Doctor, What Would You Do?: An ANSWER for patients requesting advice about value-laden decisions

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Abstract

This article presents a previously published framework, summarized in the mnemonic ANSWER (A-Active listening, N-Needs assessment; S-Self-awareness/reflection; W-Whose perspective?; E-Elicit values; R-Respond) for how to respond to the question, “Doctor, what would you do?,” when considering medical decisions that are preference-sensitive, meaning there is limited or debatable evidence to guide clinical recommendations, or are value-laden, such that the ‘right’ decision may differ based on the context or values of a given individual. Using the mnemonic and practical examples, we attempt to make the framework for an ethically-appropriate approach to these conversations more accessible for clinicians. Rather than a decision rule, this mnemonic represents a set of points to consider when physicians are considering an ethically-acceptable response that fosters trust and rapport. We apply this approach to a case of periviable counseling, among the more emotionally challenging and value-laden antenatal decisions faced by providers and patients.

A-Active listening

N-Needs assessment

S-Self-awareness

W-Whose perspective?

E-Elicit values

R-Respond

The patient is a 32 year-old gravida 1, now at 23+1/7 weeks gestational age, dated by a 9 week ultrasound, who presents with confirmed rupture of membranes. Her medical, surgical, social and family histories are noncontributory. The pregnancy has been uncomplicated. Her prenatal labs, quad screen, and anatomy scan were all normal. She is not contracting or dilated. Her exam is negative for vaginal bleeding and shows no signs of infection. Fetal status is reassuring. The estimated fetal weight is 582g (50th percentile). The patient has been counseled by the NICU but remains undecided about whether to pursue resuscitation. When you return to the room to discuss the plan of care with the patient's family, she looks up and asks you, "Doctor, what would you do?"

Doctor, what would you do? (*WWYD*) Many physicians dread this question. Commentators and researchers have observed that physicians are relatively reluctant to disclose their personal preferences or opinions to patients who make such inquiries about value-laden or preference-sensitive treatment decisions.[1-5] In the setting of periviable treatment, neonatologists in one study declined parental requests for treatment recommendations, despite reporting that they felt more than 75% certain about what should be done.[1] This may reflect a physician's recognition that what she would choose for herself is not what she would recommend for her patients. In fact, studies show that physicians tend to choose fewer and less invasive interventions for

themselves than they recommend for patients.[3, 4, 6-9] Even more significant, physicians choose fewer interventions for their children[10] and make recommendations based on treatments available at their institutions.[11] In turn, physicians' decisions for patients do not always accurately reflect patients' preferences.[4] Conversely, in the setting of periviable care, it is possible that many providers would indeed choose intervention for their own child, but may not want to recommend it for someone else's, for fear of coercion. All this considered, a measured approach to making recommendations in such settings is understandable.

In turn, physicians often decline to answer the question, *WWYD*, in an effort to respect patient autonomy.[12] They may worry that their response will be overly influential in the patient's decision.[13] Physicians may also worry that if they give recommendations, they have increased liability for adverse outcomes—for which they do not desire to be either personally or professionally responsible. To that end, some authors have championed value-neutral and/or non-directive[14] approaches to responding to patients' requests for guidance regarding value-laden decision-making. This approach has the potential to leave patients feeling unsupported or abandoned by their providers—with concerns left unaddressed or dismissed—or feeling burdened with shouldering the entire responsibility for making high-stakes decisions. In fact, some parents in intensive care settings will not want to take responsibility for life and death decisions, even for decisions that they agree with. Lantos and Montello question the wisdom of placing so much emphasis on parental autonomy. In the end, there may be ambiguity about who the decision maker really was, parent or physician.[15]

Indeed, at the end-of-life, observational work among families in ICU family meetings suggests that roughly 30-40% of patients or family members will request a recommendation from their physician regarding whether to limit life support.[16] Studies of parents facing periviable resuscitation decisions find that parents desire more than information and options from their providers in this setting as well.[17-19] Interviews with parents suggest that the majority of families want information and desire to be active participants in decision-making, but also express a need for a recommendation from the physicians.[15, 18] Because families may not feel that they have adequate expertise, or may not want to take sole responsibility for such decisions, shared decision-making has been proposed as the optimal model in periviable care.[20]

Shared decision-making is characterized by a bidirectional flow of medical and personal information between physicians and patients, resulting in deliberation and negotiation between these parties, which is followed by the physician and patient jointly deciding on a treatment strategy.[21] In this, a deliberative model of interaction, physicians are expected to discuss health related values that affect or are affected by the patient's disease and engage patients in a dialogue regarding the best course of action.[22] In keeping with this model, authors have refuted the notion of 'values-neutral' counseling and, instead, made the claim that providing patients with a professional recommendation is an important part of shared decision-making[21] and the informed choice process,[5] even suggesting that recommendations can improve patients' decisions.[13] For example, the authors Beauchamp and Childress assert that for informed choice to occur, "professionals are obligated to disclose a core set of information, *including . . . the professional's recommendation*."[23] (p. 81; italics added) To that end, they outline a "morally acceptable" approach to making professional recommendations in response to a patient's request for advice.

Fig 1 depicts the basic structure of their framework. Here, we present a novel application of the framework, and organize their arguments into step-by-step guidance and examples to manage communication, represented by the mnemonic, "ANSWER." The goal of this practical guide is to provide physicians with a structured approach to navigating this challenging moment in patient encounters. With each step, we provide example statements or questions.

A-ctive listening

The first step in formulating a response to the patient's question is to take the time to seek out, engage, and understand the patient's perspective through active listening. Active listening has been described as "giving free and undivided attention to a speaker … placing all of one's attention and awareness at the disposal of another person, listening with interest and appreciating without interrupting."[24] (p. 1053) Active listening requires physicians to attend to patients' clues, i.e., manner of speech or behaviors, that are subtle and suggest ideas, concerns, and expectations the patient may wish to share.[25] Observational studies show that physicians dominate clinical encounter interactions. Studies in primary care settings have shown that when patients try to voice concerns, they are typically interrupted within 18 seconds of speaking,[26] and that patients' concerns are rarely returned to; instead, the agenda is determined almost entirely by the provider. In the intensive care setting, family members, on average, spoke 29% of the time and clinicians spoke 71% of the time. In keeping with these patterns, in audio-recorded encounters with simulated patients playing the role of patients facing periviable resuscitation decisions, the majority of the time (54%) was spent delivering medical information—reportedly the easiest and most comfortable aspect of counseling for the physicians.[1] The first step in providing a response to a request for a recommendation is to begin with asking open ended questions about the

patient's understanding, values, concerns and fears, and then actively listening to their responses. Only *after* hearing the patient's level of understanding, personal experience with prematurity and/or disability, concerns, and expectations are we in a position to offer guidance regarding an appropriate plan of care.

"Help me to understand what you took away from the conversation so far? In your own words, how will you explain what's going on to your family members?. . . And of all the things you've heard, what worries you the most?"

N-eeds Assessment

An important initial step in formulating a response to a request for a recommendation is to understand what expectations the patient has in making the request. This can best be accomplished by spending a few moments asking clarifying questions. What's really being asked? What is it that the patient actually wants or needs from the provider? It may or may not be a specific recommendation. Is she, in fact, requesting something else? Empathy? Reassurance? Permission? A sense of the professional standard of care? Perhaps the patient's concern is one of trust—*would you offer the same options to me as you would to someone you care about? Your own mother or sister or friend?* Patients might pose the *WWYD* question for a number of reasons. Rather than assume their intention, ask the patient for clarification and/or specification. Sometimes, what a patient is really saying is that she does not even have an idea of to how to approach or think through the decision; *WWYD* may actually be a request for an answer to the question "What should one consider?" or "How should a person think about what to do?" A physician might assess the patient's actual needs with a statement such as:

When you say, "What would you do", are you asking me to make a recommendation? Help me understand why you asked me that question.";[27] or a comment such as, *"When people ask such an important question, sometimes they don't really want an answer, but they may need help with how to think about the question. Tell me more about what you are asking and what you need to know."*

S-elf awareness

If you establish that the patient is, indeed, asking you for guidance, there are several aspects of one's own biases and the nature of the relationship with the patient that need to be considered. Baylis and Downie describe an 'adequate disclosure' as one that makes the physician's basic thinking transparent to the patient.[5] Because most clinical reasoning is guided both by fact and value judgments, they explain that physicians who are willing to disclose or provide a recommendation must be prepared to disclose both the factual information and the value-judgments that underlie their recommendations. In this sense, they argue that limiting a recommendation to factual information "with no effort to expose the personal and/or professional values that have influenced the information communicated" (p. 22) is an inadequate response. It may be useful to ask yourself: *Do I systematically prefer less intensive vs. more intensive therapies in the face of a poor prognosis*, and *How much am I willing to share about how my own values color my perspective about this decision?* This means that a physician's ability to provide an ethically acceptable and adequate disclosure hinges on the physician's ability to reflect upon and articulate the value-judgments that are implicit in his or her own counseling and practice patterns. The physician must be attentive to the manner in which their own values translate into positive or negative framing effects, shading the messages they convey to patients:

“I have to tell you that I’ve seen many patients in this circumstance and my own view has been greatly affected by having seen many babies born with tremendous medical problems that last throughout their lives. I have also seen some success stories. But I would say I worry more about the bad outcomes.”

A provider with a different perspective might frame their message as:

"Well, most babies who are born at this gestational age today do not survive. But of the babies who survive, many do well. And we can usually predict much better after a few days which babies are going to survive and which survivors will be impaired. So if it was my baby, I would give the baby a chance, knowing that I could always choose to withdraw treatment later if things look bad."

W-hose values?

This is a critically important step in the conversation—clarifying the question—determining whose values the patient is interested in applying to the situation—*What would I do as ME?* or *What would I do if I were YOU?* The answer to this question differentiates whether the physician is being asked to operate in a deliberative role—helping to guide the patient in articulating their values; or an interpretive role, whereby the physician is expected to elucidate and interpret relevant patient values then determine the treatments that best realize the patient’s values.[22] If the patient wants to know what the physician would do in the situation, the physician, having already done the work of self-reflection, can either answer or decline to answer

depending on his or her willingness to disclose information about their personal context and values. In doing so, it is important that the physician indicate that his/her 'preferences' are informed by his/her own values and context—which may differ dramatically from the patient's—and not solely be based on medical facts. To avoid unduly influencing the patient, who may defer to a physician's 'medical expertise,' it is important to remind the patient that physicians have no particular moral authority or ethical expertise related to what is a good or right choice for the patient given *their* particular context and values. The key is to enter into this part of the discussion by first laying the ground rules:

"I want to give you a helpful answer to the question about what I would do, but I want to make sure that you understand that the right decision for me may not be the right decision for you, because our values, and the way we look at the world, may be different"

E-licit/Explore Values or Evoke Hypothetical Patient

But what if the patient is actually asking, *what would you do if you were me? What should* I *do?* The provider has options. Many physicians are inclined to simply state, "I am not you" or "I do not know your values," –neither of which offers an adequate response. Baylis and Downie explain that, "evasion or unexplained refusal does not satisfy the requirements of adequate disclosure for informed choice." (p. 23) Put simply—when a patient asks for a recommendation, they deserve an answer. However, physicians have an obligation to elicit the patient's values so

that the recommendation can be in line with the patient's values and goals of treatment, rather than their own values and goals.[22]

While many providers may not be inclined to disclose their own values and preferences to the patient, they are still well-positioned to help patients and families clarify relevant values of their own which should rightly shape such difficult decisions: their level of social support or financial resources; does the patient have deeply held beliefs—religious or otherwise—that would lead them to value survival above all other considerations; are they very concerned about the quality of that child's life and the impact of a disability on their family-life. These are sometimes difficult topics to broach. It may help to connect such topics to other routine components of pregnancy care, such as prenatal genetic diagnosis. For example:

"Can you think back to the time in your pregnancy when you were offered screening for Down's Syndrome? Did you think about what you would do if you were to find out that your child had the disorder? Did you have any conversations with your family about what that would mean and how you would handle that? I'm only bringing that up because at this early point in pregnancy, we are faced with a high likelihood that your child could end up with serious mental or physical disabilities if she survives. It would help us to know how you feel about disability and what kind of concerns you might have about raising a child with disabilities."

Alternatively, for physicians unskilled or uncomfortable with the task of directly eliciting values, there is also the option of evoking a hypothetical patient and describing what 'some patients' might consider or 'other patients' have considered in making the decision:

"I've taken care of patients who feel that survival is always the goal, no matter the potential for disability or limitations the child may face; I tend to recommend resuscitation for those types of patients. On the other hand, I've cared for other patients who feel strongly that their goal is to minimize suffering for their child; comfort measures are often preferable for those families. Either choice can be made from a place of compassion and care for your child."

Notice the bridging statement here. The recommendation is couched in context, conditional upon the values or concerns that a patient might express. This opens the door for the physician to then inquire more directly, '*Which kind of person are you*?'

R-espond/Recommend

Taken together, the medical facts and clinical presentation of the case, the patient's expressed values and preferences related to life, death, disability (or other identified concerns), and the physician's prior experiences in patient care should be integrated and transparently communicated to provide a reply to the question, "*What would you do?*":

"While I can't say that I definitely know what I would do, having never faced this decision before, I can tell you what I would be concerned about. As a busy professional, married to another busy professional, I'd be worried that we don't have enough family in this area to help and support us in taking care of a child with special needs or significant disabilities. As a mom to a 4 year old, I'd be worried that there would not be enough of me to go around. I'd be worried about whether my child might live with pain or suffer. Those would be the kinds of things I'd consider, and those concerns might lead me to choose to focus on comfort."

Or respond with a recommendation to the question "*What should I do*?":

"Well, since we just met, it's really hard for me to say what I think you should do, but from what you've shared with me so far, it sounds like you'd always be left worrying and wondering if your child could have beat the odds if you had given her a chance. It sounds like you'll have a really hard time living with that uncertainty, and that you might even feel like you failed her by not trying. If that's how you feel, and you're prepared for the possibility of your child living with limitations or disabilities, then it probably makes the most sense to try to resuscitate her once she's born."

So, is it ever appropriate not to provide an answer to this important question? There are, of course, appropriate grounds upon which Baylis and Downie state that a physician may decline to provide a recommendation for a patient. In the case of 'strangers', wherein the physician is unable to elicit the patient's values, either because they lack the skills to do so or the patient lacks the insight and/or ability to articulate them; then it is reasonable to express that you cannot make a recommendation apart from having some sense of who the patient is and what they value. Also, if the physician is simply unwilling to share their values with the patient for personal reasons, they can inform the patients of this in a transparent manner. In such cases, refusing to answer is better than providing a recommendation as though it were based on medical certainty rather than personal values.[5] Barring these unusual circumstances, it holds that a patient's request for advice or guidance should be met with a response or recommendation from their physician.

Summary

In summary, ANSWER provides a set of points to consider to structure one's thinking about and approach to providing guidance when patients request advice for value-laden or preference sensitive treatment decisions. The outline presented here highlights the importance of first clarifying the patient's *intentions* and clarifying *whose value judgments* the patient is asking you to apply. It also emphasizes the need to inform one's professional recommendations by first explicitly eliciting—never presuming to know—patients' values. Reframing the response in terms of a hypothetical patient is considered an acceptable alternative if the patient is unable to articulate her values or the physician is uncomfortable eliciting values. Refusals are reserved for interactions wherein patients are unwilling to articulate values or physicians are unwilling to share the values that would inform their own decision-making with the patient.

Conclusion

Being asked the question, "*What would you do*?" represents a pivotal moment in the doctor-patient relationship. The question gives physicians an opportunity to join with patients in a meaningful way to build trust, which is essential in delivering patient-centered care. When faced with antenatal decisions that are exceptionally emotionally charged and value-laden, and often occurring in time-sensitive circumstances where physicians and patients may not have been able to establish a prior relationship, providing an 'ANSWER', is both brave and risky because it places values—yours and your patients'—front and center in the discussion. It requires elicitation of patients' values, and potentially, disclosure of physicians' values. In fact, even when a physician chooses not to answer, there is a moral obligation to, at the very least, acknowledge the request and reply with transparency about the reason for choosing not to

disclose. Ultimately, with or without disclosing personal opinions, these patient inquiries can create an opportunity for physicians to elicit patients' values, which are necessary to guide decision-making and to provide patient-centered care.

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Figure 1.

Depicts a structured approach helpful to ‘A-N-S-W-E-R’ requests for advice in value-laden clinical decision-making.

A-Active listening

N-Needs assessment

S-Self-awareness

W-Whose perspective?

E-Elicit values

R-Respond