

ETHICS CASE

Who Should Ration?

Case and Commentary by Philip M. Rosoff, MD, MA

Abstract

A principal component of physician decision making is judging what interventions are clinically appropriate. Due to the inexorable and steady increase of health care costs in the US, physicians are constantly being urged to exercise judicious financial stewardship with due regard for the financial implications of what they prescribe. When applied on a case-by-case basis, this otherwise reasonable approach can lead to either inadvertent or overt and arbitrary restriction of interventions for some patients rather than others on the basis of clinically irrelevant characteristics such as ethnicity, gender, age, or skin color. In the absence of systemwide reform in which the resources saved from one patient or group of patients are reallocated for the benefit of others, prudence is urged in the application of “bedside rationing.”

Case

Mr. J is a 58-year-old black man who has been mostly homeless for the past eight years. He has a number of chronic medical conditions of which end-stage renal failure is his most critical. He has been receiving hemodialysis for six years. Because he does not have health insurance and is not eligible for Medicaid in the state in which he resides, Medicare covers many of the costs associated with care for his kidney disease under the end-stage renal disease benefit. Mr. J is not a known substance abuser but does have significant mental health issues and has preferred to live on the streets rather than in the shelters and the halfway houses to which he has been assigned. He has also proved to be unable to maintain a relationship with outpatient dialysis centers, despite multiple attempts and interventions by social services. He is an ultra-frequent visitor to the university hospital emergency department (ED), with up to ten visits a week in the cold winter months. Most of his dialysis is administered there or at the hospital’s inpatient dialysis facility. Not surprisingly, his erratic care and his lifestyle have contributed to a slow deterioration in his overall condition. The physicians who see him most often—ED physicians and hospitalists—believe that further provision of dialysis is a waste of hospital and national resources (and their time); they believe that Mr. J is incorrigible and is “using” them and the system for his own purposes. They wish to unilaterally stop treatment and switch him to hospice care, even though Mr. J retains decision-making capacity and expresses a desire to continue living as he has been doing. Should the

physicians be able to limit his access to specific kinds of care by appeals to his excess consumption of resources they believe to be in short supply?

Commentary

The example of Mr. J—and many thousands of similar cases that occur regularly in emergency departments, hospital wards, and clinics throughout the country—raises significant questions about how we prescribe and dispense interventions and care to patients and the reasons we give for both largesse and parsimony. Are the resources Mr. J's physicians are so concerned about conserving really scarce in the same way that we think about the absolute shortage of livers, hearts, and kidneys used for organ transplantation? It is not simply tangible resources that are subject to our scrutiny, as physicians also might differentially allocate the time they devote to particular patients or make recommendations based partly upon whether the patient is likeable, more or less similar to them, and so on [1]. Is it a fundamental part of a physician's professional duty to both patients and society to act as a representative and responsible [steward](#) of these resources? Or are these decisions simply a convenient justification employed to limit access for a particular patient? After all, one wonders how the ED physicians would view Mr. J's frequent visits and consumption of their valuable time and supplies if he were white and wealthy, even if he did have similar apparently self-destructive and imprudent unhealthy behaviors. (While they very well might feel the same way, they probably wouldn't express it so openly.) This is not to say that many (perhaps most) physicians who are susceptible to these sorts of hidden or implicit biases might not be acting in good faith and honestly believe they are safeguarding either society's or their institution's valuable and possibly limited goods. However, the problem with individualized or [bedside rationing](#) (as opposed to systematic, systemwide rationing that applies similarly to similarly situated patients), is that it can fall prey to deep-seated prejudices about certain kinds of people and even certain kinds of diseases especially when it uses "rules" that might be idiosyncratic and arbitrary. Alcoholic liver disease—which might require liver transplantation—is one example of a disease that many believe to be more representative of a personal moral failing than an illness deserving of compassion, sympathy, and care [2].

In the remainder of this essay, I will discuss so-called bedside rationing under the control of individual physicians and compare it to rationing that applies to an entire health care system, even though both have the laudable goal of conserving scarce resources and apportioning them to those who need them the most and can presumably benefit the most from receiving them. I will argue that there are moral hazards associated with the former that can (mostly) be avoided with the latter.

Problems of Bedside Rationing

All physicians ration. An inherent part of the practice of medicine is the creation of "menus" of reasonable options of diagnostic and therapeutic interventions that are

tailored to the patient's clinical needs, tempered with deference to her desires and life goals. Ideally, the list should be reasonably similar for patients similarly (clinically) situated, with modifications suited to the specific circumstances in which the patient (and often her family) find themselves. In the United States, more so than in most other wealthy industrialized nations, a key component in this calculus is the patient's ability to afford what is on the list, and one should not underestimate the impact affordability can have on patient care [3]. In a more quotidian manner, we also constantly make decisions about who is more clinically deserving of what—presumably meaning who can benefit most when there are not sufficient resources (like ICU beds, ED triage, and even our time) for all who could conceivably benefit—and these decisions are an essential constituent of doctoring. However, there are important differences between resources that are in [short supply](#) relative to demand, such as livers and hearts, and those that are relatively scarce or fungible, such as money [4, 5]. While both could (and surely have) certainly fallen prey to discriminatory and biased allocation methods, the former are less likely to suffer from willful bigotry and favoritism, especially if the supply is centrally controlled and organized in an open manner and is dependent upon public cooperation (i.e., for donation). Because the latter resources are so contingent upon the personal views of the dispensing agent (a physician or member of the legislature controlling a health care budget, for example), they might be more open to individual assessments and opinions about what should be the case and for whom. While these less-than-salutary facets of how many people view the world can affect actions such as willingness to donate organs [6-8], it is notable that an important feature of most organ allocation rules is their disregard of personal features unless they could have a direct impact on clinical outcomes (such as graft survival) [9].

It is important to note that rationing only makes sense—indeed, this is true of health care in general—when it pertains to interventions that can help people, such as relieving their suffering [10]. If we do it right by ignoring features about people that are usually (but not always) clinically irrelevant, such as their skin color, gender identity, sexual orientation, immigration status, and the like, we can act as good stewards of the local resources at our disposal and serve our patients well by offering them choices that could conceivably help them and limiting options either that they do not reasonably need [5] or from which they can have little-to-no chance of benefiting [11, 12].

If, however, we physicians assume a role that is not necessarily ours to take—that of stewards of nationwide, potentially commonly held, resources and attempt to solve systemic resource constraint issues on an individual patient basis—we run a great risk of making arbitrary, capricious, and biased decisions that fail both the patient and the profession. Of course, in a disjointed, decentralized health care system such as exists in the US, the notion of communal resources is generally limited to such things as organs for transplantation, even though a more circumspect analysis would also recognize that more might be shared than is commonly recognized, such as money (meaning that all of

us are affected in numerous ways by how health care dollars are spent). Nevertheless, it is common to conflate bedside and system-based rationing when there is a motivation to act as responsible guardians of the nation's (or hospitals', insurance companies' or even individual patients') goods. More frequently than we would like to admit, some physicians justify withholding treatments from patients by claiming good stewardship when in reality it is prejudice masquerading as rationing [13, 14]. This is not to say that physicians engage in widespread and overtly prejudicial practices in the manner in which they care for their patients, simply that rationing of the sort that takes place at the bedside—that involves often on-the-spot decisions about what is reasonable to offer a specific patient—could be vulnerable to a rationing rationalization in which some clinically similar patients are treated differently for ethically (and possibly medically) indefensible reasons. This is the essence of what I see as the structural problem with this form of decision making.

Can Bedside Rationing Coexist with Systemwide Rationing?

How do we reconcile the daily allocation decisions made by physicians—we might call this “micro-rationing”—with more systemic distributions that have a much wider scope—we might call this “macro-rationing”? The former is generally focused on particular, individual patients and what they might want, need, or are thought to deserve by their physicians (or whoever is paying for their health care), while the latter more generally applies to the allocation of larger quantities of goods to groups of patients. Examples of the latter might include the national organ transplant system or the plans that were developed to distribute the influenza vaccine in the event of a pandemic several years ago [15-17]. Renal dialysis falls somewhere in the middle between the two. Since it is a socialized program available to all US citizens and permanent residents as a defined Medicare benefit (irrespective of age), it is not a prime illustration of a scarce resource (although some might view the money funding the program as such). However, physicians have some discretionary power in deciding to whom to offer this therapy [18, 19]. (This form of discretionary choice is more of an open issue in the United Kingdom and its National Health Service [20].) Examples of micro-allocations permeate clinical practice, the most common perhaps being the rationing of time. While it might be true that some concierge physicians are able to devote virtually unlimited amounts of time to their privileged clientele, most of the rest of us must carefully parcel out our face-to-face (and other) time, presumably based upon what a patient needs in the moment. Undoubtedly this time pressure contributes to the frequent delays in seeing physicians, as the careful planning of 15 minutes per visit (or whatever the allotment might be) quickly goes awry when a complicated or challenging situation presents itself.

Moreover, physicians are only human and hence susceptible to the implicit biases that almost all of us possess to a greater or lesser extent, as could appear to be the situation in the case presented here. Not only can these covert (and sometimes not-so-covert) prejudices lead to substantial and measureable differences in clinical outcomes for

identifiable groups such as members of ethnic minority groups [1, 21], they can also profoundly affect other areas of medical practice based upon something as simple as whether a patient is likeable or not [22, 23]. In the case of Mr. J, it might be tempting to assume that the emergency department staff's treatment of him was value neutral, meaning that their concern for the conservation of resources (their time, hemodialysis "chair time," supplies, and so on) was similar to what it would have been for any other patient similarly clinically situated. But there could be reason to suspect that this might not be the case. We naturally wish to spend more time with people who are friendly and respectful and whom we identify as trustworthy. Conversely, while we might feel a duty to care for all patients, we hasten out of the exam or hospital room of those who are surly, belligerent, or demanding. Not surprisingly, patients we might view negatively in the moment might also have characteristics (such as skin color) that trigger implicit negative biases we might hold, thus producing a double whammy of aversion and animating our judgments about personal desert, worthiness, and other clinically irrelevant inferences about specific patients. These responses could lead to narrowing the "menu" of available options for some but not all patients.

The dangers of micro-allocations of this very personalized type—in which physicians take it upon themselves to serve as arbiters of who should get what for perhaps the wrong (i.e., unjust) reasons—are that patients might not receive the care or interventions that they by rights should have (meaning the care that would be offered to clinically similar patients who differ from them in some other, clinically irrelevant manner) [24]. In addition, physicians might be singularly unsuited by temperament, training, and knowledge to understand and hence implement rationing decisions for patients on the basis of larger resource supplies and demands. For example, prior to the implementation of the model for end-stage liver disease (MELD) score for determining priority for eligibility listing for liver transplantation, there were significant racial and ethnic disparities between organ recipients. The practice had been for transplant physicians to advocate individually for the gravity of their patients' condition and hence the urgency of their need. This relatively simple, numerical score—composed of the total bilirubin, creatinine, serum sodium, and the international normalized ratio—virtually eliminated the discretionary ability of physicians to argue more persuasively for some patients than others, resulting in a near elimination of subjective forms of discrimination [25].

To be sure, physicians have an integral role to play in deciding who gets what (and why) on a population basis, as exemplified in the leadership responsibility they have in formulating organ transplant allocation rules. But these activities are at the level of policymaking for all patients of a given category (e.g., liver failure, advanced heart failure) rather than at the level of a single physician making allocation decisions for a single patient at the bedside and appealing to scarcity of resources (which might or might not be the actual case) as a reason for her chosen course of action. On the other hand, there

could be advantages to encouraging physicians to make these kinds of decisions in that they support and enhance the sort of individualized attention that physicians are educated to deliver so as to tailor any treatments specifically for the improvement of a patient's welfare. Yet to make these decisions in an ethically defensible manner by minimizing the influence of both implicit and explicit biases would require some form of oversight—either prospective or retrospective—as well as efforts like the MELD system to assist physicians in treating their patients as equally as possible. But attempting to distinguish “bad” micro-rationing from customized therapy can be tricky. Moreover, imposition of a structured and monitored framework for controlling these kinds of decisions might be cumbersome and generate even more bureaucratic headaches for physicians who are already overburdened with paperwork, external oversight, and the like [26].

In Mr. J's case, there is little doubt that his clinical situation, his frequent visits to the emergency department, and his inability to take advantage of more efficient outpatient dialysis, clinic visits, and so on, not only is detrimental to his overall health, but also arguably consumes resources that he wouldn't need if he were able to adhere to a more standard clinical course. But is his case substantively different from legions of other patients on whom we lavish as much if not more medical effort—think of patients with advanced cancer receiving extremely expensive novel medications to extend their lives for a few months—except for the fact that he is homeless, a member of an ethnic minority group, and does not heed medical advice?

Finally—and this might be the most significant flaw in bedside rationing—there is no way to ensure that the resources conserved by not providing them to one patient would be put to better use for another patient. Since these resources are not kept in a central pool to be allocated to a perhaps more deserving patient (or at least one whom the physician believes would benefit more from access to them), all that results from a bedside decision of this type—even a well-intentioned one—is that a patient doesn't receive something to which she might be entitled under different circumstances in which she has a physician who either doesn't hold or express personal biases. Unlike the organ transplant system, in which the decision to not offer a liver to patient A means that patient B will receive it, not giving dialysis to Mr. J has no effect whatsoever on the availability of dialysis to anyone else. Conservation of resources that relies on bedside rationing, or rationing on this micro level, does nothing to help others and does much to potentially harm individual patients.

Conclusion

Can “unauthorized” or unregulated bedside rationing be prevented or minimized? Physicians not only have to deal with their own implicit biases, but also are continually bombarded with the dual—and competing—demands to generate more income and spend less or cut costs. The general news media as well as publications from

professional organizations are rife with discussions of runaway health care costs, waste, and so on [27-29]. Meanwhile, insurance companies do their best to limit payments for expensive interventions and the words “prior approval” (the time-consuming mechanism by which insurers demand clinical justification before approving payment for a procedure or treatment) often strike dread into the hearts and minds of physicians throughout the land. Health care disparities thus might result from clinicians’ rationing care to particular patients—or particular kinds of patients, like Mr. J—out of their general concern about the inexorable rise in the nation’s health care budget. But the alternative—a top-heavy, management-level imposition of rules and regulations to limit costs that relies on systematic micromanaging of single patient-physician encounters, similar to that used in managed care in the 1990s when physicians were often rightly viewed as making decisions corrupted by personal financial conflicts of interest—is a nonstarter [30].

I do not wish to convey the impression that physicians should be profligate with either their patients’ or society’s resources, and I have argued for prudence elsewhere [4, 31]. The hazards of giving physicians uncontrolled discretionary power to be solo gatekeepers of what their patients have access to can lead to abuses that might conserve resources—but at a price. Few would argue that the escalating costs of the US health care system are not financially ruinous (or will be if unchecked). But unless there is a systemic and systematic mechanism in place that can ensure that the resources that are “saved” would be put to equal or better use elsewhere, there can be little warrant for permitting physicians (relatively) unfettered authority to make these sorts of *ex ante* decisions. Personally, I believe that proper health care resource rationing can only be accomplished within a framework of a wholesale remaking of the US health care system that emphasizes fairness of allocation based upon individual and group medical needs. However, this is an argument for another time and place. In whatever manner the distribution of shared or common resources is achieved, in a democracy, it should be a matter for public debate and deliberation, and not take place solely within the privacy of the hospital or office examination room [4, 5].

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