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A Forced Choice: The Value of Requiring Advance Directives

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INTRODUCTION

Interest in advance directives has re-emerged in light of the tragic case of Terri Schiavo.[1] The conflict among Schiavo's family highlighted the unresolved problem of making medical decisions for incompetent patients who do not leave an advance directive, either a living will or healthcare proxy.[2] Without objective evidence of an incompetent individual's wishes, any surrogate — whether it be spouse or parent, child or sibling, physician or judge — is left to construct those wishes in the abstract. Inevitably, often surrogates will make decisions that are inconsistent with the patient's preferences,[3] and conflict in end-of-life decision making will remain a ubiquitous problem.[4]

Ironically, the calls for increased use of advance directives come at a time when living wills, although not necessarily healthcare proxies, are increasingly criticized for lack of effectiveness.[5] In addition, advance directives have failed to be widely adopted despite more than 25 years of advocacy inspired by the similarly tragic cases of Karen Quinlan and Nancy Cruzan, whose deaths even led to the implementation of the Patient Self-Determination Act, a federal law requiring hospitals who care for Medicare and Medicaid patients to provide information about advance directives to their patients. Thus, we are not optimistic that the case of Terri Schiavo will do much to solve the continuing problem of decision making for incompetent patients. Although we certainly favor the use of advance directives, we believe advance directives must be improved through systematic changes in their use. It is time we start requiring them.

We will argue that insurance and care provider institutions should be allowed to require patients to declare an advance directive. The directives we favor would give patients the option to limit *or pursue* life-sustaining interventions in common death trajectories as well as name a healthcare proxy. Federal and state laws that currently prohibit such practices should be changed. We believe requiring patients to express their preferences in advance directives will promote better end-of-life decisions, decisions that not only prevent conflict but are more likely to be consistent with patients' preferences than our current troublesome approach.

A FORCED CHOICE

The goal in end-of-life care should always be to provide care that is consistent with the wishes of the patient. Unfortunately, end-of-life care is often at odds with what patients would have wanted.[6] Since death

is ubiquitous and periods of incapacity prior to death are common, it is shortsighted not to establish routinely the goals of care for patients. Requiring individuals with decision-making capacity to complete an advance directive — a forced choice — would largely resolve the open question of how to decide for incompetent patients, while at the same time respecting and promoting patients' autonomy.[7]

As implied by the term "choice," individuals, when completing the advance directive, should be presented with the opportunity to declare their preferences for either a life-prolonging or a comfort-oriented approach. Unlike traditional living wills, the directives we envision would do more than merely allow patients to limit the use of life-sustaining interventions. In addition, an individual could complete a living will, a healthcare proxy, or a combined form. While including an instructional, or living will, component would provide some substantive guidance regarding an individual's values, all individuals would, at a minimum, be required to complete a healthcare proxy. However, unlike most current statutory proxy requirements, any proxy would be required to provide his or her assent and to confirm that he or she has discussed end-of-life wishes with the patient.

Since individuals can still pursue a preference for either life-sustaining interventions or limiting interventions, such an approach is only minimally paternalistic.[8] No particular type of care or vision of a good death is being forced on anyone. More importantly, any small infringement of individual rights that occurs as a result of requiring a declaration of preferences before the time of illness is justified by the preservation of those same rights at the critical time of incapacity.

An ideal opportunity to require completion of an advance directive would be at the time of initiation of healthcare insurance, whether provided privately or publicly, or the initiation of care with a healthcare provider or system. Completing an advance directive would be required within a reasonable time period, perhaps three to six months from initiation. This time would allow for thoughtful consideration and consultation with loved ones and medical providers. To improve the reliability of the advance directives, individuals must be sufficiently informed. Written or multimedia educational information, which clearly explains the full range of patients' options and provides examples to help individuals understand how advance directives are used in various contexts, would be sufficient for many people.[9] Others who require additional information and counseling would have sufficient time to meet with their physician or confer with a provider skilled in advance care planning.[10] Since willingness to accept life-sustaining interventions is known to decline over time as disability increases,[11] individuals would be asked to update their advance directive on a regular basis, most likely annually, and could alter their advance directive at any time.

Although most people actually welcome the opportunity to discuss end-of-life preferences,[12] some policy makers may object to forcing all patients to complete an advance directive. One reason often cited is that members of minority groups have tended to distrust advance directives in the past.[13] However, many minority patients do accept palliative care approaches.[14] In addition, some studies suggest that the differences in the use of advance directives across ethnic groups are modifiable and such differences may not exist for some communities.[15] In addition, previous advance directives have generally only been written to limit care, which has led patients who prefer life-prolonging approaches to distrust advance directives. Since with our approach individuals would be free to pursue all options, we believe trust may even be *increased* as people gain familiarity over time with the way these advance directives actually work.

We recognize that there may be some individuals who are uncomfortable confronting these issues formally. We suspect this will be a small number of people, but regardless, life inevitably presents uncomfortable questions that we must confront. There is evidence that many individuals who are uncomfortable discussing these issues still prefer limiting life-sustaining interventions in some situations.[16] These preferences are unlikely to be met, however, unless they are known. Societal policies should not shelter people from reality, particularly when the reality of death and dying has profound effects that extend beyond the individual, affecting not only the individual's family but also the community as a whole.

The idea of requiring advance directives of individuals has been discussed previously.[17] However, our approach is unique. For example, we do not advocate for legislation that would require all individuals to complete an advance directive simply by virtue of being a member of society or require all healthcare

insurance and provider institutions to obtain advance directives for their insureds and patients. Rather, we favor an approach in which institutions can freely choose to pursue a forced-choice policy for their clients or patients.

Our approach places the choice to require advance directives in the private sphere, which presents several distinct advantages. First, it avoids free speech and privacy concerns that are inevitably raised when dealing with governmental actors mandating advance directives.[18] And although these legal hurdles may be overcome,[19] completely avoiding them will reduce political concerns, which, as will be discussed below, are not insignificant.

Second, and more importantly, with our approach institutions can more freely develop advance care planning mechanisms that fit the needs of their patients or clientele. Thus, only if requiring advance directives routinely of individuals is found to be effective, useful, and worthwhile will this practice become the standard of care. Even if our institutionally based forced-choice approach is shown to be effective, it is highly conceivable that forced-choice approaches and traditional approaches would coexist in the same marketplace. Therefore, by leveraging the market accountability of insurance companies and healthcare providers to insureds and patients, individual choice is at least to some degree retained.

A mandated approach, such as that used in the Patient Self-Determination Act, is less likely to be sensitive to the costs and benefits encountered in developing and administering such a policy. In fact, it has been argued that the financial costs incurred by the Patient Self-Determination Act have been wasteful.[20] Indeed, they have been. Requiring the simple distribution of information about advance directives without the expectation of having patients execute an advance directive was shortsighted. The better reason to invest resources in advance directives is to actually obtain information about patients' preferences, not simply to inform them of their rights. However, a mandated approach is not easily abandoned if indeed the policy of requiring advance directives of patients, like the policy of mandatory hospital-provided information about advance directives in the Patient Self-Determination Act, is not found to be useful.[21]

LEGAL, ETHICAL, AND POLITICAL ISSUES IN IMPLEMENTING A FORCED CHOICE

Unfortunately, there is no place in the United States where an institutionally based forced-choice policy could be implemented today because insurers and providers have been forbidden from pursuing such strategies by state and federal statutory limitations on the use of advance directives: 48 states and the District of Columbia prohibit insurance companies from requiring advance directives of their insureds; 33 states prohibit providers from requiring advance directives.[22] In addition, the Patient Self-Determination Act prohibits conditioning care on the execution of an advance directive.

We presume these prohibitions exist to protect individuals from being forced to accept unwanted limits on treatment, limits that may appeal to third parties because of the cost-savings they may represent. If individuals were required to execute advance directives and many patients chose options that limited care, it is possible that these directives would subsequently lead to greater withholding and withdrawing of costly life-sustaining interventions and result in cost-savings. In fact, early proponents of advance directives hoped that they would lead to savings by reducing marginally beneficial care at the end of life.[23] Taking this assumption for granted, it is possible to imagine insurers offering an insurance premium discount to those individuals who complete an advance directive that limits life-sustaining interventions.

We acknowledge that such an approach is ethically controversial because it may be seen as coercive for individuals of modest means, as it provides these individuals limited alternatives. Although the degree of savings may not be substantial,[24] if the savings were large enough, one might predict that health insurers and hospitals that cater to patients of low income would be more likely to embrace a forced-choice policy in order to avoid marginally beneficial but costly care, thus disproportionately compelling low income patients to complete an advance directive. Indeed, similar concerns were raised in negotiations over the Patient Self-Determination Act even after initial attempts to mandate advance directives were abandoned.[25]

However, a forced-choice policy cannot be seen as discriminatory against the poor if it is implemented as we suggest. The advance directive would present both options of limiting and pursuing life-sustaining interventions. If a forced choice actually saves resources and lowers premiums, the poor will benefit the most from improved affordability of insurance and thus increased access, while still retaining choice at the individual level. Indeed, the forced-choice policy that we embrace creates a mechanism by which an individual's preferences for end-of-life care can be more clearly known no matter his or her preference. A forced choice is still a choice.

Nevertheless, one may still be worried about price discrimination against those who indicate their preference for greater access to life-sustaining interventions. Differential pricing signals important differences in insurance products to consumers. However, if price discrimination in this area is considered ethically unsound, it is possible to avoid this problem while still requiring a declaration of preferences. In this scenario, any savings that may accrue would benefit all individuals in the insurance pool as a whole rather than benefit only particular individuals. In fact, 26 states have passed laws forbidding insurers from using advance directives in underwriting.[26]

It should be noted that depending on the presence of a statutory anti-underwriting provision and its expansiveness, it may currently be legal in some jurisdictions for institutions to offer financial incentives to complete an advance directive, since a financial incentive that is not tied to a patient's premium has no effect on underwriting. Although financial incentives without institutional obligation to complete one may still raise the same ethical concerns, particularly if the incentive is only offered for completing an advance directive that limits life-sustaining interventions, such use of financial incentives today should be seen as ethical. No one is made worse-off than before by offering financial incentives. Individuals are only better-off because a new option of some financial value is now being offered. If the individual is uninterested in completing any advance directive, the individual simply need not participate. Of course, as in the case of price discrimination in the setting of a forced choice, regulations could be developed to assuage any ethical concerns that financial incentives will only be triggered for completing an advance directive and not for its content.

Daniel Callahan has argued that requiring advance directives is unethical because the inevitable tying of advance directives to monetary concerns corrupts the trust underlying the doctor-patient relationship.[27] Financial considerations are an inescapable aspect of seeking healthcare today, and yet the doctor-patient relationship survives. We do not think that doctor-patient relationships are so fragile that they are likely to be undermined should individuals be asked about their care preferences as a result of initiating an insurance or patient relationship. In fact, for many individuals trust may be strengthened, because they may not only benefit immediately financially, but may have greater confidence that their future preferences for care will be honored.

Although we would welcome the use of financial incentives for advance directives as well as statutory changes, when necessary, to allow financial incentives to be more readily available, we prefer our forced-choice approach because it promises greater participation in the use of advance directives. Therefore, we advocate for changes in federal and state legislation that would allow insurers or providers to require advance directives of their patients at the level and discretion of the institution.

We do recognize that there would be significant political opposition to such legislative changes. The legislation leading to the Patient Self-Determination Act initially embraced a mandatory approach that was abandoned on account of political pressure.[28] Given the inherent political responsiveness of the Centers for Medicare and Medicaid,[29] government institutions are unlikely to initiate a forced-choice policy, particularly given the sensitive nature of end-of-life care. Ironically, Medicare likely has the most to gain from successful implementation of such a policy, if indeed such a policy results in substantial cost-savings. The elderly, who are covered by Medicare, have higher end-of-life costs than younger patients do.[30] It is well known that approximately one-quarter of Medicare spending occurs in the last year of life, 70 percent of which occurs in the last six months.[31]

Our approach actually presents an opportunity for such political opposition to be minimized. We believe institutionally required advance directives are more politically palatable than legislatively mandated universal advance directives because, under our approach, the introduction of required advance directives would likely be gradual, not universal, and more sensitive to market demands and individual preferences. Indeed, our approach presents a constructive middle ground on which greater political consensus regarding the requiring of advance directives may be built. If private insurers and providers can successfully implement the policy and demonstrate that it is both ethical and effective, then political opposition will likely recede, and the practice may eventually be embraced by governmental institutions.

Thus, it is time to lift the ban on preventing insurers and providers from requiring advance directives of individuals. At the very least, federal legislation granting waivers of current prohibitions to a small number of willing insurers or large health systems, to test institutionally required advance directives, would be a valuable exploratory step. Any congressional action allowing or exploring the requiring of advance directives by insurers and providers would be a far more useful federal intervention aimed at improving future end-of-life care than the actions taken by Congress in the life of Terri Schiavo.

IS REQUIRING ADVANCE DIRECTIVES WORTH THE EFFORT?

A Second-Best Reality

Some may question our approach, given the ambiguity of living wills and the suggested inefficacy of advance directives generally.[32] But the reality is that the alternatives are worse. Whereas there is no appetite to return to the days of unbridled paternalism in medicine, upholding patients' autonomy through surrogate decision making is often little more than surrogate autonomy. Surrogates present particular challenges to implementing the end-of-life wishes of a loved one,[33] the least of which is that sometimes no surrogate is available.[34] More importantly, surrogate decision making is especially prone to bias and error in executing patients' wishes.[35] In addition, surrogates are less likely to withdraw care for a relative than they would be for themselves,[36] which is why we question the conventional wisdom that discounts living wills in favor of healthcare proxies.[37] Since healthcare proxies simply name the surrogate decision maker rather than rely on state default rules of surrogacy, proxies can minimize conflict but they do not necessarily increase fidelity to patients' wishes.[38] Even if proxies do discuss end-of-life wishes with the patient, surrogates themselves prefer that patients express their wishes not just orally, but in writing.[39] And more than 80 percent of patients and recently bereaved family members reported that they believed that having preferences in writing was important.[40]

Of course, some may question the autonomy paradigm that underpins the logic justifying both surrogacy and advance directives. Rebecca Dresser has been one of the most ardent advocates of embracing an objective best-interests standard. She argues that precedent autonomy is flawed. That is, since individuals cannot accurately predict future preferences for a hypothetical life state, such preferences should not bind our future selves.[41] Rather, she argues that decisions should be based on what the community, including but not limited to the family's preferences, determines to be in the patient's best interests.[42]

A full discussion of the merits of the best-interests standard is beyond the scope of this article, but, ultimately, we construct our approach on traditional precepts regarding the autonomy of patients because best-interests standards have not been able to establish consensus on normative ideals. The national debate that took place surrounding the case of Terri Schiavo only serves to remind us that we remain far from developing normative end-of-life care standards as a society.[43] And even if the autonomy of patients is a second-best alternative, the fact remains that patients' autonomy serves as the foundation of modern medical ethics and health law. Ironically, pursuit of a forced-choice strategy may eventually lead us to a best-interests standard, in that more universal agreement on normative standards may evolve when we increasingly learn about individuals' attitudes about life-sustaining interventions in a more global fashion.

Since we as a society have accepted a framework built around the autonomy of patients, we have an obligation to embrace policies that actually promote the provision of care in alignment with individuals'

preferences. Given that surrogacy is failing us, requiring advance directives offers much promise, even though past empirical research has failed to demonstrate the effectiveness of advance directives. A careful review of the history of and research regarding advance directives, suggests that there is room for continued optimism regarding the potential efficacy of advance directives. It is important to note that past research that utilized hypothetical scenarios or voluntary advance directives has told us little about how institutionally required advance directives would affect care.[44] This past research simply does not apply to this policy. The policy we suggest has never been tested, nor can it be tested without a change in the law. However, past research is useful in suggesting how future advance directives must move beyond the recognized problems of the past.

Drafting Applicable Advance Directives

Advance directive statutes evolved in the midst of skepticism and concern about the withdrawal of care. Thus, they were intentionally drafted narrowly to apply to cases of terminal illness, in which death was thought to be inevitable, or to the rare case of suspended life in which recovery was not possible, such as a persistent vegetative state. This terminology makes intuitive sense, but is misleading. It implies that the disease has progressed to a point where recovery is unlikely despite continued treatment. But for the physician who carries the primary responsibility of interpreting an advance directive, the language of terminal illness is a term of art used with great caution.

Whereas a doctor may be willing to predict that recovery is unlikely, stating that a patient is "terminal" requires a greater confidence that in practice is generally lacking. Judging an illness to be terminal before the fact is difficult. Physicians, aware that they are poor prognosticators of death,[45] describe a disease as terminal only when the natural history of the underlying disease process is uniformly known to lead to death. The paradigmatic case of terminal illness is metastatic cancer, but cancer only accounts for 22 percent of elderly deaths. The majority of elderly deaths occur in the setting of an acute and sudden illness or from an acute decompensation in the setting of a chronic illness or frailty. In fact, a condition of frailty precedes the deaths of almost half of all patients age 65 and older and 20 percent of those age 85 and older.[46] Furthermore, 27 percent of elderly patients who die have at least some degree of dementia, a figure that will likely increase.[47] These deaths are the result of a critical illness that is not readily described as terminal until the time of death, or very close to it.[48] In the mind of a physician, the potential for the reversibility of the acute component, even if unlikely, disqualifies an illness from being described as terminal.

This framing effect of terminality may help to explain the negative results of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT).[49] SUPPORT, the largest study of end-of-life care involving more than 9,000 patients across the U.S., attempted to study end-of-life care and to develop an intervention to improve end-of-life decision making. Although the study included patients with advanced medical illness, half of whom died within six months, the use of a nurse-based communication intervention to provide physicians with information regarding patients' preferences, as reported by the patient or surrogate, made no difference in the type of care that patients received.

One possible reason physicians in the study did not implement end-of-life preferences, even when these were known, was a belief that preferences to withhold life-sustaining interventions should not be acted upon until patients are terminal, since a perception of terminal illness has been the standard paradigm on which polices promoting the withholding and withdrawing of life-sustaining therapy have traditionally been based. A qualitative substudy of SUPPORT patients provided further evidence of this terminality problem, as it particularly relates to advance directives. Physicians generally did not view an advance directive limiting life-sustaining interventions as applicable until the patient was seen as "absolutely hopelessly ill" or "actively dying."[50] Other studies on the use of advance directives in SUPPORT also failed to demonstrate any effects on the type of care received or the costs of care provided.[51] However, most of the directives utilized in the study were simply healthcare proxies, which, as we previously noted, have limited value when not combined with an instructional component.

Earlier proponents of advance directives have recognized this terminality problem and have attempted various solutions. A second generation of advance directives has attempted to refocus care decisions regarding unwanted medical interventions and utilized a bidirectional approach, allowing individuals to limit or prolong care that we favor.[52] A third generation focused on incorporating patients' values.[53] However, neither approach improved surrogate accuracy in hypothetical scenarios nor has either been widely utilized in practice.[54]

It is worth noting some useful developments in advance directives as formulated by the Uniform Health-Care Decisions Act (UHCDA), a model for advance directive legislation.[55] Similar to past efforts, the UHCDA relies on traditional operational language, such as irreversibility, permanent unconsciousness, and burdens outweighing the benefits. However, the UHCDA combines a proxy with an instructional living will component and is bidirectional. It also separately addresses artificial hydration and nutrition, which many individuals value differently from other life-sustaining interventions. Although the model act has been explicitly adopted by six states and has likely influenced many other states that have incorporated some of these features, the value of the UHCDA remains unclear, and we suspect it is limited due to its reliance on traditional terminality language.

Future advance directives need to be uncoupled from a perceived requirement of terminality or irreversibility to be able to respond to common death trajectories, such as multisystem organ failure, congestive heart failure, chronic obstructive pulmonary disease, and advanced dementia. In order to become more widely applicable across a wide range of death trajectories, advance directives should focus on two key preferences that are widely shared by many patients. First, patients share an overwhelming desire for a chance at recovery.[56] However, patients commonly do not desire indefinite life-sustaining therapies. Most patients only want a reasonable trial of life-sustaining therapy attempted before care is withheld or withdrawn.[57] Thus, advance directives should specifically address whether a patient would like a reasonable trial of life-sustaining interventions in critical illness for an attempt at recovery, versus life-sustaining interventions administered indefinitely to prolong life as long as possible. The requirement for terminality or irreversibility is simply too rigorous and too narrowly construes patients' intentions, and it should be abandoned.

The other critical preference that advance directives should address is the preference for care in severe, irreversible neurologic compromise. The desire to avoid a life dependent on machines and not to be a "vegetable" is a well-known preference that is poorly articulated in current advance directives.[58] Most patients do not want life-sustaining therapy continued if recovery results in severe neurologic compromise.[59] And most patients would withhold life-sustaining interventions in the setting of advanced dementia, frequently including artificial hydration and nutrition and dialysis.[60] Although physicians prefer a more specific advance directive when making decisions, the specificity must also be useful.[61] Rather than simply focusing on terminal illness, an advance directive should contain sufficient specificity to apply to the most common death trajectories without the complexity of previous intervention-specific advance directives. We believe that an advance directive should address preferences for a reasonable but limited trial of life-sustaining interventions in critical illness. An advance directive should also assess preferences regarding the use of life-sustaining interventions in advanced dementia, separately addressing the use of artificial hydration and nutrition and dialysis. We believe that such well-tailored advance directives will positively and meaningfully affect care by conveying an individual's intended goals of care in these death trajectories and addressing important values about acceptable health states currently not well articulated in today's advance directives.[62] We suspect these values can be more easily applied in common end-of-life health states by physicians in practice than preferences in traditional advance directives.

Of course, there remain legitimate questions regarding the accuracy, validity, and the effect of advance directives. Perhaps communication in advance care planning is inadequate to elicit patients' preferences, choice in end-of-life care is a fiction, or advance directives are simply insufficient to capture patients' preferences reliably or in a manner that may affect care.[63] We cannot hope to settle such deep skeptical worries here. Indeed, only time and experience can reveal whether our approach to advance directives avoids these

problems. However, we think a trial of our policy is worth it, given the alternatives. Of course, we agree there is need for more and better communication about advance care planning between providers, patients, and family members. However, in a world in which surrogates remain unreliable and an objective consensus on what is in patients' best interests is lacking, we remain optimistic that advance directives remain a vital mechanism to improve decision making at the end of life.

Ambiguity, Accountability, and Accessibility

Even when an advance directive does not provide definitive guidance, limited objective information can still be helpful to both physicians and surrogates in assisting end-of-life decision making. Often what is at issue in end-of-life decision making is whether a patient would accept *any* withholding or withdrawal of life-sustaining interventions. As a patient's status deteriorates, surrogates may cling to the hope provided by prolonging life as long as possible and claim that patients would not be one to give up fighting. Thus, the presence of an advance directive that limits the use of life-sustaining interventions presents an opposing and more objective view of a patient's true preferences. Such evidence converts the decision to withhold or withdraw life-sustaining interventions from a philosophical one to a practical one about medical appropriateness.

Advance directives should be interpreted flexibly. Many patients desire flexibility in the interpretation of their living will, generally deferring to surrogates.[64] Physicians as well may not always execute an advance directive literally.[65] To some extent, this variability on the part of physicians is desired precisely because physicians play a leading role in determining medical appropriateness. Regardless, strict interpretation of a living will is not necessarily critical to its effective function in many end-of-life scenarios. For example, physicians are more likely to accept withholding and withdrawal of life-sustaining interventions when patients are suffering from dementia or recovery is unlikely, particularly when patients are receiving mechanical ventilation or dialysis.[66] Thus, physicians are likely to accept withholding and withdrawal of interventions in the common death trajectories with which we often struggle.

Acknowledging that living wills will never be universally strictly interpreted and placing this responsibility primarily in the hands of physicians does create a potential opportunity for abuse by physicians. However, a forced-choice policy actually creates greater accountability and may help to mitigate this inevitable weakness of advance directives. One major barrier to the use of advance directives has been the nonavailability of an advance directive at the time it becomes relevant. In SUPPORT, less than 10 percent of the patients in the study who had advance directives had their advance directive placed into the medical record.[67] In another study, only about 25 percent of patients had their advance directive documented in the medical record, although, once documented, the directives did appear to influence care.[68] A forced-choice policy would likely lead to an improvement in the accessibility of advance directives. In fact, it is likely that a legal obligation based in malpractice law to have documents accessible would follow from any institutional policy to require them. Insurers would make sure the information would be readily available to providers, and providers would develop internal systems of documentation to allow easy access to advance directives. The ongoing development of electronic medical record systems makes this technical barrier increasingly possible to overcome.

With greater accessibility to living wills comes increased accountability to follow their instructions, by both providers and surrogates. Systems could be developed to monitor and enforce compliance with the advance directive, including a mechanism by which one may seek to escape the plain terms of a directive. We suspect that such a system would actively involve an institution's ethics committee, but such forecasts are beyond the scope of this discussion.

Greater accessibility to advance directives through a forced-choice policy also responds to the growing problem of discontinuity of care in our healthcare system. Discontinuity of care places increased importance on the objective documentation of patients' preferences. A lack of continuity in care can severely undermine general efforts at advance care planning in which discussions about end-of-life wishes take place, but an advance directive is not formally completed. When such discussions transpire without the presence of poten-

tial surrogates, as they often do, surrogates may not find documentation by providers alone compelling enough to overcome their own understandably conflicted views, particularly when the provider who documented the prior conversation is not an active member of the care team at the time of illness.

Discontinuity of care has progressed in the last decade as in-patient medicine has been redefined with the rapid growth of hospitalists.[69] Advance directives may not have been as necessary in the past when most hospitalized patients were cared for by their primary care physicians, but now, in some markets, more than 50 percent of patients are cared for by hospitalists.[70] In one study, advance directives did not have any effect on the accuracy of decision making by surrogate family members or primary care physicians, but did improve the accuracy of emergency room and critical care physicians.[71] Like these types of hospital-based physicians, hospitalists tend not to have pre-existing relationships with patients and are likely to benefit from an advance directive in improving end-of-life decision making.

The Role of Advance Directives in the Evolving Paradigm of Palliative Care

Advance directives evolved in response to an era of paternalism by physicians that valued the prolongation of life above other goals. The language and legal authority of advance directives evolved directly from common law rights to refuse unwanted bodily invasion and treatment.[72] Thus, advance directives were created to protect patients from the medical profession. However, as the medical profession tolerates, and in many cases promotes palliative approaches to care, the role of advance directives has shifted. Advance directives serve less to protect patients from physicians who are unwilling to allow their patients to die than from family members who are unwilling to accept the inevitable.

We have witnessed dramatic changes in medical orthodoxy regarding palliative care in the last decade. Partly as a result of the disappointing findings of SUPPORT, many individuals within the ethics and palliative care community have successfully worked to transform medicine. Palliative approaches to patients with advanced complex disease have not just become acceptable alternatives, but are quickly becoming the mainstream professional paradigm.[73] Accepting death by withholding and withdrawing life-sustaining interventions has become more common. In one study, approximately half of the patients who received mechanical ventilation who later died had the ventilator withdrawn in anticipation of death.[74]

Further evidence of this change in medical orthodoxy can be seen in the types of cases presenting to hospital ethics committees. In the past, physicians went to ethics committees to obtain approval to withdraw care after a family's request. But today, ethicists increasingly note that requests for an ethics consultation are being made to manage conflict when surrogates insist on pursuing marginally beneficial care for patients with advanced complex illness who are dying. At Beth Israel Deaconess Medical Center in Boston, Lachlan Forrow, MD, the director of the ethics service, estimated that in the last 15 years 80 percent of the ethics cases were right-to-die cases, whereas now 80 percent involve families pushing for care that is perceived to be inappropriate by the medical staff.[75]

Palliative medicine and ethics consultation have evolved in large part as ways to manage this common end-of-life scenario. But given our current reliance on surrogate decision making, these approaches often resolve conflicts only by validating the right of the surrogate to speak for the patient. Physicians in these situations could invoke futility, but the concept of futility is problematic, generates greater distrust and conflict, and should be avoided.[76] Thus, without an advance directive, physicians must defer to the flawed decisions of surrogates.

Surrogate decision making is frequently complicated by the clinical reality of multiple surrogates, who are generally members of the same family.[77] In such cases disagreement amongst individual family members is not uncommon. Despite legal hierarchies to identify a primary surrogate, families commonly attempt to attain consensus or, if that is not possible, to minimize conflict. However, attempts to minimize conflict amongst surrogates may increase the likelihood that life-sustaining interventions are continued inappropriately. Advance directives, as we envision here, could be very useful in resolving such cases of family disagreement and prevent these cases from entering the courts.[78] Such advance directives would not simply insert a legal certainty into an area of uncertainty, but would provide valuable objective evidence that would

help both physicians and surrogates steer a course based on the best understanding of the patient's preferences. Of course, dialogue and shared decision making will, and should, continue to be a prominent aspect of end-of-life decision making,[79] but advance directives can serve as an appropriate foundation from which such conversations begin. Advance directives are, indeed, most useful when used as the basis of such open discussions with surrogates.[80]

Today's physician may be more accepting of palliative approaches, but authority to withhold or withdraw life-sustaining therapies must still be obtained, generally from a surrogate. By loosening the operational language of the advance directive beyond terminal illness as we suggest, advance directives may more readily apply and subsequently influence physicians in their discussions with surrogates. Physicians may become more comfortable framing decisions for surrogates with direct recommendations to withhold or withdraw life-sustaining interventions when patients stated such preferences in an advance directive and when such action is medically appropriate.[81] Physicians must be confident in knowing patients would not want to receive continued life-sustaining interventions prior to withdrawing care. In fact, a physicians' belief that care is undesired is a stronger predictor for withdrawing care than a physician's prognosis of survival or future neurological function.[82] And such recommendations may be received with greater trust when accompanied by an advance directive, rather than a recommendation made solely on the basis of the physician's medical opinion.

Thus, an advance directive may serve as permission for surrogates to let go. In those cases when a surrogate does not agree with such recommendations, despite an advance directive, or conflict remains amongst surrogates, an applicable, well-tailored advance directive may give sufficient confidence to the medical team to proceed with a unilateral withdrawal of care. Even when such cases go to court, advance directives can play a critical role in resolving end-of-life legal disputes.[83]

In light of the increasing willingness of physicians to embrace palliative approaches, we need better ways for those patients who want palliative care to get it. Through institutional requirements of advance directives, their greater availability offers much hope to address the continuing disconnect between the kind of care at the end of life that patients want and the care they actually receive.

CONCLUSION

It is time we start requiring patients to complete advance directives. Legal prohibitions against such an approach should be modified to allow insurers or providers to require advance directives of their patients. Requiring advance directives has the potential to improve the fidelity of the provision of end-of-life care to patient's preferences as well as build consensus and resolve conflict in end-of-life decision making. In light of the increasing willingness of physicians to embrace palliative approaches, we need better mechanisms for all patients to realize their own desires for palliative care. Through institutional requirements of advance directives, systematic use of advance directives can serve a valuable role in actually allowing patients to realize their final wishes.

DISCLAIMER

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