

Dialogue: The characteristics of information and avoiding surprises

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In his article "What information should be disclosed to patients" ¹ (*Lahey Clinic Medical Ethics Newsletter*, Fall 2002). David Steinberg notes that none of the traditional standards for determining what information patients should receive is wholly satisfactory. Instead of these standards, Steinberg suggests that physicians consider eight characteristics of the information they are thinking about disclosing. ²

I agree with Steinberg that his list of characteristics can be a useful tool for thinking about when to disclose a certain bit of information, and that the traditional standards he discusses often don't work. I also applaud the fact that he would give patients more information than traditional standards require. Unfortunately, although consideration of his characteristics may be a useful guide, I doubt that it can serve as a standard for judging when withholding information is permissible. Before looking at Steinberg's suggestion, I will present my own principle. This is the principle of avoiding unsurprising surprises. ³

According to the principle of avoiding surprises, what physicians should aim at is not merely that patients have sufficient information to give (or withhold) informed consent - as traditional standards require - but at protecting their patients from being surprised by anything having to do with their health care situation. ⁴ So, for instance, patients should be told about the discomforts they'll probably experience while recovering from surgery. And this is so even when no one in their right mind believes that the information will affect the patient's treatment decision. Most people simply like to know what to expect, and this is especially true when they are going into situations that are already scary.

But to demand that physicians tell patients about every possible outcome that might surprise them, no matter how unlikely, is to demand too much. It would also mean overloading patients with information, much of which physicians are certain will not actually protect them from any surprises. Therefore, if a possible outcome is so unlikely that the physician himself would be sincerely surprised if it occurred, then the physician isn't required to disclose that possibility. In short, this principle says that unless a physician would be willing to say that he was unprepared for a given outcome, he should ensure that his patient is prepared for it as well.

Now let us return to Steinberg's characteristics, and compare them with my principle. His characteristics are: 1) relevance, 2) probability, 3) significance, 4) availability of interventions, 5) subjective need, 6) harms of telling, 7) patient autonomy, and 8) the decision-maker's perspective. We will consider them in turn:

We might first collapse Steinberg's first characteristic into his second. A fact is relevant insofar as it has a bearing on the probability that the patient will suffer a certain harm, or gain a certain benefit. If the director of a blood bank learns that the donor of a unit of blood has recently been arrested, he clearly has no obligation to provide the recipient of that blood with this information. This is because the information is irrelevant, and it is irrelevant in the sense that it has no bearing on the probability that the recipient will develop or avoid any medical problems.

Of course, the principle of avoiding unsurprising surprises takes relevance and probability into account as well. But it also gives a reason for this: Relevance and probability are important because, among other reasons, it is important to help patients avoid surprises. Whether or not a physician must pass along a given bit of information depends on how probable it is that doing so will ensure that the patient avoids being surprised. If the probability is high enough that the physician would not be seriously surprised by an outcome, then she

should give the patient that information. To use Steinberg's example, if what the director of the blood bank has learned is that a donor has developed Creutzfeldt-Jakob Disease (CJD), and he would not be surprised that CJD can be contracted in this way, then he is obligated to inform the donor that she may have contracted CJD.

Significance is important as well, and this is Steinberg's third characteristic; developing a rash is less significant than developing CJD. But significance will also affect whether or not a patient is surprised, and how surprised he is. It is much more surprising to discover that you have CJD than that you have a rash. But patients are surprised by rashes, and should be warned of them. Thus, whereas talk of characteristics encourages us to think of significance as a continuum, I am inclined to see it as a threshold. If an outcome is significant enough to cause surprise, then the patient should be informed about it.

One of the main reasons patients want information is so that they can use it to make informed decisions. This fact is reflected in Steinberg's fourth and fifth characteristics; availability of interventions and subjective need. In talking of subjective need, Steinberg reminds us that information about one's prognosis, what to expect during recovery, etc., can affect many decisions beyond those about medical interventions; the decision to reconcile with a family member or friend, for instance, or when to schedule an important meeting. The need to make decisions such as these is what Steinberg calls subjective need.

One way of putting the gist of the principle of avoiding surprises is to say that patients often have a legitimate subjective need for information, even when that information will not affect any decisions in or out of the medical context. That is, they have a subjective need to avoid surprises. For instance, patients often feel tricked or betrayed when they experience unexpected pain while recovering from surgery, or even when they are surprised by less than pleasant aspects of hospital routine. Again, this is true even when they acknowledge that the information would not have affected their decision regarding treatment *or any other decisions*.

The sixth characteristic Steinberg discusses is the harm that being informed might cause the patient. As with most other moral principles, the fact that someone might die, or be permanently disabled - and has not voluntarily accepted this risk - is normally overriding. So I agree that this consideration can also override the principle of avoiding surprises.

Nonetheless, the fact that bad news will harm by causing anxiety does not weigh strongly against informing a patient. That Steinberg's seventh characteristic is autonomy hints at this, but I would stress it more strongly. He also notes that sometimes patients don't want information, and that in these cases autonomy requires not telling. This is also consistent with the principle. As with other obligations, the person to whom the obligation to inform is owed can waive it. So a patient can tell her physician that she waives protection from surprises, and prefers not to have certain information. But merely preferring not to be told is not the same as waiving the obligation to tell. Thus, the physician's sense that her patient does not want information is not enough to justify withholding it. She should get explicit permission.⁵

Finally, Steinberg's eighth characteristic concerns physician-rather than patient-centered considerations. He notes that medical professionals working in a setting that frowns on delivering bad news will find it difficult to deliver such information. That is true, but the principle of avoiding surprises encourages us to criticize the culture of such a setting. This seems a good thing to me. As I hope it's easy to see, I agree with Steinberg that health care workers should take the characteristics he lists into account. But I think his suggestion is vulnerable to one of the same worries he expressed about the subjective (conversation) standard: it depends on the good will of physicians. In the odd case where a patient or ethics committee is dealing with a physician who does not believe that patients should be informed, a requirement to *take into account* characteristics is simply not enough. Such a physician can truly take characteristics into account and still always decide to withhold information.

The principle of avoiding surprises, on the other hand, provides some recourse. This is because most of the time there is general agreement about which possible outcomes would be surprising. Moreover, if the patient is surprised, that is some - albeit inconclusive - reason to believe that the physician should have provided the information. Also, a physician who fails to warn a patient must be willing to say that he was unprepared for that outcome, and so may be open to the criticism that he should have been. Granted, there will be instances in

which it is not clear that the physician should have been prepared for an outcome, or should have found it unsurprising. But these correspond with the instances in which it simply is not clear whether the physician had the obligation to provide that information. There are gray areas. Although Steinberg's characteristics will be helpful for physicians sincerely looking for guidance, my concern is that they cannot provide a standard, and would not allow criticism of those rare physicians who stubbornly refuse to inform their patients.

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Footnotes

¹ >www.Lahey.org/Ethics/Newsletter/Fall2002.asp

² In the interest of space, I will use the term "physician." But I really have in mind health care professionals more generally.

³ Gert HJ. Avoiding surprises. A model for informing patients. *Hastings Cent Rep* 2002;32(5):23-32. For simplicity's sake, in what follows I will usually drop the "unsurprising" and refer to this as principle of avoiding surprises.

⁴ Steinberg does not explicitly represent these standards as specifically concerned with informed consent, but this is how they are usually discussed in the literature.

⁵ It might even be an explicit condition of treatment or testing that a patient waive that obligation. For instance, testing done to detect a specific genetic malady can result in information about paternity. Many believe that it is best to have an explicit policy noting that such information, collected inadvertently, will not be provided. If the patient freely releases the physician from this obligation, she is no longer obligated to provide the gathered information.

Steinberg's reply

Although I listed the characteristics of information I thought warranted consideration, Gert is correct in noting that I did not provide a standard or formula to weigh and balance those characteristics to make a disclosure decision. To her credit she attempts this next step. Gert does this using the notion of surprise.

This is an intriguing but problematic solution. She is judging an action with moral content - disclosing medical information - by a psychological reaction. Some patients are inattentive, forgetful or prone to denial; information can be appropriately disclosed yet the patient will nonetheless be surprised by a disclosed event. Other patients have an innately pessimistic view of life and may suffer an expected, untoward event that was not disclosed, yet they will not be surprised because they believe that bad things happen. In both cases the reaction of surprise would incorrectly judge how appropriately information was disclosed.

Physicians are also subject to the vagaries of human behavior; what surprises one physician might not surprise another. For the notion of surprise to be a useful concept it cannot be subject to the whims of human psychology. This forces us to ask the question, when should a physician be surprised? If a side effect randomly occurs once in every 25,000 patients who receive drug X, should the physician be surprised when it happens to his patient? He should not be surprised because the event is known to occur and, because it is a random event, there is no reason for him to believe it could not happen to one of his patients. However, the physician might be surprised in the way I would be surprised if I won the lottery. I know it is possible for me to win, but I'm surprised because I won despite long odds. If the physician should be surprised at an event that occurs once in every 25,000 patients, should he be surprised at an event that occurs once in 150 patients? What is the threshold for surprise?

To make the notion of surprise useful, we need a developed ethics of surprise that provides the rules for determining when a patient or physician should be surprised. Because Gert has not yet developed this, the notion of surprise, although useful in many instances, cannot serve as the final arbiter of disclosure decisions.

Some of the characteristics of information I've identified may in some cases clearly trump the others. However, disclosure decisions are often made within a hazy web of complex and conflicting factors. We often have to weigh one against the other and struggle to make the most defensible decision. I do not see a simple universal solution on the horizon.

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