices Committee (IAPC) becoming a member of the International Collaborative for Best Care for the Dying Person. We thus become part of a group of 15 countries whose aim is to improve care for the dying person to achieve a good death. A first foundation course of the collaborative was held in January 2016 at the Bangalore Baptist Hospital, in which 30 participants from 16 palliative care centers from all over India participated. "Project India," a work package of the collaborative, was created. These centers then looked at the feasibility and acceptability of the international document keeping our situation and cultural context in mind. This report is now published in this edition of the IJPC. Based on these inputs, an initial care plan document has been worked on and is being piloted in the Karunashraya Hospice and Baptist Hospital in Bangalore. This will be circulated to the 16 participating centers, and a final document called "Guidance and Care Plan for the Dying" (GCP-D) will be decided. This will be then sent to the International Collaborative for congruence assessment. After approval by the collaborative, the GCP-D will be applied in all the participating centers. It is hoped that such an integrated care plan will facilitate good documentation, training of staff, direction for the team, and research to improve care of the dying. It is planned to complete the study in a years' time, and the published data will be used for further advocacy with the government.

There are two other important developments about EOLC for the dying. One is formation of EOLC in India Task Force by the ISCCM, IAPC, and Academy of Neurological Sciences coming together to draft an EOLC Bill and engage with the government.[5] The second is inclusion of EOLC requirements in the Fourth Edition of NABH guidelines.[6] This will make good EOLC, a requirement for accreditation by NABH.

All these are significant developments in improving EOLC for the dying. However, without adequate training of all staffs involved, these will remain developments on paper. Several workshops are being held to train medical staff on EOLC. To make such training ongoing and covering medical staff in a large country like India, an online course with a clinical component and certification on "EOLC" can help, and it should be made mandatory for all medical staffs involved in clinical care.

Furthermore, there must be a national commitment to integrate palliative care into all health cares as per the WHA resolution[7] and emphasized in the IAPC Pune Declaration 2015. Perhaps all hospitals and nursing homes with an Intensive Care Unit should also have a trained palliative care team to take care of dying patients discharged to the ward and to support with home care in a 5 km radius around the hospital if required. Registered general practitioners could also be trained for providing help at home, especially with death verification or certification as appropriate. Trained volunteers can also provide much-needed support to families during this difficult phase and in bereavement support later.

There is a need to promote EOLC as part of comprehensive care in all end-stage conditions. In the context of palliative care of the elderly, IAPC is making efforts to join hands with the Indian Academy of Geriatrics, Alzheimer's and Related Diseases Society of India, and HelpAge India. Efforts are also on to join hands with neurologists, nephrologists, and HIV/AIDs specialists to make appropriate EOLC available in all these areas. An EOLC plan can facilitate this process and make every death a "good death."

The taboo around death needs to be removed with more talk and discussion among all so that the inevitability and reality of death becomes acceptable. National media programs can help increase public awareness and prevent inappropriate care and exploitation.

It is high time we health professionals in India recognize the urgency of this unacceptable situation of injustice and suffering and respond with commitment and love to rectify it. We cannot remain neutral, and we must strive to do what is ethically right. The law will soon catch up to support us. We have a great heritage and two great strengths of "Faith" and "Family" through which we can develop an ideal palliative and EOLC service. Let us all join hands and do it!

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