

Tools to help seriously ill patients near death make decisions about their care aren't commonly used in routine practice

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Dartmouth Ph.D. student Catherine Saunders led a study which found that although there are dozens of tools available to help people make difficult decisions near the end of their lives, very few are actually available for patients and families to use in hospitals. Credit: The Dartmouth Institute

Many seriously ill people in the United States—and around the world—are not dying as they would like. Yet, a new study by researchers from The Dartmouth Institute for Health Policy and Clinical Practice found that although there are dozens of tools available to help people make difficult decisions near the end of their lives, they are of varying quality and very few are actually available for patients and families to use in hospitals.

Previous research has found that most people would prefer to die at home free from aggressive therapies or interventions. Yet, nearly one in five dies the hospital and one in seven dies in the [intensive care unit](#) (ICU), where aggressive care is common. While many factors account for this disparity, most experts agree that better communication between [patients](#), their families, and [healthcare providers](#) is an important strategy for reducing it. The use of patient decision aids—tools that help people make healthcare decisions that reflect their values and preferences— has the potential to improve communication and to help patients near death make more informed [healthcare decisions](#). Yet, little is known about the availability, quality or use of decision aids for people facing choices about their care toward the end of their lives.

"As the population ages, the number of people in the U.S. older than 85 will balloon—to 20 million by 2050. We need to understand as much as we can about tools that are available to help people near the end of their lives. This will help us improve experiences for people who are seriously ill or dying, who are already so vulnerable," says lead author and Dartmouth Institute Ph.D. student Catherine Saunders, MPH.

The researchers looked at the availability and quality of patient decision aids for people facing treatment decisions near the end of life. In their investigation, known as a systematic environmental scan, the team sought to answer four questions: what English language patient decision aids are available; what are their characteristics; what is their quality,

including readability; what organizations use them as part of routine care? They used peer-reviewed literature, online sources, and a survey of experts to identify decision aids designed for seriously ill people near death. Of the 105 potential decision aids identified from these sources, 27 met the study criteria, which included factors such as being for people who are making immanent decisions about life-sustaining treatments.

Among their findings recently reported in the *Journal of Hospital Medicine*:

- 50% (14) of decision aids were tailored to seriously ill individuals with specific conditions, such as cancer or heart failure
- 39% (11) were for specific life-sustaining treatments
- Yet only two focused on general treatment approaches, such as life-sustaining treatments vs. palliative care

When reviewing the decisions for quality (by two independent reviewers), the research team found that the quality of the decision aids was high in several categories, including presenting options in a balanced way, disclosing funding sources, and reporting publication dates. The tools ranked lower in other criteria recommended by The National Quality Forum, including clearly listed evidence sources, stating competing interests, and offering an update policy. They also ranked low in terms of reporting outcome probabilities, with the researchers noting that reporting "outcome probabilities in ways that people who are ill and their relatives can understand, especially during times of heightened emotion, is critically important. Therefore, it is a cause for concern that the available decision aids often neglect to use evidence-based techniques for conveying outcome information."

"We know it's difficult to implement any new innovations in routine

care, and this is a particular concern for decision aids, " Saunders says. "When it comes to serious illness and death, there could be additional barriers to meaningful implementation, like the complex and emotionally charged decision making that often occurs when someone is dying. And it doesn't help that so few [decision](#) aids for serious illness are broad enough to be useful for most patients and their families. "

The researchers say they hope that their review will be a step toward helping healthcare providers and health systems find appropriate tools to use with their patients.

More information: *Journal of Hospital Medicine* (2019). [DOI: 10.12788/jhm.3110](#) , [www.journalofhospitalmedicine... mental-scan-decision](#)

Provided by The Dartmouth Institute for Health Policy & Clinical Practice

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