

ETHICS FEATURE

A Reflective Case Study in Family Medicine Advance Care Planning Conversations

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Advance care planning conversations traditionally have been promoted using the Standard of Substituted Judgment and the Standard of Best Interests. In practice, both are often inadequate. Patients frequently avoid these conversations completely, making substituted judgment decisions nearly impossible. Surrogates are also often unable to make clinical decisions representing the best interests of family members as patients. Many physicians are unskilled at discussing these difficult and complex decisions with surrogates as well. Using an integrative family medicine ethics approach, we present a case study that demonstrates how skillful family physicians might introduce and conduct these conversations at routine office appointments, reconciling ethical theory with both patient-centered and physician-centered considerations in a practical and time-sensitive fashion. We believe 3 physician behaviors will help prepare patients to engage their surrogates and help empower surrogates to serve their role well, if and when that time comes: 1) thinking broadly about clinical issues and ethical considerations; 2) engaging in a mindful and contemporaneous deliberation with the patient—and surrogate when appropriate and possible—about these issues and considerations; and 3) cultivating a reflective responsiveness to these interactions, both when things go well and when they do not. (J Am Board Fam Med 2019; 32:108–114.)

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Advance care planning conversations traditionally have been promoted using the Standard of Substituted Judgment and the Standard of Best Interests.¹ In practice, both are often inadequate. Patients frequently avoid these conversations completely. In the estimated 10% to 20% of cases when Advance Directives are executed, patients and surrogates often have only cursory conversations about future decision making.^{2–4} When patients and surrogates do have more meaningful conversations, they still tend not to discuss the specific future treatment decisions and terminal care scenarios that enable

surrogates to make decisions in the same way that patients would make them.^{5–8} Studies also note that people change their minds about end-of-life care decisions over time, making accurate substituted judgment decisions even more difficult.^{9,10} At the same time, because surrogates tend to see their loved ones as valued, living members of the family, they are also often unable to make clinical decisions that truly represent the best interests of family members as patients.

For all these reasons, surrogates describe being ill prepared to make decisions on behalf of their loved ones, and they report that serving in the role of proxy decision maker is extremely stressful.^{11,12} Many physicians are unskilled at discussing these difficult and complex decisions with surrogates, as well.¹³ Fortunately, recent work has shown some progress in advance care planning and surrogate decision making. One study, for example, demonstrated that patient participation in ambulatory group visits improved advance directive completion and understanding.¹⁴ Another noted that individuals who have had their own prior advance care

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Table 1.

Clinical Conversation (what the parties are saying)	Family Medicine Ethics Reflection (what the physician is thinking)
<p><i>Dr. Smith:</i> Ted, today is a good news day. You're doing well. I can tell you have been continuing to exercise: your weight is down another 5 pounds since your last visit. Your blood pressure looks great. And you are now eligible for Medicare.</p> <p><i>Mr. Jones:</i> That's right. I came in a few weeks ago and took care of the paperwork with the help of your care manager. Thanks to her!</p> <p><i>Dr. Smith:</i> Thanks to you. Medicare doesn't pay much, but it does help us make our bottom line. Speaking of bottom lines, Ted, how are your worries going?</p> <p><i>Mr. Jones:</i> I still worry. I don't want to knock off one day, just like my dad and granddad.</p> <p><i>Dr. Smith:</i> I hear you.</p> <p><i>Mr. Jones:</i> That's why I've been trying to lose the weight I put on after I got laid off.</p> <p><i>Dr. Smith:</i> Good to hear.</p> <p><i>Mr. Jones:</i> And take my pills.</p> <p><i>Dr. Smith:</i> Mmm-hmm.</p> <p><i>Mr. Jones:</i> And Betty still seems to like havin' me around. You know, we've been together 25 years now. I got something right the second time around. And all our kids, on both sides, have their own kids.</p> <p><i>Dr. Smith:</i> Great. I think you're doing really well right now. I am not at all worried about you like you are—you're taking much better care of yourself than either your dad or his dad did—and I like to bring up advance care planning when people reach 65.</p> <p>Do you know what advance care planning is?</p> <p><i>Mr. Jones:</i> I do now. Your care manager gave me some info on it when she signed me up for Medicare.</p> <p><i>Dr. Smith:</i> And?</p> <p><i>Mr. Jones:</i> I am up for talking about it, but I just don't think Betty could make decisions. Don't get me wrong, I don't want to go before my time, but should it happen, I don't want to be a vegetable, either. And I don't think Betty could pull the plug on that one.</p> <p><i>Dr. Smith:</i> Have you thought about who could or should make decisions for you if you are not able to make them for yourself? Or is your family one in which everybody together makes important life decisions? What about your kids?</p>	<p><i>Normalize the conversation with patients.</i> Talking about advance care planning is just part of the work I do in providing comprehensive, person-centered primary care.</p> <p><i>Have in mind a repertoire of possible ethical approaches.</i> As I address issues, I try to integrate principles, case-based analysis, virtues, rules, narrative ethics, and the ethics of care throughout the conversation.</p> <p><i>Have available a repertoire of ready responses.</i> When discussing medical issues, some people want me to be honest and to the point; others want me to "sugar coat" things. Do you have a preference for how I discuss information with you? Let's build on our relationship together.</p> <p><i>Assess where patients are, emotionally and cognitively.</i> Have you considered how medical decisions should be made, or who could or should make such decisions, were you not able to make them for yourself? Have you already discussed these issues with someone else? What experiences, thoughts, values, and emotions came up in the process?</p> <p><i>Generalize care—make it inclusive and supportive.</i> As you think about your future, is there anything else we can do to help you? While it may well be stressful for you and your family to plan ahead, it is one of the best and most enduring gifts you can give them. Let your family know that you love them and trust them.</p> <p><i>Recognize the challenge.</i> Talking about these situations is very difficult, but it will help us make decisions for you—as much as possible anyway—in the same way that you would make them for yourself, if you could. I want to support Respect for Autonomy.</p> <p><i>Explore family relationships, style, and specifics.</i> Who is in your family? How does your family make decisions together? Who among your family members might be the best spokesperson(s) to talk with me or other doctors or nurses, were you not able to talk for yourself?</p> <p>While I support Autonomy, I need to balance it with my experience of past cases and detailed knowledge of this patient and this family. I need to fill in the 4 Boxes: Medical Indications, Patient Preferences, Quality of Life, Contextual Features.</p>

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Clinical Conversation (what the parties are saying)	Family Medicine Ethics Reflection (what the physician is thinking)
<p><i>Mr. Jones:</i> Let me think on that, and let's talk more at my next visit.</p> <p><i>Dr. Smith:</i> Good by me. I am going to suggest you talk with Betty and your kids, right up front, between now and then. It can be a scary thing, but once it's done, everyone sleeps easier. Trust me on that. It helps families out. And invite them to come in with you when you return.</p> <p><i>Mr. Jones:</i> Thanks, doc. Bye now.</p> <p><i>Dr. Smith:</i> See you soon. And be sure to bring in those papers the care manager gave you. I look forward to hearing how it all goes.</p>	<p><i>Encourage conversations with family/loved ones.</i> Are you comfortable discussing your medical and personal values with your family? Do you need suggestions on how to talk about these issues? The virtues of compassion, courage, and trust are part of all these conversations.</p> <p><i>Use time wisely.</i> We don't need to come up with the answers to all of these questions today. Sometimes, the best plan is simply planning follow-up. I know that the virtue of prudence—practical wisdom—is ever present in the office.</p>
<p><i>At the next visit. . .</i></p> <p><i>Dr. Smith</i> (shaking hands): Nice to see you, Ted, Mrs. Jones.</p>	<p><i>Acknowledge uncertainty.</i> None of us can clearly predict the future. I can review a few examples of common clinical situations for you, but the future is still ultimately unknown. And discernment needs time.</p>
<p><i>Mr. Jones:</i> Doc, I brought Betty with me to go over what we talked about last time, and I brought those papers. There are a few things I don't understand.</p> <p><i>Dr. Smith:</i> There always are. It's complicated stuff. I suppose that's why I am here to help. What questions?</p>	<p><i>Continue to think broadly about the common theoretical approaches to addressing ethical questions.</i> Looking at your particular medical situation from several perspectives may help both of us make good decisions if and when things get complicated.</p>
<p><i>Mrs. Jones:</i> I am going to butt in. Ted's always worried about his heart, but with all this running he's been doing, I am worried that he is going to get run over. What then?</p> <p><i>Mr. Jones:</i> Betty, just wait. . .</p> <p><i>Dr. Smith:</i> Just a moment, Ted. Betty has a good point. None of us can see into the future—I certainly can't. The three of us talking here and these forms are all to help us out, regardless of what the future brings, or when. It's about knowing what your thoughts and feelings are, so that if it ever happened that you weren't able to make decisions for yourself, about your own medical care, someone else, a loved one, could help me to help you out. Does that make sense?</p> <p><i>Mr. Jones:</i> It does. But what would happen if I get run over?</p>	<p><i>Address specific issues, from the patient's perspective.</i> Are there specific treatments that you clearly know you do want—or that you clearly know you do not want—to be done to you, under any circumstances? Do you have a clear guiding “rule” for us? How do you see your story playing out?</p> <p><i>Accept diversity of opinion.</i> I know that some people, for example, really want to avoid pain. Others, often for religious reasons, want to live as long as possible. Some people want to live only if they can be awake, talking and thinking clearly. Still others want treatments only if those treatments will help them get out of the hospital and back home. Some people want not to be a burden to their family. What values, virtues, principles and details of your situation and your care are important to you?</p>
<p><i>Dr. Smith:</i> Well, have you thought about if there are specific treatments that you are <i>completely certain you do want</i> to have done to you or that you are <i>completely certain you do not want</i> to have done to you?</p> <p><i>Mr. Jones:</i> Well, we talked about it and I'm sure I don't want anybody pumping on my chest. I watched my dad go through that, and it didn't help one bit. It's hard to know what to do and what's most important.</p> <p><i>Dr. Smith:</i> Any thoughts from your side of things, Mrs. Jones?</p>	<p><i>Touch on life's meaning through narrative.</i> Tell me, what are the most meaningful parts of your life now? How do you imagine that might change in the future? What are your next chapters?</p>

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Clinical Conversation (what the parties are saying)	Family Medicine Ethics Reflection (what the physician is thinking)
<p><i>Mrs. Jones:</i> I am not so sure I agree, but—yes, we did talk about it—and he is really sure about this. Now, Ted doesn't think I can be the one to make decisions, but we've been together a long time—you know this is both our second marriages, but we made it work—and I'll be damned if we put this on someone else.</p> <p><i>Mr. Jones:</i> I'm okay with that. I really do trust you, Betty, to use that good common sense of yours. It's why I married you. (Winking). Well, partly...</p> <p><i>Mrs. Jones:</i> I trust you, too, Ted. Now don't go knockin' off on me tomorrow. (All chuckle.)</p> <p><i>Dr. Smith:</i> Ted and I, and all the doctors and nurses in your care, will all work together—we'll do our best—to make sure that doesn't happen.</p> <p>And all of the medical team will be here to assist both of you and your family in making decisions, too. Now—and in the future—however you all think we can best help.</p> <p>Okay, Ted?</p> <p><i>Mr. Jones:</i> Okay.</p> <p><i>Dr. Smith:</i> So let's pull out that form and spend the time we have walking through what it says. I'll help guide you as best I can. Then you can take it home, if you want, and think about it some more, and I'll be happy to have our care manager follow up with you. I also want you to know that the one certainty in life is that things change, so anytime you want to review this information, or I think we need to, I am here.</p> <p><i>Mr. Jones:</i> Sounds good. Let's do it.</p>	<p><i>Empower patients to empower their surrogate decision-makers.</i> Are you comfortable giving your loved ones your blessing, telling them that it really is OK for them to use their judgment and simply do their best so that they can tell this next part of your story? To help your surrogates make caring decisions that are both thoughtful and practical, are you able to suggest that they make decisions for you in the same way that they would make them for themselves? At the end of the day, we all want to take the best care of you.</p> <p><i>Support a team approach/broaden the "T" of personal care.</i> When I am not available or on call, one of my professional colleagues will be there to help, either by phone or in person.</p> <p>I know that the concept of shared decision-making is key for all of us.</p> <p><i>Focus on the person. Document as a reflection of the patient's concerns.</i> Advance directive forms are important because they enable us to write down your thoughts for your family and to put them into the medical record. It takes what we have talked about today and interprets it for doctors and nurses and your loved ones. Let me know if you have any concerns as we go through it together.</p>

planning conversations are better equipped to make surrogate decisions for patients in intensive care units.¹⁵ A third found that conversations between terminally ill hospitalized patients and their surrogates which are actively facilitated by the health care team improve subsequent decision making.¹⁶ Little has been written about how to conduct advance care planning conversations during routine office visits.^{17,18}

Based on these informative works, our own observations, and dialog with colleagues, we propose a family medicine-focused approach to advance care planning. This integrative approach in the routine office setting reconciles ethical theory with the patient's medical issues and personal values and interests, the physician's goals for the visit, and the realities of ambulatory practice. It addresses such questions as how urgent is this conversation? How much time is available today? When should follow-up be scheduled? Should anyone else be present during this discussion? We believe this approach will improve the quality of family phy-

sicians' patient education on this topic and help all of us make the best possible decisions together, when that time comes.^{19–24} The following Reflective Case Study is a composite example of how this may be done.

In this encounter, we pair the words from the clinical conversation with the mindful internal thinking of a seasoned clinician. Our intent in demonstrating what she is thinking while using this approach is 2-fold: 1) to help family physicians better prepare and encourage patients to talk to their friends and family about their values, expectations and fears about future care, and 2) to help patients and physicians empower surrogates to make decisions with confidence and serve this intimate and challenging role with dignity and grace, if and when that time comes.

Reflective Case Study

Mr. Theodore Jones (a pseudonym) is a 65-year-old man who presents at the local Community

Health Center to his family physician, Dr. Nadine Smith (also a pseudonym). They have a professional relationship of 5 years, one that started when Mr. Jones lost his work and insurance coverage. Mr. Jones has hypertension, for which he has been taking 2 generic medications. Even though his blood pressure has been under good control during these 5 years, Mr. Jones continuously expresses anxiety about having a heart attack and dying suddenly, as his father and grandfather both did in their sixties. We join the discussion between him and Dr. Smith.

Discussion

Advance care planning conversations in the office setting are often challenging. Patients frequently avoid them, and surrogates are stressed when asked to participate. Many clinicians struggle with how to raise the subject, and, when they do, continue to struggle with how to discuss it in a supportive and meaningful, yet still practical and time-efficient way. Our experience, however, is that most physicians and patients support future health care planning, even if they do find it difficult. We also strongly believe that the best clinician to discuss an individual's goals of care is that person's family physician—the medical professional whose relationship with the patient addresses the fullness of the patient's bio-psycho-social situation.

The integrative approach we present here is an application of one we have previously described as a “family medicine ethics.”²⁵ Such an approach begins with developing an ethos of asking the question, “What, all things considered, should happen in this situation?” at every clinical encounter. Answering this question involves 4 broad steps: 1) identifying situational issues, 2) identifying involved stakeholders, 3) gathering subjective and objective data, and 4) analyzing issues and data to direct action and guide behavior.

Applied specifically to the anticipatory discussion of advance care planning in the office, this approach addresses the patient's personal situation and medical facts²⁶; examines the values, experiences, and relationships among the patient, family, and medical team^{27–29}; acknowledges the role of shared decision making, according to the patient's and surrogate's interests and needs³⁰; and considers several ethical theories, including principles,³¹

case-based analysis—including the “4 boxes,”^{32,33} virtues,³⁴ rules,³⁵ narrative ethics,³⁶ and the ethics of care,³⁷ in making thoughtful, meaningful clinical decisions. It also addresses the practical reality of ambulatory practice, reconciling these considerations into the scenario of an office visit that relies on careful time management and followup.

As with any real-life, real-time discussion, what the doctor is thinking does not always “line up” with the dialog. This example is not intended to represent a perfect approach; there is no one perfect approach. Our observations confirm that the process of communicating itself may be as important, if not much more important, than actually signing an Advance Directive document.³⁸

To that end, we believe 3 physician behaviors are crucial to prepare patients to engage their surrogates and to empower surrogates to serve their role well, if and when that time comes: 1) thinking broadly about the clinical issues and ethical considerations, as noted above; 2) engaging in a mindful and contemporaneous deliberation with the patient—and surrogate when appropriate and possible—about these issues and considerations; and 3) cultivating a reflective responsiveness to these interactions, both when things go well and when they do not.

Conclusion

Addressing advance care planning in the routine office setting is often challenging for patients, surrogates, and family physicians. The current literature offers useful suggestions to assist in certain aspects of planning conversations, yet it fails to help clinicians integrate the many bio-psycho-social dimensions that come to bear as this process unfolds. The integrative approach we illustrate in the Reflective Case Study, above, models a dynamic family medicine ethics approach to these conversations.

We invite thoughtful replies to this approach and case study. Our hope is that others will use it in graduate and continuing education venues, both as an example of how advance care planning conversations can be conducted and as a stimulus to interactive discussion among family physicians regarding how they “do” ethics in their own practices. Finally, we strongly encourage ambulatory-based research on the process and outcomes of routine advance care planning.

To see this article online, please go to: <http://jabfm.org/content/32/1/108.full>.

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