Back to Basics – Simplifying Advance Care Planning

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Abstract

Documenting discussion(s) with every adult about their choice for an agent in the event of future incapacity is a best practice. And yet, measurable progress on this has been incremental and insufficient. Despite years of patient and community education, only about a third of Americans have completed advance directive documents. Despite years of effort, our health system performs only slightly better than most. We realized that no amount of clinician training and patient-family education alone was likely to improve performance. It was necessary to redesign advance care planning.

Working with leading clinicians and attorneys at our health system, we designed a simple framework for enabling patients to verbally express their choice of an individual to speak on their behalf. This framework, named our Trusted Decision Maker (TDM) framework, offers a verbal designation process; simplified living will preferences; streamlined electronic documentation; and a system-wide policy that recognizes these verbally appointed individuals.

We launched in earnest in January of 2021. Initial results from focus sites are promising and have led to the creation of best practices as well as primary care physician champions. So far, 1943 trusted decision makers have been designated. Our initial group of primary care physician champions are showing 80% of their Medicare panel as having a designated TDM. We are encouraged by these results and are spreading implementation resources across our health system. We believe that the policy, workflows, and electronic health record tool could be adapted to become part of standard best practice in advance care planning.

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Objective

Despite decades of effort among the nation's largest health systems, clinicians, and advocacy groups we have not made meaningful progress towards the number of advance directives completed and uploaded to the electronic health record. On average, the rate of US adults that have a completed advance directive on file hovers around one-third.[1,2] There are variations within the data associated with patient characteristics including age, race/ethnicity, religion, language, literacy rates, and health status, but overall, the average continues to stagnate at 35%.[1,3,4] Studies have delved deep into factors that may influence low completion rates.[1] Common findings site the challenging nature of legal requirements to formalize the documents and lack of prompting on behalf of care providers.[5] Additionally, these discussions can be difficult in the absence of serious illness and require nuanced language and skills from providers.[6]

Anecdotally, we know that when asked, most individuals can easily identify someone they trust to make decisions for them but struggle with anticipating the care they would want amongst a plethora of potential clinical scenarios and cultural and religious factors. Indeed, this task is overly abstract and can be difficult for even medical professionals to complete. The odds are stacked against us, yet we collectively persevere and continue to think creatively about how to ease the way for patients, families, and busy clinicians. We still believe in patient autonomy and shared decision making. We keep trying.

Design

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Our organization, along with many other health systems, considers the information contained within an advance directive to be a crucial part of goal concordant care. We have been exploring solutions to make the process easier for both clinical teams and patients. In 2018, we elevated the priority of this work by creating an enterprise-wide metric that tied advance directive completion rate to compensation for primary care providers. Even with these incentives, we were unable to make significant progress. In focus groups, we heard the process was too complex to complete within a single visit, while also attending to other equally important medical tasks.

Rather than be defeated, we returned to the drawing board to reduce barriers. Was a fully executed advance directive always needed to ensure we respected patient's wishes? Had we considered the power of technology as a solution? Could we leverage the functionality in our electronic health record to make impactful progress? It was within the context of these questions that the Trusted Decision Maker (TDM) framework was created.

The TDM provides a viable solution to the barriers we have been struggling to mitigate since the Patient Self Determination Act passed in 1991: witness requirement, length, and care decisions.

Distilling the TDM process down to four central components was vital to reducing barriers:

1. *Allowing verbal designation* – Completion of a fully executed advance directive is ideal, but also requires steps taken by the patient beyond the locus of control of the primary care provider. By allowing an adult patient with current decision-making capacity to verbally appoint someone as their 'trusted decision maker', providers are able to complete steps in the span of a single visit.

2. *Simplified living will selections*– Most advance directives present a list of medical treatments that individuals are asked to select or decline in a future life-threatening condition. For people who are relatively healthy, this can be challenging to think through. Rather than specific interventions, our approach offers *general preferences* for healthcare in a future life-threatening condition among four options that range from maximal life-prolonging interventions, through a balanced approach, to comfort-measures only. The section's first option reads: "I am not sure at this time which statements below I most agree with. I trust my health care agent to do what is best for me."

3. *Streamlined documentation* – Completing the documentation takes an average of three minutes in our electronic health record. Inspiration for the electronic tool's design was drawn from TurboTax®. Rather than presenting complex, visually unappealing legal documents, TurboTax® presents simplified questions in a pleasant, easily navigable graphical user interface. Our solution uses key design principles inspired by this software to reduce the amount of time and effort providers need to spend documenting these important choices in the clinical record.

4. *Creation of system-wide policy* – To ensure that this documentation was valuable and applicable across our seven states footprint, we partnered with our department of legal affairs to create a health system-wide policy that recognizes the TDM's validity across the entire continuum of care. Our organization's policy enables providers to involve individual(s) named as a TDM in making decisions for the patient who has subsequently

lost decisional capacity. The TDM does not replace or supplant an advance directive or the statutory decisional hierarchy that some states have embedded in law. However, in many situations in which a patient is seriously ill or injured and unable to communicate or mentally incapacitated, the patient's verbally expressed preferences conveyed within a TDM and input from the individual named are welcomed by the patient's clinical team.

Applicable Setting / Patients

The TDM framework can quickly and completely be completed in a single ambulatory visit for any and all adult patients. This framework has been especially impactful for providers with large panels of older adults. Amidst the ever-growing list of screening requirements for Medicare patients, providers report lowering the barriers have made it easier to address. Anecdotally, we've found that even young adults, where rates of advance care planning are historically very low, are interested in designating a trusted decision maker, especially if they are estranged from their family of origin.

Despite its success, the TDM framework is only the first step in ACP, easing patients' way into these conversations. Indeed, we encourage and educate providers to re-visit these ACP conversations upon the diagnosis of a serious illness to include goals of care conversations and completion of a POLST if/when appropriate.

Measurements

We have created several automated enterprise-wide online dashboards that allow any clinician to explore performance on ACP, including completion of a TDM. Each of these dashboards runs in a Tableau or PowerBI environment, allowing for on-the-fly filtering of reports by end users.

No additional work is required to update these dashboards – when new data is entered anywhere within the health system into the clinical record, the dashboards automatically account for this information. Each of these dashboards are used by our individual clinics to target areas for continuous quality improvement.

Results of the approach

Since the framework was launched in January 2021, 1943 patients have designated a trusted decision maker. While available across our health system, we have focused our efforts at a few primary care practices to optimize clinical workflows, recruit physician champions, and adapt our messaging. Because of this effort, the majority have been completed in Oregon (N = 839) and California (N = 647). Based on this success, clinical leadership in these states have incorporated the TDM process into their provider onboarding education and have included TDM completion rates into their success metrics. Indeed, physician champions have emerged and are demonstrating impressive results with several physicians at these initial sites now showing 80% of their Medicare panel having a TDM designated.

Replicability of the approach, program, or project

The success at our pilot clinics is beginning to be noticed and spread across the health system. And yet, a single health system's experience is not enough to demonstrate this should be more widely adopted. To address this, we are in discussions with other health systems in California to adopt the TDM framework. We believe that the policy, workflows, and electronic health record tool could be easily adapted elsewhere and might become part of standard best practice in advance care planning. If additional centers had similar success, this might lead to the

opportunity to revisit California probate code – establishing that an adult, who is deemed to have capacity, may verbally appoint a trusted decision maker as long as this is witnessed and documented by a physician or advanced practice provider.

Implications/conclusions

The Trusted Decision Maker framework shows promise as an efficient solution to many of the most common issues we have faced in the advance care planning since 1991. This lower barrier method is not intended to replace traditional advance care planning, but to make it easier for people to begin thinking through these complex decisions. Indeed, it may well be a critical first step towards preparing surrogates for the inevitable "in the moment" decisions rather than asking patients to prepare to make premature decisions based on incomplete information.[7] Our focused work in several primary care clinics has demonstrated marked improvement over prior initiatives, where at most we were able to achieve a few single digit percentage point increases per year.

By leveraging thoughtful policy and technology, clinicians can easily elicit and document a patient's key persons to be included in decision making. More importantly, knowing who can make decisions for a patient can better allow us to align care with patient's goals and wishes. There is still much work to be done around advance care planning, but the TDM framework offers an easy step in the right direction towards delivering goal concordant care.

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