

Patient Regret in Medical Decision-Making

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According to an article written by two doctors, regret in medicine typically refers to the feeling a patient has following a poor outcome. In these situations, patients think that the outcome would have been better if they had made a better choice.¹ The doctors rightly state that there is an element of uncertainty and risk of regret in choosing or declining any medical treatment, and disappointment is an often unavoidable consequence of making difficult decisions. Disappointment, however, is different than self-recrimination and regret. One reason that this happens often is that medical training does not address how to deal with these issues or how to prevent them.

Drs. Groopman and Hartzband write that when they began researching this issue, they were surprised to find that poor outcomes do not always result in patient regret. They write that the key to reducing regret is informed choice. There is a term that is used for patients who do not consider information about ***all of their available choices*** before making a decision – it's called "process regret." It's common. It has been our experience at Wellness Forum that very few people are ever given a comprehensive list of options, along with risks and benefits, before making healthcare choices. Most of our members do suffer from process regret when they first join. The reason is that benefits have been exaggerated, risks have been minimized or not discussed at all, and options such as active surveillance or alternative treatments have not been presented or considered.

Another surprising discovery was that good outcomes do not always prevent regret. This can happen, for example when a patient is talked into having surgery instead of choosing active surveillance when an abnormality that might be cancer is discovered. Instead of being relieved that no cancer was discovered, some patients regret undergoing unnecessary surgery. Pressure and significant influence of others can lead to passivity in choosing treatment, and "role regret" is the result.

Our experience in this area is that considerable pressure is applied by doctors to get patients to have tests, take medications and to have procedures. I'm sure that this is partly based on the doctors' confidence in their recommendations. But this confidence is often misguided, is not always fact-based and does not take into consideration the patient's goals, objectives, and values. Even when acknowledging that the decision is up to the patient, many doctors make comments that undermine the patient's thoughts of being in control. These include statements such as "It's up to you, but I think the only option is _____." Or "Sooner or later you will have to do what I'm telling you so there's no sense in putting this off."

The authors cite a large body of evidence showing the various causes of regret in medicine. Omission bias is the tendency toward inaction and inertia, and leads to the

avoidance of medical tests and procedures. Commission bias is the tendency to believe that any action is better than inaction, and can lead to experience regret if the outcome is not favorable. When people are in pain or acutely anxious, they are likely to make choices that they think will resolve their health issues quickly, and are likely to both discount the risks and overestimate the chances for success in choosing a treatment. Patients who choose elective procedures in what is referred to as a "hot state" are particularly at risk for regret.

The authors advise that the way to reduce the incidence of regret is for doctors to first "reduce the emotional temperature" and advise patients not to make decisions in a highly emotional state. Doctors should also help patients to clearly understand the risks and benefits of their various options before moving forward. Physicians should also be alert to the potential for role regret when patients are unduly influenced by others. They state that there is usually no reason to rush decision-making in most cases, and a much more deliberate process is almost always better.

What Drs. Groopman and Harzband are writing about is the importance of InforMED™ Medical Decision-Making, which is one of the most important ways in which we help our members. Many states have laws that cover medical informed consent, which is defined as an individual's right to be informed of and consent to a procedure or treatment suggested by a physician or professional.

These laws state that prior to making a decision, **ethics dictate that the physician providing or performing the treatment and/or procedure should discuss with the patient the patient's diagnosis; the purpose of the treatment or procedure; the risks involved; alternative treatments; and the risks and benefits of refusing treatment.** The patient can then make an informed decision to accept or refuse the treatment or procedure. In the event that the patient is incapacitated to the point of not being able to make an informed decision, a family member, as authorized by law, can replace the patient.²

The American Medical Association has published rules governing informed consent as well. This information is currently posted on the organization's website:

Informed consent to medical treatment is fundamental in both ethics and law. Patients have the right to receive information and ask questions about recommended treatments so that they can make well-considered decisions about care. Successful communication in the patient-physician relationship fosters trust and supports shared decision making.

Doctors are supposed to:

(a) Assess the patient's ability to understand relevant medical information and the implications of treatment alternatives and to make an independent, voluntary decision.

(b) Present relevant information accurately and sensitively, in keeping with the patient's preferences for receiving medical information.

The physician should include information about:

(i) the diagnosis (when known);

(ii) the nature and purpose of recommended interventions;

(iii) **the burdens, risks, and expected benefits of all options, including forgoing treatment.**

(c) Document the informed consent conversation and the patient's (or surrogate's) decision in the medical record in some manner. When the patient/surrogate has provided specific written consent, the consent form should be included in the record.³

If some states laws mandate that patients be informed, and the AMA has published rules mandating that doctors properly inform their patients, why are so many patients uninformed or misinformed? It's because there are almost never any consequences for doctors who don't inform patients, or for institutions who do not make informed decision-making an expected part of practice.

There are only two things that can lead to better outcomes, in my opinion. One is that patients need to become informed on their own and take more control over their interactions with doctors and the healthcare system. The other is stronger laws with more serious penalties for violating them. One of the ways in which such laws might get passed in the future is through lawsuits against doctors and institutions who withhold important information from patients resulting in poor outcomes.

One thing I can state for sure – the medical profession has demonstrated that it does not change unless there is overwhelming pressure to do so. Educated patients can apply such pressure and financial loss due to lawsuits can be a powerful motivator too. We intend to do our part by continuing to educate patients.

¹ Groopman J, Hartzband P. "The Power of Regret." *NEJM* 2017 Oct;377:1507-1509

² <https://www.hg.org/informed-consent-law.html>

³ <https://www.ama-assn.org/sites/default/files/media-browser/code-of-medical-ethics-chapter-2.pdf>