Research Paper

Living-Will: The Ultimate Right over One's Life

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ABSTRACT

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. The authors have tried to pinpoint the challenges encountered with their use briefly with special reference to India and have tried to add some valid suggestions. Lastly to make it more user friendly, a suggestive format of writing a 'living-will' has also been provided.

Keywords: Advance directive, living-will, euthanasia, persistent vegetative state, patients' rights

INTRODUCTION

A 90-year-old women named Suzanne Hoylaerts, in Belgium, on contracting COVID-19 died after she selflessly refused to be on ventilator and, reportedly, stated to her doctors, "I don't want to use artificial respiration. Save it for younger patients. I already had a good life" (India Today, April 2, 2020).

Aditya Singhal (name changed) had lost his 88 years old father to COVID-19. A banker, a father of two children and husband of a school teacher, Aditya lives in an apartment house in a middle income group locality in Delhi. Last twelve days have not been less than a nightmare for the Singhal family. On March 17, 2020, after developing symptoms of corona infection, the aged father having comorbidities of hypertension and asthma, was rushed to hospital. Seeing acute difficulty in breathing, he was put on ventilator. However, his condition deteriorated and he stopped responding to medical treatment even hours after he was hospitalized. Aditya was hardly updated on the actual condition of his father. By 11th day Aditya had submitted fifteen lakhs rupees. Drained out of all his savings and loan taken from friends and relatives, he requested the doctors to discharge his father as he would take him to some government hospital. Next day, the dead body of his father was handed over to him (anecdotal record, April 2020).

These cases point out towards a debatable issue – does an individual have a right to choose death or is it the prerogative of medical practitioner to keep on merely prolonging life of a patient through life-sustaining treatments, at the heavy cost of finances and quality of life?

Conceptualizing Living-will/Advance Directive

The living-will is an advance directive for the medical care professionals and care givers at the terminal stage of one's medical treatment. It is a statement declaring the kind of medical treatment or life support system a patient would want for himself or herself. As an out-growth of the doctrine of rights based approach and informed consent, living-will is a written legal document regarding one's instructions for medical care if he/she is unable to make decisions

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for self because of being terminally ill, seriously injured, in a coma or in a persistent vegetative state (see: Emanuel et al., 2000).

With the success of medical science and advances in public health systems, life expectancy has increased and death rate has reduced leading to population ageing (Kaushik, 2014) and soon medical science was seen as a promising instrument to postpone death. It is in response to the increasing ability of medical fraternity to delay death through ventilators, feeding tubes, etc. that the notion of advance directive came into existence. This concept gained ground in 1950s in the West (Kastenbaum, 2003). In all these conditions the common factor is that the end of the sick person seems near.

The idea of advance directive denotes a paradigm shift in the doctor-patient relationship where traditionally the doctor enjoyed almost absolute decision-making power related to the treatment of the patient. It depicts the right and control of humans over their own bodies. It realizes that individual patients have right to autonomy and self-determination regarding the treatment they wish to continue or discontinue. It has direct bearing on their living status and death. Laws related to advance directive protect medical staff from any criminal liability (Kinlaw, 2005).

Living-will is enforced when the individual is still alive, though incapacitated to communicate his/her wishes, and, therefore, it is termed as the ‘living-will’.

Childress (1989) notes that advance directives are of two types – living-will and healthcare powers of attorney. Living-will is a written statement directing whether or not an individual wants life support system and medical treatment, particularly in the event of a terminal illness. On the other hand, in a healthcare power of attorney or a proxy, a family member or friend decides on the behalf of the ailing patient who is not in a condition to decide. A combination of living-will and a power of attorney as a single document can be the most effective (see: Emanuel & Emanuel, 1989). Thus, living-will is a part of advance directive. In the present article as well as other related literature, these terms have often been used interchangeably.

Need and Relevance of Living-will

Several individuals are unable to convey their wishes regarding their choices of passive euthanasia over continuing vegetative life through medical treatment. Wilkes (1996) notes that about two million people in America are confined to nursing homes and more than 1.4 million are surviving only through life support systems such as feeding tubes (American Academy of Neurology, 1995). Covinsky et al. (1994) observe that on an average nearly 30,000 Americans are kept alive in persistent vegetative states. It severely hampers their quality of life. Such a kind of medical treatment puts heavy financial liability on the patients’ family.

Public healthcare system in India is in precarious condition. With limited resources, vast majority of Indians are unable to afford quality health services of private sector while the government funded health services are characterized by staff shortage, overburdened and poor coverage (see: Thakur et al., 2011). Public Health Foundation of India finds that nearly 55 million people in India are pushed into poverty every year due to health related expenditure and 38 million fall below poverty line because of medicinal expenses alone (Times of India, June, 13, 2018). Ghool, Dhru & Jayant (2016) note that the private healthcare services are better and effective but expensive, and treatment may continue beyond a reasonable period if patients or their families are paying for it. It is in this backdrop that the relevance of living-will becomes imperative.

In the absence of living-wills, many critically ill patients receive aggressive medical interventions. Savitha and Kiran (2013) bring out that at times, private corporate hospitals view sustaining patients in persistently vegetative state on life support system as an opportunity to boost their income. Moreover, certain doctors consider it is their moral duty to prolong patients' life and deploy every possible means for it. The economic implications of such 'futile' treatments are severe.

It is often held that making living-will is the task of elderly people while it is not necessarily exclusively meant for older adults. All the individuals are equally prone to serious sickness or unexpected end-of-life situations and at that crucial juncture they may not be able to communicate their wishes. Therefore, it is advisable for all adults to prepare their living documents (*Ichhamaran*) well before the time. By planning ahead, one can give advance directions regarding the medical care one wants to be meted and avoid unnecessary suffering and relieve caregivers of decision-making burdens during moments of crisis or grief.

The context of living-will is based on the premise that all individuals have a right to live as well as a right to die with dignity. A person's life may reach a point where attempts to prolong it are futile, and that condition may only compromise the quality of life and dignity of the patient (Cherniack, 2002). Living-will provides the right to self-determination at the end of life, which is an empowering aspect.

Tracing evolution of the concept of living-will

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, the document 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 a living-will is referred to as '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. However, in some states like Canberra one cannot refuse palliative care (NSW Government, 2019).

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 (Health Law Institute, n. d.). And, 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’.

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-willis 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).

The highlights of this landmark verdict include:

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

REVIEW OF LITERATURE

Death is an ultimately reality of life. Population Reference Bureau and the World Fact Book (2011) estimate the world death rate as eight deaths per 1000 persons, there are 151,600 deaths each day. The World Health Organization (2018) notes that 71% of the total global deaths were due to non-communicable diseases mainly including cardio-vascular diseases, cancers, diabetes and chronic lung diseases. Several researchers (Fried & Guralnik, 1997; Fried & Mor, 1997; Bernabei et al., 1998) observe that chronic diseases such as organ failures (heart, liver, lung, kidney,), cancer, stroke and dementia are the prominent causes of death among Americans, and fewer are dying suddenly. It implies that end of life is associated with increased suffering among dying individuals and substantial care giving and financial burdens to family members (Lynn et al., 1997; Teno et al., 2004; Emanuel et al., 2000; Steinhauser et al. 2000). Further, Fried et al. (1999) and Quill (2000) find that in the USA, nearly 80% of deaths occur in hospitals or nursing homes, generally on life support systems; though when asked most people preferred to die at home. Though sophisticated life-saving technologies, equipment and procedures delay death, these interventions largely fail to improve the quality of life and the dying process (Seymour et al. 2004; DeLegge & DeLegge, 2005).

Several studies (Brown, 2003; Fagerlin & Schneider, 2004; Hawkins, et al. 2005; Hickman et al. 2005) have shown that despite ample efforts to promote advance directives through legislations and advocacy, for more than twenty years, rate of completion of living-will is quite low. Among Americans it is 18% to 30% (Kagawa-Singer & Blackhall, 2001). The rate of completion of advance directives among chronically and acutely ill patients is only a little higher than healthy individuals (Bravo, Dubois & Paquet, 2003; Kish, Martin & Prince, 2000).

Gill and Voss (2005) note that stigma and discrimination against disabled people indirectly coerce them to opt for living-will. Researchers have examined the barriers in adopting living-will, prominent ones are: inadequate knowledge (Knauft et al. 2005), belief that family members would know what is best for the patients (Eiser & Weiss, 2001), perception that its execution is difficult (Jezewski & Meekar, 2005), views that advance directive is not for them (Fagerlin, et al., 2001) and cultural notions of not thinking about death (Shrank et al. 2005). Older adults and those having greater disease burden more often opt for living-will (Lorenz et al., 2005; Wenger & Phillips, 2000).

Located in South Korea, a study by Kong et al. (2015) show that most terminally ill patients (89%) preferred palliative sedation over aggressive life-sustaining medical treatment. In addition, a significant proportion of patients wanted their spouse to take a call on withholding or withdrawal of life support system, showing a high level of acceptance of proxies. Factors like age, religion and ethnicity are linked to completion of living-will (Chacko et al., 2014) and people of Indian origin were found to be less inclined to adopt advance directives than Caucasians (Doorenbos & Nies, 2003).

EMPIRICAL STUDY

Literature review depicts the low awareness and much lower adherence to advance directives, despite its high relevance. In this context, empirical data were collected with the aim to appraise the level of awareness and perceptions on advance directives among people. Using Descriptive Research Design, the study has followed Survey research format. Carried out in April, 2020 during the lockdown period, the information for the study was gathered through sending questionnaire through WhatsApp. Corona pandemic has brought issues and emotions related to death in the forefront. Respondents found the questionnaire relevant. However, the channel of conducting research had the advantage of reaching out to several people but alongside the disadvantage of hardly any scope of rapport formation and making understand the context and usage of highly short and crisp set of questions. Out of 235 questionnaires sent, only 117 were returned and out of them 96 were completely filled in. The table (Table 1) presents the findings on awareness and perceptions regarding living-will.

Among the respondents, there are 58% males and 42% females. The age range is from 36 years to 87 years. And, 52% respondents are below 60 years of age and 48% are 60 years and above. Educational qualification of the respondents ranges from 12th standard to Ph.D. Most respondents in the older age group are retirees and rest of them are self-employed. In the younger age group, nearly 40% of females are housewives and rest are in professions like teaching, banking, NGOs, corporate sector, etc. Among younger males, 60% are in professional jobs in public and private sectors and about 40% self-employed. Almost all of the respondents belong to middle income group families.

Table 1: **Distribution of Respondents on Awareness & Perceptions regarding Living-will**
Codes: Y = Yes N = No DK= Don't Know/can't say

Parameters	**Male**	**Female**	**Total**	**<60 years**	**>60 years**
Is death preparedness required?	27 Y	32 Y	59 Y	24 Y	35 Y
	11 DK	07 DK	18 DK	10 DK	08 DK
	20 N	03 N	23 N	14 N	09 N
Do you have enough resources to meet expenses on health emergencies?	13 Y	10 Y	23 Y	10 Y	13 Y
	15 DK	30 DK	45 DK	15 DK	30 DK
	30 N	02 N	32 N	23 N	09 N
Heard about Advance Directives/ Living-wills?	17 Y	09 Y	26 Y	08 Y	18 Y
	11 DK	11 DK	22 DK	06 DK	16 DK
	30 N	22 N	52 N	34 N	18 N
Would you recommend living-wills?	3 Y	1 Y	4 Y	2 Y	2 Y
	35 DK	17 DK	52 DK	29 DK	23 DK
	20 No	24 No	44 No	21 No	23 No
Have you prepared living-will?	00 Y	00 Y	00 Y	00 Y	00 Y
	00 DK	00 DK	00 DK	00 DK	00 DK
	58 N	42 N	100N	48 N	52 N
Are you thinking of making one?	02 Y	00 Y	02 Y	01 Y	01 Y
	32 DK	18 DK	50 DK	31 DK	19 DK
	24 N	24 N	48 N	20 N	28 N
What are the hurdles in endorsing living-wills? **Qualitative data**					

Major inferences

Table 1 depicts the bird's eye view of the findings of the study. Almost 40% respondents do not see or realize the need to prepare for death. No stark difference is noted between younger and older persons on their perceptions related to death preparedness. More females felt the need for death preparedness. Less than one-fourths of the respondents reportedly feel that they have enough finances to meet medical emergencies while most are either uncertain about it or realize that they do not have enough.

Almost one-fourth of the respondents have heard of the notion of living-will and meagre proportion of them affirmed to recommend others to have living-will. None of the respondents have prepared living-will and only two males, one younger and one older than 60 years have thought of preparing living-will.

Based on the thematic analysis of the qualitative data, respondents identified following hurdles in drafting a living-will:

- Lack of awareness about the concept
- No knowledge, hesitation and fear to deal with related legal complications
- Religious beliefs that birth and death are in the hands of the God and no one can change the destiny in its relation
- Beliefs that thoughts and discussions on death are bizarre. Cultural as almost three-fourths of the respondents have not heard about it
- Strong belief in fatalism and karma: one should bear the pain in this life only, else the pain and suffering would continue in the next life too

Ethical dilemmas and Living-will

Attention may be paid to certain ethical dilemmas with regard to living-will. There are no legislative measures related to advance directives in India. Despite the Supreme Court's directions in relation to Aruna Shanbaug case, passive euthanasia is still a debatable issue. Active euthanasia is not in consonance with Articles 14 & 21 of the Indian Constitution and hence totally unacceptable.

High chances of being misused is one of the most potent risks of legalizing advance directives and passive euthanasia. Appointment of a proxy is another knotty issue as it would not be uncommon to proxies having vested interests and they may not adhere to high standards of integrity and honesty. A comprehensive legislation vividly defining the acceptable and unacceptable advance directives is the need of the hour.

Religion has played a critical role in matters related to death and Indian culture too resorts to religious texts, irrespective of religious affiliations, that invariably maintains that 'life is a gift of God and shall not be terminated without His will'. This goes against the adoption of advance directives.

Another challenge in acceptance of the concept of living-will is discrepancies in definitions. There is a confusion between passive euthanasia and physician assisted suicide. Terminal sedation is another related term. Variations in the practice of these often remain under the carpet (see: Cuervo et al., 2016; Radbruch et al., 2016; Ngo et al., 2015; Robijn et al, 2015).

Shukla (2016) identifies another dilemma among doctors to accept and abide by advance directives who believe that they are morally and ethically duty bound to prolong life of patients at any cost.

Keeping this debate unresolved, the authors reflecting their unflinching commitment to the right to self-determination of patients, delineate below the steps, process and suggestive format for developing a living-will. This attempt is also made in the light of the finding of the empirical study that most people are unaware and yet desirous to draft living-will. Relevant digital material from reliable sources was consulted for developing prescriptive format and guidelines of living will (see: American Bar Association, 2016; Mayo Clinic, n.d.; NSW government, 2019; Williams, 2020).

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 mind. It is voluntarily executed without coercion. The declarant should be an adult person with a sound mind who is writing the advance directives specifying his/ her medical preferences in case he/she experiences serious health issues. Following are the essential requisites for documenting an advance directive:

a. Power of attorney

The person in whom the power is entrusted is called 'healthcare agent' or 'healthcare surrogate' or even 'patient advocate'. Choosing a person to act as one's healthcare agent is advisable as it is quite possible that due to failing health condition the author may not be in a position to decide whether to continue with the treatment or withdraw life support. In such scenario the healthcare agent takes decisions on behalf of the dying patient. The written instructions serve as guidelines in arriving at a decision as the dying patient desires. The healthcare agent should not be patient's doctor or medical core team member. The person entrusted with the power of attorney may be a spouse, other family member, friend or a member of a faith community. There can be one or more persons delegated with power of attorney, in case the first choice is unable to fulfil the assigned role due to unforeseen circumstances.

b. The instructions to healthcare team

Following conditions should be spelled out in the living-will:

- **Cardiopulmonary resuscitation:** It means restarting the heart when it has actually stopped beating. It implies making a choice if one would want to be resuscitated through devices delivering electric shocks in stimulating the heart or not.
- **Mechanical ventilation:** It takes over one's breathing if he/she is unable to breathe on his/her own. The person has the freedom to decide for how long one would want to be placed on a mechanical ventilator.
- **Tube feeding:** It supplies the body with nutrients and fluids intravenously or via a tube in the stomach. The patient has a choice to decide how long he/she wants to receive this treatment.
- **Antibiotics or antiviral medications:** This medication can be used to treat many infections. The pertinent question is if one is near the end of life, would he/she want infections to be treated aggressively or would one rather let infections run their course? This choice to permit the use of antibiotics and antiviral medicines on his body again lies with the patients.
- **Transferring to ICU /Hospital:** It includes the desire of the patient not to be transferred to hospital or ICU if he/she so desires at the end of his/her life. The individual has a right to die peacefully at his/her home near family members.
- **Comfort care (palliative care):** It includes any number of interventions that may be used to keep one comfortable and manage pain while abiding by his/her treatment wishes. This may include being allowed to die at home, getting pain relief medications, being fed ice chips to soothe mouth dryness, and avoid invasive tests or treatments.
- **Organ and tissue donations:** This implies the choice of the patient for donating his/ her organs to the needy people. This can also be a part of the living-will being executed. If one's organs are removed for donation, he/she can be kept on life-sustaining treatment temporarily until the procedure is complete.
- **Donating one's body:** The choice to donate one's organs for scientific study to a medical college can also be specified by the patient in his/her living-will. The author can suggest the healthcare surrogate to contact a local medical school, university or donation program for information on how to register for a planned donation for research while the patient is already at the end-of life.
- **Do not resuscitate and do not incubate orders:** This implies that one does not need to have an advance directive or living-will to have '*do not resuscitate (DNR) and do not incubate (DNI) orders'*. To establish DNR or DNI orders, the doctor needs to be told about one's preferences. The orders shall be put in the individual's medical record near his/ her bedside while the patient is sick.

Even if one already has a living-will that includes his/her preferences regarding resuscitation and incubation, it is still a good idea to establish DNR or DNI orders each time one is admitted to a new hospital or healthcare facility.

c. Keeping the living-will safe

It is important to keep the living-will safely so that it can be used by the health agent appropriately at the right moment. Therefore, a copy of the living-will should be kept at the following places/ with the people:

- Keep the originals in a safe but easily accessible place.
- Give a copy to one's doctor.
- Give a copy to one's healthcare agent and any alternate agents.
- Talk to family members and other important people in one's life about the advance directives and one's health care wishes. By having these frank conversations by the patient while he/she is in good health, it can be ensured that his/her family members clearly understand and respect his/her wishes. This is very important to relieve the family members from inner conflict and continued feelings of guilt.
- Carry a wallet-sized card in the purse that indicates one has advance directives, identifying the healthcare agent and stating where a copy of living-will be found.
- Always keep a copy with oneself when he/she is travelling.

d. Reviewing and changing living-will

The person can change one's directives at any time. If one wants to make changes, he/she must create a new form, distribute new copies and destroy all old copies.

The person who is writing the living-will should discuss changes with his/her primary care doctor and make sure a new directive replaces an old directive in one's medical file. New directives must also be added to medical charts in a hospital or nursing home. Also the adult should talk to the healthcare agent, family and friends about changes one has made.

It is advised to consider reviewing old directives and creating new ones especially in the following situations:

- **New diagnosis:** In the event of a diagnosis of a disease that is terminal or that significantly alters one's life, the person may make changes in the living-will. The person should discuss with the doctor the kind of treatment and care decisions that are required to be made during the expected course of the disease.
- **Change of marital status:** When one marries, get divorced, or separated or is widowed, he/ she may need to select a new healthcare agent.
- **About every 10 years:** Over time one's thoughts about end-of-life care may change. Review the directives from time to time to be sure they reflect his/her current values and wishes.

e. Process of Writing a Living-will

The writing of living-will should incorporate following aspects:

Declarant's Name and Address: Enter the declarant's full name, as well as his/her full address (including city, state, and zip code and mobile and email id.

Details of the Healthcare Agent: Declare the name of the healthcare agent with address, contact numbers and email id. It is desirable to provide the full contact details of alternate healthcare agent(s) too.

Agents Authority Commencement: Enter the stipulations in which one would like the declarant to make necessary decisions. This can be upon a diagnosis, upon a medical treatment, or other situations that would trigger the agent's power into effect.

Stating the General Powers of the Agent: State the provisions that will be granted to the agent. Here, specify the circumstances in which the agent will be granted decision-making power.

These circumstances include:

- Falling into an unconscious state
- Being diagnosed with a terminal illness
- Falling into a marginally unconscious state
- Being diagnosed with an untreatable condition

Specifying Directives: Further specify the circumstances in which the agent will be required to take actions on behalf of the sick patient. These circumstances will range from receiving life-saving treatments such as Cardio pulmonary Resuscitation to medications like antibiotics.

Anatomy/Organ Donation desire: State whether or not one wishes to donate his/her body, or organs. This step allows the individual to specify which, if any, organs or tissues he/ she wishes to donate and the possible situation. Additionally, one may donate one's entire body should he/ she so desires. The declarant may also delegate the purposes one would like his/her body, organs or tissue be used.

Provisions for Pregnancy (optional): If the declarant is a female and becomes pregnant, she may appoint her primary care physician to make decisions on her and her fetus' behalf. To appoint a primary care physician, the information like physician's names, address, and contact details may be provided to the healthcare professional.

Signatures of declarant and witnesses: Last but not the least to officiate the document, the declarant must sign and put a date on the document, certifying that these are his/ her wishes and that he/she is of sound mind at the time of making this declaration. Additionally, the signatures of two witnesses along with their address, date of signing, their email ids and contact numbers must be incorporated.

Notary Public Certificate of Acknowledgement: Many states require that a Living-will be certified by a state-registered Notary Public. Therefore it is essential that this document is notarized, and that the Notary Public fills out the appropriate information.

Living-Will - A suggestive Format

To my family, doctors, hospitals, surgeons, medical care providers, and all others concerned with my care:

I, [Name], aged [Age in Years]a resident of [City], [State], in [Country], with an address at [Address], being of sound mind, memory, disposition, do will fully and freely, by this Living-will, direct my family, physician(s), attorney, and any other individuals who may in the future become responsible for my health and well-being and any decisions related thereto, whether partly or fully, to take in the event of my becoming terminal ill, and go into a coma with no reasonable expectation of regaining consciousness, or reach a persistent vegetative stage with no reasonable expectation of regaining significant cognitive functioning, or have a disease state from which I have no reasonable expectation of coming back to a life with reasonable quality of life.

This declaration and the following directions are an expression of my legal right to refuse medical care and treatment. I expect and trust the above-mentioned parties to regard themselves as legally and morally bound to act in accordance with my wishes, desires, and preferences. The above-mentioned parties should therefore be free from any legal liabilities for having followed this declaration and the directions that it contains.

I request that this 'declaration' should be honoured by my family members and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences of such refusal.

This declaration reflects my firm, informed, and settled commitment to refuse life-sustaining medical care and treatment under the circumstances that are indicated below.

Directions

I direct my attending physician to withhold or withdraw life sustaining medical care and treatment that aims only at prolonging the process of my dying when I am in an incurable or irreversible mental or physical condition with no hope of recovery. In such a situation the treatment may be limited to measures which are designed to keep me comfortable and to relieve pain temporarily. I specifically want/ do not want following forms of medical care and treatment:

• Cardiopulmonary resuscitation (CPR)	Yes/NO
• Mechanical ventilation	Yes/NO
• Tube feeding	Yes/NO
• Antibiotics or antiviral medications	Yes/NO
• Transferring to ICU /Hospital	Yes/NO
• Comfort care (palliative care)	Yes/NO
• Organ and tissue donations	Yes/NO
• Donating my body	Yes/NO
• Do not resuscitate and do not incubate orders	Yes/NO

Further I appoint…………………….............Resident of and………………………… Resident of……………………........…as my health attorneys………... who have expressed their acceptance to be my attorneys for the purpose of securing compliance with the terms of this 'declaration' and will have the authority to make decisions and take action on my behalf with regard to wishes expressed in this 'declaration', notwithstanding any contrary views held by any other person.

In the absence of both of these authorised attorneys at the time of taking the required decisions on my medical treatment, any member of my family will have the authority to express the wishes on my behalf regarding the above treatment.

I declare that this 'Declaration' and 'Attorney Authorisation' shall remain in force during my life time unless I revoke it at any time and until notice of its revocation has been received by my attorneys.

I understand full importance of this 'Declaration' and 'Attorney Authorisation' and am fully competent to make it.

Date & Place (Signature of Declarant)

This 'Declaration' and 'Attorney Authorisation' has been signed in the presence of undersigned by ……… (Name of Declarant) who is known to me and I believe that the signatory is of sound mind.

Witness I
Name and address

Witness II
Name and address

The above 'Declaration' and 'Attorney Authorisation' has been signed in the presence of undersigned (Name of Declarant) who is known to the undersigned and who I believe to be of sound mind.

Authorised Attorney No. I
Name and Address

Authorised Attorney II
Name and Address

This document will need to be executed on stamp paper. Persons signing as witnesses can also be the Authorised Attorneys.

Challenges in the execution of living-will:

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 at extending 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 bureaucratic 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 as well as 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.

CONCLUSIONS AND SUGGESTIONS

In the 21st century due to unimaginable advancement in the field on medical science, it is possible for a human to stay alive with the help of machines for months or even years. However, it enhances the quantity but not the quality of life. Under these circumstances there is a need to recognize the right of the patient to refuse treatment at 'the end of life situation' and choose to die with dignity. It is important to understand that by refusing treatment a patient is not committing suicide. Several nations and international covenants have taken progressive step by considering advance directives as a matter of individual rights and passed relevant legislative measures in this regard.

People, in general, lack awareness on the concept and significance of living-will and its endorsement is even poorer. There are several administrative and legal glitches and ethical and moral dilemmas associated with the notion of living-will.

There is a need to create awareness amongst common people and doctors, lawyers and magistrates on this crucial aspect. Media can take up the role of sensitization and resolving knotty issues through debates and discussions on passive euthanasia including living-will. It is a highly relevant topic for social researchers and gerontologists. Appropriate legislative measures with minimal administrative hurdles in drafting, endorsing and implementing living-wills is the need of the hour. It is believed that the Constitutional Right to Life implicitly carries in itself the right to end life, which is the base of right to autonomy and self-determination.

The arguments and debates raised in the paper on living-wills may illicit criticisms. The purpose of authoring this paper is to bring to the surface this challenging issue so that academicians, policy makers, social planners and researchers, collectively and cordially, may arrive at appropriate solutions.

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