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Review Article

Living wills vis a vis right to die

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ABSTRACT

The word "Euthanasia" relates to two different words from the Greek language "Eu" which indicates "good" and "Thanatosis" which indicates "death", suggesting a "satisfactory Death" or "easy and painless Death" The phrase "mercy killing" has become associated with this meaning. It comprises inflicting painless death on a person suffering from an incurable and dreadful illness. It's the practice of terminating a person's life by administering a lethal injection or ceasing medical treatment. Informed and shared decision-making between the patient and the health professional caring for him or her is crucial for the quality of care and its outcomes. Living wills are nothing more than a tangible representation of this truth. As a result of their legal approval, patients' autonomy has been recognized. However, there are some differences in the regulations that have been adopted, and the health practice linked with these documents raises a number of practical and ethical questions that should be considered.

Living-will is a written statement depicting individuals' directions regarding future medical treatment in situations in which they are no longer able to express informed consent. Based on the secondary literature and substantiated with empirical findings, it carves out the need for death preparedness in general and endorsing living-will in particular. The paper covers the prevailing legislations and legal measures permitting passive euthanasia in different countries including India. It further entails all the essential requisites for writing a 'living-will' incorporating all the procedures and steps needed to be followed.

A thorough assessment of the current accessible literature on living will has been conducted, just to focus on the knowledge of euthanasia in detail. Most importantly, the social impact of the concept of euthanasia needs to be understood by the society. Moreover, it must be considered that euthanasia is different from suicide. Few communities may show the interference of their religion with euthanasia. So it is essential to enlighten the idea of euthanasia in legal ways for different countries.

1. Introduction

A living will—also known as an advance directive—is a legal document that specifies the type of medical care that an individual does or does not want in the event they are unable to communicate their wishes. [1,2]

In the case of an unconscious person who suffers from a terminal illness or a life-threatening injury, doctors and hospitals consult the living will to determine whether or not the patient wants life-sustaining treatment, such as assisted breathing or tube feeding. In the absence of a living will, decisions about medical care become the responsibility of the spouse, family members, or other third parties. These individuals may be unaware of the patient's desires, or they may not wish to follow the patient's unwritten, verbal directives.

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2. Key Takeaways [1–3]

1. A living will is a legal document detailing the type and level of medical care one wants to receive if they are unable to make decisions or communicate their wishes when care is needed.
2. A living will address many life-threatening treatments and procedures, such as resuscitation, ventilation, and dialysis.
3. A person can appoint a healthcare proxy to make decisions regarding care when they are unable to do so.
4. A living trust is a legal document that addresses how the assets of the incapacitated person should be managed.
5. People can enlist the services of an estate planner or an attorney to help draft or review a living will.

3. Understanding a Living Will [2–4]

Living wills and advance directives come into play only when one faces a life-threatening condition and is unable to communicate their desires for treatment. Doctors don't consult the wills for standard medical care that doesn't involve life-threatening situations.

Every state provides for the drafting of a living will, although some states call the document a medical directive or a health-care proxy. Some states let you prepare a detailed, customized living will, while others require you to fill out a standardized form.

4. What is Included in a Living Will ? [2–4]

A living will addresses many of the medical procedures common in life-threatening situations, such as resuscitation via electric shock, ventilation, and dialysis. One can choose to allow some of these procedures or none of them. One can also indicate whether they wish to donate organs and tissues after death. Even if the patient refuses life-sustaining care, they can express the desire to receive pain medication throughout their final hours.

5. How To Make a Living Will [2–4]

Before making a living will, it's best to understand that it will not serve as a last will and testament, whereby property and personal effects are allocated to others upon death. A living will stipulates the type and levels of medical care one receives if incapacitated and for how long.

The living will details the goals and wishes of a person in the event they can no longer care or make decisions for themselves. When creating a will, consider how you want to integrate your personal or religious beliefs into the care received.

It might be helpful to segment the living will into categories of care. You could first identify the circumstances in which care should be extended to preserve life and what types of life-saving or preserving care, such as blood transfusions and dialysis, should be administered.

Include a category to address whether you want care if you are in a vegetative or unconscious state. Indicate where you want to receive medical care: nursing home, at home, or in some other facility. You can also request how nutrition will be provided, whether it be given intravenously, by mouth, or withheld.

Another category to consider is pain management. Indicate the types and levels of treatment to manage pain. You can further break down this category into life-sustaining pain management and pain management in lieu of life-sustaining care.

If you have family or friends who will be responsible for overseeing your care, discuss your plans with them. It might be helpful to include them in the decision-making process as they might have insight into areas otherwise overlooked when planning alone. Lastly, enlist the help of a professional, such as an estate planner or attorney. These experts can help you make decisions for the best possible outcomes.

6. Healthcare Proxy [2,3]

In addition to the living will, one can select a health-care proxy who is allowed to make decisions if they are incapable of making those choices. Some states call this individual a healthcare power of attorney. Living wills cover many medical decisions, but a health-care proxy can consult with the doctor on other issues that may arise.

When facing the loss of a loved one, families often disagree over treatment, so having a healthcare proxy reduces confusion over one's final wishes. One should discuss wishes with the proxy before naming this person and be sure the proxy is willing to follow through with their desires.

7. Evolution of Living-Will Across Ages

7.1. Across the World: [4–6]

Luis Kutner in 1969 first time proposed the concept of 'Advance Directives' indicating individuals' expressions to control their end-of-life medical treatment. Since the contents of such a statement(s) are operational when the person is alive, it is called 'living-will'. Soon, this concept gained popularity in the USA leading to enactment of 'The Patient Self Determination Act' in December 1991. It required health care providers to give information to all patients related to their rights to make living-will.

The Act allows the patients to frame their desires, appoint healthcare proxy for themselves and specify the medical procedures to be administered on them under such circumstances (United States General Accounting Office, 1995).

Viewing other countries, all Australian states, using different terminologies have passed legislations in relation to execution of living-will. In Queensland, it is called 'Advance

Health Directive', in Australian Capital Territory it is 'Health Direction', in South Australia - 'Anticipatory Direction (Grant or Refusal of Consent)', in Victoria- 'Refusal of Treatment Certificate'. With variation in nomenclature, they all permit a patient to give advance directive to refuse life support system or refuse a specific kind of treatment in specific conditions.

Further, in Canada, though there are no legislations pertaining to advance directive but the Supreme Court of the country accepts the rights of the patients to refuse treatment that could sustain their life. In 2008 a nation-wide project was initiated to create awareness among patients and engage healthcare professionals in advance care planning that covers living-will. In England and Wales, people may make an advance directive or appoint a proxy under the Mental Capacity Act, 2005 (see: Age UK, 2020).

In various countries like Germany, Netherlands, Italy and Switzerland, laws have been passed very recently on advance directives which are based on the right to die with dignity and the principle of the right of self-determination. There are minor variations in the modalities and in nomenclature such as in Netherlands it is known as 'Euthanasia directive' and in Italy it is called 'Lavon health care directive'.

7.2. Indian Scenario:[3–5]

Viewing the situation in India, there are no laws related to advance directive but the judgment of the Supreme Court of India in March 2018 allows passive euthanasia by withdrawal of life support to patients who are in a permanent vegetative state under strict guidelines. Living will is implicitly covered in the said judgment.

This decision was made as part of the verdict in a case involving Aruna Shanbaug who had been in a persistent vegetative state (for 42 years) until her death in 2015. Pinki Virani, a social activist and a friend of Aruna had filed a petition in 2009 in the Supreme Court arguing that the 'continued existence of Aruna was in violation of her right to live in dignity. The Supreme Court of India in its judgment dated 7th March 2011 dismissed the plea for mercy killing but laid down comprehensive guidelines to process cases related to passive euthanasia.

However, on 25 February, 2014 a three-judge bench of the Supreme Court termed the judgment in the Aruna Shanbaug case to be "inconsistent in itself" and referred the issue of euthanasia to its five judge Constitution bench. Thereafter the matter of mercy killing was examined in consultation with the Ministry of Law and Justice and it was decided in 2018 that the laid down guidelines by the Supreme Court should be followed and treated as law in such cases. "It implies that the government would honor living-wills allowing consenting patients to be passively euthanized once the patient suffers from a terminal illness or is in a persistent vegetative state."

The Supreme Court specified two irreversible conditions to permit passive euthanasia. These being; the brain dead for whom the ventilator can be switched off and persistent vegetative state for whom the feed can be tapered out and pain managing palliatives be added. This is in accordance to international specifications. The same judgment also asked for the scrapping of article 309, the code which penalizes those who survive suicide attempts.

This judgment of Supreme Court is considered landmark judgment since it allows 'peaceful death'(passive euthanasia in medical terms) of terminally ill (vegetative state) patients when according to medical advise the patients are in 'coma' or in a state of condition where their chances of survival are considered 'remote'. Alongside, it is mandatory to set strict guidelines that will govern when the same is permitted. The 'living-will' thus becomes a crucial piece of document in this scenario (Law Commission of India, 2016).

7.3. The highlights of this landmark verdict include

1. The right to live with dignity also includes smoothening the process of dying;
2. Though the sanctity of life has to be kept on a high pedestal, in the case of terminally
3. I Persons, priority shall be given to the right to self-determination;
4. There is a proper statutory regime to take care of the apprehensions that are expressed
5. Against Euthanasia; and
6. The directive and guideline shall remain in force till parliament brings legislation.

8. Procedure:[3–11]

8.1. Drafting a living will

It is advisable to write down the living will and is instituted by any person who is an adult (= >18 years) and is of sound and healthy state of mind. It is written only under one of the 3 conditions-

1. Person is suffering from chronic illness
2. The person is in unconscious condition for prolonged period of time
3. The person is suffering from an end stage illness.

Procedures to be followed during recording and preserving as laid by the Supreme Court:-

1. The document should be signed by the executor in the presence of two preferably independent witnesses.
2. It should be countersigned by the jurisdictional Judicial Magistrate of First Class (JMFC) so designated by the District Judge concerned.

3. The witnesses and the jurisdictional JMFC shall record their satisfaction that the document has been executed voluntarily and without any coercion or inducement or compulsion and with full understanding of all the relevant information and consequences.
4. The JMFC shall preserve one copy of the document in his office, in addition to keeping it in digital format.
5. The JMFC shall forward one copy of the document to the Registry of the jurisdictional District Court for being preserved. Additionally, the Registry of the District Judge shall retain the document in digital format.
6. The JMFC shall cause to inform the immediate family members of the executor, if not present at the time of execution, and make them aware about the execution of the document.
7. A copy shall be handed over to the competent officer of the local Government or the Municipal Corporation or Municipality or Panchayat, as the case may be. The aforesaid authorities shall nominate a competent official in that regard who shall be the custodian of the said document.
8. The JMFC shall cause to hand over copy of the Advance Directive to the family physician, if any.

9. Implementation: [2,3,8,10–12]

1. When the executor of living will become terminally ill with no hope of recovery, the treating physician is made aware advance directive. He at first checks the authenticity of the document before acting on the same.
2. The physician then informs the person's close relative or guardian about the condition and the possible treatment available. He must ensure that the guardian/relative beliefs that the withdrawal of treatment is the best available choice.
3. Then a medical board comprising of at least 3experts from general medicine, neurology, cardiology, psychiatry and oncology is formed in the hospital where the person is admitted to form a preliminary opinion whether there should be withdrawal of treatment or not.
4. If the board certifies to carry out the will, then the physician informs the jurisdictional Collector about the proposal. The jurisdictional Collector shall then immediately constitute a Medical Board comprising the Chief District Medical Officer of the district concerned. (not the same members of the previous board)
5. The Chief District Medical Officer, shall convey the decision of the Board to the jurisdictional JMFC. The JMFC visits the patients, after examining gives consent to the board to carry out further action.
6. All the experts of the board jointly visit the hospital, take consent from the patient (if in right state) or from the guardian with clear instructions regarding the consequences of withdrawing the treatment and implement the action.

10. Review: [2–5,8,9,12]

The patient can revoke the will at any time of the procedure. He can even change the measures by discussing it with the healthcare agent. Some important information that must be included are-

1. New diagnosis: It must be included as it can alter the treatment aspect as well as the patient's view.
2. Change of marital status: Marital status ie married/divorced/widowed play a great role in the persons state of mind as well as health so it must be included.
3. About every 10 years: The will should be reviewed after every ten 10years as there can be a change in the approach of patients as well as doctor.

11. Some Specifying Directives: [3,4,7,9]

1. Cardiopulmonary resuscitation: - The patient can decide whether their heart is to be stimulated by electric shock after it stops works. If yes then for how many times.
2. Mechanical ventilation- It should include if the patient should be placed on mechanical ventilation in case of breathing difficulty. IF yes then for how long should it be given.
3. Tube feeding- The patient can decide for how long nutrients and fluids should be supplied to their body via the tube.
4. Medications- It depends on the patients if they want to take the medications. If yes it should be mentioned for how long and if no then when should it be stopped.
5. Transferring to ICU /Hospital: It depends upon the patient to be transferred into ICU or hospital. The patient has the right to not admit to hospital and die peacefully at home.
6. Organ donation- The patient can even include their choice of donating organs or tissue to the needy people and for medical studies.

12. Benefits of Living Will: [3,9,10,12]

1. The most significant benefit living wills can potentially bring is a reduction in health care costs.
2. It safeguards against the abuse of euthanasia.
3. It legitimises a physician's action of withdrawing treatment by providing proof of a patients intention.
4. It can help patient with a sense of control over death.
5. They provide comfort and confidence for patients and their families, relieve relatives of the burden of making

critical decisions, and reduce disputes among family members.

13. Challenges in the Execution of A Living-Will: [2,3,9,10,12]

The living-will primarily deals with the rights of patients to express their wish while they are still able to communicate their preferences about life prolonging treatments in the event of them being 'terminally ill.' Though it sounds simple and easy to comprehend, but carries inherent difficulties in its implementation, especially in Indian context.

An advance directive generally includes two basic components: the power of durable attorney and a living-will. The decisions described in the will mostly document patients' preferences about life prolonging treatments like CPR, feeding and breathing machines aiming atextending life with no hope of reviving the patient back to life.

But using an advance directive is complicated because of lack of awareness on the part of the significant others of the patient by keeping it in the custody of a lawyer or in the locker at home/bank and thereby denying the possibility of it being used at the right moment. Sometimes family members' wishes differ from patients'. While a patient may have opted out of life sustaining treatment, a healthcare proxy, overwhelmed by the prospect of losing a loved one, may decide to override the patient's wishes. It can also be the incapability of the individual in deciding comfort care options for him/her in advance for the unforeseen situation at the end-of life stage.

The jurisdictional magistrates and judicial magistrates, who have such a nuanced role in the whole process are also not aware of their duties. It is imperative to create awareness amongst the masses as well as the authorities regarding the said guidelines.

It is also not uncommon to witness the dilemmas on the part of the treating physicians who are overloaded with work and at the same are expected to follow so many formalities if they decide to help the patient being treated by them with no hope of reviving him back to life while respecting the right of self-determination and autonomy of the patient. Thus, there is a strong indication to relook into the suggested guidelines and make the entire process of execution of living-will a simple one which can be followed by those who show such preferences well before the time.

The other difficulties which are especially important in our country are the existing illiteracy and poverty. The illiteracy makes vast majority of people unaware and they are not able to assess what is available. The majority of the families struggle hard in meeting their two square meals so there is neither time no knowledge about the concept and process of living will.

It is also suggested that since advance directives are such decisive documents, a database of the same should be made or instead of making a database the document should be linked to his/her identity cards so that in case of an emergency the health care providers are aware of whether the person has an advance directive or not.

14. Conclusion

In sum, end-of-life patients either need to better understand medical issues in their unique contexts and hence make decisions that are consistent with their values and goals, or forego their autonomy and depend on significant others to make decisions for them. Preparing under-informed and poorly understood living wills not only undermines patient autonomy but, more importantly, fails to capture patients' real needs. Most terminally ill patients see living wills as a means of preparing for death and dying, processes where personal values, family relationships, cultural conventions, and religious beliefs count far more than exercising autonomy. Making a living will allows doctors and patients to talk about death and dying and opens the door to a positive, caring approach to end-of-life patients. To do anything less is to underestimate the complexity of end-of-life decision-making and to miss the opportunity to understand and meet the multidimensional needs of end-of-life patients.

In a developing country like India, medical science is progressing. We now have the latest technology and fresh approaches to artificially improve quality and life span, just as we do everywhere else in the globe. However, this has the downside of causing people to suffer in anguish to the point of death as well as increasing the cost of treatment. All of this was inadvertent. As a result, in current medical research in India, end-of-life issues are becoming increasingly important ethical considerations. Proponents and opponents of euthanasia and PAS are active in India, as they are in the rest of the globe. On the other hand, the Indian parliament looks unconcerned about these difficulties. While the Supreme Court's decision offers pro-euthanasia advocates hope, there is still a long way to go until the legislation is passed by the government. Misuse issues must also be addressed before the law is implemented in India.

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16. Conflict of Interest

None.

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