

Virtual Mentor

American Medical Association Journal of Ethics
January 2013, Volume 15, Number 1: 9-17.

ETHICS CASES

Communicating Evidence in Shared Decision Making

Commentary by Paul J. Christine, MPH, and Lauris C. Kaldjian, MD, PhD

Dr. Garrison is a third-year resident in internal medicine who takes pride in helping patients make educated decisions regarding their health care, informing them of recent research and answering their questions.

One afternoon in the outpatient medicine clinic, Dr. Garrison spoke with Mr. Mendez, a 62-year-old man who had come in for a yearly physical. In reviewing Mr. Mendez's chart, Dr. Garrison noted that his total cholesterol was high at 242 mg/dL, while his HDL cholesterol was low at 35 mg/dL. He was otherwise healthy, having normal blood pressure, no other symptoms or signs of cardiovascular disease, no family history of cardiovascular disease, and no history of smoking. According to the Framingham 10-year risk calculator, this picture corresponded to a 15 percent risk of a myocardial infarction in the next 10 years ("moderate risk").

After discussing the findings of the physical exam with Mr. Mendez, Dr. Garrison entered into a discussion of the lab results. "Mr. Mendez, your lab results indicate that you have high cholesterol. Based upon your current state of health and lab results, you have about a 15 percent risk of experiencing a heart attack in the next 10 years. For patients in your situation, we typically recommend treatment with a drug known as a statin, which helps to lower your bad cholesterol." Dr. Garrison proceeded to explain the benefits and side effects of statin therapy to Mr. Mendez, who stated that he was willing to try whatever the doctor thought was best.

Dr. Garrison added, "You should also know that, for the average person with your medical history and state of health, the number needed to treat—that is, the number of individuals who must be treated with a statin to prevent one death from a cardiovascular event such as a heart attack or stroke—is generally between 60 and 100, which means that if I treated 60 people in your situation, 1 would benefit and 59 would not. As these numbers show, it is important for you to know that most of the people who take a statin will not benefit from doing so and, moreover, that statins can have side effects, such as muscle pain, liver damage, and upset stomach, even in people who do not benefit from the medication. I am giving you this information so that you can weigh the risks and benefits and then make an informed decision."

Mr. Mendez looked surprised. He said that he felt fine and, having heard the statistics, did not wish to start statin therapy at this time.

Later that day, Dr. Garrison met a fellow third-year internal medicine resident, Dr. Parra, for coffee in the hospital cafeteria. Discussing some of their cases from the day, Dr. Garrison remarked that several of her patients had elected to try lifestyle modifications rather than initiate drug therapy for hyperlipidemia and some other conditions. “That’s remarkable,” Dr. Parra observed, thinking that most of her patients elected pharmacologic treatment despite her encouragement to consider behavioral changes. Dr. Garrison continued, “I’ve found that providing patients more evidence regarding the effectiveness of drugs, and giving them information such as the number needed to treat, encourages them to think more realistically about the benefits and risks of pharmacologic treatment.”

Dr. Parra wondered about this and responded with concern: “Really? I don’t think our patients can make sense of all this information. They’re not trained in statistics and don’t know how to interpret scientific data. That’s our job.” Dr. Garrison asserted that it is an ethical obligation for physicians to provide information such as the number needed to treat and asked Dr. Parra, “How can our patients make informed decisions regarding their health care if they don’t know the evidence?”

Commentary

The disagreement between Dr. Parra and Dr. Garrison highlights one of the fundamental ethical issues surrounding Mr. Mendez’s care: How much information about evidence should physicians communicate to patients to enable them to make informed decisions? The answer will most likely depend upon the varying assessments of different physicians, the varying preferences of different patients, and the varying professional knowledge available in different clinical situations. Yet there is a general recognition in contemporary medicine that something needs to be said about the available research evidence related to a specific clinical decision in order to enable patients to make informed decisions about their health—even if wisdom is needed to understand how that evidence should be interpreted and communicated.

Shared Decision Making and the Need for Communicating Evidence

Communicating information about prognosis and treatment is recognized as one of the clinical cornerstones of respecting patient autonomy. The patient’s right to informed self-determination implies a corresponding obligation for physicians to provide relevant and understandable information. This is no small task when dealing with the complexities of risk communication. Patient numeracy, physician framing of risks, and embedded mental shortcuts that simplify complex information and decisions (i.e., heuristics) are but a few of the challenges physicians face when sharing treatment information. One critical issue is the degree to which Mr. Mendez understands his prognosis and the risks and benefits of his treatment options. Such challenges have been discussed in a recent *Virtual Mentor* article [1] and need not be recapitulated here.

Instead, we focus on fundamental questions of professional ethics that lie beneath the surface of Mr. Mendez’s case. Dr. Garrison’s and Dr. Parra’s disagreement about

their perceived ethical obligations to share evidence reflects different conceptions about the balance of control over decision making in the patient-physician relationship, which can tilt more towards the patient or more towards the physician in any given patient-physician dyad.

These issues are given greater relevance in the context of shared decision making, which is characterized by the involvement of both the patient and the physician in the process of selecting among treatment options [2]. Through patient-physician dialogue, shared decision making aims to promote the ethical principle of respect for patient autonomy by empowering, or “conferring agency” on, patients [3]. It explicitly involves patients in decision making by eliciting their preferences and communicating information about treatment options [4]. The communication of evidence is therefore a necessary pillar of the shared decision-making model.

If it is agreed that respect for patient autonomy means that patients need to be informed about evidence pertaining to treatment options, then physicians have a professional obligation to provide such information. But if this obligation is viewed within the complex network of accountability that connects patients, physicians, and society [1], fulfilling it requires us to balance the principle of respect for patient autonomy with the ethical principles of beneficence and justice [3].

Because the complexities of striking such a balance may be underappreciated, we discuss below each of these principles and attempt to show how they can inform our understanding of the nature and extent of a physician’s obligation to disclose to patients evidence related to treatment options. Our purpose is to suggest that the decision regarding how much information a patient should receive depends on more than patient numeracy and lessons learned from the science of risk communication. More fundamentally, we believe this decision depends on a physician’s professional understanding of his or her ethical obligations that flow from the roles of patient and physician in the context of shared decision making.

Relational Autonomy and the *Shared* in Shared Decision Making

Respect for patient autonomy refers to a physician’s obligation to respect those patient preferences and decisions that accord with that patient’s values and beliefs [5]. Communicating treatment options, eliciting patient preferences, and explicitly recognizing the authority of the patient to make treatment decisions are all practices that promote patient autonomy. These practices stand in contrast to more paternalistic approaches in which the locus of decision making tilts more toward the professional authority of the physician.

While promoting patient involvement is a necessary corrective to paternalistic approaches [6], it would be misguided for physicians to assume that shared decision making is only about patient autonomy. As one author put it, “That one party becomes more responsible does not necessarily make the other party less responsible” [7]. This is particularly relevant when patient autonomy is framed as *relational autonomy*. Relational autonomy recognizes that an individual’s identity

and values do not exist in a vacuum, but are “constituted in and by” interpersonal relationships and the broader social environment [8]. In this view, a patient’s social relationships (especially their relationships with physicians) inform his or her medical preferences and treatment decisions.

Seeing patients and their autonomy as existing in relation to other persons, including physicians, can help us think about how much evidence related to treatment options we should communicate to patients. If social relationships and circumstances shape a patient’s autonomy, physicians ought to be sensitive to how these factors may bear on treatment decisions [8]. For example, if difficult or negative prior encounters with health professionals or treatments have caused a patient to discount or prematurely dismiss what a physician perceives to be a good treatment option, part of the “relational work” to enhance autonomy may involve providing more detailed evidence, or more carefully explained evidence, in order to show respect through patient explanation and listening and, thereby, gain trust.

Relational autonomy also helps remind us to consider the question of who decides *which* treatment options should be offered in the first place, a role largely assumed by physicians. We acknowledge that access to information on the Internet about traditional and alternative therapies can have an extraordinary and independent impact on a patient’s understanding of treatment options. Nevertheless, it is important to appreciate that, when physicians communicate about evidence pertaining to treatments and define the treatment options available, they are contributing to the relational autonomy of their patients.

The principle of respect for patient autonomy is relevant to Mr. Mendez’s case in several ways. First, considering the notion of relational autonomy, we should ask: What social circumstances inform Mr. Mendez’s understanding of his high cholesterol? Are there circumstances that strongly discourage Mr. Mendez from taking a statin, even if his primary goal is to avoid a future cardiac event at all costs? How is Mr. Mendez’s capability to enact his goals for care shaped by these social circumstances? Secondly, what treatment options did Dr. Garrison present to Mr. Mendez, and how did these shape his decision-making autonomy? Exploring the answers to the above questions would have enabled Dr. Garrison to appreciate Mr. Mendez’s circumstances and how they shaped his ultimate treatment decision. They would have informed her approach to providing evidence such as the number needed to treat and provided an ethical rationale with which to engage Dr. Parra’s objections.

Beneficence

The principle of beneficence refers to a physician’s obligation to act for the good of the patient [5]. Implicit within this definition is the recognition that a physician must act in accordance with what *he or she believes* is best for the patient, as informed by his or her expertise and clinical judgment. With respect to deciding what treatment options to present to patients, beneficence plays a vital role. What “option set” a

physician selects is inherently influenced by what the physician believes to be the best and most appropriate treatments for promoting the patient's well-being [6].

With regard to communicating evidence, beneficence also supports efforts to promote a patient's understanding of the treatment options offered (here one sees evidence of the interrelationship between autonomy and beneficence, since one of the ways to act for a patient's good is to enhance his or her autonomy). For example, it has been well documented that people are often overly optimistic regarding health risks. In one study in which participants were informed that 4 out of every 100 persons would suffer a poor outcome, some people were unreasonably optimistic that they would not be among the unlucky 4 percent [9]. Thus, even if a patient selects a treatment that the physician favors, beneficence may oblige the physician to offer more information to ensure that the patient takes both the risks and benefits seriously.

Dr. Garrison proposed statin therapy as a reasonable treatment for someone in Mr. Mendez's state of health. What she thinks is good for Mr. Mendez most likely influenced the information she shared about taking statins and the treatment alternatives she offered (if any). In describing the number needed to treat, Dr. Garrison may have been trying to make sure Mr. Mendez fully understood how the benefits and risks of treatment applied to him. Dr. Parra's objection to Dr. Garrison's approach most likely reflected her own notion of beneficence, which could include an interpretation of the evidence and making a recommendation for a preferred treatment (a recommendation that could be changed if side effects happened to occur).

Justice

Justice in the setting of health care usually pertains to questions of fair distribution ("distributive justice") or to questions about what each person deserves, or is "due," as an individual endowed with human dignity [5]. However, what exactly a person is due with respect to evidence pertaining to treatments is not clear, especially when that evidence pertains to populations as well as the individuals who comprise them. Physicians are traditionally trained to focus on the needs and preferences of individual patients, one at a time. But there are also times when physicians are called upon to weigh simultaneously the needs of an individual patient and the needs of a population or society. Such situations raise challenging questions of distributive justice.

Due to cost concerns, we appear to be in a time of increased attention to the needs of society, as can be seen in the new emphasis on "value-based" and "cost-conscious" health care that takes into account the health outcomes achieved per dollar spent [10]. According to a society-focused view, the success of a treatment is evaluated not only by its effect on the individual patient's well-being but also on the cost-effectiveness of the treatment over the long term (e.g., prevention of hospitalization from a myocardial infarction) [11]. With limited health care resources, there is an increasing premium placed on treatments that are backed by quality evidence, offer

more than marginal health gains for individuals, and come at acceptable costs to society.

We would suggest that there is often a deep tension at play when a physician is expected to act simultaneously in the interests of an individual patient and a population or society. A discussion of this tension is beyond the scope of this essay. Suffice it to say that there appear to be increasing expectations that physicians become more cost-conscious about the care they authorize and should see cost-consciousness as part of their accountability to society.

But it should be noted that the effort to balance the needs of individuals with populations (and societal costs) is not a new concern for physicians. Take vaccination programs, for example, and consider the similarities between statins and vaccines. Both statins and vaccines require a financial investment to prevent the occurrence of potentially fatal and costly outcomes. Both have possible side effects and adverse reactions. Both are less than 100 percent effective in preventing the disease in people who receive the treatment.

In the case of vaccines, there is also a societal expectation that patients should be encouraged to receive treatment to benefit society, not only themselves. The physician's obligation is to encourage patients, insofar as it is medically and personally acceptable, to contribute to this societal benefit by being vaccinated. One could think about statin therapy in a similar way. A study evaluating the cost-effectiveness of expanding statin therapy to all low-risk patients found that such an expansion could prevent nearly 14,000 deaths from coronary heart disease and save approximately \$1.4 billion per year [12]. One could imagine such cost savings translating into funding for other pressing health issues. On this view, does Mr. Mendez's decision not to take a statin undermine the well-being of society by potentially diverting funds away from other causes? Does society expect Mr. Mendez to choose statin therapy as a cost-effective treatment plan? Most importantly for our discussion, how does (or should) a physician weigh these considerations when he or she thinks about an individual patient's care? Will a physician's thoughts about societal benefits impact what information he or she decides to communicate with patients about treatment options and their benefits?

We make the comparison of statins and vaccines not to advocate the use of statins, but to highlight how a physician's perceived responsibility to society could have an impact on shared decision making in the patient-physician relationship. To the extent that calls to incorporate cost-consciousness in clinical decision making are justified by considerations of distributive justice, it is understandable that physicians should be encouraged to recommend treatments that promote individual health and are cost-effective for society. But such encouragements should not lose sight of the double responsibility this involves and the potential or actual tension between the well-being of individual patients and the cost savings for society.

In sharing the number needed to treat for statin therapy, Dr. Garrison may have provided evidence that discouraged Mr. Mendez from accepting a pharmacologic treatment that could have been personally beneficial and cost-effective for society. Alternatively, Dr. Garrison could be seen as having encouraged lifestyle modifications that, if successful, could also be beneficial to the patient and cost-effective for society. While Dr. Parra's objection to Dr. Garrison's practice appeared to focus upon the interpretability of the evidence, she might also have objected to Dr. Garrison's disclosure of information that discouraged the acceptance of a potentially cost-saving therapy. One wonders whether Dr. Garrison should have considered communicating information to Mr. Mendez about potential cost savings to society, either as a matter of disclosure (since it could possibly have influenced her recommendations) or as a means of encouraging of civic cooperation. This is a very significant question, one we raise not to promote a position but to stimulate discussion about the tension between individual and societal benefit.

Evidence and Uncertainty

Our discussion would be incomplete if we did not acknowledge that evidence always carries a degree of uncertainty. Statistics such as the number needed to treat are derived from population studies, and probabilities from such studies do not map perfectly onto individual experiences. For Mr. Mendez, the treatment effects of the statin cannot be predicted with complete accuracy. This uncertainty is amplified when the evidence and opinions surrounding a certain treatment are conflicting, as is the case for prescribing statins to low-risk individuals [13]. Without a shared understanding of the uncertainty surrounding both the evidence provided and the decision to pursue a course of treatment, the potential for true patient involvement in decision making may be limited [6].

Shared Decision Making and the Balancing of Ethical Principles

How physicians understand their professional obligations will influence what information they communicate to patients and their approach to clinical decision making. To engage in shared decision making honestly requires that physicians acknowledge (1) their responsibility to the patient (respect for patient autonomy), (2) their responsibility to be true to their own clinical judgment about the best interests of the patient (beneficence), (3) their accountability to society (distributive justice), and (4) the uncertainty of the evidence. While it should also be acknowledged that these ethical principles interact within a broader web of treatment guidelines, local institutional practices, and payer policies—all of which influences the context of shared decision making [6]—how these principles are balanced in a given clinical scenario should be expected to influence what information about evidence a physician decides to share with his or her patient.

The complex interplay of ethical principles in this case reminds us that information about risks and benefits of treatment should not be seen as a self-interpreting package of data ready for delivery. Rather, the information we share with our patients reflects our own ethical values and our interpretations of the evidence. It also reflects our implicit understanding and balancing of our responsibilities to

individual patients, ourselves, and society. Appreciating that a patient's autonomy is relational and shaped in part by the information a physician provides does not weaken the ethical imperative for shared decision making. It strengthens it. Through the process of patient-physician communication, patient preferences can be elicited to help shape the evidence that physicians share. By recognizing the ethical principles and value judgments at stake in such dialogue, physicians should be in a better position to decide what evidence to share with patients and, we may hope, more likely to truly engage in shared decision making.

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