

Ethical Issues of Using Advance Directives for the Terminally Ill

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What is an advance directive? What purpose does it serve?

- AD are vehicles through which patients who have full decision-making capacity express their preferences of medical decisions, in the event that they become incapable of making medically-related decisions;
- They are intended to extend competent patients' right to refuse medical treatments they don't want, based on the principle of respect for autonomy or self-determination;
- It is considered an exercise of the person's "prospective autonomy" or "precedent autonomy".



Some historical contexts

- Use of AD began in the late 70s and early 80s in the U.S. in the midst of 2 highly publicized cases of Karen Quinlan and Nancy Cruzan and culminated in the “Patient Self-Determination Act” passed by U.S. Congress in 1990;
- AD originated in contexts of **refusing** certain life-sustaining treatments such as mechanical ventilation and mechanically delivered fluid and nutrition in terminally ill patients.



The different forms of advance directive:

1. Living wills (instructional directive) (LW):

- It specifies what treatments the patient accepts or rejects under certain particular circumstances when the patient has lost decision-making capacity.
- It can be either in written or oral forms, although the former is more preferred and recommended by the HKLRC.



The different forms of advance directive:

2. Durable power of attorney for healthcare (proxy directive) (DPAHC)
 - To appoint and empower a proxy who is trusted by the patient either
 - (i) to interpret and implement instructions (e.g. LW) on patient's behalf when patient is no longer capable to make decisions or
 - (ii) in the absence of any previously given instructions, to make healthcare decisions on patient's behalf.
 - HKLRC has rejected this form of AD for fear of "exploitation and abuse"



The difficulties of LW: How successful does it maintain the person's autonomy?

- LW and “Informed Consent” share the same bioethical basis of self-determination; in both cases, patients:
- Must be **well informed** of the health situations they are in and available and recommended treatment options ;
- Be able to rationally and **meaningfully assess** the risks & benefits of having or rejecting treatments;
- Be given **time to consider**, re-consider, and if necessary modify or reverse their decisions;
- To voluntarily make a decision that best serves their life **values and goals** under the specific medical circumstances.



How well can we expect patients to understand the medical conditions they will be in, and treatments they are asked to reject in some ill-specified future situations?

- The LRC model LW form puts it this way: ‘If I become **terminally ill** or if I am in a state of **irreversible coma** or in a **persistent vegetative state** as diagnosed by my attending doctor and at least one other doctor, so that I am unable to take part in decisions about my medical care and treatment, my wishes in relation to my medical care and treatment are as follows...’



Difficulty with specifying the type of illnesses for which patients truly reject treatment.

- The model form defines ‘**terminally ill**’ as ‘suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death...’
- Imagine a 93 years old patient with severe chronic congestive heart failure, generalized crippling osteoarthritis and carcinoma of the prostate with signs of metastasis. In what sense is he “terminally ill” in the context of the LW?
- “**Irreversibly comatose**” and “**PVS**” are clinically complex concepts, unfamiliar to most people, and mean different things to different people.



Patients are asked to make prospective decisions in hypothetical situations

- In a conventional “informed consent”, patients are asked to respond to an immediate real-time medical condition and to consent to a concrete, identifiable intervention; and they have difficulties because patients do not know enough about illnesses and treatments;
- In LW, instead of being asked to make an “active, contemporaneous personal choice”, patients are asked to make prospective decisions for future events that are unidentified, un-specifiable and unpredictable, it is unlikely that they can adequately envision and consider particular situations.



Difficulties with defining "life-sustaining treatments" (LST)

- HKLRC model form defines LST as “any of the treatments which have the potential to **postpone the patient's death** and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialized treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration.”



Difficulties with defining "life-sustaining treatments" (LST)

- Whether a treatment is life-sustaining or death-postponing has more to do with the patient's medical contexts than the nature of treatments themselves;
- In LW, treatments can only be specified with limited certainty because the patient's condition is uncertain;
- Hence, it is critical that the conditions under which particular treatments are to be withheld be specified;
- In the previous example of the 93-year old man, if he provides a LW to withhold CPR in the context of his "terminal illnesses", does the DNR applies if he unexpectedly develops cardiac arrest in the course of a minor dental surgery?



Difficulties with defining "life-sustaining treatments" (LST)

- Benefits and risks of treatments can not be properly weighed or fully appreciated under hypothetical circumstances even by the HCP;
- Most of the information about success or failure rates and short or long term consequences are not fully known;
- For example, not all patients know that the artificial nutrition and hydration that they reject in a LW are the only treatment that keep them alive.



In LW, patients are not given the relevant context to process the options available

- “Important life decisions will not turn entirely on the calculus of rational considerations. These decisions will also include assessment of emotions, desires, fears, and other feelings that cannot possibly be made, except in the actual presence of those sentiments.”
- “To be “informed’ in such circumstances means not merely to have access to data ... but to be aware of one’s own re-action to the situation in the concrete – information that cannot be obtained apart from actual confrontation with the situation.” (Pope:195)
- In LW patients are asked to process abstract information in an emotional vacuum.



LW: easy to become an uninformed or under-informed directive:

- In a LW, patients cannot meaningfully process abstract information because there isn't a real life context;
- Scholars have argued that “no response can be said to be a genuinely informed one until the full reality of the choice is present to the individual.” (Pope)
- Conclusion: If we use conventional standard of informed consent to judge the decision in a LW, most would fall below the required level of being truly ‘informed’.



Empirical data: patients are confused & reluctant and the preferences in their LW are not genuine:

- Studies have shown substantial differences in the understanding of the terms of the LW by patients, their family members and their doctors (Upadya A)
- People often issue mutually inconsistent instructions in LW e.g. will accept CPR if there is a small chance of survival but reject mechanical ventilation under any and all circumstances (Brett)
- Studies have shown that patients often have contradictions between preferences and wishes expressed in their LW and values they expressed in other hospital assessments (Stubbs)



Empirical data: patients are confused & reluctant and the preferences in their LW are not genuine:

- Many studies concluded that LW have not been an effective means to elicit patient preferences, and researchers are uncertain of the best way to do so.
- In the U.S., even after the passing of the Patient Self-Determination Act in 1990, the number of people executing AD remains unchanged at about 15% to 20%.



How do you make a LW work?

- It is not enough that the patient has a LW. Unless there has been full and open discussion among the patient, the patient's family and the physician about the LW and the patient's wishes and preferences, the effectiveness of the LW will be greatly diminished;
- One way to tell if patients are truly processing the information is whether patients seek additional information;
- One study shows that only 2% of patients ask questions about the LW they are prepared to sign.



How do you make a LW work?

- But patients may not ask if they don't know that they don't understand.
- It is not enough that information is simply 'presented' to patients and leave them to make their own decisions with regard to LW;
- Patients must be assisted to understand issues in their own unique contexts and to make decisions that are most consistent with their values and goals;
- i.e. Patients need to be empowered to decide in a LW.



How do you make a LW work?

- “The quality and effectiveness of a directive is largely determined by the quality of the physician-patient dialogue that occurs in the process of preparing and ... revising that directive.”
- “Advance directives are limited by being no better than the counseling that preceded them; thus, appropriate counseling is an important obligation of caregivers.”



Potential benefits of using LW

- LW allows the doctor and the patient to talk about death and dying and opens the door to a positive, caring approach to death;
- LW may create a feeling of comfort and confidence for patients and their families (even when the confidence is not necessarily soundly grounded);
- Relieves relatives of the burden of making critical decisions of life and death;
- Reduce disputes among family members regarding the wishes and preferences of the incompetent patient.



Potential benefits of using LW

- Use of LW reduces cost of terminal hospitalization.
- A retrospective study (Weeks 1994) of a cohort of 336 patients who died in a university hospital shows:
- Patients without previously completed AD had hospital charges 1.35 X > patients with previously completed AD;
- Patients with AD spent < 3 days in ICU while patients without AD spent a little > 5 days;
- Another study of patients who died in a university hospital (Chambers 1994) reports: hospital charges of 342 patients without AD were > 3 times that of 132 patients with AD;
- LW has the real potential to reduce cost.



Do LW meet elderly terminally ill patients' real needs?

- Multi-dimensional experience of the terminally ill:
 - Physical
 - Psychological
 - Social & Relational
 - Experiential & Transcendental
- A multi-dimensional approach provides a systematic and ethical framework to care for terminally ill patients.



Implications of a multi-dimensional experience of terminally ill patients

- Dying is not an exclusively medical experience;
- Interventions should be directed at all dimensions to reach beyond the conventional bio-medical paradigm;
- Only the outcome of the multi-dimensional interventions determines the meaning of “a good death” and the amelioration of the patient’s suffering.



What do elderly terminally ill patients want?

- Ethics and law regard LW as a tool that ensures the respect of patient autonomy in medical decision-making;
- Yet, autonomy is usually not the only value taken into consideration by terminally ill patients; they have less desire to be autonomous and to make treatment choices;
- In one U.S. study of 646 seriously ill adult in-patients and 513 older in-patients, 78.0% and 70.8% respectively would prefer family or physician to make CPR decisions rather than preparing LW (Puchalski).
- Hence, preparing an un-informed and poorly understood LW not only undermines patient autonomy but more importantly misses patients' real needs.



What do elderly terminally ill patients want?

- What does the terminally ill patient value most?
- If a LW has to be prepared, most terminally ill patients would see it as a means to prepare for death and dying where personal and family relationships counts far more than exercising autonomy and control;
- Hence in preparing a LW, patient's diverse values, cultural conventions, religious beliefs and social relationships must be included and carefully considered and that may exceed the capability of LW;
- To do less than this is to under-estimate the complexity of human decision-making and not to truly respect the patient's autonomy.



END

Thank You. Questions Please.

