

Many Lay People Lack Clear Understanding of ‘Futile Treatment’

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NEW YORK (Reuters Health) – When patients are terminally ill, shared decision-making is often complicated by the **public’s lack of understanding of what is meant by “futile” or “potentially inappropriate” treatment, coupled with the belief that the patient or family should have the final say**, a focus-group study suggests.

“Although it is difficult to recommend the discontinuation of life-sustaining treatment, it is crucial that physicians communicate to families **when treatments are non-beneficial, will not change patient outcomes, and potentially prolong suffering,**” said Dr. Thanh H. Neville of David Geffen School of Medicine at UCLA, in Los Angeles.

“It is important that physicians have the courage to make recommendations. These recommendations should be explained not in the context of resource limitations, but in the context of patient-centered care,” told Reuters Health by email.

The medical community perceives aggressive treatment that may keep a patient alive but not result in meaningful benefit as being inappropriate or futile. But how the general public perceives and understands the terms “potentially inappropriate” and “futile” remains unclear.

Dr. Neville and colleagues conducted six focus groups, including a total of 39 community members, to gain insight into the public’s understanding about the concept and implications of potentially inappropriate/futile treatment.

The average age of focus group members was 68, and most were white (31/39, 79%) and female (30/39, 77%) and had at least completed college (35/39, 90%).

Most participants had not heard either term before, and the concept was foreign to them. Many participants thought the term “potentially inappropriate” was more confusing than clarifying, as they felt it was synonymous with “malpractice.”

Suggested reasons for this lack of understanding included difficulty understanding physicians, the lack of discussion of death in society, skepticism that medical treatment can ever be definitely futile, and the fear that doctors will use the concept of futility to justify limiting care and overriding family decisions.

All but three focus-group members felt that in situations of conflict, patients and their families should have the final say in determining whether they should receive potentially inappropriate treatments, the researchers report in *Annals of the American Thoracic Society*.

Even when focus-group members agreed that treatment was futile in a clinical scenario that most clinicians would consider to be potentially inappropriate treatment (maintenance of life support for a 90-year-old with widely metastatic cancer), they **believed the family should be able to demand ongoing life support against the doctor’s recommendation.**

“Our study reveals that more work is needed to introduce the concept of futile or potentially inappropriate treatment to the American public,” Dr. Neville said. “The U.S. healthcare system does not have unlimited resources, and such treatments will eventually be at the expense of others who have greater chances of recovery. This concept is incredibly important in light of the current COVID-19 pandemic.”

“We will need to engage the lay public in extensive education and deliberation focused on how democratic citizens can make justifiable societal decisions despite fundamental disagreements,” he said. “Now, while we are confronted by an imbalance of needs and resources and anxious about our health, may be a good time to jumpstart the discussion.”