The living will: Patients should be informed of the risks

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Living wills are designed to ensure that patients' preferences will be respected at the end of life should they lose capacity to make decisions. However, data on living will use suggest there are barriers to achieving this objective. Moreover, there is evidence that completion of a living will creates a risk of an unwanted outcome: the potential for premature withdrawal of interventions. We suggest a multifaceted approach to improve the ability of living wills to achieve their goals. However, acknowledgment of the current reality should oblige providers offering a living will to their patients to present a balanced view of living wills that includes enumeration of the risk, barriers to achieving the purported benefits, and alternatives to completing a living will, in addition to discussion of the potential benefits. This requires a change in current practice that would encourage shared decision making regarding whether completing a living will or other type of advance directive is desired by the patient and discourage the proliferation of living wills completed without providing these important advantages and disadvantages to the patient.

INTRODUCTION

Over one-quarter of elderly adults require surrogate decision making.[1] The living will is a type of advance directive wherein patients can suggest the care that they hope will be provided to them in the event they become unable to make decisions. Many living wills state that the patient preferences indicated therein become operative when its author becomes terminally ill without hope of recovery and is unable to make decisions for herself.[2] As they are not medical orders, these can be completed without the involvement of a health care professional.[3] Advance directives fall under the jurisdiction of state law, and their composition and legal requirements for their completion vary by state.[4] Currently there are several available online platforms for assistance with completing a living will (see Table 1 for examples).

The purpose of the living will is manifold. Its major intent is to increase respect for patients' wishes by promoting the treatment they say they want if they lose decision-making capacity.[5] Second, it attempts to protect the patient's family from having to make difficult decisions on behalf of the patient.[6] Third, it is meant to reduce futile interventions that lead to suffering of the patient and wasted health care resources.[6,7]

Data as to whether living wills accomplish their intended goals are of suboptimal quality, consisting mostly of

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Table 1: Online resources for the completion of living wills

Resource	Link
Free downloadable advance directive forms by state	https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/
Free downloadable advance directive forms by state, with some additional information	https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/Stateforms/
Free downloadable advance directive forms by state, with glossary of terms, and contact information for asking questions	https://www.nhpco.org/advancedirective/

associations without clear causation or enough clinical context to eliminate confounding factors. Nonetheless, the data are cautiously encouraging. It has been shown that having a living will is associated with dying at home rather than in a hospital, spending less time in the intensive care unit,[8] and minimized use of life-sustaining treatment including ventilators and feeding tubes,[9] without compromising on patient satisfaction, mortality, attention to symptoms, or communication with patients and families.[10] Comprehensive programs such as Respecting Choices have retrospective evidence of improvement in patient and family satisfaction with hospital care, increased surrogate understanding of the patient's goals of care, reduced stress and anxiety on families, and reduced decisional conflict in the presence of a living will.[11]

However, it must be remembered that these data suggest a strong benefit to living wills on a societal level, and to many individual patients. Yet it is inconceivable that such positive outcomes will occur with every patient, especially given that other studies have shown a limited effect of living wills on specific end of life-related treatment decisions.[12] Recent authors have decried a lack of tangible benefit to advance directives despite years of research, attempted improvements, and great financial investment.[13]

While there has been a positive public campaign for living wills, there has been insufficient attention to the possible risks and harms of living wills. Our aim is to describe the existent barriers that can prevent achievement of the living will's goals, as well as the risk created by completing a living will. We then suggest a multifaceted response to these challenges but argue that acknowledgment of them creates a moral obligation on anyone engaging a patient in a discussion about the opportunity to fill out a living will to honestly and openly discuss and weigh the benefits against the risk with the patient prior to completing the living will.

BARRIERS TO ACHIEVING THE BENEFITS

Lack of availability

In clinical practice, one part of what limits the efficacy of living wills is their frequent lack of availability to health care providers.[5,13] Living wills often do not accompany patients while they are transferred between facilities.[3] Emergency providers are often unable to find them,[14] and medical providers are often unaware of their presence.[15,16] Some patients and families who have completed living wills may not carry them or bring them to hospital admissions, nor recall what was documented. Recent attempts to remedy this using the electronic health record have largely focused on the more recently developed physician orders for life-sustaining treatment (POLST) forms rather than living wills.[13]

Inadequate patient understanding

In order for a living will to be a reflection of patient autonomy, it must be assumed that patients have adequate understanding of the decisions they document. However, there are some components of the living will that are difficult for anyone to understand, including the subtleties of defining terminal and irreversible illness.[5] Furthermore, if the language of a living will suggests a patient is documenting treatment decisions to be implemented in a future setting, rather than simply making suggestions or enumerating values and goals of care, the "adequate understanding" required for autonomy would need to include an appreciation of his existence in that future setting. This is likely an impossible task.[14,17] In fact, some have suggested that discretionary decisions by the designated health care power of attorney have advantages over documented preferences in the living will, especially when the clinical scenario was not anticipated by the patient.[18] If providers cannot be certain the patient had an adequate understanding of their documented preferences or the relevant clinical context, one cannot assume the living will improves patient autonomy or increases respect of true patient preferences.

Ambiguity of terms leads to imposition of the values of the provider and surrogate

The ambiguity of important terms contained in most standard living wills may also shift the implemented plan of care away from reliance on the patient's documented preferences and toward the opinions of the provider and/or durable power of attorney. Several studies have shown that both physicians and surrogates are imperfect at

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determining treatment preferences of the author of a living will.[17,19] This is certainly related in part to the ambiguity of the document. Legally, a terminal condition is one that will lead to the patient's death.[20] In medicine the definition is more complicated, as many conditions that can lead to a patient's death if untreated, are easily treatable.[20] Even physicians have difficulty defining terminality and reversibility of illness, and the definitions they use and thus their decision-making process may in part depend on their values, experiences, and even subspecialty.[17,21,22] In some situations the physician's personal opinions may figure into the plan of care as prominently as the patient's.[17] The same is true for surrogates. Furthermore, many physicians may not even think to consult a living will as long as they are permitted to manage the patient in the way they deem appropriate. It is often conflict between a physician and patient or the surrogate that prompts reevaluation of the case and consultation of the living will. In this way it is the physician who retains the majority of control. While this level of involvement of the physician may be appropriate in some cases, it creates a reality that falls short of the level of control a patient thought she was getting when she decided to complete a living will. This is not necessarily a disadvantage, as the purpose of the living will is to promote and advocate for the patient's autonomous preferences, not to blindly follow them. In fact, that physicians can make treatment decisions that seem in opposition to the living will can be seen as a protective mechanism against blind adoption of documented treatment decisions that have clearly become unreasonable or irrelevant. Still, it also means the physician's personal opinions regarding futility or value of certain interventions plays a significant role in treatment decisions even in the setting of a living will. Therefore, it would be misguided for patients to expect that completion of a living will can assure control over all future plans of care. If this misconception is suspected, it should be dispelled.

RISKS

Despite the potential for great utility in end of life care, creation of a living will can potentially lead to harm. The essential risk is the possibility that a patient will receive care not in accordance with his preferences specifically because of the presence of the living will. The most clear and serious example of this is premature withdrawal of interventions that would not have occurred had the patient not previously completed an advance directive. It is possible a provider will limit or withdraw interventions, thinking he is acting in accordance with the patient's documented preferences on the living will when in reality use of the living will in the particular clinical setting was inappropriate. In that setting, the patient would have been better off without a living will, with the default code status of full code and preference for full treatment. We will first explain how and why this may occur, and then argue that discussion of this risk of completing a living will and its underlying causes should be a prerequisite to completion of a living will.

Provider misinterpretation

One reason early withdrawal of interventions may occur is misinterpretation of the living will by those who implement it. Unfortunately, most health care providers charged with interpreting living wills are not properly trained in their interpretation.[23] The Pennsylvania Patient Safety Advisory, an independent state agency tasked with reducing medical errors and promoting patient safety through data-driven interventions, reported more than 200 mistaken events from 2004–2008 related to mishandling of living wills and POLST, some involving misinterpretation of living wills and Do-Not-Resuscitate (DNR) orders that may have inadvertently resulted in withholding appropriate interventions.[24] Both small and large scale cross-sectional studies have shown that a majority of all types of health care workers are likely to incorrectly assess a theoretical patient's code status as DNR even when the patient presents with an acute, reversible illness, due to misinterpretation of the living will.[22,25,26] Observational studies have shown that while patients who indicated a preference for all care possible or no care at all received care in concordance with their living will, many patients in between these extremes sometimes did not.[1,15,27] This did include some instances of unwanted resuscitation at the end of life, but more importantly for our discussion, many cases of living wills being misinterpreted as operational DNR orders.[20,28]

There is a need for more detailed studies that incorporate clinical context with large-scale observational data to further cement the effects of these deficiencies on true patient outcomes. Nonetheless, the combination of theoretical and observational data shows that patients do not always receive care concordant with the preferences indicated on their living will, as can be expected. Among the types of discordant care a patient can receive, premature withdrawal of interventions in particular is the type least likely to have occurred in the absence of any documented preferences.

Confusion surrounding proper implementation

The second reason early withdrawal of interventions may occur relates to confusion about when to implement a living will, even among those who recognize that a living will is not an operational DNR order. The proper time for implementation of living wills is ambiguous given the need to interpret vague terms such as "terminal," "incurable," "irreversible," and "reasonable hope for recovery."[17,19,20,29] Applying terminality and irreversibility to a clinical situation also requires accurate prognostication, which is often lacking among physicians.[30] There must also be an ability to re-evaluate the living will constantly as the clinical situation evolves.[2,22] Studies have shown that there is significant variability among physicians' definition of a terminal condition,[16] ranging from any acute illness from which the patient will die if not treated, to the end stage of a chronic, irreversible disease in a patient near death.[31]

With confusion and variability among physicians, even more ambiguity likely exists among patients. Surely the text of the living will as completed by the patient does not offer clear definitions of these terms, nor are patients always afforded the opportunity to provide their personal definitions. There is often disagreement on what a recovery would look like, and what would constitute an acceptable enough quality of life to constitute a meaningful recovery.[29] What results is a lack of clarity as to when criteria for activation of a living will have been met. This creates a risk that a living will may be prematurely activated at a time the patient would not have wanted, even if the physician understands the living will is not a DNR order and consults with surrogate decisionmakers.

Mutability of treatment preferences

The third reason early withdrawal of interventions may occur is due to the evolving nature of patient values. The ability of a living will to accurately predict patients' future preferences has been fundamentally questioned for decades.[32] Studies have even shown inconsistencies between patients' documented preferences and their verbally expressed ones.[33] By completing a living will, patients sign a document requesting a plan of care to be implemented at a time when they can no longer evaluate whether the document continues to be consistent with their values. However, there is evidence that people's preferences and values evolve over time. Competent patients who in health preferred death to disability sometimes reject that preference after becoming ill.[14,19] It has also been shown that patients tend to decline life-sustaining treatment after hospitalization but desire it at prehospitalization levels within 6 months of discharge.[19] It is difficult to imagine a patient's preferences remaining stable in the setting of a complete overhaul of his life.[34] Completing a living will, then, involves a risk that a plan of care could be implemented based on old wishes that may no longer represent the patient's preferences. Such a plan of care could involve withdrawal of interventions at a time the patient might have truly wanted them continued, something that may not have occurred had the patient been without an advance directive and the providers were forced to create a de novo treatment plan without the influence of a minimalist living will. Though this may be mitigated to a degree by close involvement of the durable power of attorney in all decisions pertaining to a living will, not all living wills are complemented by appointment of a durable power of attorney Moreover, surrogates are often unprepared for this degree of involvement, may have difficulty deciding what is best for the patient, and may not be consulted as often as they should.

Direct orders for life-sustaining treatment

Orders for life-sustaining treatment differ from living wills in that they are medical documents that are operative upon completion.[3] As a medical order they must be signed by a physician, though they are often prepared by other health care workers.[35] Besides for directives regarding cardiopulmonary resuscitation (CPR), many states have developed more encompassing order forms, such as the POLST form. These feature direct physician orders on how to treat a patient should a cardiac arrest occur, and also include several orders on whether to provide forms of life-sustaining care such as intubation and ventilation, artificial nutrition and hydration, and antibiotics in noncardiac arrest situations.

Forms like the POLST avoid many of the difficulties of living wills. They are immediately operative so their applicability is not left to interpretation. The concern for mutability of patient preferences is also significantly mitigated, as the document is not designed for future use at a time when the patient's values may change. Furthermore, while there is ample evidence that DNR orders carry a significant risk of early withdrawal of treatment,[36] in theory POLST forms' inclusion of other forms of care should mitigate much of this as well and provide more clarity on the patient's desired level of intervention.[37]

However, even POLST forms remain imperfect in this regard. While some studies have shown patients who indicate full code on their POLST form are not at risk of having CPR withheld based on the presence of a POLST form alone,[35,38] other studies found the risk of not receiving desired CPR ranges from 4 to 16%.[3,39] Furthermore, POLST forms are far less effective at ensuring care concordant with the patient's wishes in nonarrest situations.[3] Provider and patient understanding of the more subtle components of the documents are poor,[39–41] and the risk of a patient not receiving an intervention they desire still exists, especially in the setting of a POLST form indicating DNR but a desire for other limited interventions.

Lastly, there is still reason to wonder whether patients truly appreciate the meaning of their documented preferences.[35] In a study that evaluated POLST use by a hospice program, the greatest barrier to its use was understanding and explaining the form.[42] In one study, only 56% of patients correctly defined DNR and only 26% correctly defined CPR.[33] Recent studies have pointed out the existence of a minority of POLST forms with inconsistent or incompatible selections,[43] and that the POLST on record does not always correlate to the patient's true wishes.[44] Patients also have a poor understanding of the success rate of medical interventions. In theory these gaps of knowledge can and should be filled in by the physician completing the document with the patient, but there is no mechanism in place to standardize whether this occurs or how effective it is.[39] Relevant concepts such as a trial of intubation or antibiotics require explanation to patients who are not experienced in health care. Given these issues and a lack of mechanism to ensure documents are revisited with changes in clinical status, recent authors have suggested caution prior to embracing POLST forms in their entirety.[33,40]

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DISCUSSION

For nearly half a century, ethicists and public policy analysts have been promoting living wills as the solution to determining the treatment preferences of the incapacitated patient at the end of life. While there are certainly positive aspects to living wills, the benefits of living wills will not be actualized in every patient. They may not always prevent unwanted overtreatment at the end of life. Lack of complete patient understanding and the involvement of a dominating physician, whether intentional or not, may prevent the treatment plan devised based on the living will from being an accurate reflection of the patient's wishes. This does not detract from the value of living wills, as no intervention should be expected to yield perfect results in every situation. Furthermore, attempts should and are being made at improving the yield of living wills, as will be outlined below. However, in the meantime, the current reality should be recognized, acknowledged, and communicated to patients.

More importantly, we have shown that living wills also have risk, and that the main risk posed by a living will is undertreatment.[23] We have explained this can occur primarily due to a fundamental misunderstanding of when living wills become operational by providers, lack of clarity as to when the conditions that trigger operationality of the living will have been met due to ambiguous terminology, and the mutability of patient preferences.

Our response to this potential harm should be multifaceted. First, we must continue to work on minimizing the risk. Education is one intervention that should be implemented to this end. Any health care provider who may interact with living wills should receive basic training on how to properly use them. Namely, they remain inactive until the appropriate criteria are met, and that they differ in this way from direct physician orders including DNR orders. Also, that they should generally not be implemented without first consulting the durable power of attorney. Health care providers and legal professionals expected to assist patients with living wills and those who are responsible for their interpretation could be required to complete specific training at the time of licensure, and also be enrolled in mandatory continuing education. Simulation has been shown to be especially effective, at least in theoretical studies,[45] and should be incorporated into such a curriculum. Such educational interventions have been effective in theoretical studies. However, improved provider education has not been shown to eliminate misinterpretation of advance directives.[3,9]

Another possible intervention is a checklist that can be used prior to implementing a living will, ensuring the provider has discussed the clinical scenario and the living will with the durable power of attorney, including perceived reversibility of the patient's medical condition. This innovation has been suggested already by Mirarchi et al.,[3] but this has not yet taken hold and its efficacy has yet to be studied.

Simultaneously, we must make an effort to better quantify and track these potential harms. As described above, data pertaining to the potential harms of living wills exist as theoretical cross-sectional studies and observational studies. Neither can be seen as definitive, since the former lack real hard outcomes, and the latter often leave the relevant clinical context unknown. While randomized controlled trials are likely not feasible or appropriate, higher quality observational studies that incorporate more clinical context would be helpful in better quantifying the potential harms. Higher quality observational studies could collect outcomes data on a large scale including location of death and invasive therapies implemented at the end of life in patients with living wills versus those without. Patients should also be stratified according to what they indicated in their living will, rather than being grouped solely based on the presence or absence of a living will. Families should also be interviewed after the death to obtain data on patient and family satisfaction with the care they received, whether they perceived any benefit or harm from their living will, and whether they have any regrets about treatment decisions that were made. Furthermore, programs such as the Pennsylvania Patient Safety Advisory should be advertised and expanded in order to obtain an accurate inventory on adverse events related to living wills. Providers and families should be encouraged to report any adverse events related to living wills and their use including misinterpretation to such a database. Widespread reporting would lead to accurate assessment of the extent of the problem. Ultimately, this may lead to the creation of informed solutions. That said, we have also discussed the ambiguity in terminology of living wills, including terms that have different definitions to different people, and may have differentiated applications in different clinical settings and contexts. All of this makes any such research difficult to achieve.

Third, we should encourage the use of living wills as expressions of values and goals at a snapshot in time only, and not as a completely binding legal document. At the very least, we suggest adding an explicit clause to the living will document stating that the treatment choices recorded in the living will should not be activated without first consulting with the durable power of attorney, if the patient has one. Appointment of a durable power of attorney for health care could then become a requirement for anyone completing a living will who has a surrogate she is comfortable appointing. This could significantly lower, though not completely eliminate, the risks of early treatment withdrawal and implementation of a plan that no longer fits with the patient's best interests.

As described above, completion of a POLST form may also complement the living will and mitigate some of the risk of premature withdrawal of interventions. However, as was also shown above these too are imperfect and do not completely eliminate the risk. One recent author has acknowledged the possibility that we may never attain the outcomes we desire with any of our advance directives.[13]

Fourth, the language of the living will should be altered to decrease ambiguity and reflect values and goals rather than listing medical therapies available to the patient. Rather than a standard formulation including challenging wording such as "meaningful recovery," the language can be individualized to reflect each patient's indicated preferences. For example, a living will could indicate that it will become active when it is clear the patient will never recover to the point of becoming independently mobile, or being able to communicate with family members, or being able to recognize family members, depending on the patient's particular values. Helpful language could include "The most important things in my life are____" "My life would not be worth living if I couldn't____". Addition of a brief video communication by the patient explaining his documented decisions does increase clarity compared to written documents alone according to one study,[46] and is now being advocated for by some in the legal community as well.[5]

With these helpful interventions, a significant reduction in the risk and increase in the yeild of living wills can be hoped for. However, until such changes are completely implemented, the current reality of potential risk with living wills continues. Furthermore, none of the proposed interventions is likely to be effective enough to completely eliminate the above-described risks. Therefore, while continuing to recommend living wills to patients, the potential harms of living wills must be acknowledged and communicated to patients in the context of a complete discussion of the advantages and disadvantages of the living will that allows for shared decision making. As part of this discussion, patients should be educated on the importance of reevaluating the living will as a clinical picture changes, and that completion of a POLST form and appointment of a durable power of attorney with the ability to reevaluate treatment choices in an evolving clinical setting based on their understanding of the patient's values can mitigate some risk and increase the odds of benefiting from the living will. Health care professionals are likely the best equipped to properly educate the patient about the clinical context in which living wills should be and are often applied, though a well-informed lawyer could in theory play this role.

Although initiating this type of risk-benefit discussion pertaining to living wills would be a significant change in current practice, it is not different from common practice in other aspects of medical care. It is widely accepted that before recommending any intervention with potential to harm, even if the risk of significant physical harm is minimal, such as a diagnostic screening test, prescribing a new medication, or administering blood products to a patient, the physician is morally obligated to discuss the risks, benefits, alternatives and important side effects with the patient. Although the living will may be completed without the input of a health care provider, as they are documents with important implications toward medical treatment we believe that anybody assisting a patient with completion of a living will should be under that same level of obligation.

The discussion of benefit and risk may change the patient's course of action in several ways. First, the discussion may prevent inappropriate overreliance on the living will and encourage ongoing discussion of values and preferences with the durable power of attorney. It may encourage the patient to give more decisional power to the surrogate than he otherwise would have, or encourage him to discuss more specific scenarios and treatments with the surrogate rather than relying on the sometimes vague terminology of the living will. It may cause the patient to decide to forego a living will, and instead pursue a direct physician order (POLST) in combination with verbal discussion with a durable power of attorney. Finally, after this discussion the patient may elect to only appoint a durable power of attorney. Introducing the patient to these alternatives and how they compare to the living will increase patient autonomy, which itself is one of the stated goals of the living will.

Unfortunately, current standard practice does not involve discussion of risks and benefits prior to completing living wills. Even organizations such as Respecting Choices that aim to improve advance care planning do not offer any recommendation on discussion of the risks or potential harms of living wills.[11] Previous authors have suggested that physicians should do more to ensure patients understand the limitations of living wills,[14] and that more extensive discussion between patient and physician would assist in clarifying ambiguity in living wills.[5] The same should apply to other health care workers or lawyers who complete living wills with patients. However, to the knowledge of this author the specific discussion of the risks of living wills has not been argued for in detail, and the contents of such a discussion have not been previously outlined.

What follows are several theoretical arguments against fully informing the patient in the way described thus far, and our response to them.

Arguments against disclosing risks prior to completion of the will

Lack of data

One can argue that providers lack sufficient data to have an appropriate risk benefit discussion. There is a dearth of research on decision quality, decision regret and patient and surrogate experiences with advance directives.[35] This is in contradistinction to surgeries and other procedures that often have well-defined and well-studied risks. Nonetheless, lack of data is not an excuse for lack of disclosure. The lack of clear high-quality data to confirm and measure the risks and benefits of living wills should be disclosed to the patient as well, but the data discussed above are suggestive enough of there being risk to

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completing a living will to warrant disclosure to the patient.

Avoiding harm to the patient

A more forceful argument is that an extensive discussion of all the complexities of living wills, rather than achieving the goal making the patient informed, would only serve to add confusion and anxiety to a discussion that is already wrought with these emotions. This may prevent the patient from completing a living will altogether, or to indicate preferences that differ from their true wishes. This could be harmful since the majority of time patients get care in line with what is indicated in their document.[35] Furthermore, from a public policy perspective, living wills may produce cost savings and improved allocation of resources,[7] so anything that would discourage proliferation of living will use should be discouraged.

One could counter this claim by again comparing living wills to any medical recommendation. Medications and screening tests are sometimes recommended to medically uneducated or emotionally overwhelmed patients. The discussion of risk opens the possibility that a patient will decline a test or medication that is beneficial to them. This possibility has not negated the practice of an open risk-benefit discussion, and neither should it for discussion of the risks of living wills. Of course, just as they are informed of the relevant risks, patients should be told they are still more likely than not to receive the care they choose when completing a living will. Despite this, should a patient choose not to complete a living will that is certainly his prerogative and should not discourage physicians from educating other patients.

CONCLUSION

Living wills are useful documents that offer an important expression of a patient's values at a juncture when he remains able to express them. However, the living will is an imperfect document. Due in part to an imperfect understanding of the document and how to apply it by patients and providers alike, completing a living will comes with a downside that is currently underappreciated. Given this, the decision to complete a living will should be a personal one, individualized to patient values, preferences and personality. The current standard of care poorly educates patients about living wills and fails to disclose the potential harms. Completion of a living will must be done by a fully informed patient in order to be a true expression of patient autonomy. Continued recommendation of living wills by health care workers or lawyers should be accompanied by disclosure of common or serious risks, including especially unintended consequences of having a living will, most notably the potential for premature withdrawal of interventions. Failure to inform patients of the potential harms of an intervention we recommend or condone represents a failure to fulfill our moral obligation to the patient.

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