

Rationing of Intensive Home Dialysis

Physicians should share all treatment options available to patients, regardless of perceived ability to pay and concerns about patient compliance.

Commentary by Mandy Garber, MD, MPH, and Robert M. Arnold, MD

Dr. Anderson, a nephrologist in practice for 15 years, sees many patients, including about 50 individuals who require dialysis 3 times a week for 4 hours each session. She has recently become aware of a new dialysis treatment whereby patients are treated with home dialysis. The home regimen must be performed 6 times weekly for 8 hours each session, but can be done at night while sleeping. Early indications are that patients on this intensive nocturnal dialysis have more energy after treatments and have more time to do personal activities because they are not spending 12 hours each week attached to a dialysis machine in the hospital.

Unfortunately, the therapy is more expensive than traditional dialysis, often prohibitively so, and patients on intensive home dialysis require training in the machine's use and maintenance. Furthermore, Medicare does not fully cover dialysis at home or in a treatment center.

Mr. Nelson, an elderly, longtime patient of Dr. Anderson, supported on Social Security and Medicare, has severe diabetic nephropathy requiring dialysis and suffers from comorbidities, including hypertension, chronic obstructive pulmonary disease (COPD), and cirrhosis. On a visit to Dr. Anderson, Mr. Nelson complains of increasing fatigue since starting dialysis 2 years ago. He used to take care of his 6-year-old grandson after school until the boy's mother got home from work but can no longer do so because of his thrice-weekly dialysis. He asks his doctor if there are other options available for a patient like him.

Dr. Anderson thinks about offering her patient the intensive home dialysis treatment but has concerns about Mr. Nelson's ability to pay for it. Furthermore, Mr. Nelson has been a no-show for several appointments and admits to poorly monitoring his glucose levels at home. Dr. Anderson has concerns about his ability to manage the care of the home dialysis machine and is reluctant to offer him the newer treatment. Dr. Anderson concludes her visit with Mr. Nelson without offering him the new treatment, but telling him she will look into other options for his dialysis treatment.

Commentary

Ethical dilemmas in clinical practice require much more than philosophical analysis. They require medical knowledge of the situation, the ability to creatively come up with solutions that maximize competing values, and the skill to communicate effectively. Although this case is described as involving "rationing," we believe that for practicing clinicians, other questions are more salient.

Good ethics begins with good facts. We are told that Mr. Nelson is a very functional 70-year-old man with multiple comorbidities who is bothered by fatigue. While it is possible that more intensive dialysis will improve his situation, the differential diagnosis for fatigue in this man is much broader. He may be fatigued because of anemia, silent ischemia, progressive kidney failure, worsening COPD, depression, or a host of other metabolic problems. Aggressive

work-up of these problems may increase his energy and render the question of intensive home dialysis moot.

Assume, however, that home dialysis will improve his fatigue. If he is rejected for home dialysis, that would constitute rationing, defined as the allocation of limited health care resources. Rationing necessarily means that beneficial interventions are withheld from some individuals [1]. In this case, the primary rationing decision takes place at the level of the health care system rather than at the bedside. The federal government's decision not to fully fund home dialysis limits Dr. Anderson's clinical judgment. If Mr. Nelson cannot afford home dialysis, he may not be able to get it regardless of whether Dr. Anderson believes it is best for him. The ethical issues raised by Medicare policies have been the source of extensive debate and will not be discussed here [2].

This analysis assumes that Mr. Nelson cannot pay for home dialysis, although Dr. Anderson has not inquired about this, nor has she informed the patient of the federal policy of not paying fully for home dialysis. This lack of disclosure raises the following ethical issues: should doctors withhold information about treatment options because of economic factors? Should doctors withhold information about treatment options because they do not believe the treatment will work? Lastly, is a physician obligated to lobby for increased insurance coverage on behalf of her patients? We explore each of these questions in turn.

First, we question whether Dr. Anderson's concern that Mr. Nelson cannot pay for home dialysis justifies withholding that information from the patient. It is widely accepted that withholding clinical information from patients is unethical because it limits their ability to ensure that clinical decisions reflect their values. The process of informed consent demands that, for a patient to make a clinical decision, pertinent information must include: (1) the clinical diagnosis; (2) the proposed treatment; (3) alternatives to the proposed treatment; and (4) the risks, benefits, and uncertainties related to each alternative [3]. By withholding information, Dr. Anderson undermines the process of informed consent and fails to respect Mr. Nelson's autonomy. Guidelines from the American Medical Association's Council on Ethical and Judicial Affairs state that physicians should disclose all treatment alternatives, regardless of cost, including those potentially beneficial treatments that are not offered under the terms of the patient's health care plan [4]. The physician may even need to explain about federal payment policies under Medicare or private health insurance rules about home dialysis.

Telling Mr. Nelson about the federal policies on funding dialysis makes him a better informed citizen. If he disagrees, he can protest the policies. This is the reasoning behind the doctor's wish to tell patients about HMO coverage [5]. Although Medicare will not pay all the bills for home dialysis treatment, Mr. Nelson may have access to other funds about which Dr. Anderson is ignorant. Autonomy thus requires that Dr. Anderson talk to Mr. Nelson about dialysis.

Second, Dr. Anderson may not want to raise the issue of home dialysis because she thinks Mr. Nelson is unlikely to benefit: she is concerned about Mr. Nelson's ability to care for the home dialysis machine in light of his history of poor medical compliance. If Dr. Anderson's decision not to prescribe home dialysis treatment for Mr. Nelson is influenced by the limited number of machines or their high cost, Dr. Anderson is engaged in bedside rationing. We have argued elsewhere that this form of rationing is an inherent part of medicine [6]. The question in this case is whether the rationing decision is morally justifiable. To justify rationing, there must be patients sicker than Mr. Nelson, high-priority patients who are in need of the limited number of home dialysis machines. Furthermore, the cost-benefit ratio of home dialysis treatment for Mr. Nelson must be unfavorable compared to that of the other patients.

Even if this is the case, we believe that Dr. Anderson should still discuss the option with the patient and explain her justification. It may be that her assumptions regarding Mr. Nelson's nonadherence are unjustified. She might find out that, with help from home nurses, Mr. Nelson's adherence would markedly improve.

Third, as a physician, Dr. Anderson is committed to ensuring that Mr. Nelson receives the best possible care. If Dr. Anderson believes that home dialysis is best for Mr. Nelson, should she argue with medical insurance companies to cover this therapy? In their article "Physician-Citizens—Public Roles and Professional Obligations," Gruen, et al state that physicians, as citizens, must be proactive about advocating for change that improves the health of individuals and for societal issues such as access to health care and insurance [7]. AMA guidelines state that physicians must advocate for any care they believe will materially benefit their patients, and, in some circumstances, physicians have an obligation to initiate appeals and argue for the provision of treatment on behalf of their patients [4]. In order to initiate

an appeal on Mr. Nelson's behalf, Dr. Anderson must be convinced that home dialysis will be of significant benefit to him.

Ethical dilemmas in clinical practice are rarely as simple and straightforward as they may appear at first glance. With analysis and a deeper appreciation of the circumstances, the clinician is able to uncover myriad approaches to resolving the conflict(s). Our analysis reveals the multiple ethical questions Dr. Anderson is facing. If and when she is able to answer these questions honestly, Dr. Anderson can communicate effectively with her patient about the care for his chronic illness.

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