

Virtual Mentor

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MEDICAL EDUCATION

Framing Permission for Halting or Continuing Life-Extending Therapies

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Editor's note: Medical students are taught how to have the "breaking bad news" conversation with patients, and many students and residents gain practice in discussing end-of-life treatment goals. Physician educators at the Children's Hospital of Philadelphia have developed a framework for the very specific and difficult conversation with parents about halting life-sustaining treatment for their child, once all agree that the child is not able to survive.

When talking to parents whose children are on advanced life support, when both the clinical team and the parents understand that the child's death is imminent despite this intensive level of care, how should we frame the decision to halt or continue invasive life-extending treatments?

What Situation Are We Discussing?

Before we begin, we need to clarify precisely the scenario we are discussing by contrasting it with the scenarios that we are not. We are not talking about situations in which parents and clinicians have opposing views about the nearness or inevitability of the child's death. Nor are we discussing cases in which the clinicians feel that further life-extending treatment is "futile," but the parents disagree or have—for any reason—expressed their desire to continue life-extending treatment. In such cases marked by disagreement or conflict, the cardinal ethical task is to identify and properly manage the disagreement, and mediation or conflict management is required rather than directive counseling. Our intent is to discuss only those cases characterized by a preceding history of clear communication and strong mutual understanding between clinicians and parents, where a consensus exists regarding the goals of care. The clinician and parents, united by a shared sense of sadness that the goal of survival has receded from view, have agreed to shift the focus to the goals of promoting comfort and working to assure that the end of life is peaceful and dignified.

We also want to emphasize that the conversation we are scrutinizing here is not the one in which "bad news" is being delivered. The difficulties of delivering and receiving bad news, for the clinician and the parent, are sufficiently daunting that we strongly advise keeping the task of providing new distressing information as a separate task, complete with a distinctive set of suggestions about how to provide this information in as clear and compassionate a manner as one can. After the "bad news" conversation, following a period of time that ideally is measured in several hours or even days but may have to be as short as minutes, the conversation we are

examining moves beyond only providing information and takes on the task of making a joint decision.

Furthermore, we want to strongly advocate that clinicians caring for children who are critically ill have an initial “hopes and goals of care” conversation with parents as early as possible, ideally as soon as medical care commences. This discussion is devoted to pondering a question that the clinician can pose to the parents as: “It will help me take better care of your child if I know what you are hoping for.” Quite commonly, the parents will first express an ardent hope that the child will recover completely, or that he or she will be cured. In cases where the likelihood of recovery or cure is virtually nil, the expression of this hope does not imply that the parents are in a state of denial, but that the power and dignity of this hope, however remote, must be acknowledged. Clinicians can empathize with this hope while at the same time expanding the list of hopes: “I also wish that that hope could come true. What else are you hoping for?” Parents at this point will usually mention several other hopes (which clinicians might speak of as goals of care), including making sure that the child does not suffer, giving the child “a chance” to survive, protecting the dignity of the child, or having family members visit. This “hopes and goals of care” conversation, which must be repeated as the clinical situation changes, can provide an invaluable framework for discussing and making decisions about medical care.

What we are addressing in this essay, then, is a topic that arises after both the “hopes and goals of care” and the “bad news” discussions, when the child’s status has deteriorated to the point of imminent death; it is the topic of choosing how to frame one aspect of conversations about potentially halting or continuing invasive life-extending therapy. In what follows, we outline the desired outcomes of and principles guiding this discussion, sketch two different ways in which the decision could be framed, evaluate how these decision frames do or do not achieve our objectives, and consider how we choose among inevitable tradeoffs between these frames.

Desired Outcomes of the Conversation and How to Frame the Decision

What are the guiding principles and desired outcomes of this conversation? As always, clinicians want to be compassionate and supportive in the ways in which we interact with parents. We don’t want parents to feel pressured. We want to enable them to have a clear and sufficiently complete understanding of both the clinical situation and their values and goals of care for their child, so that their decisions on behalf of their child are well-informed and well-framed (which is the entire point of this essay). We do want them to feel, when they have made their decision, that they have acted in the best interests of their child and have exemplified what a good and loving parent would do under unimaginably sad and difficult circumstances.

How can we frame the decision of whether or not to halt life-extending therapies? Here we have two contrasting options: one in which the default action is to continue, and the other in which the default is to desist from, life-extending therapies.

How would these alternative framings be put into words? Both would start with the same preamble reviewing information about the clinical situation that should have been initially delivered in the preceding “bad news” conversation. For instance, the clinician might say to the parents of an extremely premature infant: “I know that yesterday I talked with you about the news that your child has suffered a massive stroke to his brain, and that this bad news in addition to his other medical problems made it extremely unlikely that he could survive. Today, he appears to be developing more problems from the stroke, which we know because his head is rapidly growing larger. I really wish that your son did not have any of these problems.” The clinician then should make a clear statement highlighting that the conversation is shifting to focus on a potential decision: “Given what is going on, we have a very difficult decision to make. I think we need to revisit the discussion where we talked about what we were hoping our medical care could do for your child, and decide whether it is time to stop invasive life support, which means stopping the breathing machine and removing the breathing tube, and devote all of our efforts to making sure your son is as comfortable and peaceful as possible.”

With all of what has been said thus far, the clinician has framed the decision in important and significant ways, but at this point it is the choice about the frame that we want to underscore. If the clinician believes (as outlined above) that further life-extending treatment will not be effective, but wants to maintain the customary default of continuing life support until a parent says to stop, then a clinician might say: “We can either proceed with treatment, as we are doing, or we can stop. What do you think you we should do?” and wait for the parents to answer. If, on the other hand, the clinician wants, within the confines of this particular conversation, to shift the default to halting ineffective therapies, offering a strong recommendation for stopping life-extending treatment while providing the parents with an unfettered opportunity to object, then the clinician might say words to this effect: “Based on my medical knowledge combined with what we’ve discussed and what you’ve told me, I recommend that we use medications to help your son be as comfortable as possible, stop the machine, remove the tube, and have you hold him. I know that these are difficult things to talk about, but if you accept my recommendation I would like to talk with you about when and how to do this. Can we make these plans together?”

Evaluation of Different Framing Options

What are the advantages and drawbacks of these two major options, especially in light of our primary objectives, namely to have the conversation result in a decision that is well informed, noncoerced, well framed, and will be looked back upon as proper and loving? In both, the clinical information provided to the parents is the same, so they are equally informed. What differs is how the questions are framed and whether the alternative frames are equally noncoercive and will have the same long-term implications for how the family looks back upon the decision.

The custom in medical practice has been to frame the continuation of therapy as the default action; but is this default always justified? In the context of individualized medical decision making for a specific patient, a customary default position about

starting or stopping treatment should have far less relevance than evaluation of the specific benefits and risks of treatment for that particular patient. In the case we are discussing here, that assessment of benefit and risk has concluded that halting treatment is in the child's best interest. Assessing the merits of these two frames also has to do with human psychology. In general, people view the act of explicitly stating a preferred course of action as fully subject to moral or ethical judgments, while they perceive agreeing with a recommendation as more morally accommodating and less open to ethical scrutiny or censure. Given these asymmetrical views about assertion versus agreement, our question then becomes: if parents (along with physicians) believe that halting therapy is in the child's best interest, should we frame the decision so that (1) by agreeing, the parent will be accepting the default position of continuing care (and must assert an objection in order to halt care), or so that (2) by agreeing, the parent will be accepting the default position of halting care (and must assert an objection in order to continue care)?

In clinical practice, we have collaborated with some families who have told us explicitly that they would rather not say "yes" to halting therapy, even when they firmly believe that doing so is in their child's best interest. We also have collaborated with other parents who, although less explicitly, have clearly expressed a preference for halting life-extending therapy by their quiet agreement with our proposed treatment plan. All of this occurs in the context of our society's general protreatment bias, which is a force to be reckoned with when deciding that halting treatment is the most appropriate and loving way to care for a grievously ill child. The evaluation of these options for framing the decision thus culminates in a final question: In the specific situations that we are considering here, should clinicians adhere to the common way of framing the discussion about halting life-extending therapy, due either to their deference to the status quo or to their belief that the common framing with its bias toward extending treatment is to be preferred as a general policy? Or should clinicians commit to a more individualized practice, rejecting the subtle coercion that the customary habits of framing the decision inflict upon these parents who have come to believe that halting life-extending therapy is in their child's best interest, and instead frame the discussion so that this course of action becomes the default?

Conclusion

We want in this essay to highlight the importance of how this discussion is framed and to underscore the inevitability of the tradeoffs between these two different ways of framing the decision. Neither frame for the decision—with the default option being to continue or to halt life-extending treatment, and the required action on the part of the parent being either assertion of an opinion or acceptance of a recommendation—is without dangers of resulting in a choice that does not conform to the child's best interest or that creates within the parents a feeling of being coerced. We do believe that, after having several such conversations with parents and paying assiduous attention to their stated goals and hopes of care for their child as outlined above, there is an ethically sound role for framing the default therapeutic option as halting life-extending treatment.

Suggested Readings

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The views expressed in this article are those of the authors and do not necessarily reflect the views or policies of The Children's Hospital of Philadelphia.

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