

## Review

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# End-of-Life Care and Psychiatry: Current Trends and Future Directions in India

Jayita K. Deodhar\*

## ABSTRACT

Although 80% of the deaths worldwide occur in middle- and low-income countries such as India, there is less awareness of end-of-life care (EOLC) for people with chronic, serious, progressive, or advanced life-limiting illnesses, including dementia. EOLC involves good communication, clinical decision-making, liaison with medical teams and families, comprehensive assessment of and specialized interventions for physical, psychological, spiritual, and social needs of patients and their caregivers. The psychiatrist can play a significant role in each of the above domains in EOLC. The current trends in India are examined, including ambiguities between EOLC and euthanasia. Future directions include formulating a national EOLC policy, providing appropriate services and training. The psychiatrist should get involved in this process, with major responsibilities in providing good quality EOLC for patients with both life-limiting physical illnesses and severe mental disorders, supporting their caregivers, and ensuring dignity in death.

**Key Words:** Advance care planning; Advance directives; Current issues in end-of-life care; Dementia; Dementia and end-of-life care; End-of-life care; Ethical principles in

\*MD (Psych), DPM, DNB (Psych), MRCPsych. Associate Professor, Tata Memorial Hospital, Parel, Mumbai, Maharashtra, India

Address for correspondence to: Dr. Jayita Kedar Deodhar, Psychiatric Unit, Room 18/20, Golden Jubilee Building Basement, Tata Memorial Hospital, Dr. E. Borges Road, Parel, Mumbai - 400 012, Maharashtra, India. Tel.: 02224177000 Ext 4515. E-mail: jukd2000@yahoo.co.uk

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*end-of-life care; Future directions in end-of-life care; Good death; Medical futility; Palliative care; Policy; Psychiatry; Psychiatry in end-of-life care; Serious life-limiting*

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## Introduction

Death is an inevitable part of life's journey, be it a natural event at the end of one's lifespan, an event at the end of an advanced or progressive, chronic, serious, life-limiting illness, or a sudden event in the course of an acute medical illness, irreversible despite intensive interventions. Health-care providers, therefore, should focus on curative and life-saving services as well as palliative care and end-of-life care (EOLC) of patients with advanced, prolonged, serious, life-limiting illnesses (Gaertner *et al.*, 2012<sup>[12]</sup>; Dzingina and Higginson, 2015<sup>[10]</sup>).

Authors have discussed the need for goals of management and care preferences in EOLC (Mack *et al.*, 2010<sup>[27]</sup>). EOLC involves good communication, clinical decision-making, liaison with medical teams and families, comprehensive assessment of and specialized interventions for physical, psychological, spiritual, and social needs of patients and their caregivers. Hence, the discipline of psychiatry has a significant role to play in EOLC. However, there is less awareness and knowledge, both among health-care professionals, including physicians and psychiatrists, about EOLC and controversies abound, especially in relation to foregoing of life support treatments and euthanasia (Gibbins *et al.*, 2011<sup>[13]</sup>).

This article aims to give an overview of EOLC, current trends, role of psychiatry in this field and future directions, with an emphasis on the Indian context.

## Need to Talk about End-of-Life Care in India

According to the World Health Organization Global Statistics 2012, 63% of the estimated 57 million deaths globally in 2008 resulted from noncommunicable diseases. Eighty percent of these were in low- and middle-income countries (WHO, 2012<sup>[52]</sup>). In 2011, an estimated 20.4 million people worldwide needed palliative care at the end of life (Macaden *et al.*, 2014<sup>[25]</sup>). The common serious illnesses were cardiovascular diseases (38.5%), cancer (34%), chronic pulmonary diseases (10.3%), human immunodeficiency virus related (5.7%), and diabetes (4.5%). Approximately 53% of deaths in India are due to noncommunicable diseases, mainly cardiovascular and chronic respiratory cancer and diabetes (Sharma, 2013<sup>[42]</sup>). In India, 1 million new cancers are diagnosed each year, two-thirds presenting in incurable stages.

There is a projected increase in the elderly population globally, mainly in the developing nations. India is referred to as the “aging nation,” with 7.7% of its population being over 60 years of age and a projected increase to 324 million by 2050 (Ingle and Nath, 2008<sup>[15]</sup>). This rise will lead to a greater health-related burden. A study in India has reported that most patients would prefer to die at home (Kulkarni *et al.*, 2014<sup>[20]</sup>). However, most patients with advanced, progressive, life-limiting illnesses in terminal stages get transferred to hospitals and Intensive Care Units for acute, medically life prolonging, or supporting interventions. They later die in the hospital in an environment away from loved ones. Due to lack of clear guidelines for physicians on EOLC, patients are subjected to futile treatments, often expensive, pushing the families into grave economic crises. Relatives, therefore, are often forced to take the patients home on leave against medical advice (Mani, 2003<sup>[28]</sup>).

The Economic Intelligence Unit report, funded by the Lien Foundation, stated that out of 40 OECD countries, India figured as the worst (40<sup>th</sup> rank) place to die (Macaden, 2011<sup>[26]</sup>). In the recently released report on the Quality of Death Index 2015, India has ranked 67<sup>th</sup> out of 80 countries included<sup>[50]</sup>.

Misconceptions exist among health-care providers about EOLC, with misrepresentations of EOLC as euthanasia, resulting in controversies. It is, therefore, necessary to have a clear understanding of various aspects of EOLC in India and future directions that need to be taken.

## End-of-Life Care: General Concepts

The concept that palliative care begins when all treatment modalities fail is outmoded. The current concept of palliative care is that its scope lies across the disease trajectory, integrating it with disease-specific treatment, focusing on comprehensive interdisciplinary care for the patients and their families. EOLC lies on a continuum with active disease modifying treatment, palliative care, and supportive care. This continuum ensures that patients and their families are cared for during the end-of-life and dying process, after the death of the patients and during the bereavement period (Luckett *et al.*, 2014<sup>[23]</sup>).

EOLC can be defined as holistic care of people with advanced/progressive/incurable, life-limiting illnesses, with the help of a multidisciplinary team, to enable these patients to live their lives as well as they can before death. This total care approach includes care of the caregivers as well (Macaden *et al.*, 2014<sup>[25]</sup>).

The objectives of good EOLC are:

1. To ensure that each patient achieves “good death,” irrespective of type and duration of disease and place of death
2. To focus on quality of life as well as that of death

3. To acknowledge that each person is entitled to a peaceful and dignified death, with freedom from pain and suffering; right to palliative care is a human right.

## Principles of “Good Death”

According to the principles of good death (Smith, 2000<sup>[48]</sup>), the dying person should:

- Be able to know that death is near, to understand what happens at this time
- Have control of pain and other symptoms
- Maintain dignity and privacy
- Be able to decide the desired place of death
- Be able to access specialist care and emotional/spiritual support
- Be able to get admitted to hospice services
- Have control over who is present at the time of death, to be able to say farewell
- Have choice of making advance directives so that the patient’s wishes are followed
- Be able to leave the world and not have unnecessary prolonging of life.

## Steps in End-of-Life Care

For initiating and implementing good EOLC, certain steps are recommended (Chapman and Ellershaw, 2011<sup>[6]</sup>). These are as follows:

### Identifying that the dying process has begun

The signs include failing vital parameters, decreased movement and response, detachedness from the environment, reduced oral intake, and altered breathing pattern. However, it should be remembered that it is not always possible to predict imminent death.

### Clear decision-making

The primary caregivers, along with the treating team, have to be involved in the decision-making process which might be complex. End-of-life decision-making (EOLD) should begin when further disease-directed therapy is not possible in the person with advanced progressive disease, or there is prolonged coma without any reversible cause, or there is a sudden catastrophic medical condition with multiorgan failure with no response to intensive management. EOLD involves open and honest communication, discussing prognosis, transition in care including stopping of a disease-modifying treatment and focus on comfort care, management of symptoms, and dying process (Raijmakers *et al.*, 2012<sup>[38]</sup>).

## Initiating end-of-life care

Criteria for initiating EOLC are of three types (Phillips *et al.*, 2011<sup>[36]</sup>):

1. Clinical: focusing on advanced condition of the illness;
2. Agreement: shared decision-making and consensus between medical teams and caregivers
3. Symptom control: management of symptoms at the last phase of life and in the dying process.

## Implementation of the process

As per the international strategies on EOLC of the Gold Standards Framework (Shaw *et al.*, 2010<sup>[44]</sup>), the process involves the following steps:

1. Identifying the patients who need EOLC
2. Assessing the needs of these patients, evaluating their symptoms, and understanding their preferences
3. Planning of EOLC in the preferred place of patients
4. Providing EOLC with ongoing review of measures and decisions
5. Reflecting on the care provided with an aim at improvement.

## After death care

This involves addressing the family's needs in a manner sensitive and culturally appropriate to the deceased patient and bereaved family and certification of death (Olausson, 2013<sup>[35]</sup>).

## Bereavement care

Support for bereaved families includes compassion, good communication, emotional preparation, and privacy.

Case Vignette 1 below illustrates all these points.

## Case vignette 1

*Mr. C, 57 years, with a diagnosis of advanced hepatocellular carcinoma with progressive ascites, was referred to inpatient liaison psychiatry and palliative medicine services for EOLC in a tertiary care hospital. Assessment revealed a decrease in patient's sensorium, with decreased oral intake, failing vital parameters, and detachment from surroundings. Discussion with primary treating oncology team confirmed the commencement of end-of-life stage for the patient. Sensitive communication with the family was of utmost importance regarding EOLC, with a focus on symptom management and "comfort care." The family reported that the patient's preferred place of death had not been discussed earlier, but they felt that hospital was the reasonable place for him at that time since they were from out of*

*town. The patient's wife was aware of his deterioration and needed emotional support. Medical and nursing staff and ward attendants carried out the after-death care in a thoughtful and sensitive manner, which included allowing the family to do prayers at the bedside. Bereavement support by counselling helpline was provided after a few days after the patient passed away.*

## **Ethical principles in End-of-Life Care**

The four pillars of bio-medical ethics are autonomy, beneficence, nonmaleficance, and justice (Beauchamp and Childress, 2009)<sup>[2]</sup>. Justice, however, in EOLC, is mainly social justice (elaborated below). All these principles are integrally connected and interdependent though, for the sake of our understanding, we may separate them into different categories. In relation to EOLC (Shreves and Marcolini, 2014<sup>[45]</sup>), these four can be briefly described as follows:

### **Autonomy**

The adult patient has the right to consent to or refuse treatment. This right should be valid across all treatment options and decisions, including those in end of life. If the patient is not competent to make this decision, a "substituted" decision from a surrogate is acceptable. An advanced directive or will, if present and applicable, as permitted for example, in the United States of America, or a Health Care Proxy, helps caregivers in decision-making during EOLC, by keeping in mind their patient's preferences made when he/she had full capacity. For those patients who do not have mental capacity, treatment decisions should be made in the patients' "best interest."

### **Beneficence**

This principle implies that all interventions should be in the patient's best interest. The physician has to weigh the risks and benefits of any intervention/treatment/procedure. With respect to chronic, progressive, or advanced, life-limiting illness, when interventions are unable to reverse the dying process that has already begun, subjecting patients to needless invasive, expensive procedures contravenes this ethical standard. It is interesting to note that some may view this as nonmaleficance, that is, "Above all, do no harm" (discussed below). To this the answer is that, actually speaking, nonmaleficance is inbuilt into beneficence (Singh and Singh, 2009<sup>[47]</sup>). Furthermore, expensive management options place the families in dire financial situations, especially if they have used up their savings on curative treatment earlier. Foregoing of life-support interventions (FLST) in the background of a terminal illness is a practical option if there are negligible advantages of an acute intervention. Again, the question may be asked: is this not

nonmalfeasance? It is in a way; however, looked at in another manner, weighing risks and benefits of interventions is in the patients' best interest; and hence, not doing an investigation or treatment in view of risks superseding benefits will be beneficence. Beneficence, ideally, should be to carry out all necessary interventions based on current knowledge, physician's expertise, and optimum facilities available, always remembering that the patient's welfare is supreme, not of the setup where he/she is treated, and not of the treating team. Moreover, while so doing, that nonmalfeasance is always ensured.

## Nonmalfeasance

This states, "first, do no harm." An action by the physician in the best interest of the patient may have unintended consequences. The doctrine of double effect is applicable here and has been explained well by Macaden *et al.*, 2014, in their position paper<sup>[25]</sup> (it may be noted that although "double effects" are applicable to all the 4 ethical principles, with regard to EOLC, they are most obviously connected to nonmalfeasance). In EOLC, this applies to situations when to achieve adequate pain control using opioid analgesics and sedation, respiratory depression may result, which may shorten the dying process. However, the intended action is meant to relieve suffering due to severe pain and is therefore ethically sanctionable. The ill effect (sedation/respiratory depression) is unintended though known as a possibility and not out of proportion to the beneficial effect.

## Social justice

All health-care resources should be equitably distributed depending on condition of the patients and the stage of the disease. Beauchamp and Childress (2009<sup>[2]</sup>) refer to justice, which includes social justice; justice means the application of all the three above principles in a fair manner and also that the patient can take recourse to judicial measures in case of dispute. However, in the case of EOLC, we are mainly concerned with social justice in view of the specific problem of allocating resources depending on the medical condition.

## Case vignette 1 [Contd. 1]

*In the case described earlier, it was not possible to get patient's decision as his/her sensorium was impaired (autonomy). However, clear communication with family, particularly patient's wife, made it possible for clinicians to work in the patient's best interest (beneficence). Futility of aggressive interventions (nonmalfeasance), for example, shifting patient to the Intensive Care Unit was discussed with the family and accepted by them. The best possible palliative care both before and after death was provided, respecting the patient/family's wishes, and social/religious beliefs, irrespective of their creed or social status (social justice).*

## Concept of Futility

Medical futility is difficult to define (McCabe and Storm, 2008<sup>[29]</sup>) as reflected in the differences of the definition given by various professional associations. The descriptions include “no reasonable chance of benefiting the patient,” “highly unlikely to result in meaningful survival,” and “the physician must be certain that the intervention will fail to accomplish its intended goal.” Medical futility can be quantitative, qualitative, physiologic, lethal condition and imminent demise futility (Myatra *et al.*, 2014<sup>[32]</sup>).

A small elaboration may be useful here. The goal of treatment in any situation should be to improve survival or quality of life. Risk-benefit assessment should include physical as well as psychological impact and effect on economic condition of the patient. If a treatment does not adhere to the above and is judged to be “futile,” considering the irreversible nature of the medical condition, administration of such an intervention is likely to cause more harm. Coming to an agreement about futility of treatment helps in initiating the communication regarding the need for EOLC. Hence, understanding perceived futility plays a significant role.

### Case vignette 1 [Contd. 2]

*Apart from the decision to not transfer patient to intensive care in the case described above, considering the unmodifiable factors in a progressively deteriorating patient with advanced cancer, interventions such as ascitic tapping, administration of intravenous albumin or antibiotics were also avoided, leading to prevention of unnecessary and futile procedures and expenses.*

## Advance Directives and Advance Care Planning

### Advance directives

Advance directives are written documents that patients can prepare prescribing what medical decisions they would want to make and interventions they want to allow or refuse when they become ill in future. These can be of two types - (1) substantive, which is a “Living Will,” allowing a patient to specify specific wishes for future care and (2) process, which is “Healthcare Proxy” or health-care power of attorney, designating a substitute decision-maker.

Certain problems arise in the use of advance directives, and research has revealed that employing advance directives did not significantly impact on EOLC-related communication or decision (Connors *et al.*, 1995<sup>[9]</sup>; Teno *et al.*, 2007<sup>[49]</sup>). There are reasons for this lack of impact. One explanation is that patients



may find it hard to envisage exactly what type of care they might want in the future. Second, patient preferences may change over time which would create problems in following the advance directive made earlier. Furthermore, it has been found that sometimes advance directives have too specific a language, creating barriers to implementation.

### *Indian position*

Sarin (2012)<sup>[40]</sup>, in discussing the concept and possible applicability of advance directives in psychiatrically ill patients in India, has pointed out the relevant advantages of using advance directives as a “clinical decision-making tool” along with the challenges of use of the same as a legal document.

### **Advance care planning**

Advance care planning is thought to be a better construct, focussing more on communication, decision-making, and emotions and having discussions about goals of care. Advance directives are very specific and static in nature. In contrast to that, advance care planning is a more comprehensive and flexible process, permitting changes in patients’ choices and values. Advance care planning is an effective way of understanding the patients’ wishes when their communication or decision-making may be compromised at a later stage due to disease progression, with the families deciding on the surrogate decision-maker who gets involved early in the patient’s care and can make a reasonable judgment about approval or otherwise of the proposed treatment. Advance care planning is an important dynamic and flexible process (Bloomer *et al.*, 2010<sup>[3]</sup>). Although formation of a written record is not the purpose as is required for an advance directive, it is advisable for the physicians to necessarily put down the notes of the results of the discussion about the advance care plans made, involving patients and their families.

### *Indian position*

Advance care planning has been recommended as a part of the EOLC decision-making process in the position statement by the Indian Association of Palliative Care (IAPC)<sup>[25]</sup>. At the time of writing this article, the author has been informed that the National Accreditation Board for Hospitals has included a section on EOLC policy in the recent edition of their standards<sup>[33]</sup>.

## **Role of Psychiatry in End-of-Life Care**

In view of the issues discussed above in and around EOLC, the role of psychiatry in EOLC is full of possibilities. The phenomenal research on death, grief, and bereavement was pioneered by Elizabeth Kubler-Ross, a Swiss American psychiatrist, published in her world famous treatise “On Death and Dying”<sup>[18,19]</sup>.

Communication skills are an integral part of patient and caregiver–physician discussion in EOLC (Quenot *et al.*, 2012<sup>[37]</sup>). The psychiatrist can meaningfully contribute to development, training, and implementation of communication interventions for this purpose. The psychiatrist, with in-depth understanding of living with a life-limiting condition, can evaluate psychological issues common to these patients and their caregivers such as hopelessness, demoralization, and anticipatory grief, especially in terminal and end-of-life phase. He/she can make a comprehensive assessment of the psychosocial and spiritual issues and the impact of physical problems and medical interventions on the mental health of the patient in end of life. He/she can distinguish between distress and clinically significant depressive and anxiety disorders and delirium, commonly seen in terminal illness and EOLC (Chochinov, 2000<sup>[7]</sup>).

The psychiatrist, by his/her expert ability to liaise and communicate with the primary team, palliative-care professionals, and the caregivers, can effectively add to relevant, occasionally difficult and complex end of life decision-making process. The psychiatrist can add to capacity evaluations, aiding in management plans made by the primary team in EOLC. He/she understands family dynamics and systems, which make him/her an invaluable member of the palliative-care team working with the caregivers.

The association between spirituality and mental health has been documented (Sharma *et al.*, 2009<sup>[43]</sup>). By virtue of training, the psychiatrist can understand spiritual and existential issues of both patients and their caregivers and address spiritual pain and suffering in EOLC. Psychiatrists working in the field of oncology and palliative care have developed advanced psychotherapies, addressing emotional, psychosocial, and spiritual issues, which are of benefit in terminal illness (Chochinov *et al.*, 2005<sup>[8]</sup>; Breitbart *et al.*, 2010<sup>[4]</sup>).

Complex psychopharmacological interventions may be required near the end of life for management of symptoms of depression, delirium, and anxiety. The psychiatrist can thus bring about relief of pain and suffering by appropriate symptom management.

Psychiatry has major part in identifying anticipatory grief and applying relevant interventions for bereavement work. Kissane *et al.*, well known for working in psycho-oncology and palliative care, have developed “Family Focused Grief Therapy,” a well-established, evidence-based psychotherapeutic intervention useful in certain dysfunctional families with patients approaching end of life (Kissane *et al.*, 2006<sup>[17]</sup>).

The psychiatrist’s skills in decision-making and knowledge about ethical principles make his/her position as a significant contributor in EOLC. He/she can recognize and manage stress in staff working with patients in their end of life and also in their caregivers.

### Case vignette 1 [Contd. 3]

*Continuing on the case vignette mentioned earlier, the liaison psychiatrist had several roles to play – (1) communication with primary oncology team, palliative-care professionals, and family, aiding in collaborative decision-making; (2) assessment of capacity; (3) identifying anticipatory grief of family and later bereavement counselling for them; (4) providing emotional support for staff involved to prevent stress and burnout.*

The prospect for psychiatry in palliative care is full of opportunities for good service provision, training, and research. Palliative care psychiatry is a specialized area, focussing not just on advanced, progressive, life-limiting illnesses but also has a function to perform in severe psychiatric illnesses such as schizophrenia and bipolar disorders (Irwin and Montross, 2011<sup>[16]</sup>).

Although controversial and having different connotations in different countries, assisted dying practices are legal in certain nations, such as Belgium, the Netherlands, Luxembourg, and states of Washington and Oregon in the USA. McCormack and Flechais have reviewed psychiatrist's role and mental illnesses in assisted dying practices internationally (McCormack and Fléchais, 2012<sup>[30]</sup>). A psychiatry referral is recommended in certain conditions such as "exclusive mental disorder," but there is no overarching policy of a mandatory requirement of psychiatry assessment in any country.

What does this mean and why is it important to know? Patients with "exclusive mental disorder" are those with mental disorders such as major depressive disorder in the absence of any terminal physical illness. These patients can request for assisted dying in the European countries mentioned above. Capacity assessments are, therefore, important and the presence of suffering is essential. The role of the psychiatrist can be crucial. However, it is not stated as obligatory in the Assisted Dying Acts reviewed by the authors.

## Psychiatry, Dementia, and End-of-Life Care

Palliative and EOLC are important in people with dementia, broad issues being symptom management, care provision, place of care, dignity in person-centered care, and training (van Soest-Poortvliet *et al.*, 2015<sup>[51]</sup>). The psychiatrist has a key role to play in EOLC for patients with dementia by addressing the concerns and providing emotional support to their caregivers. A thoughtful editorial in the British Journal of Psychiatry has emphasized the standing importance of EOLC in patients with dementia and the need to better the same (Sampson *et al.*, 2011<sup>[39]</sup>).

The median survival in patients with dementia is about 4.1 years and in those with advanced dementia is 1.3 years (Sampson *et al.*, 2011<sup>[39]</sup>). These patients have severe problems with pain, dyspnea, feeding difficulties, risk of infection

and aspiration, and pressure sores. The symptom burden in dementia patients is comparable to those of terminal cancer patients. The family members have a high caregiver burden and need support for emotional distress.

Other issues include capacity evaluations, inappropriately aggressive investigations or hospitalizations, and placement for care. Good person-centered care is crucial at the EOLC in advanced dementia. Although there are nursing or residential homes for regular and respite care of the elderly with dementia in the developed nations, there are still difficulties about adequately trained staff, less use of advance care planning, and poor quality of care (Lawrence *et al.*, 2011<sup>[22]</sup>). van Soest-Poortvliet *et al.* 2015, in their prospective study on comfort goal of care and outcomes in dementia patients in end of life, have noted that family's satisfaction with care received by the patient is an important factor<sup>[51]</sup>.

The standardized guidelines have incorporated palliative and EOLC in the algorithm of management (National Institute for Health and Clinical Excellence 2006)<sup>[34]</sup>. Patients with dementia also deserve good quality EOLC to achieve a good death with freedom from pain and other distressing symptoms, breathing their last in the midst of family and loved ones, affirming the whole person. There is, thus, an overwhelming role of the psychiatrist to be working in this area, for developing guidelines, training professionals involved in dementia, and providing suitable services for addressing EOLC needs in this vulnerable population. Psychiatry has a prime responsibility in this field.

In the case of psychiatry in India, Shaji (2009)<sup>[41]</sup> has outlined the principle of incorporation of palliative care in addressing need-based interventions of patients with dementia and has stated the objectives as part of the 10/66 Dementia Research Group's India Network.

## **International Perspectives in End-of-Life Care**

Service, education, and research in palliative and EOLC are well ensconced in health-care models in the United States of America, Canada, the United Kingdom, and most other countries in Europe and Australia, with established standards and care pathways (Singer and Bowman, 2002<sup>[46]</sup>). There are different service delivery models including home-based services and hospices facilitating EOLC. There are clear-cut procedures for advance directives, advance care planning, and guiding principles for withdrawing and withholding life-support measures. Although there are debates about legality of euthanasia, there exists a clear separation of the concept of euthanasia from EOLC. Recommendations for best practice have been reviewed, the broad themes in EOLC being symptom control, relational and social aspects, preparation for death, existential issues, quality of life, end of life

decision-making, and dignity (Barazzetti *et al.*, 2010<sup>[1]</sup>). A systematic review has advocated validated measures for use in research (Luta *et al.*, 2015<sup>[24]</sup>).

## **Current Issues in End-of-Life Care in India**

In India, in contrast to the western world, “paternalism” still tends to outweigh “patient autonomy.” The physician is thought to be the sole decision-maker, and patients and families are often compliant with this situation. Patient choices, family collaborations, and discussions about end of life care are fraught with difficulties in EOLC (Macaden *et al.*, 2014<sup>[25]</sup>).

Health service delivery is based mainly on an acute model of care. Although palliative care has made inroads into health care in certain parts of the country, the awareness of EOLC is quite poor.

Patients and families have unrealistic expectations and hope for a cure, for which they spend on “futile” treatments which are expensive, with minimal chance for a good outcome. Physicians are also reluctant to stop active, or limit, life-support interventions due to lack of clear guidelines in this area. Myatra *et al.* found in their study in Mumbai that foregoing life-support interventions was greater in public hospitals as compared to private hospitals (Myatra *et al.*, 2010<sup>[31]</sup>).

## **Reforms Needed in India**

End of life care is not well conceptualized and formulated in India, with no clear policy. There are complex legalities as discussed below. Comprehensive and clear guidelines or recommendations are required to be translated into clinical practice, along with appropriate education, and relevant service provision to take care of the terminally ill and dying patients. Recognition of the importance of care for patients at the end of life, clear decision-making processes, effective symptom control, and holistic care need to be incorporated into routine clinical practice for quality end of life care.

## **Legal Scenario Regarding End-of-life Care Issues in India**

In India, the right to consent to or refuse treatment is recognized by law. Although in an earlier case, law allowed the right to die when in a situation of excruciating suffering, the Indian Supreme Court later overturned this. These cases, however, related to suicide and attempted suicide and not to EOLC (Macaden *et al.*, 2014<sup>[25]</sup>). What does this mean and what does it imply? The law has been used to interpret all decisions relating to life support interventions as suicide and not as end of life care. This creates a barrier for professionals wanting to initiate appropriate management options in the end of life.

Euthanasia is defined as administering a lethal drug by a doctor to the patient at the latter's request to bring an end to his/her suffering. The Law Commission of India has made a definite distinction between euthanasia and end of life decision about foregoing life support interventions. The decision could be made by the patient having the capacity to make this decision but not by the family on behalf of the patient (Myatra *et al.*, 2014<sup>[32]</sup>).

In the Aruna Shanbaug case in India, the judgment stated that "involuntary passive euthanasia" was legal but subjected to strict procedures and safety measures (Chakravarty and Kapoor, 2012<sup>[5]</sup>). However, the term "involuntary passive euthanasia" is not in accordance with the current medical terminology. Withholding and withdrawing life support interventions could be considered in certain situations, as per the ruling. Application of these guiding principles is feasible in persistent vegetative states (Macaden *et al.*, 2014<sup>[25]</sup>). However, ambiguities remain following this judgment. Issues around critical care settings concerning initiation, discussion, and process of EOLC with all its integral components necessary to achieve a good death for the dying patient are still being debated.

A consensus position statement by the Indian Association of Palliative Care (IAPC) has been published on a policy on end of life care (Macaden *et al.*, 2014<sup>[25]</sup>). The Indian Society of Critical Care Medicine (ISCCM) and the IAPC have published guidelines and recommendations for an integrated plan for the dying (Myatra *et al.*, 2014<sup>[32]</sup>).

The guidelines comprise an effective and comprehensive pathway for the assessment, communication, decision-making, and process in EOLC. There are recommendations about physicians' assessment of dying process, consensus or agreement among care providers, sensitive communication with family and discussion about EOLC, concept of shared decision-making, appropriate and relevant documentation about the process and decisions, maintaining consistency among family caregivers, instituting the EOLC process throughout the dying process, after death and bereavement period, with ongoing review.

The current legal scenario is that "Common Cause," a nongovernmental organization, has filed a petition for the right to die with dignity to be recognized as a fundamental right along with provisions for "Living Will and Power of Attorney." A five-judge committee has been formed by the Chief Justice of India to address problems and questions around euthanasia and dignity in death. An impleadment appeal has been filed by the ISCCM in response to the writ petition (Myatra *et al.*, 2014<sup>[32]</sup>).

## **Future Directions and Responsibility of Psychiatry in End-of-Life Care in India**

There is an overwhelming need for awareness in India, among health-care

professionals and public alike, on EOLC. A study conducted in Northern India reported that physicians had less knowledge about EOLC issues in terminally ill elderly cancer patients (Gupta *et al.*, 2007<sup>[14]</sup>). To facilitate the movement and service provision, a policy on EOLC should be formulated for implementation. The different stakeholders have to bring it to the forefront of healthcare issues in the country. Palliative and EOLC services have to be set up, incorporated, and provided by hospitals, community clinics, and home-based services throughout the country. Although some Indian states such as Kerala do have a mandate on palliative care and these services are existent, in other states, barriers are being faced in implementation despite having a policy (Kumar, 2013<sup>[21]</sup>).

Service provision implies a role of training in palliative and EOLC. The ISCCM and IAPC have arranged educational programmes for medical and nursing professionals through different centers in India around World Hospice and Palliative Care Day on October 11. Such systems must be in place as part of round the year curriculum in hospitals, organizations, and associations.

In this context, psychiatrists, by virtue of their knowledge, skills, and competence, have a great role to play in EOLC. They have to apply their skills in EOLC for patients with both chronic, serious, advanced/progressive, life-limiting diseases as well as those with severe, persistent, mental illnesses including dementia.

Various authors have discussed education of psychiatry trainees in palliative and EOLC (Fairman and Irwin, 2013<sup>[11]</sup>). Palliative care psychiatry, end of life care and end of life decision making need to figure in the curriculum of postgraduate education as well as continuing professional development in psychiatry. Advance directives have been introduced in the draft Mental Health Care Bill, making it the duty of all psychiatrists to be experts in advice, application, and implementation of these concepts to their patients, which could be a valuable measure in end of life care (Sarin, 2012<sup>[40]</sup>).

End of life care in dementia is a major area for psychiatrists to be involved in. Patients with severe mental illnesses are more at risk for developing serious physical illnesses, which can shorten their life span. Physicians have a duty to look after these patients throughout their illness trajectory. It is their ethos to maintain dignity in life and ensure dignity in death for all their patients. The role of psychiatry in end of life care is a significant one and can be a rewarding experience. Psychiatrists should make all efforts to get involved in the discussion around end of life care to ensure proper guidelines, procedures, service, and legal provisions which are put in place in India and be at par with international standards [Figure 1].

## Concluding Remarks

Patients who have a chronic, serious, advanced or progressive, life-limiting illness need, in their terminal phase, comprehensive, compassionate care for

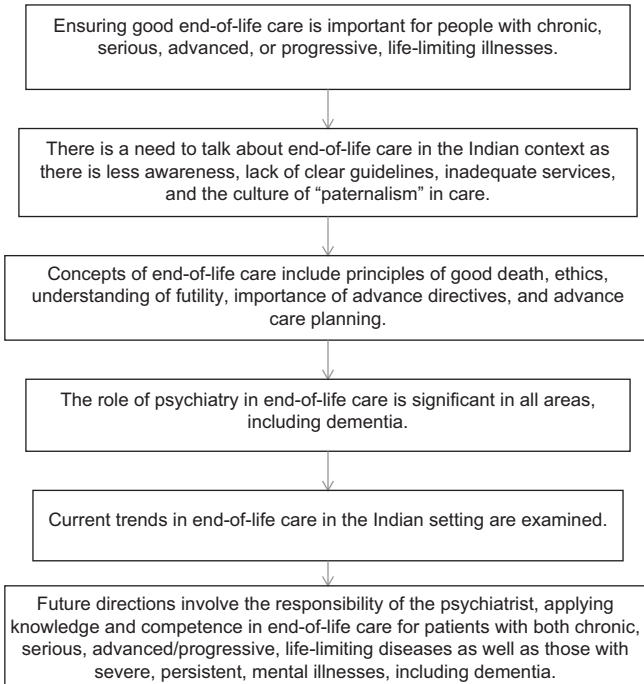


Figure 1: Flowchart of the paper

freedom from pain and symptoms, psychological, social, existential, and spiritual distress, so as to achieve a "dignified exit" or "good death." There is inadequate service provision and awareness about end of life care in India. Good end of life care ensures patients can have dignity in death as in life, and caregivers receive the support they need. Psychiatry has a significant part to play in this process, which can be both learning and rewarding experience for the psychiatrist working in end of life care in all the aspects of clinical services, education, training, and research.

## Take Home Message

1. Understanding of concepts, practice, and education of EOLC are essential for psychiatrists.
2. The psychiatrist has a major role to play in the area of EOLC in patients with both chronic, serious, life-limiting physical diseases as well as severe, persistent, mental illnesses.
3. A lot has to be done to improve EOLC facilities in India.



## Conflict of interest

None declared.

## Declaration

This is my original, unpublished work not submitted for publication elsewhere.

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### Questions that this paper raises

1. What is the impact of inclusion of a liaison psychiatrist in the Intensive Care Unit team?
2. What are the psychiatric interventions of benefit for patients in end-of-life care in India?
3. What are the barriers to inclusion of a psychiatrist in end-of-life care services in India?
4. Is there a change in the belief systems of the caregivers when patients are in their end of life?
5. What is the effect of culture on bereavement interventions?

#### About the Author



*Jayita Deodhar MD (Psych), DPM, DNB (Psych), MRCPsych, is a Consultant Psychiatrist and Associate Professor, working full time in psycho-oncology for the last 10 years at Tata Memorial Centre, Mumbai, India. She has an active interest in psychodynamic psychotherapy and cognitive-behavioral therapy. She is interested in research in psycho-oncology and palliative care psychiatry. She has been the Country Coordinator for the International Psycho-Oncology Society's Special Psychosocial Academy held for the first time in India, which she organized in November 2013 at Tata Memorial Hospital in Mumbai. She is Editor, Archives of Indian Psychiatry (official publication of the Indian Psychiatric Society - Western Zonal Branch). She serves on the Education Committee of the International Psycho-Oncology Society.*