



Policy Document

Institutional end-of-life care policy for inpatients at a tertiary care centre in India: A way forward to provide a system for a dignified death

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India has a high share in the global burden of chronic terminal illnesses. However, there is a lack of a uniform system in providing better end-of-life care (EOLC) for large patients in their terminal stage of life. Institutional policies can be a good alternative as there is no national level policy for EOLC. This article describes the important aspects of the EOLC policy at one of the tertiary care institutes of India. A 15 member institutional committee including representatives from various departments was formed to develop this institutional policy. This policy document is aimed at helping to recognize the potentially non-beneficial or harmful treatments and provide transparency and accountability of the process of limitation of treatment through proper documentation that closely reflects the Indian legal viewpoint on this matter. Four steps are proposed in this direction: (i) recognition of a potentially non-beneficial or harmful treatment by the physicians, (ii) consensus among all the caregivers on a potentially non-beneficial or harmful treatment and initiation of the best supportive care pathway, (iii) initiation of EOLC pathways, and (iv) symptom management and ongoing supportive care till death. The article also focuses on the step-by-step process of formulation of this institutional policy, so that it can work as a blueprint for other institutions of our country to identify the infrastructural needs and resources and to formulate their own policies.

Key words EOLC policy - end-of-life care - formulation - implementation - India - institution

A peaceful and dignified death is the right of every person with a life-limiting illness¹. A ‘good death’ can be an outcome of a holistic approach towards the patients, taking into account their wishes, cultural

Institutional End-of-Life Care Committee:

Chairman: Dr Randeep Guleria, Director, All India Institute of Medical Sciences (AIIMS), New Delhi

Core Committee Members (in alphabetical order of the departments): Drs Ambuj Roy, N Nayak, Department of Cardiology; Praveen Agarwal, Department of Emergency Medicine; D. Bhowmik, Department of Nephrology; M.V. Padma Srivastava, Department of Neurology; Nishkarsh Gupta, Rakesh Garg, Sachidanand Jee Bharati, Seema Mishra, Sushma Bhatnagar, Vinod Kumar, Department of Onco-Anaesthesia & Palliative Medicine; Anant Mohan, Department of Pulmonary Medicine; S.V.S Deo, Department of Surgical Oncology; T.P. Singh, Chairman, Ethics Committee, AIIMS & Ms Dhvani Mehta, Vidhi Center for Legal Policy, New Delhi

background, ethical considerations alongside symptom management². As per the World Health Organization report in 2014, worldwide 68 per cent of the deaths are due to chronic non-communicable diseases³. India shares 15 per cent of this global burden⁴. Despite this high death rate due to chronic terminal illnesses, India seemingly lacks the capacity to provide end-of-life care (EOLC). As per the Economist Intelligence Unit report in 2015 India ranks 67th out of 80 countries which were studied for quality of death⁵. According to the Global Atlas of Palliative care, 2nd edition in 2020, India was found to be at the stage of the isolated palliative care provision (level 3a)⁶. The major factors that act as a barrier for practicing EOLC in developing countries include failure to recognize EOLC as a requirement of public health, lack of related systematic data, and lack of a national-level policy⁷. To top it off legal ambiguity further deters physicians from initiating EOLC discussions, resulting in the initiation and continuation of invasive life-sustaining procedures at end-of-life. However, the duty of care for the physician is bound not only by the national laws but also the principles of professional ethics (autonomy, non-maleficence, beneficence, and justice). The physician bears the duty to save a patient's life, but this duty does not mean continuing a potentially non-beneficial or harmful treatment which can further increase the suffering of the patient and their caregivers^{8,9}.

To date, only a few studies are available which give an idea of the EOLC scenario in India¹⁰⁻¹². Mani *et al*¹³ concluded that only a small proportion of terminally sick patients in the intensive care unit (ICU) had an end-of-life decision (EOLD). Despite a shift in a few legal paradigms over the past few years, still many questions prevail among physicians regarding patient selection, difficult communication, legal dilemma, *etc.* Thus, it is important to find solutions according to the resources available at the individual institutional level so that EOLC can be provided keeping in mind the medical ethical principles⁹. This article discusses the journey of formulation and initial training strategies for the implementation of an EOLC policy at a tertiary care hospital in India and may provide a road map for other institutions in India and possibly in other developing countries.

End-of-life care (EOLC) policies in India: How far we have come?

The first Indian policy document on EOLC was published in 2005 by the Indian Society of

Critical Care Medicine (ISCCM)¹⁴. It focused primarily on minimizing non-beneficial or harmful treatments and initiated a standard process to forego life support. The summary of legal solutions that could be used by physicians for their defense was published in the same year by ISCCM¹³. They revised and updated their guidelines in 2012 because of the landmark judgment of the Aruna Shanbaug case in 2011¹⁵. These were followed by a few more position statements and consensus guidelines by different societies in India¹⁶⁻¹⁹. The document by the Indian Council of Medical Research (ICMR) described regarding the principles of do not attempt resuscitation, as well as focussed on algorithm for its implementation²⁰. A critical analysis focusing on these policy documents has been presented in Table I. Though the Federation of Indian Chamber of Commerce Industry and End-of-Life Care in India Taskforce (ELICIT) comprising of members from ISCCM, Indian Association of Palliative Care, and Indian Academy of Neurology released an information guide in 2019²¹, providing sequential strategies for implementation of EOLC for the first time, it, however, lacked a documentation format for the process.

The BLUE MAPLE protocol²² published in March 2019 was the first document developed in India that provided procedural guidance for the limitation of life-sustaining treatment and EOLC at an institutional level. It provided an algorithmic approach, sequential steps, and guidance documents and templates for; (i) recognition of medical futility in various clinical settings; (ii) developing physician consensus on medical futility and template for endorsement of medical futility; (iii) providing a framework for communication and a family meeting while discussing prognosis and template for documentation of a family meeting; (iv) consenting and template consent forms for withholding and withdrawing life-sustaining treatment; (v) ratification of futility, withholding/withdrawing decision by the hospital clinical ethics committee and template for ratification; (vi) procedure for implementing withholding and withdrawing life-sustaining treatments; and (vii) EOLC plan (initial and ongoing assessment and management), and after death care protocol.

In November 2019, the Vidhi Centre for Legal Policy and the ELICIT drafted a bill on EOLC which adopted a rights-based perspective, in context to the reality of the healthcare system of India²³.

Table I. Summary of important landmark policies in India for the end-of-life care

Year	Authors	Association	Title	Key points	Limitations
2009	Mani <i>et al</i> ¹²	ISCCM	“Limiting life-prolonging interventions and providing palliative care towards the end-of-life in Indian intensive care units”	First guideline in India of its kind and provides an answer to the question of ‘when to initiate EOLC discussions’ Addressed issues of shared decision making and withdrawing life support with patient’s consent. Provides rationale and advisories to deal with various end-of-life care situations	Limited to patients in critical care settings
2005	Mani and Balakrishnan ¹⁴	ISCCM	“The constitutional and legal provisions in Indian law for limiting life support”	ISCCM position that summarizes the existing legal solutions that can be used by physicians for their defence	Not a guideline <i>per se</i> and did not provide solution to existing ethical dilemmas
2012	Mani <i>et al</i> ¹³	ISCCM	“Guidelines for end-of-life and palliative care in Indian intensive care units: ISCCM consensus ethical position statement”	Emphasized on statements made in 2005 guidelines. Took into account the Shanbaug case judgment of 2011	Limited to the critical care patients and did not add much to the previous statement
2014	Macaden <i>et al</i> ¹⁶	IAPC	“End-of-life care policy for the dying: A consensus position statement of the IAPC”	First document that emphasized the need for integration of palliative care and EOLC in hospital and community based programmes	No proforma for EOLC consent. No specific algorithm was given for the management of EOLC symptoms
2014	Myatra <i>et al</i> ¹⁷	ISCCM and IAPC	“End-of-life care policy: an integrated care plan for the dying”	ISCCM and IAPC layouts a care plan for the dying. It highlighted the process of withholding or withdrawing life support and socially acceptable bereavement care	Did not incorporated the ethical principles, decision making on behalf of the patient and documentation in the EOLC
2015	Kumar <i>et al</i> ¹⁸	ISCCM	“Framework for decision making and management of end-of-life decisions in intensive care units: A modified protocol”	Based on guidelines recommended by ISCCM and IAPC. But also inculcated points from Australia and New Zealand Intensive Care Society statement about EOLC in critically ill patients	Limited to critical care settings and although implemented points from Western countries did not add much to the existing policy guidelines
2017	Mishra <i>et al</i> ¹⁹	IAP	“End-of-life care: A consensus statement by IAP”	First document to acknowledge and establish guidelines for EOLC in paediatric age group. Included DNR for neonates and presented a hierarchy for decision-making	Difficult to implement in paediatric setting in reality as it may be a greater source of potential conflict between child’s caretakers than in the case of adult patients

Contd...

Year	Authors	Association	Title	Key points	Limitations
2020	Mathur ²⁰	ICMR	“Consensus Guidelines on DNAR”	Describes the principles of DNAR, provides an algorithm of its implementation and guidance on frequently asked questions	It relates only to cardiopulmonary resuscitation and does not include withholding or withdrawing life-supporting measures Principles of DNAR are limited to certain situations only

ISCCM, Indian Society of Critical Care Medicine; EOLC, end-of-life care; IAP, Indian Association of Palliative; IAPC, IAP Care; DNR, do not resuscitate; DNAR, do not attempt resuscitation

India demonstrates inequality in terms of delivery of healthcare facilities²⁴. Cultural and economic diversities make the implementation of these existing policy guidelines even more difficult, especially for patients with terminal illnesses in the general wards of hospitals. Thus, implementation of EOLC is still a challenge even for the tertiary care institutes, and formulation of institutional guidelines seems to be a reasonable solution in the absence of a uniform national policy.

Initial assessment of the EOLC scenario at the institute level: Identifying the barriers and scope

At our tertiary care health centre (Dr. BRAIRCH, AIIMS, New Delhi), total outpatients in the year 2019-2020 were 44,14,490 and total admissions were 2,68,144²⁵. The department of Palliative Medicine provides EOLC services in a palliative care ward and attends all the referrals from other departments for EOLC. The referral data of the Palliative Medicine department for EOLC over 14 months (January 2018-February 2019) were analyzed to assess the baseline service provision at the institute. It was found that only 49 out of 239 (18%) patients with life-limiting illnesses, attending the emergency department and 19 out of 197 patients in general wards (9.64%) received EOLC counseling (regarding potentially non-beneficial or harmful treatment, supportive care, and symptom management).

An EOLC service needs many support systems to sustain, like space and availability of palliative care physicians, guidelines or policy for implementation, and standardized documentation of the process²⁶. So, the first step of formulation of the policy was to explore the adequacy of these different components

at the institutional level. An initial meeting was arranged under the chairmanship of the director of the institute, involving representative faculties from a total of 15 departments, including Oncology, Pulmonary Medicine, Neurology, Nephrology, Emergency Medicine, and Palliative Medicine. The major factors which were found to be responsible for the lack of EOLC practice at the institutional level are schematically shown in Figure. 1.

Based on these, the committee had a consensus opinion regarding the evident scope and need of an institutional policy to guide the healthcare providers in practicing the process of EOLC and standardized documentation.

Formulation of policy

The major goals of the policy were to cover the following purposes: (i) Identify the terminal stage of illness and facilitation early discussions about prognosis promoting realistic expectations of the patient and family; (ii) enable patients to have a dignified dying process ensuring care at all levels – physical, emotional, social, spiritual, and ethical; (iii) empowering the patients in deciding their treatment. This will include a patient-centered holistic approach with the inclusion of family and the clinical team in the decision-making process; and (iv) create awareness among staff for dignified death for terminally ill patients, empowering them with skills of communication, knowledge about the steps of EOLC practice, and its documentation.

The major steps of formulation of the policy included defining the steps of EOLC, designing consent forms for disclosures, and developing documentation strategies for the daily progress of EOLC. A team of the legal advisory was included in the committee

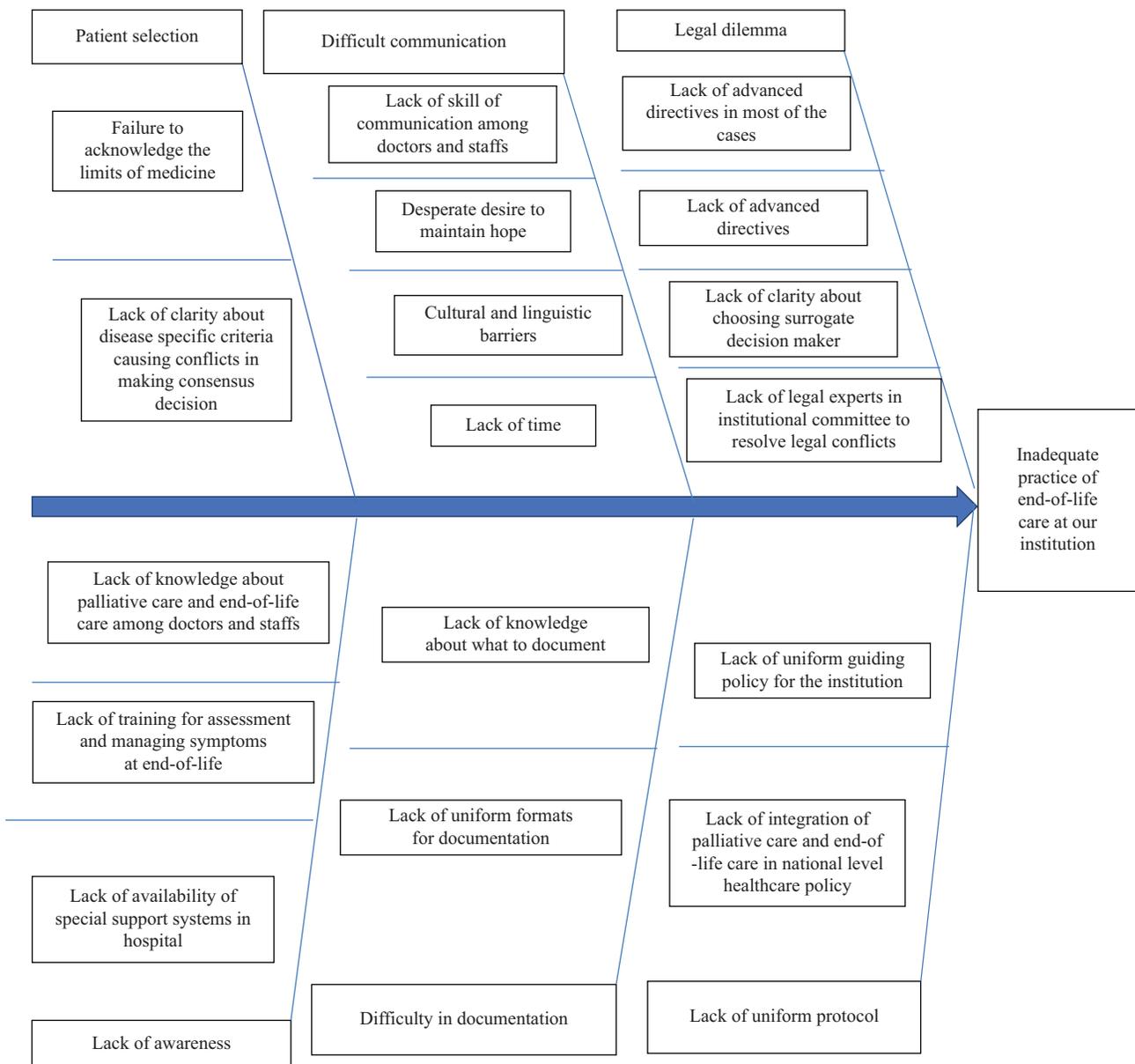


Fig. 1. The existing barriers for practicing end-of-life care at our institution, as perceived by the physicians of the expert committee.

to clarify the legal questions and doubts prevailing in our country regarding the practice of EOLC. The initial draft of the policy was circulated amongst all the faculty members of the institute for feedback. After the necessary corrections, the final draft was put up on the institutional website for public opinion. In the end, the committee members again scrutinized the final document and after approval by them, it was uploaded to the institutional website.

The policy document includes the following four steps as also shown descriptively in Figure 2; (i) recognition of potentially non-beneficial or harmful

treatment by the physicians; (ii) the consensus among all the caregivers on potentially non-beneficial or harmful treatment and initiation of the best supportive care pathway; (iii) initiation of EOLC pathway; and (iv) symptom management and ongoing supportive care till death.

Recognition of potentially non-beneficial or harmful treatment by the physicians: Potentially non-beneficial or harmful treatment should be recognized initially by primary physicians based on some general as well as disease-specific criteria. The general criteria include (i) shortened survival expected to be in days to

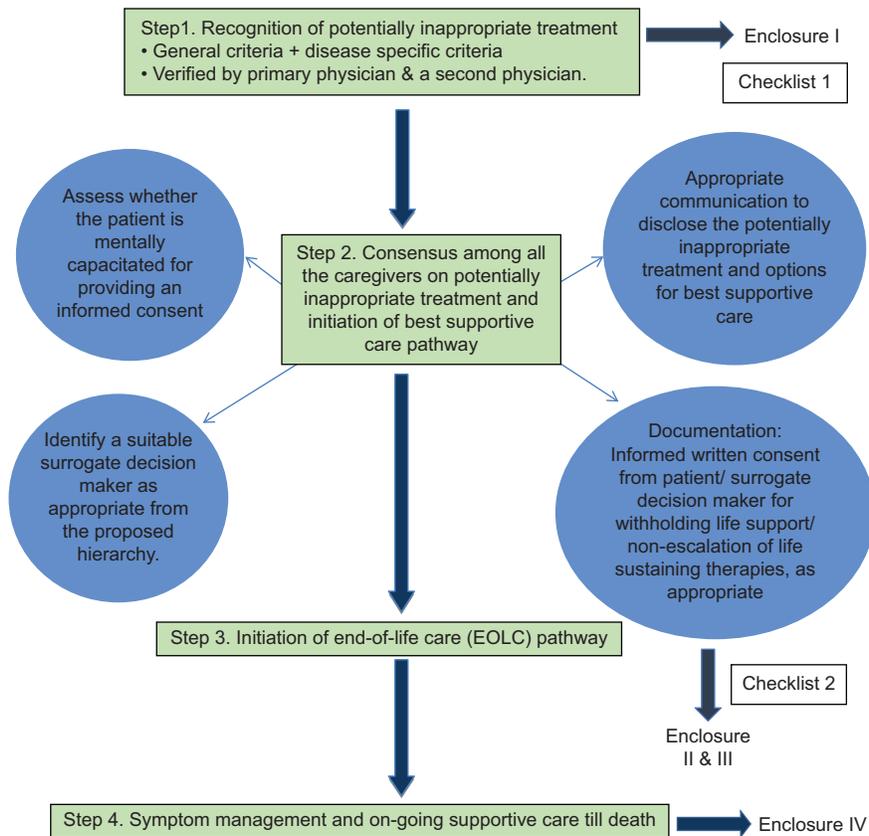


Fig. 2. Summary of end-of-life care policy.

weeks; (ii) any condition where the clinicians predict a low chance of achieving an acceptable quality of life according to the patients’ values; and (iii) post-cardiac arrest status with poor neurological outcomes. The general criteria mentioned helps us in recognition of non-beneficial or harmful treatment.

In different specialities, (*i.e.*, critical care units, pulmonary medicine, paediatric medicine, neurology, neurosurgery, oncology, *etc.*) the specific criteria for further potentially non-beneficial or harmful treatment can be decided by the team of clinicians of the concerned speciality considering the disease-specific details.

Once the potentially non-beneficial or harmful treatment has been identified by the primary clinician, the same must be confirmed by another clinician of the same speciality who is not directly involved in the care of the patient. After the consensus, a mandatory referral has to be made to palliative care services. The consensus among the clinicians must be documented in proper format (Supplementary Enclosure I).

Consensus among all the caregivers on potentially non-beneficial or harmful treatment and initiation of

the best supportive care pathway: Four basic steps should be followed to reach a consensus:

(i) Assess the mental competence of the patient for taking an informed decision: Check for the ability to understand, appreciate, reasoning and expression of choices. If a patient is not found to be mentally capacitated to give valid informed consent, a surrogate decision-maker should be identified.

(ii) Identify the responsible surrogate decision-makers: If the patient does not have the capacity to make healthcare decisions or is unable to participate in the healthcare decision making, the process of decision-making rests on patient surrogates, which is usually the patient’s family who makes the medical decision in consultation with the treating team in best interests of the patient. If there are no documented surrogate decision-makers, the hierarchy for surrogate decision-makers as described in Table II are to be followed^{27,28}. The list is valid only if the patients’ advance directive, if any, has not named a surrogate decision-maker.

(iii) Appropriate communication to disclose the potentially non-beneficial or harmful treatment and

Table II. Summary of the training strategies

<i>Training of physicians:</i> Sessions focussed on creating awareness regarding EOLC, skills of communication, detailed information about the policy document and process of EOLC and documentation
A mandatory training session for all residents at the entry level
Interdepartmental training sessions for discussing speciality specific concerns
<i>Training of the staffs</i>
Training sessions led by palliative care team and an ELNAC, (an international education initiative by the AACN, Washington since 2000) trained senior nursing staff appointed by the institution. To date, >1000 nursing staff of the institution have been trained through these sessions
<i>Palliative care training</i>
IAPC certified training course conducted at our institute twice a year. This is a two-tier process
‘Part A’ explains various palliative care scenarios, methods to dispense opioids, and how to effectively communicate with patients
‘Part B’ provides hands-on training in palliative care for 10 days
<i>Multidisciplinary palliative care service</i>
A 24×7 specialist palliative care service for patients in all departments on a referral basis
Rotational postings of palliative medicine students to various departments
EOLC, end-of-life care; ELNAC, end-of-life nursing education consortium; AACN, American Association of Colleges of Nursing; IAP, Indian Association of Palliative; IAPC, IAP Care

options for best supportive care: The primary clinician along with the palliative care physician and nursing officer should communicate to the patient and/or all concerned family members together in a meeting. The communication should take place in a language, with which they are comfortable. The communicating team must introduce themselves to all the family members present in the meeting.

The communication should include explanations related to the terminal nature of illness with an emphasis on conveying empathy, short life expectancy, burden versus benefit of further aggressive management, option of EOLC as an alternative, change of goals of treatment from cure to care, symptoms expected in the last few days or hours and their comfort measuring strategies, clarification of the patient’s values and beliefs by the patient or surrogate, clarification of any myths or misunderstandings regarding illness and treatment and recheck and ensure the understanding of the prognosis and process of EOLC among all the caregivers.

At the end of communication, the checklist for communication should be filled by communicating team’s clinicians (Supplementary Checklist I).

(iv) Documentation: If the patient is mentally capacitated to take an informed decision, the patient’s wishes for withholding of life supporting measures should be recorded and signed (Supplementary Enclosure II).

If the patient does not have the capacity to make informed decisions, then once consensus amongst all family members is established, a written disclosure of further potentially non-beneficial or harmful treatment and withdrawal or withholding of life supporting measures should be obtained (Supplementary Enclosure III). ‘Do Not Attempt Resuscitation’ Form, if applicable, to be filled (Supplementary Enclosure IV). The form has been adopted from the ICMR Consensus Guidelines on ‘Do Not Attempt Resuscitation’¹⁹.

Initiation of EOLC pathway: Once consensus for initiating EOLC is achieved among all the caregivers and physicians, palliative care physicians must ensure all the prerequisites have been adequately addressed (Supplementary Checklist II).

Symptom management and ongoing supportive care till death: This includes: (i) daily assessment of the patient to be done for holistic palliative needs, e.g., psychological, spiritual along with symptoms management at the end of life (e.g., pain, breathlessness, delirium, vomiting), (ii) daily supportive care plans and treatments given should be documented for all in-hospital EOLC (Supplementary Enclosure IV). Any change in plan (Care to Cure) must be documented, and (iii) if the patient is not already on any life-sustaining support, patient/surrogate decision-makers may be given an option for home-based/hospice-based care.

The oversight committee is the Institutional Ethics Committee which will be referred to in case of any discrepancy related to this policy.

Navigating India's uncertain legal framework around the end-of-life decision (EOLD)-making

While euthanasia and physician-assisted suicide remain illegal in India, the Supreme Court gave legal recognition to withholding and withdrawing life-sustaining treatment with strict guidelines in the Aruna Shanbaug's case in 2011¹⁵. Court of law, however, required all such decisions to be approved by the jurisdictional High Courts before being implemented. In 2018, Supreme Court made the EOCL refusal of life-sustaining treatment as a part of the fundamental right to liberty and dignity. The court also recognized the legal validity of advance directives^{29,30}. However, it laid down a restrictive process to implement such decision-making, involving multiple rounds of approval by multiple authorities³¹. These practical difficulties made it difficult to follow the court's guidelines in real-life critical care settings. The ICMR clarified the confusion that was created by the use of the phrase 'passive euthanasia' in the supreme court verdict of 2018. It says "euthanasia cannot be passive and withholding or withdrawing a potentially inappropriate treatment in a patient dying with a terminal illness that only prolongs the dying process, cannot be construed as an intention to kill"³²⁻³⁴. The government of India sought public comments on the draft bill posted on their website before making a law of passive euthanasia in 2016. The government, however, did not proceed with this proposed legislation³⁵.

In response to these legal restrictions, hospitals are coming up with their own EOLC policies, which, while capturing the essence of the Supreme Court's declarations around patient autonomy and the role of physicians in the best interest of the patients, also incorporate principles of transparency and accountability. This institutional policy proceeds on this understanding and seeks to create practical standards of EOLC decision-making. Two key innovations that the policy brings about are: (i) proposing a clear hierarchy for identifying surrogate decision-makers, who will participate in EOLC decision making and (ii) creating an institutional advisory EOLC committee. Hierarchy includes spouse or de facto spouse or a partner with whom the patient has a relationship in the nature of marriage or a friend of long-standing who regularly attends to the patient in the hospital; available adult

children; available parents; available siblings and any other lineal ascendants or descendants of the patient who are present in the hospital and regularly attend to the patient.

The EOLC policy's hierarchy of surrogate decision-makers accounts for societal shifts in India by going beyond relationships in heteronormative family structures and giving primacy to the principal caregiver. The institutional advisory EOLC committee has been set up with the twin objectives of resolving conflicts and giving ethical guidance during difficult decisions. It also complies with the spirit of the Supreme Court's directions to set up institutional expert committees that can oversee decisions regarding the withdrawal or withholding of life-supporting measures.

Implementation of the policy: Strategies we adopted: After vigorous feedback by the 15 committee members, the policy was finalized and uploaded to the institutional website for faculty and public opinion for a month. For strengthening the implementation process of the policy, some major steps were initiated (Table II).

Impact on the practice of EOLC by various departments after implementation of the policy: Our initial experience

The journey of formulation of policy and implementation of training programmes started in July 2019. This showed a sharp and consistent increase in the specialist palliative care referral rate from various departments for EOLC over the next seven months (Fig. 3). Data from the Palliative Medicine departmental audit revealed that after formulation of policy (September 2019 to February 2020) the total number of EOLC referrals for the malignant and non-malignant diseases increased by 110 and 83.3 per cent, respectively compared to before (March to August 2019) (Fig. 4). Thus, this policy document has shown a positive change in awareness and attitude regarding EOLC among physicians.

Limitations

Although many legal complexities were answered in the policy by involving the legal expert and proposing a hierarchy of surrogate decision-makers, the medicolegal sanction of such an approach is still pending. The exhaustive communication checklist and structured documentations are expected to minimize future conflicts but a clear legal defense is still unavailable. As our initial pre-policy barrier assessment was solely based on feedback from the

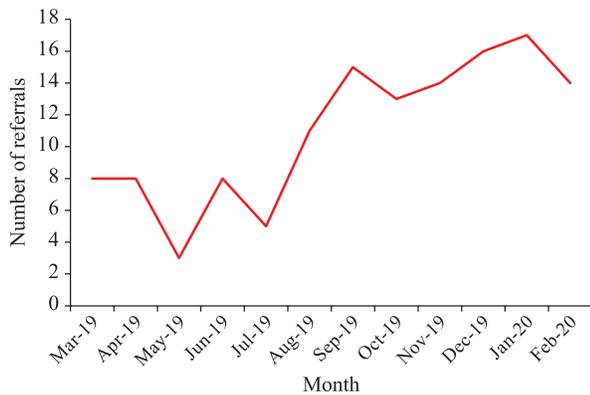


Fig. 3. Trend showing end-of-life care referral over one year (March, 2019- February, 2020).

expert committee members, some of the important perspectives of patients and relatives may have been overlooked. Furthermore, the efficacy of the policy is yet to be ascertained by assessing the quality of deaths with validated questionnaires. Spiritual support and structured bereavement care services are the arena with great challenges for us given the extreme diversities in the population base. Also situations like acute catastrophic illnesses where there was no or limited time to initiate EOLC were excluded from our policy.

Future direction

Implementation of the policy is a long process and we are still enroute. The outcome of this policy will serve as a framework for the revision of the EOLC policy. For future assessment of the quality of the EOLC process, postgraduate dissertations of palliative medicine students have been allotted to many departments, *e.g.*, Oncology, pulmonary medicine, neurology, nephrology, *etc.* Another goal of these dissertations is to develop and validate robust disease-specific criteria for EOLC. This will be helpful in resolving conflicts of choosing patients. The ongoing training programmes for staff and physicians will further be intensified by arranging more frequent communication workshops and focussed sessions in individual specialties. Privacy is often lacking when a terminally ill patient is admitted to the general ward and ICUs. To overcome such problems in the future, a dedicated EOLC ward under the palliative medicine department is planned to be set up. Hospices or homes are usually the preferred places of death for the patients instead of hospitals³⁶. The development of a service system for those patients who are willing to undergo home-based EOLC can be integrated with this policy in the future. Hospice centres should be

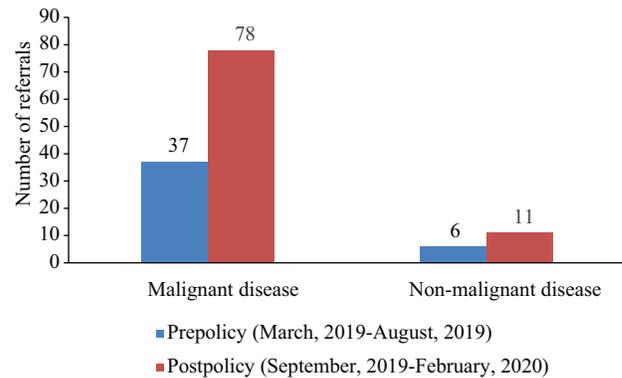


Fig. 4. Bar chart showing the break-down of end-of-life care referrals between malignant and non-malignant cases six months before and six months after institutional end-of-life care policy discussion.

roped in for all those who do not want to spend their last days in the hospital and do not have good home care facilities.

Conclusion

Institutional policies are the need of the hour in developing countries like India, where a 'dignified death' is still a myth for most of the terminally ill patients in the hospital. It should focus on patient selection, documentation of the whole process, and resolution of the conflicts arising in the process. The inclusion of legal experts in the institutional advisory EOLC committee will facilitate identifying and providing solutions for some of the legal lacunae. Aggressive and repeated training and educational workshops for the health staff are needed to implement the policy. Although a wide-scale assessment of the quality of deaths provided under the policy is still pending, it can act as a working plan for other institutes in developing countries with poor awareness and knowledge about EOLC. The outcomes of policy implementation whether anticipated or unanticipated will influence future policy-making or its modification. One may also hope that it may stimulate the national level policy making to standardize the practice of EOLC across India.

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Supplementary Material

Enclosure I

Recognition of potentially non-beneficial or harmful treatment by clinicians

I hereby certify that with UHID No. admitted at AIIMS, New Delhi suffering from is being reviewed for further potentially non-beneficial or harmful treatment. I feel that initiating or continuing life-sustaining treatment in this patient is potentially non-beneficial or harmful based on following clinical criteria.

.....
.....
.....
.....
.....

In consensus with the primary care clinician, I recommend palliative care referral to facilitate dignified end of life care for this patient.

Place:

Signature of the Clinician: (along with seal)

Signature of the Primary Clinician: (along with seal)

.....

.....

Date:

Date:

Enclosure II

Patient's wishes for withholding of life supporting measures

I _____ with UHID No. _____ admitted at AIIMS, New Delhi, have a critical/terminal illness where disease modifying options are no more applicable.

I understand that my general health is poor.

I also understand that the life supportive measures such as endotracheal intubation, cardiopulmonary resuscitation will cause suffering without any reasonable benefit.

My goal of care would be symptom relief, comfort measures and quality of life.

I hereby request you to allow natural death in the event of cardio-pulmonary arrest *i.e.* (no external chest compressions, no intubation, and no chemical or electrical cardio version)

I understand that signing this document would not deprive me of required medical and nursing care, pain and symptom relief modalities, and nursing care as appropriate with the highest priority to maintain dignity of life.

I say that I am making this declaration out of free will and there is no coercion.

Name of the patient	Signature	Date/Time
Name of Clinician	Department	

Enclosure III

Family acceptance regarding potentially non-beneficial or harmful treatment & Withdrawal or withholding of life sustaining treatment

I/We the family members of the patient with UHID No. acknowledge that we have attended the family meeting convened by the Department of on at.....

I/We have been explained regarding advanced state of illness. We understand that the benefit of initiating life-sustaining medical treatment has the potential to cause suffering.

I/We have decided and requested the doctors to withdraw life sustaining treatments on behalf of the patient.

OR

I/We have decided and requested the doctors to withhold life sustaining treatments on behalf of the patient.
(Tick any one statement)

I/We understand that signing this document would not deprive our patient of required medical and nursing care, pain and symptom relief modalities, and nursing care as appropriate with the highest priority to maintain dignity of life.

I/We hereby request you to allow natural death in the event of cardio-pulmonary arrest *i.e.* (no external chest compressions, no chemical or electrical cardio version).

I/We represent the patient's wishes and there is no conflict amongst the family members regarding the decision.

Signatures of the family members attending the meeting

S. No.	Name	Age	Relationship	Signature

Signature of the clinicians conducting the meeting

S. No.	Name	Designation	Signature

Date and Time:

Place:

(Adopted from ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation')
DO NOT ATTEMPT RESUSCITATION (DNAR) FORM

'In consideration of the medical status of Mr./Ms./Mrs., the team of treating physicians finds that in the event of cardiac and respiratory arrest, any attempt at reviving the heart by cardiopulmonary resuscitation (CPR) (mouth-to-mouth respiration, artificial compression of the heart, artificial ventilation of the lungs, injectable medication and associated measures) is not likely to be beneficial and is likely to cause suffering rather than restoration of life of any significant quality. Hence, in the event of cardiac and respiratory arrest, while all appropriate care and treatment to maintain quality and dignity of life will be continued, no attempts at CPR will be made'

Name of the patient:

Name of the Primary Clinician:

UHID:

Name of the Department:

1.

Assessment of treating clinician (s) decision on DNAR to the patient with summary of reasons:

1.1

Does the patient have capacity to make/or willing to and communicate decisions about CPR?

Yes/No

Comments if any:

1.2

If 'No' to 1.1, then is/are there a surrogate (s) available to receive information and to discuss DNAR on behalf of the patient? Yes/No

If Yes, details of surrogate (s):

Name:

Contact details:

Relationship:

2

The details have been duly explained to the patient/surrogate (s)? Yes/No

Comments if any:

3

Name of the members of treating team (if applicable):

1.....

2.....

3.....

4.....

Name of patient:

Name of surrogate (s) and relation with the patient:

Signature (if patient has decision making capacity):

Signature:

Name of other clinician (s)/expert consulted who may or may not be in the treating team, if applicable:

Name of the Clinician In-Charge:

Signature:

Signature:

Date (DD/MM/YYYY):

Time:

Place:

Enclosure IV

Documentation of daily progress note for in hospital care

- Date (Time)
- Competent to make decisions (Y/N)
- Pain (Y/N)
- Breathlessness (Y/N)
- Oral secretions (Y/N)
- Nausea & vomiting (Y/N)
- Bowel problem (Y/N) If yes mention _____
- Bladder problem (Y/N) If yes mention _____
- The person's personal hygiene needs are met (Y/N)
- Patient's psycho-spiritual needs addressed (Y/N)
- Caregiver's psycho-spiritual needs addressed (Y/N)
- Any change in goals of care (Y/N)

Y= Yes

N= No

Date/Time	Special remarks	Signature of the nursing staff :

Checklist No 1: Disclosure of Prognosis and potentially non-beneficial or harmful treatment

Language for communication:

1	Ability to communicate in ____ language	Y <input type="checkbox"/> N <input type="checkbox"/>
2	Introduction of self and team	Y <input type="checkbox"/> N <input type="checkbox"/>
3	Confirmation of decision makers (Patient/Caregiver)	Y <input type="checkbox"/> N <input type="checkbox"/>
	Name and address checked	Y <input type="checkbox"/> N <input type="checkbox"/>
	Surrogate decision maker noted _____	Y <input type="checkbox"/> N <input type="checkbox"/>
4	Insight into condition assessed	Y <input type="checkbox"/> N <input type="checkbox"/>
	Awareness of diagnosis and prognosis	Y <input type="checkbox"/> N <input type="checkbox"/>
5	Prognosis discussed	Y <input type="checkbox"/> N <input type="checkbox"/>
	Goals and Plan of care explained and discussed	Y <input type="checkbox"/> N <input type="checkbox"/>
6	Understanding of prognosis and plan of care checked	Y <input type="checkbox"/> N <input type="checkbox"/>
7	Religious/spiritual needs assessed/offered	Y <input type="checkbox"/> N <input type="checkbox"/>
8	Option for organ donation discussed with family and/or patient where appropriate	Y <input type="checkbox"/> N <input type="checkbox"/>

Signatures:

JR/SR

Faculty.....

Date

Date

Checklist No 2: Initiation of EOLC

All potentially reversible causes of patient's condition excluded	Yes	No
Consensus among clinicians involved in the treatment	Yes	No
Patient is able to take part in the decision making	Yes	No
Patient is aware of irreversibility of his/her condition	Yes	No
Any advance directive available	Yes	No
Family is able to take active part in decision making	Yes	No
Family is able to comprehend fully about irreversibility of the patient's condition	Yes	No
Family meeting documented	Yes	No
Family consensus and agreement of further potentially non-beneficial or harmful treatment	Yes	No
Family explained about further course of care plan	Yes	No
Guidance and Care Plan for the Dying explained and initiated	Yes	No
Organ harvesting planned	Yes	No
Place of Care opted by patient/caregiver	Hospital/Home/Hospice	
Patient/Family not willing/refusing to stop potentially non-beneficial or harmful treatment	Yes	No

Signatures:

Palliative Care Team:

1.....

2.....

Date:

Primary Care Team:

1.....

2.....

Date: