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Is Information Always a Good Thing?

Helping Patients Make "Good" Decisions

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In most cases, patient preferences are crucial in making good health care decisions. For example, choices between chemotherapy and radiation treatment usually hinge on trade-offs that only patients can decide about. In recognition of the importance of patient preferences in clinical decisions, health services researchers have begun developing decision aids to help patients understand complex medical information. But these decision aids might lead to "bad choices"—choices that are inconsistent with people's stated preferences. In this paper, the author provides examples of how people make inconsistent medical decisions, and briefly discusses future directions for exploring ways of structuring information so that patients are less likely to make inconsistent choices.

Key words: Cognitive psychology; decision making; informed consent; medical ethics. (Med Care 2002;40[supplement]:V-39–V-44)

Hypothetical Case

Lung cancer was recently diagnosed in Ms. Reynolds. The news was more than shocking at first. When the physician told her she had cancer, she was bewildered. The physician briefly discussed her treatment options at that first visit, but that information is nothing but a blur to her right now. She remembers hearing something about chemotherapy and something else about radiation, but all she could really think at the time was, "I have cancer!" Now it is time for her to figure out what to do with her life. And high on her list of priorities is to decide how to treat this cancer.

What kind of information will help Ms. Reynolds make this difficult decision? At a minimum, Ms. Reynolds wants to know how each possible treatment will affect her long-term survival. She wants to know how arduous each treatment is, and what its side effects are. She also wants to talk to people who have undergone each of these treatments.

In most cases, patient preferences are crucial in making good medical decisions. A choice between chemotherapy and radiation treatment may hinge on trade-offs between the types of side effects incurred by each treatment and the chance of surviving after each treatment. Only the patient can decide how to make these trade-offs. In recognition of the importance of patient preferences in clinical decisions, health services researchers have begun developing decision aids to help people understand complex medical information.[1–3] Unlike simple patient education pamphlets or videos, decision aids provide people with specific information relevant to their decision. A decision aid can be individualized to take account

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of the patient's age and the specifics of the diagnosis. In this way, a patient receives accurate information about the probability that he or she will experience various outcomes based on his or her treatment choice. For example, a decision aid for a patient with lung cancer will not only explain what surgery and radiation are, but will also provide specific information about the likelihood of surviving either treatment option.

Decision aids are a promising development. In conjunction with clinical visits, they can help patients get involved in their treatment decisions. They can also give patients time to digest information, outside of brief clinical encounters. Patients can bring home information about their treatment options to mull over the implications of their decision and to make sure they (and their loved ones) understand the information. But despite these advantages, there is the concern that decision aids may lead to bad choices. More specifically, a large body of psychology research has shown that people make systematic errors when asked to make certain kinds of decisions.[4,5] Researchers who have been developing decision aids have done very little to minimize the chance that such errors could occur.

In this article, I provide examples of how people make inconsistent medical decisions. I discuss several cognitive errors (ie, decisions that are inconsistent with people's own preferences) that could arise when patients are given decision aids. These errors are not unique to decision aids, but in fact could arise through any good informed consent process, when patients are involved in decisions about treatment or whether to enroll in research trials. I then discuss some of the clinical implications of these errors, and briefly reflect on how clinicians and clinical researchers can provide important information to their patients while minimizing the chance that the information will lead to bad decisions.

Two Caveats

Emotions

Many medical decisions are made in the midst of very strong emotions. When patients face serious illness, they often have strong feelings. These feelings can influence their clinical decisions, or their decisions to enroll in research trials. Emotions, of course, are important to consider when making medical decisions, but we all know of instances in our own lives when strong emotions led us to make bad decisions. In fact, early opposition to patient autonomy was led by many physicians who felt that patients were too emotional to make good decisions in many situations. Elsewhere, George Loewenstein and I have argued that a cold analytic approach to decision making sometimes leads to worse decisions than more intuitive approaches.[6] But the circumstances under which one approach is better than another are not well defined.

In this article, I do not intend to determine the good and bad effects of emotion on medical decision making. Instead, I will focus on barriers to optimal decision making that occur even when people are hyperrational—an area that has been underaddressed in discussions of medical decision making and informed consent.

Ethics

My article is motivated by a simple ethical goal—to find the best ways to involve patients in their health care decisions. But rather than discuss ethical issues, I focus on cognitive issues that I think should be of interest to ethicists, clinicians, and clinical researchers. Nevertheless, several ethical points are worth mentioning before I plunge ahead in the world of cognitive biases and decision aids. First, bioethics does not demand that patients make "good" or "rational" decisions. Instead, the ethical goal of informed consent is to give patients comprehensible information and let them make uncoerced choices. If patients make decisions that others consider to be irrational, that is their right.

I do not dispute this bioethical view. However, in many of the examples that I discuss, people make what can plausibly be described as irrational decisions. And in many of these examples, the people making these decisions may not be aware of their irrationality, and may in fact want to avoid making bad decisions. Moreover, as I point out, the manner in which decision aids present information to patients may unwittingly encourage irrational decisions. I expect that no one in the bioethics community thinks that that type of encouragement is a good thing!

Cognitive Errors Relevant to Health Care Decision Aids

Innumeracy. Most medical decisions involve uncertainty. Treatment choices do not inevitably lead to one outcome versus another. Instead, one choice leads to various probabilities of several possible outcomes, while another choice leads to other outcomes at other probabilities. This uncertainty is confusing, especially to many members of the general public who simply do not understand probabilities. The disturbing findings of a study that appeared in the *Annals of Internal Medicine* in 1997 demonstrated how common it is for the general public to misunderstand probabilities.[7] The authors asked three questions to assess people's numeracy. First, they asked people to estimate how many times a fair coin flipped one thousand times should come up heads. (They counted as correct any answer between 450 and 550, even though the true answer should be 500.) Second, they asked people to convert the number 1% to some number out of 1,000 (with the correct answer being 10). Third, they asked people to convert the ratio 1 in 1,000 to a percent (with the correct answer being 0.1%). They found that only one third of respondents were able to answer all three questions correctly. In short, people have difficulty understanding probabilities and percents. If clinicians or health services researchers informing patients about their health care choices communicate medical information to them in terms of probabilities and percents, many patients will get confused.

I will not delve further into research that has explored people's ability (or inability) to understand probabilities. Some researchers have devoted their lives to helping people comprehend risk information. And many health services researchers who develop decision aids are aware of this literature and try to incorporate its findings into their decision aids. For example, most decision aids that provide percentage figures to people also try to explain these numbers. In fact, some decision aids provide people with graphics and other pictures that make the numbers easier to comprehend.

Nevertheless, even if people understand probabilities, they are often uncomfortable thinking about probabilities. Many people do not like math. If medical decisions feel like math tests, people are likely to withdraw from the decision making and rely on family, friends, or physicians to make decisions for them. This is a major challenge to decision aid development and to informed consent more generally, but it is only one of many challenges. People can have difficulty making good decisions, even when the decision is laid out in ways that make it understandable by anyone, and even when the decision has nothing to do with probabilities or uncertainty.

One Too Many Choices?

Consider the following, simple, nonmedical decision that requires no knowledge of mathematics or probabilities. You are a student walking to the library to study. On the way, you pass a billboard announcing an interesting lecture. How likely are you to go to the library? Now imagine that instead of a single billboard, you pass two billboards, one announcing an interesting lecture and another announcing an enticing foreign movie. Now how likely are you to go to the library? When presented independently with these scenarios, people were more likely to go to the library in the second scenario, when choosing among three alternatives, than in the first scenario, when choosing from only two alternatives.[8] In other words, for some people, when choosing between the lecture and the library, the lecture looked more promising. But, when choosing between the lecture, the library, and the movie, they ended up going to the library. People had such a hard time choosing between the lecture and the movie that they went to the library in default.

This kind of decision violates accepted norms of rational choice. If I think that A is preferable to B, then when option C is added to my list of choices, I should still favor A over B. To choose B over A and C is simply inconsistent!

There is nothing complex about understanding a choice between going to a library, a movie, and a lecture. There are no probabilities involved in this decision, nor any complicated medical information. Instead, people are being asked to make a simple choice among three familiar alternatives. But difficulty in choosing between two potentially preferred options, in this case the lecture and the film, causes so much stress that some people shift to a third, less preferred option: the library. A similar phenomenon could easily occur in health care decision making. In fact, in a related study, Redelmeier and Shafir[8] asked physicians to imagine that they were referring a patient with severe arthritis to an orthopedic surgeon because of uncontrollable pain. They then asked physicians whether they would prescribe a new, nonsteroidal antiinflammatory drug (NSAID) for the patient in addition to the referral. When they were told that there was one new pain medication available for the patient, physicians were more likely to prescribe an NSAID than when told there were two new pain medications available. It appears that even "sophisticated" physicians are susceptible to this kind of error—they had difficulty choosing between the two new pain medications, so they opted to refer the patient to an orthopedic surgeon without any new pain medicine.

Similar issues could easily influence patients' decisions. Imagine a woman who finds out that she is at high risk for breast cancer because of a genetic mutation. She is deciding between a prophylactic mastectomy, raloxifene, or tamoxifen. The later two options are relatively similar new medicines that can reduce the chance of breast cancer. Perhaps, for this woman, the medications are preferable to the surgical alternative. Difficulty choosing between these two medicines might push her toward the otherwise less desirable surgical option.

Cognitive biases like this one raise crucial challenges for clinicians and health services researchers who want to inform patients about their options. Clinicians want to help patients make good decisions, but how do they do so in ways that will not lead to such cognitive biases? I will come back to that question later.

Too Many Side Effects?

In a recent pilot study, I asked members of the general public to imagine that they had colon cancer that was recently diagnosed, and that there were two surgical treatments available: surgery 1 cures 80% of patients without complications, but the remaining 20% die of colon cancer. Surgery 2 also cures patients without complications, but it reduces one's chance of dying of colon cancer to 16%; however, of the 4% of patients who do not die of the cancer, 1% need a permanent colostomy, 1% have chronic diarrhea, 1% have an intermittent bowel obstruction, and 1% have a wound infection that takes 1 year to heal.

The majority of people to whom I have presented this question choose surgery 1, even though it leads to a greater chance of dying. At the same time, when asked, most people indicate that the four side effects of surgery 2 (colostomy, chronic diarrhea, intermittent bowel obstruction, and wound infection) are preferable to dying of colon cancer. It appears that people are so overwhelmed by the sheer number and graphicness of the four complications of surgery 2 that they choose surgery 1. I would argue that for most people, for whom each of the four complications is preferable to death, surgery 1 is the wrong choice.

In the last 20 years, clinicians and clinical researchers have been encouraged to describe all the potential side effects of any significant procedure or treatment that they offer to their patients. In the United States, at least, this informed consent ritual has been formalized in a series of consent forms that list outcomes that occur with the smallest of probabilities. Anyone practicing clinical medicine or conducting clinical trials knows the risk of this approach to informed consent. People may overreact to bad outcomes that occur with low probabilities, as in the colon cancer example described previously.

To be clear, the inconsistent decisions that are made here are not inconsistent because people do not understand probabilities. In fact, mathematically inclined people that I have surveyed have chosen surgery 1 in the previous colon cancer example through no inability to understand what 1% means. The inconsistent decisions are not due to innumeracy; instead, they occur because people are intimidated by the sheer number of complications of surgery 2. A major challenge to health services researchers seeking ways to inform patients about treatment options is to learn how to do so without scaring patients away from the "best" option.

Hazards of Eyewitness Accounts

When faced with difficult medical decisions, most people would probably like to speak with, or hear from, patients who have faced similar decisions. Hearing what these patients think about radiation and chemotherapy might help new patients decide which treatment is best. In fact, health services researchers developing decision aids often include patient testimonials in the decision aid, so that new patients can learn about what previous patients have experienced when faced with a similar choice.

Many people like to receive information in ways that make it more human. Statistics and educational materials only go so far—what people really want to hear are anecdotes. But the vividness of patient testimonials may overwhelm rational choice. For example, in a classic experiment, students were given statistical information about the proportion of previous students who had enrolled in two college courses and would recommend them to their classmates.[9] These new students then received testimonials from a small number of previous students who relayed their personal experiences. These testimonials overwhelmed statistical information and had a huge effect on students' enrollment decisions. In other words, prospective students might have heard that 90% of previous students disliked one class and only 10% liked it. But if they heard one testimonial from a student who liked the class and one from a student who did not, upon which bit of information will they make their decision? Will they remember that 90% of students surveyed disliked the class, or that 50% of the students who gave testimonials disliked it?

I conducted a study on this topic and found that when faced with a hypothetical treatment for angina, people were significantly influenced by the number of patient testimonials they heard in favor of one or another treatment.[10] In other words, holding statistical information (about the likelihood of successful angina treatment with either balloon angioplasty or bypass surgery) constant, the number of testimonials in favor of either option strongly influenced choice.

Testimonials can probably influence choice in many ways. If I receive a testimonial from someone who reminds me of myself, perhaps that will influence me. This might be rational, if the similarity between the other person and me is relevant. But I might overweigh the testimonials from people who I think resemble myself, perhaps dismissing testimonials from people of different race or gender, even if I should not do so. Perhaps one person giving a testimonial is more dynamic than another. Should that influence choice?

Those people trying to help patients make good decisions need to find ways to include patient testimonials in decision aids without biasing choice. The same challenge faces all clinicians. Clinicians often introduce patients to support groups, hoping to help them cope with their illness and think through their medical decisions. Many clinicians freely encourage patients to surf the Internet, to help them learn more about their treatment options. But all these sources of information create the chance that patients will be unduly influenced by the number or persuasiveness of testimonials from previous patients in ways that will overwhelm other important information that they should consider.

How Do We Improve Health Care Decision Making?

So far, I have described several types of biases that can occur when people try to make difficult medical decisions. But I have not given any advice about how such biases can be avoided. In part, I have hesitated to give advice because no easy solutions have been found for the problems that I have raised. I am currently undertaking a series of research studies to illuminate these very issues. I hope several years from now to have better answers than I do currently.

But I can give you an example of the types of things I plan to study, to hint at how clinicians and patients may want to go about improving medical decisions. Let us go back to the example of whether a student should go to the library, a lecture, or a movie. The bias that resulted from that decision occurred because students had a hard time choosing between the lecture and the movie. When faced with all three offers at once, they avoided these two similar options and chose the very different option. Suppose instead of choosing among all three options, students were first asked to make a series of paired choices among these three options. A student could be asked to choose between the library and the lecture, the library and the movie, and the lecture and the movie. Given these three paired choices, a student who thinks the library is the least attractive option should choose the lecture and the film over the library in those two paired choices. If this student finds that it is difficult to choose between the lecture and the movie, he or she will no longer opt for the library, because the prior paired choices showed him or her that the library was an inferior option. Perhaps these three-paired choices will force the student to make the difficult choice between the lecture and the movie.

Another approach is to lump choices in ways that reduce decision complexity and minimize the chance that tension between two options will drive people to a less preferred third option. For example, consider again the example of a woman deciding how to deal with a breast cancer genetic mutation. She is asked to decide between taking raloxifene, tamoxifen, or prophylactic mastectomy, and is so torn between the two medical therapies that she chooses the surgical therapy. Suppose when informing a woman of her options, we lumped raloxifene and tamoxifen therapy together into one category: "medical therapy." Then, we discuss each of the medicines and talk about their similarities and dissimilarities, but keep them in one category. We then ask her to decide between medical therapy and "surgical therapy" (prophylactic mastectomy). Once she decides which of these basic approaches she prefers, she can look within the approach and make the next level of her decision. In this case, if she chooses medical therapy, she can now decide between raloxifene and tamoxifen. If she chooses prophylactic mastectomy, she may still have some other decisions to make, such as whether to have reconstructive surgery. If she decides to have reconstructive surgery, she might have to decide between different kinds of implants, and the decision-making process continues.

In fact, this suggests a general approach to making clinical decisions easier to make: do not lay out all the options at once and leave an undifferentiated set of alternatives to choose among; instead, help the patient by grouping some of these options. Discuss all treatment options up front, then group them in ways that make choices easier.

Conclusion

It is not always easy to define "good" and "bad" medical decisions. In rare circumstances, such decisions can be identified, or it can at least be determined whether people are making decisions consistent with their own expressed preferences. And in many circumstances, people make choices that are not consistent with their own preferences.

In such cases, I do not endorse withholding information from patients to "improve" their medical decisions. Instead, we need to study how to structure the information that we give patients so that it reduces the chance that their decisions are susceptible to cognitive biases. The same information presented in different ways might lead to better choices.

Thanks in part to bioethicists, most people now agree that patients deserve information about their treatment decisions. The next challenge now awaits us: we have to find the best ways to present this information to patients so that they make the best possible health care decisions.

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