American Medical Association Journal of Ethics

November 2015, Volume 17, Number 11: 1028-1034

ETHICS CASE

Grow a Spine, Have a Heart: Responding to Patient Requests for Marginally Beneficial Care

Commentary by Bjorg Thorsteinsdottir, MD, Annika Beck, and Jon C. Tilburt, MD, MPH

Dr. Perry is a primary care physician in a busy urban clinic in East Harlem in New York City. He is already behind schedule and has been somewhat apprehensive about seeing his next patient, 42-year-old Ms. Hollowell, whose medical problems are prediabetes and obesity. Ms. Hollowell comes to clinic for both scheduled visits and urgent care walkins. Dr. Perry has seen her perhaps once a month for the past several years.

Today, she asks Dr. Perry for a referral for a mammogram. She is concerned that breast cancer may run in her family. An aunt of hers had breast cancer in her 60s, and two years before Ms. Hollowell had convinced Dr. Perry that she should get a "baseline" mammogram. That test was indeterminate, and she then was sent for a right breast ultrasound and diagnostic mammogram, which were both negative.

Dr. Perry believes that, because Ms. Hollowell is between 40 and 50 and is in a low-risk group based on the new screening guidelines, a mammogram is unnecessary at this time. Still, he recognizes that Ms. Hollowell is anxious and wants to get a mammogram to "make sure everything is alright." He explains the risks of false positives again, but Ms. Hollowell points out the "close call" and "cancer scare" she had two years ago and her desire to be reassured. He fears that not referring her will hurt the therapeutic relationship that has been built over the years. Perhaps she will seek out another physician if he refuses her request for a referral. Dr. Perry quickly checks the computer and sees that he is running behind schedule; there are three other patients waiting to be seen.

Commentary

Through the power of their prescriptions and orders for tests and procedures, physicians are the de facto gatekeepers of medical resources. In the era of health maintenance organizations and the Patient Protection and Affordable Care Act (ACA) [1], physicians face renewed pressure to practice parsimonious medicine [2]. The Choosing Wisely campaign orchestrated by the American Board of Internal Medicine Foundation encourages doctors to limit the use of minimally beneficial services [3]. The Patient-Centered Outcomes Research Institute aims to compare the effectiveness of different treatment options to allow physicians to choose the most beneficial and effective care

for their patients [4]. International and domestic awareness of the harms and costs associated with overdiagnosis and overtreatment [5, 6] is increasing, challenging medicine to have a smaller footprint [7]. These are good and important developments that will help patients and the profession. But how should the doctor at the bedside navigate these currents? What is the right thing to do when a <u>patient requests</u> services that are judged by the physician to be <u>unnecessary</u> or even harmful?

Here we will deconstruct the current case by focusing on the physician's ethical obligation as a gatekeeper of health care resources in an environment in which minimizing overutilization is a priority but outright rationing is dismissed. The ethical issues raised by the current case are broader than those of resource utilization; other ethical principles come into play when addressing patients' requests for minimally beneficial or even harmful tests or procedures. Physicians have never been obliged to offer nonbeneficial care and they can confidently recommend against marginally beneficial care that they believe is not worthwhile. The principle of nonmaleficence is particularly pertinent in the case of this young woman, inasmuch as many have called attention to the risk of harm from overdiagnosing breast cancer in women her age [8, 9]. Since 2009 the United States Preventive Services Task Force guidelines no longer unequivocally recommend mammograms for women younger than 50 but rather defer to shared decision making based on individual risk-to-benefit assessments [10], and in 2015 the American Cancer Society updated its guidelines, recommending that women with average breast cancer risk begin regular screening mammograms at age 45 [11].

While recommending against testing in this case is parsimonious practice, good clinicians also have a heart and recognize that all requests are coming from somewhere. Ms. Hollowell is clearly fearful that she is at risk for breast cancer and needs reassurance from her physician that it is safe not to pursue further tests. Navigating such concerns skillfully can stem the tide of requests for marginally beneficial tests and procedures. Appeasing the patient through ordering more tests may not help; diagnostic tests for symptoms with a low risk of serious illness do little to reassure patients and decrease their illness anxiety [12]. On the contrary, false positive mammogram results and recalls for further testing often result in lingering anxiety, as may have been the case for Ms. Hollowell [13].

The role of the individual physician in limiting overtreatment or allocating valuable resources is a particularly divisive subject in the fragmented US health care system. In the US, physician restraint with an individual patient, even one with government insurance, will not reliably redistribute those resources to benefit other patients [14]. Bedside rationing is a reality in many countries [15], and some argue that physicians are uniquely positioned to determine which patient would benefit from treatment and thus have a duty to ration marginally better treatments [16, 17]. This role raises the concern that rationing makes a doctor a "double agent" and risks compromising her ability to

fulfill her duty as a patient advocate when tasked with allocation of a limited resource [18, 19]. In a recent survey, the majority of US doctors seemed to agree: respondents felt that the responsibility for limiting access to care and rationing lies more with insurance companies, health systems, trial lawyers, and even patients than with physicians. The majority of those surveyed, however, still emphasized both the need to adhere to guidelines that discourage the use of marginally beneficial care and the role of doctors in limiting the use of unnecessary tests [20]. These sentiments highlight the difference between rationing and parsimonious care [2].

To alleviate the concerns about dual agency and conflict of responsibilities, an intermediate way of ethically limiting access to health care resources at the bedside, so-called administrative gatekeeping, has been recommended [18]. Therein, the physician is required to act out fair policies adopted at higher levels within the health care system while at the same time being prohibited from considering cost in clinical deliberation. This approach relies on the development of agreed-upon processes for determining coverage and dealing with requests for treatment that is not covered [21]. Debating these issues is necessary so physicians can maintain fidelity to patients' best interest within the constraints of available resources.

While we endorse parsimonious medicine, we agree that physicians should not serve as self-appointed negative gatekeepers at the bedside. Below we outline why it is hard to justify such a role for the physician in the US context using Ms. Hollowell's case as an example. To adequately address the question of how Dr. Perry should respond to Ms. Hollowell's request, we need more information about her breast cancer risk and insurance status. For the purposes of this discussion we will assume that Dr. Perry's estimate of low risk of breast cancer is accurate. We will address the ethical question in the US context for three different insurance scenarios—private pay, private insurance, and public insurance—since each insurance status introduces unique resource allocation concerns.

If Ms. Hollowell pays out of pocket then there would be no ethical concerns about overutilization unless there was limited access to mammography, in which case the fairness of allocation of scarce resources by ability to pay could be questioned. Ability to pay is currently an accepted form of rationing—a kind of "soft" rationing—in US health care [22]. Mammograms are widely available in the US, so *it is hard to invoke an obligation to withhold a mammogram if Ms. Hollowell is willing to pay.*

If she has private insurance, the ACA mandates that her plan cover a screening mammogram without cost sharing [1]. (This is interesting given the weak evidence supporting mammograms for women 40-50 years old [10] and points to the strong political sensitivities surrounding breast cancer screening.) Refusing to refer an insured patient for mammography will not reliably benefit other patients more in need of

services since the money is just as likely to increase the takings of insurance company shareholders. Such savings offer little justification to withhold the service [23]. If all physicians restricted the use of mammograms for this low-risk group, it could possibly decrease the cost of insurance and thus benefit other patients. Given the universally mandated insurance coverage for breast cancer screening and fear of litigation for delayed breast cancer diagnosis, however, there would have to be a paradigm shift in both insurance coverage and tort reform for the practice patterns of physicians to change. Thus Dr. Perry has no ethical obligation based on resource allocation to limit Ms. Hollowell's access to a mammogram covered by her insurance in accordance with the law. Best interest or nonmaleficence arguments could be used to justify not yielding to Ms. Hollowell's autonomous request and limiting her access because of the risk of harm from overtreatment as outlined above. However, in the current environment, in which mammograms are considered standard of care, Dr. Perry would be incurring significant personal liability were Ms. Hollowell to be diagnosed with breast cancer at a later stage.

Finally, if Ms. Hollowell has government insurance, the gatekeeper role becomes more relevant since money saved by withholding services might plausibly be reallocated toward services for other patients. In this context, one could argue that the cost effectiveness of tests and procedures should influence resource allocation at some level. This is done in many countries and has been tried in the controversial Oregon Medicaid experiment [14, 24]. However, the use of cost effectiveness to govern coverage decisions is explicitly prohibited in the US Medicare system [25], which covers screening mammograms for Ms. Hollowell's age group [26]. Thus our question becomes: should Dr. Perry feel ethically obliged to go beyond what clinical guidelines and government insurance policy state and withhold the desired screening mammogram from Ms. Hollowell? As a physician acting in Ms. Hollowell's best interest and trying to protect her from the stress of another "cancer scare," Dr. Perry is justified in counseling her against doing the mammogram based on his assessment of the risk-benefit balance. Going beyond that and refusing to refer her for desired services that are covered by her insurance, however, would require appeal to an ethical principle other than fair resource allocation. While we hold physicians to high standards of professionalism and ethical conduct, the physician cannot be expected to make up for unfair insurance and government policies at the bedside. Thus, it is hard to assign Dr. Perry an ethical obligation rooted in fair resource allocation to withhold the mammogram from Ms. Hollowell under the present US system, even if she has government insurance. Rather, physicians collectively should actively participate in shaping policies and guidelines to help address the problem of overtreatment.

Conclusion

The lack of consistency and accountability in US insurance policy, and the lack of reliable and fair redistribution of resources on a societal level, ought not to be compensated for by individual physicians' actions to limit care at the bedside. We believe instead that, collectively, physicians have a social responsibility to share their knowledge and

experience at the policy level for the benefit of society at large and move our society toward fair and equitable systems [27]. This is best achieved through a fair process in open democratic deliberations. At the bedside, the physician should be focused on the individual patient's welfare and be willing to say "no" based on her best interests alone. The art of medicine lies in balancing respect for patient autonomy against beneficence and nonmaleficence.

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