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## **Critical Analysis of The Medical Treatment of Terminally-Ill Patients (Protection of Patients and Medical Practitioners) Bill, 2016**

The Medical Treatment of Terminally Ill Patients (Protection of Patients and Medical Practitioners) Bill (referred to as the Bill in this chapter) was published by the Ministry of Health and Family Welfare in May, 2016. The Bill is derived from of a draft law that was first attached to the Law Commission of India's 196th Report in 2006<sup>684</sup> and later updated in 2012<sup>685</sup>. In this chapter, we study the Bill's provisions, analyse them critically and offer recommendations for necessary amendments to fill up the lacunae in the bill in its current form.

The Bill has been drafted “to provide for the protection of patients and medical practitioners from liability in the context of withholding or withdrawing medical treatment including life support systems from patients who are terminally ill and for matters connected therewith and incidental thereto.”<sup>686</sup> For terminally ill

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<sup>684</sup> The Law Commission of India, “196th Report on Medical Treatment of Terminally Ill Patients (Protection of Patients and Medical Practitioners), (2006).

<sup>685</sup> The Law Commission of India, “241st Report on Passive Euthanasia – A Relook”, (2012).

<sup>686</sup> The Medical Treatment of Terminally-Ill Patients (Protection of Patients and Medical Practitioners) Bill, 2016, (Bill No. 293 of 2016)

patients who do not wish to start or continue treatment, this Bill tries to legalise passive euthanasia. When a decision is made in accordance with the requirements of the Bill, it also protects the patient and the treating physician from any civil or criminal liability. Additionally, the Bill aims to make living wills and medical power-of-attorney legal. Some crucial definitions provided in the Bill are as mentioned below.

- Section 2 (a) of the Bill uses the terms ‘advance medical directive’ and ‘living will’ synonymously and defines them as “a directive given by a person that he or she, as the case may be, shall or shall not be given medical treatment in future when he or she becomes terminally ill and becomes an incompetent patient”.<sup>687</sup>
- Section 2 (c) defines competent patient as someone who is not incompetent. Section 2 (d) defines incompetent patient as “a patient who is a minor below the age of sixteen years or person of unsound mind or a patient who is unable to, - (i) understand the information relevant to an informed decision about the medical treatment; (ii) retain that information; (iii) use or weigh that information as part of the process of making the informed decision; (iv) make an informed decision because of impairment of or a disturbance in the functioning of his mind or brain; or (v) communicate the informed decision, whether by speech, sign, language or any other mode, as to medical treatment”.<sup>688</sup>
- Section 2 (h) defines medical power-of-attorney as “a document of decisions in future as to medical treatment which has to be given or not to be given to him if he becomes terminally ill and becomes an incompetent patient”.<sup>689</sup>
- Section 2 (k) defines palliative care as “the provision of reasonable medical and nursing procedures for the relief of physical pain, suffering, discomfort or emotional and psycho-social suffering; and the reasonable provision for food and water”.<sup>690</sup>
- Section 2 (m) defines terminal illness as “such illness, injury or degeneration of physical or mental condition which is causing extreme pain and suffering to the patient and which, according to reasonable medical opinion, will inevitably cause

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<sup>687</sup> The Medical Treatment of Terminally-Ill Patients (Protection of Patients and Medical Practitioners) Bill, 2016, s. 2(a)

<sup>688</sup> *Id.*, s. 2(c), 2(d).

<sup>689</sup> *Id.*, s. 2(h).

<sup>690</sup> *Id.*, s. 2(k)

the untimely death of the patient concerned” or “which has caused a persistent and irreversible vegetative condition under which no meaningful existence of life is possible for the patient”.<sup>691</sup>

The provisions of the Bill can be summarized as below

- Every competent person aged 16 years and above, suffering from a terminal illness, can request the treating doctor to withhold or withdraw treatment. Such a request is binding on the treating doctor as long as the doctor is satisfied that the patient is competent to take such decisions and the decision has been taken with free will. In case of minors above 16 years, consent of the parents or legal guardians or next friend must also be taken.<sup>692</sup>
- The doctor should inform the decision taken by a competent patient to the family members or next friend. He should also inform them his own opinion regarding continuation or discontinuation of treatment. He should then wait for 3 days to proceed with the decision taken by the patient. The doctor should maintain the records of such decisions including the personal details of the patient, the request made by the patient and his own opinion on whether such a decision is in the best interest of the patient. When requested, the doctor should provide a copy of these records to the family members without delay. Palliative care can be provided to the patient even if medical treatment is discontinued or withheld.<sup>693</sup>
- The Bill protects the patient from prosecution under any provisions of the IPC for refusing medical treatment. Similarly, when the treating doctor withholds or withdraws treatment from a patient according to the procedures laid out in the Bill, he is protected from prosecution.<sup>694</sup>
- The Bill proposes constitution of panels of medical experts for each state. Such panels will be consulted to obtain expert opinion as and when required by the jurisdictional High Courts.<sup>695</sup>
- In case of incompetent patients, their family members, next friend, legal guardian, the treating doctor or the paramedical staff attending the patient can approach the

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<sup>691</sup> The Medical Treatment of Terminally-Ill Patients (Protection of Patients and Medical Practitioners) Bill, 2016, s. 2(m),

<sup>692</sup> *Id.*, s. 3(1),3(2),

<sup>693</sup> *Id.*, s. 3(3),5 and 6.

<sup>694</sup> *Id.*, s. 7 and 8.

<sup>695</sup> *Id.*, s.4.

jurisdictional High Court for permission to withhold or withdraw treatment. The Court, after considering the expert opinion of the panel of doctors and the wishes of the applicants will pass orders granting or refusing permission or granting conditional permission. The family members or next friend and the treating doctor who withholds or withdraws treatment in accordance with such orders from the High Court shall not be liable to prosecution.<sup>696</sup>

- The advance medical directives or the medical power-of-attorneys are not binding on the treating doctor.<sup>697</sup>

## 6.1 Critical Analysis of the Bill

1. The Bill states that advance medical directives and medical power-of-attorney are not binding on the treating doctor when deciding on the matter of withdrawing or withholding treatment to a terminally ill patient who is not competent to make their own decision. This goes against the principle of autonomy and, in effect, diminishes the dignity of the dying patient. Such a provision is also discriminatory as it will treat a person who has documented their wishes in advance but has now become incompetent to convey the same than a person who has remained competent and can express their wishes to the treating doctor.
2. The definition of terminal illness provided in section 2 (m) of the Bill uses the phrases ‘untimely death’ and ‘meaningful existence’.

Using the phrase untimely death can potentially exclude elderly persons from the purview of the Bill as they will inevitably have a limited life expectancy, and one may consider that their death from any illness cannot be considered ‘untimely’. Instead of such vague terminology, a clearly defined prognosis (e.g., less than six months) can be used to avoid discrimination.

The term "meaningful existence" is ambiguous and might signify different things to different people. This will lead to subjective interpretation, particularly when the patient becomes incompetent to convey their wishes.

3. Section 6 allows the treating doctor to provide palliative care to a terminally ill patient even when they have refused medical care. This provision also goes

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<sup>696</sup> The Medical Treatment of Terminally-Ill Patients (Protection of Patients and Medical Practitioners) Bill, 2016, s. 9(1) to 9(5).

<sup>697</sup> *Id.*, s. 11.

against the principle of autonomy. The decision to accept or refuse palliative care should be the prerogative of the patient. They should receive palliative care only when they have provided informed consent for the same. Providing palliative care, even as basic as artificial feeding to a patient in a persistent vegetative state can sometimes prolong survival. This can potentially prolong the suffering of the patient, thereby defeating the purpose of refusing medical care in the first place. Similarly, while providing palliative care, the patient may die inadvertently (e.g., from the effects of opioid analgesics given to patients suffering from painful metastatic cancers). Therefore, providing palliative care without informed consent, wherein, among other things, the patient is informed about the possible adverse effects, can lead to situations where the medical professionals can be sued for malpractice and negligence.

4. The Bill also appears to put the onus on the treating doctor to decide the appropriateness of the decision taken by the patient to accept or refuse treatment. The doctor's role should be limited to providing all the necessary information that the patient requires to make an informed decision. The patient should have information on the nature and prognosis of the illness, the available treatment options, including palliative care, the possible adverse effects of the various treatment modalities, and the consequences of choosing not to accept treatment. Thereafter, whatever decision a competent patient makes should be binding on the treating doctor. The opinion of the doctor on whether such a decision is in the best interest of the patient or not should be irrelevant.
5. A few aspects of the Mental Healthcare Act of 2017 (MH Act) appear to be at odds with the Bill.

Patients who opt to refuse medical treatment under this Bill while being competent are exempt from legal culpability under the Indian Penal Code, 1860 ("IPC"). A person's ability to make such a decision, however, may be hampered by provisions of the MH Act that permit physical constraints on people with mental illness in specific circumstances. The MH Act allows for 'supported admissions' of people with mental illnesses to mental health facilities for 30 days if they make threats or actual attempts to hurt themselves or show a severe lack of self-care to the point where they put themselves in danger.<sup>698</sup> If approved by two

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<sup>698</sup> The Mental Healthcare Act 2017, Clause 89

psychiatrists, this forced admission may be kept for a longer period of time than 30 days. Additionally, under the MH Act's 'emergency treatment' provisions, any medical treatment may be administered to a patient in order to avert death, irreparable injury to their health, or to stop them from seriously harming themselves.<sup>699</sup> If seclusion, solitary confinement, or physical restraint are the sole methods available to protect the person from impending danger, those measures may also be used.<sup>700</sup>

The definition of 'incompetent patient' under section 2 (d) of the Bill includes persons of unsound mind and they are not allowed to take decisions regarding withdrawing or withholding treatment if they become terminally ill. It is feasible for a competent patient (of sound mind) to also have a mental disease, nevertheless, because 'unsoundness of mind' is a more specific term than 'person with mental illnesses. Given the MH Act's expansive definition of 'mental illness' its restrictions would apply to these 'competent patients' as defined by this Bill. Therefore, the MH Act's provisions relating to supported admissions, emergency care, and solitary confinement could be used to prevent such people from making a decision to stop receiving treatment. As a result, it's possible that the MH Act's provisions would be abused in order to stop people from making fully informed, autonomous decisions. It is vital that the Bill takes into consideration existing laws (such as the MH Act) that could potentially interfere with or limit patients' capacity to exercise their right to refuse or withdraw treatment under this Bill.

6. Section 9 of the Bill provides the procedure for withholding or withdrawing treatment for incompetent individuals. This section allows a broad category of people, including the family members, next friend, legal guardian, treating doctor, and attending paramedics to approach the High Court for discontinuation of treatment. Involving too many parties in the decision making will lead to differences in opinion because of everyone's own beliefs and biases and can potentially undermine the actual wishes of the patient.

Involving the High Courts, even in cases where there are no differences in opinions among all the stakeholders, can defeat the purpose of the Bill by

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<sup>699</sup> The Mental Healthcare Act 2017, cl. 94

<sup>700</sup> *Id.*, cl. 97

lengthening the process of decision making. Moreover, people residing in remote areas of the country will find it difficult to approach the High Court. A large section of the population will also find it difficult to afford the financial burden involved in filing petitions in the High Courts.

Given the difficulty of access indicated above, it is not advisable for the High Courts to serve as the first-resort forum even in cases of disagreement. In its place, approved tertiary care hospitals or District Hospitals might establish Ethics Committees while making sure that a sufficient number of such facilities are likewise established in rural areas. These Committees should include medical professionals, attorneys, social workers, and laypeople, just like ethics committees established for clinical trials. Other hospitals within a certain radius should be served by these Ethics Committees.

Any objections to withholding or withdrawing treatment from an incompetent patient who has not given a valid advance directive, should be brought to the attention of the Ethics Committee first. The patient's best interests should be considered when the Ethics Committee decides what to do, having in mind that any evidence of what the patient would have preferred will be significant in assessing their best interests.

The Ethics Committee's judgement should be considered final if it determines that withholding or withdrawing treatment is in the patient's best interests. However, those who disagree with the Ethics Committee's decision may appeal to the High Court on specific grounds: i) that the Ethics Committee made a major factual error; or ii) that the Ethics Committee made a decision that was made in bad faith.

## **6.2 Recommendations**

There is a need for a new law that would permit people with terminal illnesses to end their lives in a dignified manner and that would regulate the practices of euthanasia and advance directives. This is in light of the various shortcomings in the 2016 Bill proposed by the Ministry of Health and Family Welfare as well as in light of the complicated procedures mandated by the Supreme Court. Following suggestions can be made to remove the shortcomings of the proposed bill.

1. The definition of ‘terminal illness’ should be revised, and the use of vague phrases like “untimely death’ and ‘meaningful existence’ should be avoided. Instead, a clearly defined prognosis should be used. The following definition is proposed.

*A terminal illness is any medical condition which, in the opinion of at least two doctors, is not likely to be cured and the patient is unlikely to survive for more than six months.*

2. It is recommended that any decision taken by a competent patient or on behalf of an incompetent patient should be documented, in the presence of two witnesses. Such a decision should also specifically document the decision to accept or refuse palliative care so that medical professionals giving palliative care are also given legal protection under the Bill.
3. Once a competent patient has made an informed decision to withhold medical treatment, there should be no role of the treating doctor in deciding whether such a decision is in the best interest of the patient or not. Only when the doctor suspects that the decision has not been taken with free will should the case be referred to Ethics Committee.
4. The Mental Healthcare Act of 2017 would allow for the use of physical restraints on mentally ill individuals who are attempting to hurt themselves. The capacity of a patient to use the option under this Bill to refuse or discontinue medical treatment may be impacted by these clauses. Therefore, it is advised that suitable provisions be put in place to make sure that individuals with mental diseases who are competent can make informed decisions.
5. It is advised that Ethics Committees be established at designated tertiary care hospitals or District Hospitals to serve as a forum in the event of conflict as stated above, instead of involving the High Court initially. Only the narrow grounds of a serious factual error or mala fide may be used to appeal the Ethics Committee's ruling to the High Court.
6. Advance directives are a crucial component of patient autonomy that is not taken into account by the 2016 Bill. Advance directives give the patient the opportunity to choose a course of treatment that, in the event of incapacity, would be used in the future. Unless there are specific reasons to disregard the directions provided in the advance directives (e.g., the emergence of newer and more effective treatment options since the time the directive was made and the knowledge of such



treatment could influence the decision making of the patient), they should be binding on the treating doctor. The reasons to not accept the advance directive should be clearly documented and such a decision should be vetted by the Ethics Committee.

The 2016 Bill has a number of serious flaws, which can potentially prevent patients with terminal illnesses from exercising their right to a dignified death without undue prolongation of suffering. Suitable amendments to the bill will make it more effective in achieving its goal and will be a significant leap forward on the journey of achieving the right to die with dignity.

