

The Grim Reaper Wields his Scythe toward an Incapacitated Uncle Sam

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Commentary

Is the incessant nicking by the Grim Reaper malevolent? Or just ineptitude with the snail? [1] Or just remarkably clear evidence of medical advances which have blurred the boundaries between life-and-death [2]. For Americans, chronic illnesses are now the arch cause of death so few will face the Grim Reaper unexpectedly. Physical disability is primarily caused by chronic diseases, such as hip fracture, various forms of arthritis, stroke and heart disease. Odds are most of us will live well into winter, stiffened by an ever-increasing disability [3]. Worse, our young believe they will survive winter.

Whether they believe it or not, young adults act as if they are immortal, too healthy or too young to need such a reminder of death as an advance directive (hereinafter at times referred to as AD) [4]. Yet Death's scythe for younger people is still often sudden and unexpected precisely when an advance directive would be especially helpful [5]. The ironic seldom instructs in the moment, but upon incisive reflection all of us would do well to recall that Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo were each under thirty. So despite what any adult, young or old, might feel, these cases expose our inherent finitude for which a reasonable societal coping mechanism would be to increase the completion rate of ADs via a federal website integrated with medical providers. Local healthcare providers' technological capabilities will also have to be integrated into the federal website.

Each and every year, more than one million souls find themselves alone in solitude ensconced to die in American hospitals after an angst-riddled decision to withhold or withdraw life support, five million more die after receiving medical treatment, instead of palliative care, they did not necessarily choose or desire [6]. Clearly, healthcare, social policy and legal practice in these United States have yet to stay this Horror Americana. For these persons, not only is there no hope of recovery, but the duration of hopelessness imposes substantial suffering [7] as well as adverse health and financial consequences to both family and this nation [8,9] and while man has created this situation, man has also created a suave in that advance directives include improved end-of-life quality, less encumbrances on both family and healthcare providers [10], and less need for life-sustaining medical treatment [11-13].

An advance directive empowers anyone to make their healthcare choices known in advance where there is no reasonable hope of recovery. There are essentially two kinds of ADs: 1) a living will wherein the patient delineates the kind of healthcare wanted or not wanted under various clinical scenarios; and 2) a healthcare power of attorney wherein the patient chooses someone trusted and competent to execute their end-of-life wishes if incapacitated.

What Causes Low-completion of Advance Directives in Advance Care Planning?

On average less than one-third of Americans have completed an advance directive [14] and even when completed, advance directives often do not drive care as originally intended [15] Practical limitations impede the use of advance directives, including: a) patients have difficulty anticipating their end-of-life treatment preferences; [16] b) ADs effectively navigate only a limited number of end-of-life medical possibilities; [17] c) healthcare agents may have difficulty converting patients' advance directives into clinical decisions; [18] d) many patients do not want pre-determined control over their end-of-life exit strategy and prefer these future decisions be made by their families, healthcare agents or physicians; [14] and e) when they believe their view of proper medicine dictates, clinical care clinicians may override the advance directives [19,20].

Researchers need to focus on why these factors are associated with a higher AD completion rate and how to inculcate their cause into the appropriate vector within society at-large. The societal factors associated with higher completion rate of an AD are: a) being of an older age, b) greater disease burden, c) Caucasian; d) elevated socioeconomic status; e) more comprehensive knowledge as to end-of-life clinical-care options; f) the primary care physician has had a long-standing relationship with the patient; and h) whether the patient's physician already has some type of advance directive [21].

Presently, even when a healthcare agent has been appointed, the advance directive completed, barriers to effectuate the patient's intent still remain. More significantly, when the ethical imperative to follow through on the patient's aspirations and/or their best interests collides with the values of the healthcare agent, the burdens of decision-making can become emotionally unbearable. Worse still, the healthcare agent for whatsoever reason has ill motive. In such cases, overriding the healthcare agent should at least be considered. Outright removing a "rogue healthcare agent" for violating their fiduciary duty or countermanding their decision(s) as to approving or foregoing medical treatments may require going to court [22].

Fortunately, research reveals many are at peace with leaving end-of-life treatment preferences to their families [23] and are comfortable letting healthcare agents quash their living will if the healthcare agent sincerely believes a specific course of action is what they would have wanted [24]. Thus, it is of the utmost most importance to name a qualified and trusted healthcare agent, since the healthcare power of attorney is qualitatively more practical and more broadly applicable than the living will. The absence of this crucial advance directive may result in under-treatment or overtreatment [25].

How Society can Increase the Completion Rate of Advance Directives

So far, efforts have been primarily educational interventions directed at patients and/or healthcare providers. Simple consumer-oriented educational materials designed to increase completion of ADs have been mostly unsuccessful, or only modestly successful. However, simple computer-generated reminders aimed at primary caregivers have increased the rates of AD discussions and their completion among elderly outpatients with grave ailments. More structured interventions with the healthy and the chronically ill, along with their caregivers have also had notable but modest results. Educational literature integrated with repeated treatment-preference discussions during clinical care were more successful. But only multi-dimensional interventions, such as education combined with reminders and performance feedback, structurally prompted physicians to dialogue with patients about advance directives [26]. An effective federal website would allow an applicant in one sitting or over time to engage in such multi-dimensional interventions.

Overall, research indicates that these multi-component, educational interventions must be periodically re-introduced to raise AD completion rates and ensure their placement into the medical record. These multi-dimensional techniques see, necessary to adequately prompt physicians and patients to initiate in-depth end-of-life discussions, the inception of which so often culminates in the AD being inserted into the EMR. The rapacity of the Grim Reaper would have it otherwise. If all these entities (doctors, healthcare providers, patients, consumers, etc...) were able to gravitate to a credible hub such as a well-funded website administrated by the US Department of Health and Human Services (Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Policy), a systematic societal solution might very well be in sight.

Can Health Information Technology better Implement Advance Care Planning?

Health information technology (hereinafter referred to as HIT) thus far, has been mostly limited to administrative IT systems involving scheduling, billing and inventory management [27]. Yet an electronic health record (EHR) absorbs various types of HIT and contains all key aspects of a patient's medical care [28]. HIT could thus facilitate completion and implementation of advance directives. Three key issues prevent more pervasive use of HIT: guaranteeing operability between systems, allaying the public's privacy concerns and cost.

These United States still has the highest per capita healthcare spending among industrialized countries yet invests less than fifty-cents per capita on HIT; whereas, other developed countries range from almost \$5 to about \$192 per capita [29]. This refusal by hospitals to spend on HIT seems pervasive and strategic. Within the realm of advance directives, these United States could largely bypass hospitals' administrative reluctance to spend on HIT with a centralized publically available website administrated by the US Department of Health and Human Services which would have every State's advance directive, guidelines and advance-care planning educational programs.

A hub-like website from the US Department of Health and Human Services would essentially resolve these challenges to great National effect, particularly if the Patient Self Determination Act (PSDA) (itself an amendment to Omnibus Reconciliation Act of 1990) were amended such that all forms and content accepted from and into the website

were legally valid in all States by Federal Law. Several uniform standards are already able to integrate HIT, such as those created by Health Level Seven (HL7), which is an American National Standards Institute operating in the healthcare arena.

Hillestad and colleagues [30] estimated potential costs of widespread HIT adoption vs. potential cost savings. The cumulative expenditure for nearly all hospital facilities to embrace an EMR system would amount to approximately \$98 billion [31]. If nearly all physicians adopt such a system the costs would be \$17.2 billion. But if this were done, the savings average to over \$77 billion per year. Most savings would emanate from reduced hospital lengths of stay, less drug use and nurse administrative time. Thus, the administrative incentive to create an integrated system looms large. But making that happen, though, will implicate all potential legal issues applicable to electronic medical records generally [32,33].

Yet the federal government can safely presume HIT increases the incidence of provider-initiated AD discussions when prompted by computer-generated reminders; and to incarnate this process via a federal website would both increase AD completion and their placement within the medical electronic record. This is key to any long-term success in grabbing the snail with both hands, the only Hope by which we somewhat impose our predetermined intentionality as to the Timing.

The Federal Website to Empower Americans to Grab the Reaper's Snail by both hands

Soon, over two million Americans will be confined to nursing homes due to aggressive medical treatment to prolong the life of the incapacitated and terminally ill, with over 1.4 million so medically enfeebled they only survive by feeding tubes [34,35]. Meanwhile, thirty-thousand are in comatose and permanently vegetative states. The financial burden upon families is not inconsiderable. A national study found that: one-in-five family members had to quit work; while one-third lost most or all of their savings even though nearly all had insurance. Yet counter-intuitively, studies show 70-95% of respondents stated they would forego aggressive treatment rather than protract their life in incapacitated or medically vegetative states, when consciousness entombed flutters between the inert and the afterlife.

States have responded to this winter by offering living will registration services online or by paper by which healthcare providers can access them. However, some of these State registries have been recently shut down due to insufficient funds, low enrollment or both. Thus, a dire need exists for Federal involvement to the extent of centralizing each State's law, forms and guidelines as to advance care planning via one National Website that also social markets its mission. No State would be compelled to utilize this federal website, but by being entirely funded by the federal government, the States would be highly incentivized.

The Department of Health and Human Services should set up a well-branded website of registration and retrieval that once given permission ensures healthcare providers are aware of a patient's AD and can access it when needed. Effective access to this website must keep in mind that people have different levels of health literacy. Consequently, the website should be simple and straightforward, identifying the AD by a unique registration number and storing it in its computer database. This unique registration number only makes the AD personal, not private. Advance directives are not private

documents since health providers must have easy access to them when needed.

Healthcare providers could contact the website by phone or online, and request a copy of their registered advance directive. The healthcare provider by law will keep it as part of the registrant's confidential medical record. If an applicant has misplaced their identifying information, the healthcare provider need only access the advance directive by searching for name and birth date, or social security number if provided (healthcare providers almost always have the social security number in their billing department). A social security number will not be mandatory to use the website since it will assign a unique identifying number to each applicant. Any provided social security number would simply serve as a second identifier. No social security number will be revealed to the entity retrieving the document. The advance directive should be included in any computerized medical records in accordance with applicable data protection laws and made available to the responsible clinician. Additionally, the healthcare agent should have a copy of the directive.

As long as the registrant has the necessary capacity, the advance directive should be updated at least every 5 years. Documents not updated for many years might have their legal validity questioned as to relevance due to any recent medical advances. Documents not changed, or only minimally so, can be re-signed and re-dated every few years. If an advance directive is revoked or amended, all copies of the former advance directive will be destroyed and the new advance directive registered in the website data bank.

The federal website should be able to easily amend or revoke an advance directive at any time, if the applicant still retains the necessary capacity to do so. If a person is incapacitated in many/most areas but firmly and clearly expresses a desire to revoke or amend an advance directive, the healthcare provider should assess their capacity and if as to the current issue there is sufficient capacity, it should be allowed. The entire process should be witnessed by an independent witness and placed in the medical file.

In addition to being witnessed in accordance with the usual legal practices, the document will need a certification of mental capacity (if not assumed by that State's law), by the clinician or another relevant professional. In States where witnesses are not legally required, witnesses may still help against any future challenges to its legal validity. This would be particularly useful if any significant others were likely to oppose the AD.

Every year and by email only, the federal website will contact each registrant to verify that their AD, and personal information remains the same. The most recent updated information to each registrant's information would be provided to the healthcare provider who retrieved any AD. So every confirmed AD and its attendant information should always be at most only one year old.

Decisions by healthcare agents should be supported by State law and be legally binding except in exceptional circumstances. Any reason for failing to respect a healthcare agent's decision should be explained to the healthcare agent along with any relevant authority. This explanation must be summarized, or placed verbatim, in the medical report.

Advance directives should be available in multiple formats such as downloadable and online as well as have multilingual applications and illustrated stories to fully clarify how ADs can be applied since ADs are usually only in English, although Spanish forms are sometimes

available. Any applicant completing the AD should also be afforded the opportunity to consider and implement organ donation documents and after completion, the applicant should be able to sign electronically. After which the registered AD will be incorporated into the applicant's electronic medical records, and forthwith receive email verification of such.

To fortify the prevalent use of this federal website, the States and Federal governments should legislate that in order to maintain their accreditation, hospital facilities and nursing homes whenever admitting a patient shall henceforth verify that the patient's AD is filed in their medical record. If the patient does not already have an AD on file, the medical facility will verify one is completed and filed. Federal subsidies and/or tax credits will fund the initiation or improvement of hospital information systems which can further assist in completing and recording advance directives.

By these means, not only will the American public complete advance directives, but by doing so via a Federal 24/7 website, their healthcare providers will be functionally integrated into their end-of-life directives.

Discussion and Conclusion

The accumulated evidence indicates advance directives are poorly implemented, the result of which is patients receiving medical treatments incongruent with their end-of-life preferences. Unfortunately, too often advance directives themselves have contributed to this debacle. Instead of encouraging substantive communication about how the patient's values would dictate choices if incapacitated, advance directives are too often viewed as ends-in-themselves. The truth is, advance-care planning is multi-dimensional and not an isolated transactional event or episodic.

In addition to the danger in misperceiving the true nature of advance directives, those who have been disenfranchised or mistrust the healthcare system are less inclined to engage in proper advance-care planning. Not considering their needs means the most vulnerable in American society suffer in this life and unnecessarily so again when incapacitated and terminal. This is unjust and avoidable.

By now, it should be clear that most barriers to advance directives being properly completed and implemented seem quite amenable to policy interventions at the federal, state and community level. Policies endeavoring to increase access and ensure ease of enrollment via a federal website, combined with States and municipalities engaging in a targeted AD campaign, will help increase the prevalence of advance directives amongst Americans.

There must always be an aspect of ourselves that must have a mind of winter, and in our mind's eye see the January sun, too often clouded by repression.

Dear Reader: I see you. You see me. My skull is the whiteness of the page, peer into the page, and come close to me, lifeless skull, and the white sheet of winter, lacy skin taut papyrus. My eye sockets you see deeply in the darkness, not the words. Yes, the ink. When you peer into me and self-reflect, I approach. I am then winter under a full moon and I am going to separate your noumenal-self from your phenomenological-self with this scythe. Your belief, or disbelief, in me is irrelevant, and if you shut your eyes as hard as possible, from the ink, from the darkness, I see you always. Your future is tense, the Raven taps your eye socket for that last morsel, but before that, I am going to kill you.

Hurry Uncle Sam, get your foot out of the coffin. We can do this.

References

1. A scythe has a wooden shaft about 65 inches long called a snaith, curved in three dimensions, allowing the Grim Reaper to stand more naturally upright. The snaith has two short handles at right angles to it –one near the upper end and another roughly in the middle. Thus, Uncle Sam's need for a multi-dimensional, two-handed counter-attack.
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