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Thorny questions on the way to disclosing rationing*

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In this issue of *Critical Care Medicine*, Young and colleagues (1) recommend a departure from current practice in intensive care units in suggesting that rationing be systematically disclosed. They argue that if patients and families are routinely notified that rationing is done to effectively meet the needs of all patients, such notification would help to set realistic expectations and prepare patients and families for disclosure in particular instances. Their paper makes an important contribution to the literature, since rarely in the literature on the ethics of rationing is the issue of approaches to disclosure addressed.

I agree with their view because we should not ignore the evidence that rationing does indeed occur and because healthcare providers owe it to patients and families to help them understand this.

Proving that rationing is happening is difficult. It requires proof that some intervention could have been beneficial, that it was not done, and that the reason it wasn't done was because of resource limitations rather than other reasons. Despite the difficulty, evidence that the care of critically ill patients is rationed can be illustrated by examining recent studies about triage (2, 3). Arguably, triage is one of the clearest examples of rationing – a process of using some well-reasoned logic for giving priority to some patients over others in the setting of limited resources. A multicentered study of over 8,000 intensive care unit triage decisions in 11 university hospitals in seven countries showed that 14% of patients who were referred for admission to intensive care were not admitted (2). While we do not have controlled trials examining the benefits of intensive care, modeling of the observational data from these hospitals, adjusted for severity of illness, suggests that being refused admission to intensive care was associated with reduced survival (3).

While triage may be the clearest example of rationing, rationing can involve a wide range of decisions. These can vary in consequence, from the most momentous ones, such as admission and discharge decisions, to decisions about staffing ratios, all the way to less crucial but nonetheless meaningful ones that are a matter of comfort and convenience.

*See also p. 261.

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Clinicians should notify patients about rationing for several reasons that Young et al clearly outline. These reasons are both a matter of respect, patients deserve and appreciate understanding the decisions about their care, and a matter of utility, when rationing must be explicitly acknowledged it is more likely to be carried out fairly and to be managed well (4, 5).

Yet even if we endorse the recommendation to disclose rationing, we must acknowledge what a demanding suggestion it is. As Young et al point out, there is much to learn about how to best communicate the idea to patients and families that rationing sometimes occurs. In surveys from a number of nations, the public expresses antipathy to rationing, largely stemming from a sense of entitlement to health care (6–8), and we must explore ways to address this sentiment. At the same time, we know from surveys in several countries that people do wish to be informed if rationing does occur (9, 10).

What do we need to convey in the messages patients and families receive? The messages will need to provide sufficient justification and provide a very clear explanation of the gap between available resources and the demand for medical services. Messages will need to help patients and families to understand that the purpose is to apportion critical care resources in a way that is fair and makes good use of limited personnel and supplies. We will have to find ways to help patients and families appreciate that some patients will not receive an intervention because they are less likely to benefit from it than other patients. This is a more complicated message to convey than the idea that a treatment is not being offered because it is not expected to be of any use at all.

But in addition to considering how to best communicate information to patients and families about rationing, there is a fundamental question to ponder. Rationing entails withholding of some benefits from patients that we assume they should receive were it not for limited resources. But there is no consensus about what range of benefits we think we ought to provide to patients. Certainly, when a critically ill patient faces the risk of premature death, everyone would agree that an intervention that has some chance of improving survival should be provided; if resources are too scarce to do so in this circumstance, we would label this rationing. But for patients who have far exceeded the average life expectancy, and have begun to decline, are decisions to advise families to consider forgoing certain life-sustaining treatments instances of explicit rationing or instances of good judgment about the goals and limits of medicine? To the extent that questions such as this about the goals of medicine are unresolved (11), much deliberation is needed in preparing to ration, let alone preparing to disclose rationing.

From a practical standpoint, the Society of Critical Care Medicine is well positioned to develop the practical tools for communicating about rationing to patients and families. The American College of Critical Care Medicine of Society of Critical Care Medicine has a strong track record of careful development of guidelines for triage (12). These guidelines are well respected and often cited in the literature. The Society of Critical Care Medicine Ethics Committee has recommended in its Consensus Statement on Triage of Critically Ill Patients that public notification is necessary (13). The Patient and Family Support Committee has experience in developing carefully worded guidelines for family support and intensive care

unit brochures that explain the intensive care unit experience (http://www.myicucare.org/Support_Brochures/Pages/default.aspx). The Patient and Family Support Committee would do well to take on the task of providing the kind of educational information for patients and families that are needed as part of systematic disclosure of rationing.

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