

Discussing Treatment Preferences With Patients Who Want “Everything”

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When asked about setting limits on medical treatment in the face of severe illness, patients and their families often respond that they want “everything.” Clinicians should not take this request at face value, but should instead use it as the basis for a broader discussion about what “doing everything” means to the patient. The discussion might include questions about what balances of treatment burden and benefit the patient can tolerate and about emotional, cognitive, spiritual, and family factors that underlie the request. After this initial exploration, the clinician can propose a philosophy of treatment and make recommendations that capture the patient’s values and preferences in light of the medical condition.

Clinicians should respond to emotional reactions, directly negotiate disagreements, and use harm-reduction strategies for the relatively infrequent instances in which patients continue to request burdensome therapy that is unlikely to help. By using this approach, patients, families, and clinicians will be better able to understand each other and join together to develop a treatment approach that best respects patient and family values in light of what is medically achievable.

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A 75-year-old man with oxygen-dependent chronic obstructive pulmonary disease, dialysis-dependent chronic renal failure, and peripheral vascular disease has been hospitalized 3 times in the past 3 months for impending respiratory failure. His performance status is progressively decreasing, but he still enjoys some aspects of his life. He values his independence and has difficulty adjusting to his progressive disability. When an intern appropriately asks about setting limits on invasive treatment, such as cardiopulmonary resuscitation (CPR) and mechanical ventilation, the patient replies, “I want everything.” (This case is a composite based on many patients we have seen under similar circumstances.)

Physicians whose patients ask for “everything” might reasonably conclude that the patient is asking for every imaginable treatment, no matter how harsh, invasive, or unlikely to be of benefit. One obvious course of action is to write a “full code—no limitations” order in direct response to the request. However, we believe that a more appropriate response, after physicians acknowledge the request, is to discuss the patient’s underlying treatment values and non-medical concerns and to provide accurate information about the patient’s illness and prognosis (1–4). With that information, physicians can make more informed recommendations, and patients can make better decisions about what should (and should not) be done to help them achieve their goals (5–7). We review this approach to requests for “everything” and provide examples of how physicians can manage some aspects of the conversation.

STEP 1: UNDERSTAND WHAT “DOING EVERYTHING” MEANS TO THE PATIENT

In our experience, the phrase “do everything” usually does not mean that the patient and family want every invasive and possibly life-prolonging treatment with a high burden and only a tiny chance of benefit (1–3). Rather, the request may reflect more nuanced wishes for how to bal-

ance the burdens and benefits of treatments and underlying affective, cognitive, spiritual, or family concerns.

For some patients, “everything” means only treatments whose probability of helping outweighs the probability of aggravating suffering. For other patients, “everything” means any treatment that has even a remote chance of prolonging biological life for a short time regardless of its adverse side effects. **Table 1** provides examples of differences in the ways patients may balance treatment burdens and benefits.

Table 2 outlines patient concerns that may underlie requests to “do everything” and gives examples of useful questions to ask. For some patients, wanting “everything” may be less about medical decisions that need to be made and more about fears associated with getting sicker, concerns that treating physicians will be less vigilant if the patient does not request all possible interventions (8), or worries about abandonment if the patient considers forgoing aggressive treatment and opting only for comfort (9). A question such as, “What are your biggest worries (fears)?” (10) might elicit some of these concerns.

Other patients may be unaware of their “true” prognosis or the limited ability of medical therapy to influence their illness, and may reconsider their wish for invasive or life-prolonging technologies once they are fully informed about the high burdens and minimal benefits of these treatments (11). In the latter instance, the only way to figure out what the patient knows about his illness and the potential role of medical treatment is to ask such questions as, “What have others told you about the status of your disease?”, “How is the treatment working?”, and “What

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Table 1. Different Treatment Philosophies Underlying Requests for “Everything”

- Everything that might provide maximum relief of suffering, even if it might unintentionally shorten life.
- Everything that has a reasonable chance of prolonging life, but not if it would increase the patient's suffering.
- Everything that has a reasonable chance of prolonging life, even if it may cause a modest increase in suffering.
- Everything that has a reasonable chance of prolonging life even a small amount, regardless of its effect on the patient's suffering.
- Everything that has any possible potential to prolong life even a small amount, regardless of its effect on the patient's suffering.

does the future look like?” The physician should offer information about treatment efficacy and burdens to ensure that the subsequent decision is as informed as possible (12) and follow up with a question, for example, “Given what you have now learned about your disease, what is most important to you?” (13).

This follow-up question is important, because patients rarely want “everything” for its own sake. Rather, most patients want a specific outcome, and conversations about what they mean by “everything” may allow exploration of their hopes and goals for those outcomes. For example, most patients want a life that allows them to accomplish certain goals, such as talking to their family or being physically active. Those goals may change over time, such as when a patient is willing to tolerate a considerable risk for suffering to be alive for a grandchild's birth and is less

willing to tolerate the same risk for suffering after the birth. Understanding what a patient means by “everything” requires an understanding of what the patient would consider a treatment success and how much the patient would be willing to go through for a chance at success (5).

In contrast, some patients may find extension of biological life most important by far, regardless of the effect of treatment on quality of life. Often, this vitalist approach to treatment comes from a spiritual or religious context, and discussions about what the patient means by “everything” can lead to an exploration of the patient's beliefs about the relationship between the patient's religion and medical treatment (14). For example, some patients may believe that their religion requires that they try “everything” to stay alive. Others may think that only God should make the decision about when someone dies, and still others might request “everything” to give God time for a miracle. A deeper understanding of these beliefs may lead to very different answers about what “everything” means and point to resources other than biomedical expertise that might be pivotal in a patient's decision making.

Because the social context of illness may be involved in requests for “everything,” exploring family dynamics is sometimes key to unlocking the underlying meaning and importance of these requests (15). As a general rule, begin with open-ended questions, such as “How is your family (children, parents, spouse) handling your illness?”, and watch for both verbal and nonverbal responses. Sometimes, this leads directly to responses that uncover critical family

Table 2. Potential Underlying Meanings of “Everything”

| Domain | Concept | What “Everything” Might Mean | Questions to Ask |
|-----------|--|--|--|
| Affective | Abandonment | “Don't give up on me.” | “What worries you the most?” |
| | Fear | “Keep trying for me.” | “What are you most afraid of?” |
| | Anxiety | “I don't want to leave my family.” | “What does your doctor say about your prospects?” |
| | Depression | “I'm scared of dying.” | “What is the hardest part for you?” |
| | | “I would feel like I'm giving up.” | “What are you hoping for?” |
| Cognitive | Incomplete understanding | “I do not really understand how sick I am.” | “What are your most important goals?” |
| | Wanting reassurance that best medical care has been given | “Do everything you think as a doctor is worthwhile.” | “What is your understanding of your condition/prognosis?” |
| | Wanting reassurance that all possible life-prolonging treatment is given | “Don't leave any stone unturned.” | “What have others told you about what is going on with your illness?” |
| | | “I really want every possible treatment that has a chance of helping me live longer.” “I will go through anything, regardless of how hard it is.” | “What have they said the impact of these treatments would be? “Tell me more about what you mean by 'everything.'” |
| Spiritual | Vitalism | “I value every moment of life, regardless of the pain and suffering (which has important meaning for me).” | “Does your religion (faith) provide any guidance in these matters?” |
| | Faith in God's will | “I will leave my fate in God's hands; I am hoping for a miracle; only He can decide when it is time to stop.” | “How might we know when God thinks it is your time?” |
| Family | Differing perceptions | “I cannot bear the thought of leaving my children (wife/husband).” | “How is your family handling this?” |
| | Family conflict | “My husband will never let me go.” | “What do your children know?” |
| | Children or dependents | “My family is only after my money.” “I don't want to bother my children with all this.” | “Have you made plans for your children (other dependents)?” “Have you discussed who will make decisions for you if you cannot?” “Have you completed a will?” |

dynamics (for example, “My wife insists I’m going to beat this, but I can’t envision getting better from here,” or, “We haven’t told the children anything yet”), which must be explored, understood, and possibly resolved before any major decision about shifting goals of treatment can be made. Sometimes a family meeting is needed to help all individuals come to a common understanding of the patient’s illness, prognosis, and future treatment goals.

Finally, inquiring about potential concerns underlying requests for “everything” is a way to learn about the patient’s and family’s psychological and emotional status in response to the loss of health (16, 17). Kubler-Ross described stages of grief that have been empirically validated (18, 19), with patients and their families experiencing a mix of shock, denial, bargaining, depression, and acceptance. Asking for “everything” in response to an inquiry about setting medical limits may initially represent a reluctance to face painful emotions connected with the patient’s loss of health and potential impending death, preferring instead to keep hope alive by avoiding any such discussion. Such requests may even touch on initially painful spiritual or religious issues (14), such as wondering how a caring God could allow such a tragedy to happen.

In summary, physicians must not assume that “everything” means any and all invasive treatments unless they have explored what the patient is trying to express with the request (6, 20, 21). Neglecting to explore the underlying meaning of a request for “everything” may reinforce patients’ denial of how critically ill and close to death they may be, potentially depriving them of the opportunity to progress through the grieving process. In addition, it may subject patients to unnecessary suffering by committing them to harsh treatment with little likelihood of benefit that they would not want if they were reassured of the physicians’ commitment to their care or if they were fully informed about their prognosis.

STEP 2: PROPOSE A PHILOSOPHY OF TREATMENT

After an adequate exploration of what the patient means by “everything,” the physician can then propose a philosophy of treatment consistent with the patient’s values and priorities and the physician’s own assessment of the patient’s medical condition and prognosis: “Given what we know about your illness and what I have learned about your priorities, it sounds like you would prefer the following balance of burdens and benefits in your treatment . . .” (Table 1 lists some potential risk–benefit balances that can be inserted). Such statements help the patient and family know that any subsequent recommendations are based on knowledge of their values and priorities. Patient and family should be invited to respond to this proposal by a follow-up question, for example, “Does that make sense to you?” and any misreading of the patient’s philosophy can then be corrected in subsequent conversation.

STEP 3: RECOMMEND A PLAN OF TREATMENT

Once the physician and patient have agreed on a philosophy of treatment, the physician can make a more specific recommendation about what should (and should not) be done to support the patient’s treatment philosophy, given the patient’s medical condition and prognosis. This often means making recommendations about CPR, intubation, and other invasive treatments, ideally framed in the context of how the recommendation to pursue or forgo interventions supports patient goals and philosophies. All recommendations should include careful attention to the patient’s treatment philosophy. To avoid the patient feeling abandoned by the physician, clinicians should emphasize what will be done to achieve the patient’s goals before talking about what will not be done. For example, “Given your desire to have any treatment that might reasonably help you but to avoid harsh treatments that have little likelihood of helping, I would recommend that we continue everything we have started, continue to look for treatments that might help, and set limits on CPR and mechanical ventilation, because they would do more harm than good. Of course, we will continue to provide the best possible pain and symptom management along with all other treatments that might help.”

STEP 4: SUPPORT EMOTIONAL RESPONSES

When physicians talk with patients and their families about their hopes and fears, the limitations of medicine, or the possibility of death, patients and families may respond with strong emotions. It is important to support and explore these emotional responses. Some simple yet powerful ways to respond to the emotions include taking time to acknowledge them (“These are difficult discussions”) and legitimize them (“Anyone confronting these issues would feel somewhat frightened”), to explore the patient’s response (“Tell me what is the hardest part for you”), and to empathize with the patient (“I can imagine that the future looks much less certain now that we have had this discussion”) (22–24). It is also important that the clinician reiterate his or her commitment to continue to care for the patient no matter what the future holds (9).

STEP 5: NEGOTIATE DISAGREEMENTS

Sometimes, patients request treatments with marginal efficacy that are outside the physician’s usual treatment recommendations. If differences between what the patient requests and what the physician recommends are substantial, the physician should begin by reviewing his or her understanding of the patient’s condition, values, and philosophy to ensure common understanding and reiterate his or her assessment of the patient’s condition and prognosis with or without treatment. Look for common ground, and try to invent new solutions that accommodate all perspectives (25).

One such option is to consider a time-limited trial. A treatment’s potential effectiveness may be too uncertain for a patient to make a nontreatment decision. Requests to try a particular treatment may be offered in a time-limited way. Then the treatment can be continued or stopped depending on its subsequent effects. For example, the patient we described in the introduction might not want CPR (too burdensome and ineffective), but he could benefit from going on a ventilator if he developed a potentially reversible respiratory problem (a mucus plug). He clearly did not want long-term ventilatory support, but the possibility of a “time-limited trial” might provide some middle ground between forgoing this possibly helpful but invasive treatment and accepting that treatment forever without limitations. The challenge is to adapt medical treatments to best serve patients’ needs and values in light of their medical conditions.

STEP 6: USE A HARM-REDUCTION STRATEGY FOR CONTINUED REQUESTS FOR BURDENSOME TREATMENTS THAT ARE VERY UNLIKELY TO WORK

Some patients and families may value life extension much more highly than avoiding preventable suffering, others may not trust the medical system enough to forgo any treatment, and still others may be unwilling to confront the possibility of dying. Once the patient’s philosophy is clearly articulated in favor of all possibly effective treatments no matter how harsh or invasive, continuing to negotiate around limit setting is unlikely to be productive and may feel abusive (26, 27). In this circumstance, as suggested in Table 3, the clinician should honor the patient’s philosophy and order “full CPR—no limits” status, even if it has high burden and low likelihood of success.

In these cases, we suggest that clinicians still exercise clinical judgment. The negotiation with the patient and family (step 5 in this process) has ended in an agreement to try all possibly life-prolonging treatments no matter how high the burden. Rather than repeatedly badgering the patient and family to reconsider a do-not-resuscitate decision (6, 28), initiating CPR if the patient has a cardiopulmonary arrest is appropriate. Under these circumstances, stopping CPR after 1 cycle if the patient is unresponsive is an

example of exercising good clinical judgment because success is so unlikely. This is very different from a “show code” or a “slow code” (29), in that CPR is genuinely, albeit briefly, attempted. This allows the patient and family to know that “everything possible” was done but avoids having staff go through the futile ordeal of prolonged CPR with no prospect of recovery.

APPLYING THIS SHARED DECISION-MAKING MODEL TO THE CASE

The physician set up a time to update the patient and family about the patient’s condition and to discuss how to move forward. The physician began by asking, “What have you been told so far about your condition?” The patient said he knew he was getting sicker. The physician confirmed that his condition was worsening and asked the patient whether he wanted any information about time frame. The patient said “yes,” so the physician explained that patients with his conditions live an average of 3 to 6 months, with possibilities of exceptions in both directions (12).

The physician asked, “What is most important to you now?” The patient spoke of his hopes of being physically comfortable, not burdening his family, and wanting to see the birth of another grandchild in a few months. The physician acknowledged the importance of the patient’s goals by saying, “Those are very important goals. We can certainly keep you comfortable, and we will do our best to keep you alive until your grandchild is born, but living that long is beyond what we can guarantee.”

Then the physician made a recommendation: “Given how your disease has progressed and what I know about what is important to you, it makes sense to work toward maximizing both the length and the quality of your life, to help you live as well as you can for as long as you can. I recommend that we continue all treatments that contribute to that goal. However, given your desire to avoid harsh treatment that is unlikely to help, I recommend that we not perform CPR or put you on a breathing machine if you get much sicker from here. We will continue to look at and discuss all other potentially effective treatments that would help you either live longer or feel better. Does that make sense to you?”

The patient agreed with the plan, with sadness and also relief. It was the first time his impending mortality had been explicitly addressed, and he appreciated the honesty and compassion even though he was not encouraged by what he had learned. His physician recommended that he make some contingency plans with his family to leave messages and gifts for his yet-unborn grandchild in case he did not make it that long, while at the same time continuing to try potentially effective treatments.

The patient and his family were able to spend meaningful time on these contingency plans, allowing them to be much more open with one another about their feelings, hopes, and fears. The patient did not require any more hospitalizations, but 4 months after this discussion (and 2 months before his

Table 3. Harm-Reduction Strategy When Patients Request Treatments That Do More Harm Than Good

| |
|---|
| Acknowledge and adhere to the patient’s treatment philosophy so that patient and family feel heard and respected. |
| Stop regularly discussing limitations on invasive treatments unless this issue is raised by the patient or family. |
| Address the medical team’s discomfort and disapproval by: <ul style="list-style-type: none"> Communicating the reasoning behind the treatment decision. Finding other patient-centered goals to work toward (symptom management, support, disease treatment). |
| Use clinical judgment to limit treatment that does not advance patient-defined goals. |

grandchild was born), he died quietly in his sleep. Cardiopulmonary resuscitation and intubation were not attempted.

CONCLUSION

Asking patients and families to explore the underlying emotions, concerns, and values that prompt their requests for “everything” is a powerful way to inform the health care team about a patient’s treatment philosophy. This exploration provides information on the relative value that patients place on extending life versus avoiding suffering in light of their medical condition. Physicians can use this information to make recommendations about invasive treatments. Many times, limits can be set after this conversation, but CPR and other invasive treatments are sometimes desired no matter how small the benefits and how high the burdens. In these cases, patient preferences should generally be honored, but clinical judgment must still be exercised to maximize benefit and minimize harm.

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