Rationing Healthcare: Who's Responsible?

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To place responsibility for rationing chemotherapeutics on the oncologist not only increases his or her emotional burden, but it also strains the doctor-patient relationship. We should not allow oncologists to become bedside healthcare raters simply because no one else wants to do the job.

Using a series of vignettes, Drs. Tenner and Helft discuss ethical challenges relevant to practicing oncologists. In our commentary, we would like to explore whether oncologists should bring up the cost of care and be held ethically responsible for rationing healthcare.

Let’s start with the easier vignette: Vignette 3 illustrates the failure of the physician to discuss transition to hospice care. As the authors describe, a dying man with pancreatic cancer “had an ECOG performance status of 3 at his last visit...you were to see him again in clinic next week to discuss hospice...” Not making time for this important communication at his last visit was a tremendous wasted opportunity, and it opened a time window for an adverse event. Why not discuss the use of hospice during the patient’s first visit and, following a best-practice approach, have a formal hospice information visit to establish this best practice and the finality of this patient’s illness when he still has 3 to 6 months left to live, as recommended by the American Society of Clinical Oncology?[1] Why bring the patient back to discuss hospice later? The authors discuss “anticipating...patient decline.” Cancer is not sudden death, and the point at which a person has less than 6 months to live is actually very predictable.[2] We have to stop making excuses; we need to have these discussions with patients at several points along the end-of-life continuum.[3,4] Patients who have these services in place when they leave the hospital have a 4% chance of readmission, vs a 25% chance of readmission if they don’t.[5]

Now for the harder part: costs and discussion of costs. These issues have been debated for decades, with no resolution.[6,7] For example, let us consider and contrast two health systems, US Oncology and Johns Hopkins Medicine. US Oncology recently started giving their patients, at every visit, a summary statement of the total cost of their care and the patient’s responsibility. At our institution, patients are only aware of their own cost responsibility, which is determined during pre-authorization. The patient may never see the total cost, and absolute financial responsibility is only determined when bills come months later. We do not know which is a better approach, but there are financial managers in the office who know the costs and can discuss them with the patient. We cannot plead ignorance forever.

In their article, Drs. Tenner and Helft have countered that while some believe rationing can only be accomplished at the level of the individual provider, many oncologists feel ethically conflicted by the idea of balancing societal needs to ration care against their professional responsibility to advocate for their patients. The authors suggest that oncologists “provide information about the relative risks (including the financial risks) and potential benefits.” This represents a substantial change in practice, as many oncologists feel unprepared to give such information, and most of us have little training or even a framework for such a discussion.[8,9] We were unable to find a single published work describing the impact of real costs on patients and the effect of care costs on the physician-patient relationship. We have just started a clinical trial to explore this question—the first of its type ever.

Acting in the best interest of our patients must encompass the whole person and prepare patients for the effects that their disease may have on their life beyond their health. This includes the financial impact of their treatment decisions and ensuring that there are no feelings of guilt for financially burdening their families. We believe this is as much an ethical imperative as providing the most life-prolonging therapy.

We should continue to bend the cost curve in cancer care by removing the financial incentives to use the most expensive chemotherapy.[10-13] Conflicts of interest and ethical challenges arise when we make money from buying and selling chemotherapy. If practices choose the chemotherapy that makes the most money rather than the least expensive one with equal efficacy, we have used both societal and patient-family resources inappropriately.[10]
Patients' trust in their physicians lies in the fact that they know that their doctors are on their side. Suspicion that doctors may be thinking out of their pocketbooks leads to more conflicts between providers and patients, who may feel they need to stand up for themselves.[14] Placing the onus of allocating cancer treatments on individual practitioners would further jeopardize this sacred doctor-patient relationship.

The United Kingdom’s National Health Service (NHS) believes the burden of rationing should not rest with the doctor, but instead must be shouldered by the government in an equitable, evidence-based manner. The National Institute for Health and Clinical Excellence (NICE) was established in 1999 as a means for determining which medicines, treatments, and procedures will be paid for by the NHS. Cost-effectiveness thresholds are based on the number of quality-adjusted life-years (QALYs) gained with a particular drug.[15] Physicians have long held that individual doctors should not be rationing care at the bedside.[4,16]

Ethics Definitions for the Non-ethicist

The authors allude to significant variability in physician thresholds for cost-effectiveness, compromising fairness in any practitioner-based cost-control system. Indeed, survey data have demonstrated significant variation in what oncologists consider cost-effective, with many believing every patient should receive effective cancer treatment regardless of cost.[17] These variable practices mirror the NHS’s impetus for creating NICE. Disparities in access to care based upon socioeconomic and geographic location, nicknamed the “Postcode Lottery,” prompted the NHS to seek a more equitable, transparent, and consistent means for rationing scarce resources through NICE.[18]

It is difficult to tell a patient that he or she is at “the end of the road.” It is easier and more tolerable to continue to offer hope and yet another line of chemotherapy than to admit defeat—or to have “the talk.”[3] To place responsibility for rationing chemotherapeutics on the oncologist not only increases his or her emotional burden, but it also strains the doctor-patient relationship. We should not allow oncologists to become bedside healthcare rationers simply because no one else wants to do the job. Our British physician colleagues, when confronted by a patient who desperately seeks additional treatments, are able to say that nothing more can be provided based on NICE guidelines. While a nationalized healthcare system is culturally and politically unfeasible in the United States at this time, approaches to healthcare in the United Kingdom offer insights into how the US could more effectively control costs of cancer care. NICE could be used as a model for an evidence-based, transparent mechanism to justly allocate scarce resources. That way, US oncologists will not be forced to make care-rationing decisions at the bedside. In the meantime, at least we can give our patients the best information about costs and help them choose what is “worth it.”

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