Opinion and Debate

Living wills in health care: A way of empowering individuals

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Advance directives are the legal document in the United States and deals with the wishes of an individual as to the choice of treatment he expects to receive sometimes in future, when he may not be able to take such decision, depending upon his mental capabilities. The living will is one such document. This is a new concept to many Pakistani physicians. This article is based upon author's views where moral values are debated and later how to develop policies and practices to be implemented are discussed in relation to our set up.

Introduction

Advance directives include living wills, durable power of attorney and health care proxy. Living will is a document that a person fills up while in sound state of mind about health care, that he expects to receive, at some point in time in future.[1] It is assumed that at some point in time in future an individual might not be in a state of mind where he could decide for himself. In this situation decisions made by him or those he entrusted with the responsibility, would help in planning treatment. The condition for which advance directive is developed can be any condition in which a person cannot communicate his wishes appropriately because the person may be permanently unconscious or mentally incapacitated.[1]

In United States a 1991 law called The Patient Self Determination Act (PSDA) requires hospitals and nursing homes to tell patients about their right to refuse medical treatment.[2] Living will is a document, in which one states one's wishes in writing, while in a related document called a Durable Power of Attorney for health care a patient's advocate is identified to ensure that an individuals wishes are carried out. It is not necessary to have a written document, a verbal expression also receives equal importance. Legal aspect of this document is still debated.[3]

Moral Principles

At a glance it seems that a living will is something that may not be applicable to our environment and social background where people believe that discussing death is a bad omen. However, if one in a casual way, discusses how one expects to live his last days, almost every one expects to die in peace without becoming a burden to his loved ones and society and at the same time does not want to bear unnecessary hardships in dying like suffering from pain.

In this era of advancement, the technology of life saving equipments are prolonging "death" of terminally ill patients rather than making it comfortable. It is almost in everybody's observation, the plight of patients in intensive care units, where ventilators and artificial means of providing nutrition do not let patients die early. So what if one expresses his own wishes as to what type of medical treatment/care he wishes to receive if God forbid, life ends up in such a state. It is an autonomous choice of that individual. Thus, if one follows instructions spelled out by an individual, it amounts to respecting an individual which carries a great moral value. It also builds up trust between an individual and his treating physician.

Debating on another principle of beneficence as terminally ill patients receive only comfort care in a vegetative state or when mentally incapacitated. Unnecessarily prolonging death at this stage amounts to harm. A slippery slope argument can be put forward as there can be mal-intentions in some cases where conflict of interest might surface between patient's advocate in some conditions that may be potentially treatable. Another conflicting value is that of the physician's obligation to treat rather than to stop potentially beneficial treatment. Futility is another issue. Religious values, where life is given sanctity and any measure that is done to withhold or withdraw treatment, thus raises controversy. Various societies may not receive the concept as perceived in the West.[4,5] Thus a debate is necessary upon this subject.

Considering all the above mentioned arguments, it is all the more important to bring an individual on board and discuss with him the purpose of advance directives. The person can then take an autonomous decision about his future medical treatment in a sound state of mind. The process is not a point in time activity, rather it is willful and voluntary choice of an individual. For this more than one session may be needed. Such directives may be changed by the individual himself, any time in the future.

Pakistani Perspective and Policy Drafting:

As the concept of living will is new to many Pakistani physicians, a comprehensive strategy must be planned so that its essence could be understood. Interactive sessions involving a team of pro active and interested individuals from different disciplines especially those involved in management of patients with terminal conditions like oncologists, nephrologists, neurologists etc should be the target. They can then be given a task to lay down a policy to be adopted in a particular hospital set up. An in put from patients attending the hospital, medical, nursing and paramedical staff should also be sought, after they receive a formal introduction of the subject. The policy decisions will help in the drafting of advance directive document.

To further disseminate the concept multiple sessions should be planned. The core material should be made available for the hospital staff and for the patients and their families. Activities like seminars and question and answer sessions help in clarifying the issues related to the subject and help build trust between health care professionals and target population. Review of the policy and its progress has to be done at least every six months initially and then at yearly interval to address the issues that may surface during this period.

Hospital policy regarding living will document should be made available on website and at various departments and outpatients units. Representation of patient's advocates, welfare societies, NGOs and religious scholars should be invited to seminars so that any emerging issues are debated. Thus the policy will be representative of the needs of our society and will be reflective of local perspective as well.

A dedicated administrative staff/department must be constituted to handle the related activities that include:

- Identifying clinical staff responsible for managing Advance Directives including living wills.
- Identifying the skills and training required of clinical and non-clinical staff.
- Communication channels up dating (example web groups, blog, one to one interaction with individuals etc)
- Reporting structures (written, verbal etc).
- Documentation guidelines.
- Storage of Advance Directives (a separate department with specially designed computer software programmes, colour coding of forms etc)
- Information to be given to the public through print and electronic media to assist in articulating their preferences regarding treatment if need arises sometime in future.

Procedure of Obtaining Living Will:

A team shall be made comprising of at least two members, one being the treating physician and a counselor, who would be an expert in communication and explaining issues other than the medical condition to the individual. The patient/individual in the presence of family members

Figure: Advance Decision About Medical Illness (Living Will)

I, (Name) …… Resident of (House No.) ……. City…….. Telephone No…….
am taking decision about my future medical treatment which should be considered as my will.
In future if I suffer from an illness due to which I may not be able to decide (any physical and medical illness that makes me incapable of taking decision) for myself, then this document may be considered as my will.

I am taking this conscious decision with full comprehension and thorough consideration.

My Will About Medical Treatment

- If I suffer from an illness from which there is no hope of significant improvement in quality of life and my life is made possible only with the help of drugs and artificial means, then such mode of treatment may not be tried on me.
- If I suffer from any mental illness that makes my life incapacitating then no means should be used to continue my life.
- If I am in a state of coma which is irreversible (vegetative state), then in such a situation my life may not be prolonged.
- If I suffer from any terminal illness (cancer, renal failure etc) which results in cardio-respiratory arrest then do not resuscitate (DNR) me.
- In all the above mentioned conditions I expect to receive comfort care including pain relieving drugs but ventilator and nutritional support may not be provided.

Special Instructions:
In order to implement above mentioned will, it must be ensured that at least two physicians, expert in their field, take decision about futility of my personhood in terms of cure from terminal illness.
I can re visit my will any time in my life.
I hereby authorize ……...……. to take decision on my behalf when due to my illness I may not be able to take decision for myself and s/he must honor my above mentioned will.
Name…….....…..Address……...….....….....Date…….
Signature……..

Witness:
We certify that above mentioned will has been made by …….. in our presence with full comprehension and he is liable to all the consequences that may result out of it.
Witness No. 1:
Name ……..Address.....…….Date…….
Signature……..
Witness No. 2:
Name ……..Address.....…….Date…….
Signature……..

whom he wishes to be present, shall meet in a separate room in the hospital assigned for such a session. The objective of the living will shall be explained and procedure told. The patient and family shall be encouraged to ask questions and express their views. If the patient wants to meet alone then session shall be scheduled accordingly. The form made in Urdu/English (Figure) will be handed over and another appointment shall be made as patient desires. This would be a process rather than a point in time activity. The option of changing the will at any time in the future, shall also be told. The form shall be made available on the website also. This will facilitate the procedure.

Following should be addressed during the process of obtaining advance directive:

- Is the patient mentally competent?
- Is there any influence of others?
- Does the patient have sufficient knowledge of the medical condition?
- Are all the possible treatment options known to an individual?
- Are all the risks of not having treatment known to the individual?

The completed form shall be put into the treatment record file of an individual. It will be mandatory for the medical and nursing staff to ensure that this is made available if in future such a need arises. All expressed wishes will be honoured by the hospital staff after fulfilling all the laid down criteria. If there is a proper referral system, like General/family physicians based referral system, then that physician shall be informed and taken on board.

Conclusions

The issue of a living will though seems quite blunt, is practical and can be implemented in our set up as well. After execution of all the policies and related practices, outcome can be assessed in terms of acceptance of the concept by patients and general population.

References

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