COMMENTARY

The living will—pitfalls, benefits and a way forward

Introduction

In August 2006, the Hong Kong Law Reform Commission (HKLRC) issued its final report on 'Substituted Decision-Making and Advanced Directives in Relation to Medical Treatment' and endorsed and recommended the use of 'living wills' to allow individuals who are terminally ill, irreversibly comatose or in persistent vegetative states, and are mentally incapacitated to refuse life-sustaining treatments and make treatment choices for themselves.[1]

There are two popular forms of advance directive. The first type, exemplified by living wills, is a written directive specifying what treatments patients will accept or reject in particular situations when they have lost decision-making capacity. The second type, called "durable power of attorney for healthcare" (DPAHC), is a proxy directive appointing and empowering a proxy to either (i) interpret and implement the patient's written or oral instructions or (ii) in the absence of any prior instructions make health care decisions based on the patient's known values and goals, or in the patient's best interests, or both. The HKLRC has rejected DPAHC for fear of "exploitation and abuse" and recommended written living wills exclusively.

Can living wills enhance patient autonomy?

Since both living wills and conventional informed consent share the same moral objective, respect for patient autonomy, the ethical standard used for informed consent can be used to evaluate living wills. In informed consent, doctors give patients information about their health and the treatment options available to them. Patients must be able to rationally assess the risks and benefits of accepting or rejecting treatments based on their own values and life-goals, and to voluntarily make a decision in the context of their medical predicament. Patients should also be given time to consider, reconsider, and if necessary modify or reverse the decision made.

In living wills, patients are asked to understand ill-specified future situations and to reject certain treatments in those situations. The HKLRC gives this model: "If I become terminally ill or if I am in a state of irreversible coma or in a persistent vegetative state..., my wishes...are as follows..."[2] It then 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...".[2] Imagine a 93-year-old patient with chronic congestive heart failure with episodic exacerbations, generalised crippling osteoarthritis, and carcinoma of the prostate with metastases. In what sense is he 'terminally ill' in the context of the living will? Living wills have limited ability to unambiguously specify particular illnesses as terminal ones for which patients reject treatments. Likewise, 'irreversibly comatose' and 'persistent vegetative state' are complex concepts that mean different things to different people. Furthermore, experience with informed consent indicates patients generally know very little about illnesses and treatments, and, even when asked to choose concrete, identifiable interventions for real-time medical conditions, are uncertain and hesitant. In living wills, choices are much more difficult because patients are asked to make decisions about future, unspecifiable, and unpredictable events. Without assurance that patients can adequately consider particular situations stated in living wills, their decisions to reject particular treatments could not be considered informed.

Living wills do not define 'life-sustaining treatments' clearly. The HKLRC defines them as "treatments which have the potential to postpone the patient's death and includes...cardiopulmonary resuscitation, artificial ventilation, blood products... antibiotics...and artificial nutrition and hydration."[3] Arguably, whether a treatment is life-sustaining or 'death-postponing' has more to do with patients' medical conditions than the nature of the treatments themselves, and since, in living wills conditions are hypothetical and uncertain and treatments can at best be tentatively specified, it is technically difficult and morally risky to ask patients to judge that particular treatments are to be withheld. In the previous example, if the 93-year-old man wants cardiopulmonary resuscitation withheld for his "terminal illnesses", does it apply if he unexpectedly develops cardiac arrest during minor dental surgery? Furthermore, it is difficult for patients or even doctors to weigh the risks/benefits of treatments since information about their success/failure rates or short-/long-term consequences are seldom fully known. For example, many patients do not know that

the artificial nutrition and hydration they may reject in a living will are the only treatments that keep them alive. Patients seldom make decisions under optimal conditions when making living wills. Life and death decisions do not depend solely on "...the calculus of rational considerations. [They]...also include assessment of emotions, desires, fears, and other feelings that cannot possibly be made, except in the actual presence of those sentiments."[4] When making living wills, patients are not actually confronting real situations and thus process abstract information in an emotional vacuum, making decisions that are not authentic choices. If conventional informed consent standards are used as our ethical benchmark, most living wills are uninformed or under-informed health care directives. They undermine rather than promote patient autonomy.

Overseas experience

Overseas studies have found that not only are patients reluctant to make living wills, when they do, their stated preferences may not be genuine. In the United States, after the Patient Self-Determination Act was passed in 1990, the number of people executing living wills remained unchanged at 15% to 20%. Others have reported that doctors, patients and their families interpret the terms in living wills very differently,[5] and patients often issue inconsistent instructions. For example, some patients accept cardiopulmonary resuscitation, even when survival chances are low, but simultaneously reject mechanical ventilation under all circumstances.[6]

Some potential benefits of living wills

Living wills are not without potential benefits. 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. But the most significant benefit living wills can potentially bring is a reduction in health care costs. Despite some early studies that found no connection between the use of living wills and health care savings,[7-9] some more recent, better-designed studies have found the reverse. A randomised controlled trial involving 1292 residents in six Canadian nursing homes found that those facilities promoting living wills had fewer hospitalisations per resident (0.27 vs 0.48) and lower health care costs per resident (Can $3490 vs Can $5239).[10] A retrospective study of 336 patients who died in a US university hospital found that patients with living wills spent less than 3 days in intensive care unit while those with none spent over 5 days and their hospital charges were 1.35 times higher (US $49 900 vs US $31 200).[11] Another recent mortality follow-back survey found that the use of living wills is associated with less use of life-sustaining treatment, greater use of hospices, and less likelihood of terminal hospitalisation.[12] Given the importance of controlling health care costs, the ethical significance of this use of living wills cannot be underestimated.

The way forward

The use of living wills poses a dilemma. On the one hand, living wills serve patient autonomy poorly; on the other hand, living wills have the advantage of reducing health care costs. Yet, moral persons ought not to cut health care costs at the expense of patient autonomy. One way to resolve this dilemma and move forward is to use living wills as occasions for doctors to engage in full and open discussions with terminally ill patients and families so that the living wills that emerge from these dialogues fully reflect patients' understanding, values, needs, and preferences.[13] Thus living wills may become fully informed instruments and patient autonomy is preserved. A terminal illness involves all aspects of patients' lives including physical, psychological, social, relational, and spiritual dimensions, thus their needs are also multi-dimensional. This implies that dying is not an exclusively medical experience and any ethical approach to managing terminally ill patients must go beyond the conventional bio-medical paradigm. Sadly, modern ethics and law narrowly construe living wills as tools ensuring patient autonomy in medical decision-making. Yet, autonomy is not the only value taken into consideration by terminally ill patients. In one US study of 646 seriously ill adult in-patients and 513 older in-patients, 78.0% and 70.8% respectively said they preferred to leave it to their family or physicians to decide whether to give them cardiopulmonary resuscitation rather than make a living will.[14]

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 multi-dimensional needs of end-of-life patients.

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