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The value in doing something:

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Abstract

Objective: Evaluate the reasons why attempts at re-direction, especially at the end of life, often fail, and patients and families insist on treating the underlying illness.

Setting: Conflicts between patients and caregivers regarding the appropriate course of treatment.

Main Results: Clinicians typically understand requests for treatment merely as means to obtain effective care. However, patients and families often request treatment as a way to exert their agency, avoid a sense of responsibility for unwanted outcomes, and express compassion.

Conclusions: In response to devastating illness, patients and families are frequently motivated by factors that go beyond obtaining effective care. Awareness of these factors can help clinicians to identify sources of potential conflict and continue to provide compassionate care.

Keywords

end of life; agency; compassion; ethics consultation; moral distress

Introduction

Patients and their surrogates sometimes request treatments that pose risks and burdens, but are not expected to offer any clinical benefit. These requests are thought to reflect a lack of understanding regarding the patient's circumstances and prognosis (1). Hence, clinicians respond by trying to educate the patients and surrogates, and re-direct them to attainable goals (2). When cure is no longer an option, extension of life may be. When this is no longer feasible, clinicians offer interventions to alleviate symptoms and help to get the patient home (3).

This approach can be effective in many cases. Yet, patients and surrogates frequently resist efforts at re-direction and insist on treating the underlying illness (4). Because these responses tend to occur in the face of devastating illness, they can lead to conflicts between caregivers and families, and moral distress among clinicians (5).

Ethics consultation has become an increasingly common response to these conflicts (6, 7). For 25 years, I have been involved in ethics consultations, and interacted with patients and families who make these requests. This experience has taught me that patients and families, especially at the end of life, are often motivated by multiple considerations. In addition to

obtaining effective care, they are motivated by the desire to exert their agency, avoid a sense of responsibility for unwanted outcomes, and express their compassion. Awareness of the importance of these factors can help clinicians to address potential sources of potential conflict and continue to provide compassionate care.

The Value in Doing Something

Illness is often experienced as an external imposition on the patient and family. A diagnosis of terminal illness can be devastating, not just for the effects it has on the patient's health, but because it robs patients and families of a sense of control over their lives. Doing something in response can help the patient and family to become active agents fighting the illness, rather than passive victims of it. Doing something can thereby help to restore a sense of control over one's lives.

Obtaining treatment for a loved one places burdens and costs on the patient's family. Insisting on treatment, and accepting these burdens, provides a way for the family and loved ones to show that they care. Many of the families with whom I have interacted sought additional treatment for the patient as a way to make manifest their concern and compassion. Doing something for the patient allowed them to show how much they cared.

These experiences reveal that the benefits of doing something in response to devastating illness go beyond obtaining effective treatment. Patients and families who persist in wanting to treat the underlying illness, despite the absence of established treatment options, may be attempting to exert their agency and/or express their compassion.

The Multiple Motivations of Patients and Families

Giant Axonal Neuropathy is a chronic neurodegenerative autosomal recessive disease that affects the central and peripheral nervous systems. Onset is typically in early childhood. By the late teens, most patients are wheelchair dependent and death normally occurs in the 2nd or 3rd decade of life.

Recognizing that there is no current treatment for Giant Axonal Neuropathy, some parents pursued an experimental gene transfer vector. Concern was expressed that the patients' and families' pursuit of the experimental treatment might trace to a lack of understanding regarding its significant risks, and the absence of data on clinical benefit. To address this concern, an ethics consultant met with the parents and patients to assess their understanding. Extended conversations revealed, not surprisingly, that these families are motivated to find an effective treatment for the patient. Yet, for the patients and families I met, obtaining an effective treatment was never the only goal and, in some cases, was not even the primary goal.

One patient had been an extremely bright and active 8 year old. By the time I saw her, she was a young teenager who frequently fell and had difficulty speaking. The disease had taken from the patient all sense of control over her life and, in response to my questions, she did not focus on the chances the experimental treatment might improve her condition. Instead, she emphasized that the illness made her feel powerless and seeking treatment offered an

opportunity to do something in response. Rather than being a passive victim of the illness, it offered her the opportunity to become an active agent who fought against it.

The mother of another patient clearly understood the severity of the illness and her child's circumstances. She acknowledged that the chances her child might benefit personally were extremely low. Still, the mother expressed frustration at the suggestion that the appropriateness of her seeking treatment for her daughter depended exclusively on its risk-benefit profile. She regarded the treatment as a way to show her child how much she cared. The experimental treatment also represented the final possible treatment option. Pursuing it offered the mother the opportunity to say "I did everything I could" and thereby avoid any sense of responsibility for her child's decline.

These cases highlight the extent to which patients and families seek treatment as a means to exert their agency, avoid a sense of responsibility for unwanted outcomes, and express compassion. The fact that these motivations go beyond obtaining effective treatment helps to explain why the need to do something can persist, even increase, when a patient is very ill and there are no effective treatment options. In these cases, the problem is often not a lack of understanding regarding the patient's circumstances. Rather, it is precisely the patient's and family's understanding of the devastating circumstances which prompts the desire to do something.

Implications for Clinical Practice

Recognizing that patients and families can be motivated by factors that go beyond obtaining effective treatment does not imply that clinicians should simply accept requests for treatment that are based on them. Instead, clinicians need to be responsive to these goals while addressing the potential for overuse and overtreatment. To do so, the value in doing something should be balanced against the need to control health care costs, allocate resources fairly, and minimize moral distress.

In my experience, balancing these factors is often best accomplished by incorporating into the shared decision making process an evaluation of the extent to which patients and surrogates are motivated by factors that go beyond obtaining effective treatment. When they are, clinicians and consultants should seek out options that help promote these goals.

Palliative care can offer a way to show compassion and love for patients with devastating illnesses. For patients and surrogates who are struggling to exert their agency, it is important to recognize that the need to do something is often not simply a need to do anything. It is a need to do something against the illness that is undermining their agency. In these cases, a limited treatment trial may provide a sense of control. Enrollment in clinical research, even phase I trials, can offer another way to do something against a devastating condition. It offers a way to ensure that every opportunity for treatment has been attempted. It also offers a way to fight the disease by contributing to efforts to find effective treatments for others (8).

Palliative care, limited treatment trials, and clinical trials offer three options to help patients and families continue to fight the underlying illness, without contributing to overuse and overtreatment. When these options are exhausted, understanding the motivations of patients

and families, and the sources of the need to do something, can help clinicians to avoid counterproductive responses. They can help clinicians to avoid rehearsals of how sick the patient is and suggestions that patients and surrogates who insist on treatment do not understand the circumstances.

Finally, requests for treatments that pose risks and burdens and are not expected to offer any clinical benefit can engender moral distress (9). Recognition that families and surrogates often have multiple goals may offer clinicians some solace in these cases. One study found that families who decided to continue aggressive treatment for children with very poor prognoses welcomed the chance to do something and did not regret their decisions afterwards (10).

These findings illustrate the extent to which patients and families can find value in trials of stressful ICU care, even when the care is not clinically effective. Such care can help families to exert their agency, avoid a sense of responsibility for unwanted outcomes, and express their compassion. Awareness of the potential for these benefits, and their value to patients and families, may help clinicians to recognize that their efforts have important value, even when they do not lead to clinical improvement. This recognition may offer one way to reduce conflicts with families and moral distress among caregivers.

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