

Virtual Mentor

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ETHICS CASES

Authority, Health Advocacy Organizations, and Scientific Evidence

Commentary by Jodi Halpern, MD, PhD, and Richard L. Kravitz, MD, MSPH

Dr. Sanders, a second-year oncology fellow, arrived for work carrying a sheath of bright pink pamphlets. He set them down on a table in the staff room and proclaimed to his colleagues: “It’s that time of year again—the annual charity walk is coming up! The sign-up sheet is on the table here for anyone who wants to participate. The work this group does is so important in the fight against breast cancer!”

A new oncology fellow, Dr. Wang, walked over to the table and picked up one of the pamphlets. “These guys want to increase access to mammography for all women under 50. That’s the opposite of the new U.S. Public Health Task Force recommendations.” The evidence was pretty good, he thought, for their guideline that mammography for women under 50 be limited to high-risk groups because of the risks associated with false positive results—unnecessary biopsies, anxiety, and so on.

Dr. Sanders replied, “Well, I think that the work the group does to help vulnerable women avoid and treat breast cancer is really important. I have a lot of respect for what they do.”

“But,” Dr. Wang interjected, “isn’t it problematic for you, a physician, to support a group that promotes health care activities that go against the evidence? This seems like bad medicine. Plus, doesn’t this group just encourage even more people to think of evidence-based medicine as rationing? You are supposed to be a steward of our profession and of the best evidence-supported medicine. I don’t think it’s right for someone in your profession to support a group like this—it seems bad for medicine and bad for patients.”

Commentary

In the vignette, Dr. Sanders and Dr. Wang disagree about what professionalism requires of them. While “professionalism” refers to doctors’ conduct, medical leaders have wisely avoided telling physicians how to behave and instead defined the goals the profession should be serving. These goals are to safeguard patient welfare, to respect patient autonomy and to promote social justice [1, 2]. In practice, professionalism often comes down to discerning how best to meet these goals, given that goals can conflict with each other and meet up with organizational and resource constraints. Here, Dr. Sanders supports a patient advocacy organization that promotes women’s health and excellence in cancer care that may be overexuberant with regard to screening. Dr. Wang believes that physicians have a stronger, perhaps

even absolute, obligation to reject any organization whose recommendations appear to skirt the best evidence.

In conflicts over professionalism, a good first step is to clarify the facts. An apparent ethical conflict can dissolve when the circumstances are better understood. Thus, we first reflect on the nature of the evidence regarding mammography and the societal context in which disease advocacy groups operate. Then, in the second half of our commentary, we turn to the possibility that the doctors' disagreement might reflect conflicting conceptions of professional responsibility.

The Context of the Case

Let us begin by considering the evidence behind the guidelines for mammography. As John Ioannidis has pointed out, many published research findings are likely to be false [3]. All evidence is not created equal. Among the reasons for misleading research findings are fraud, error, bias, and chance. Beyond the raw data, guidelines produced by reputable organizations frequently disagree. In the case of breast cancer screening, the American Cancer Society continues to recommend that women under 50 should discuss the value of mammography with their personal physicians [4], whereas the United States Preventive Services Task Force (USPSTF) recommends against *routine* screening in this age group [5]. Because scientific evidence is inevitably context-dependent and often subjective it should not be ignored but neither should it be worshipped.

Importantly, even if a therapeutic or preventive intervention is of limited or no benefit for most patients, the intervention might still be worthwhile for selected subgroups. This is what statisticians and epidemiologists call heterogeneity of treatment effects (HTE) [6]. In the case of breast cancer, women between 40 and 49 may obtain greater-than-average benefit from mammography if: (1) they have higher-than-average risks of developing breast cancer; (2) they have less dense breasts, allowing easier diagnosis; or (3) they are already very worried about cancer or are phlegmatic enough to be unperturbed by false positives and the downstream risk of unnecessary biopsy and overtreatment.

Reflecting on the facts also includes considering the range of services provided by the women's advocacy group. Let's say that, while overselling the benefits of mammography, this advocacy organization also fights cancer-associated stigma, educates women who need testing and might not otherwise seek it, provides crucial support for women with breast cancer, and supports research efforts that may help ultimately prevent or cure breast cancer. Given how little societal support there is for people grappling with illness in our country, advocacy groups can make a profound difference in women's lives. Just as people frequently support political parties without endorsing their entire platforms, perhaps physicians can ethically support a health care advocacy organization without agreeing with everything it says and does. Thus, Dr. Sanders might be justified in supporting the advocacy organization if he concludes that the group does, on balance, more good than harm.

On the other hand, supporting a group that ignores important scientific evidence can contribute to a very dangerous “antiscience” societal trend. At a time when 40 percent of Americans don’t believe in evolution and think that humans were created in the “last 10,000 years or so” [7], the standing of science in America is perilous. Furthermore, as Dr. Wang implies, the rising cost of health care threatens our national well-being but any attempt to rationalize use of medical resources is painted by regressive forces as “rationing” or “death panels.” Under these circumstances, it could be argued that physicians, trained in science, have a duty to defend the scientific method. What is to be given greater priority: patient groups that support and improve women’s health now or scientific integrity, which is critical to medical progress in the future?

Models of Professional Responsibility

To address such questions requires analyzing our ethical as well as factual assumptions. Note that we have already been considering the ratio of good to harm, which suggests a utilitarian approach. Utilitarianism focuses on the outcomes of actions and defines right actions as those that an impartial spectator would calculate as having the greatest aggregate benefit. Should doctors attempt to guide their professional conduct by such calculations? How could doctors accurately weigh the long-term social costs of downplaying evidence-based recommendations against the current benefits of supporting an advocacy group that works on behalf of women’s health?

Not only would attending to every such issue make practicing medicine impossibly demanding, it would distract doctors from their primary responsibility, which is to pay attention to their patients. It is not just that, as John Rawls famously argued, utilitarianism is blind to the individual, favoring aggregate outcomes even when this sacrifices individual welfare and autonomy [8]. Rather, it is that doctors are not morally positioned to be impartial social planners, as they are not independent of particular relationships and duties. Patients trust physicians with their lives based on the expectations that physicians are committed to them, to putting their interests first. Recall the patient-centered focus of the principles of professionalism: physicians are responsible for serving each patient’s welfare, and for respecting each patient’s autonomy.

How does taking a patient-centered approach resolve the conflict between Drs. Sanders and Wang? It reminds these physicians that practicing evidence-based medicine is not a good in itself; it is a good when it enables better care of each individual patient, present or future. In this case, better care includes social and psychological support as well as the information provided by advocacy groups.

According to their roles as trusted fiduciaries, Drs. Sanders and Wang should redirect their attention back to their patients’ lives. They might ask: how can I act today in a way that best serves Mrs. Jones, Ms. Arquette, and Ms. Martinez? Do they each truly depend on this health advocacy organization? Do they have other sources of support? Can I educate them to avoid unnecessary mammograms despite the role

of emotions in driving decision making? If not, are there other organizations that provide accurate information as well as social support?

Additionally, doctors' responsibilities extend beyond their known patients. The third principle of professionalism, to promote social justice, reminds doctors that their role responsibilities extend to broader populations. Moreover, doctors are responsible for sustaining the public's trust in physicians. In addition to the questions above, then, doctors might also ask themselves: Am I considering the unmet needs of women from disadvantaged communities? Am I upholding the scientific integrity that sustains public trust? Am I promoting the science that may discover new treatments?

Addressing these questions reveals that in this case there is a strong link between evidence-based care and promoting the welfare of individual women. Yet it is crucial for women to be informed about advocacy groups that can empower them and promote their health. The challenge for physicians is to balance both of these obligations to best serve the goals of medical care.

Thus, while it may be fine to bring brochures to the medical staff room, we would recommend against distributing brochures in the patient waiting room. Absent discussion with their doctors, women might take this to be an endorsement of this particular group's views of mammography. Instead, Dr. Sanders should inform individual patients about the organization and its pros and cons as part of educating them both about the need for discernment regarding mammography and about the health value of social support. Assuming that Dr. Wang does not know of another comparable source of social support, we think that, despite his misgivings, he too should inform women about this organization as one source of possible social support even as he shares his concerns with them. Perhaps Dr. Sanders and Dr. Wang might also support the development of more evidence-based advocacy groups (through speaking or writing about the science, for example).

In summary, physicians' strongest moral obligation is not to impartially protect science, but rather to fulfill their role responsibilities to patients. Still, practicing evidence-based medicine is one of the most powerful ways to serve individual patients, so professionalism will most often coincide with favoring scientific practice. The ethical issue is to see that science—as it constitutes the “evidence base”—is a means to the end of helping real people. Good clinical practice integrates clinical research, professional experience, and knowledge of the individual patient.

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