

## *Informed Consent: Good Medicine, Dangerous Side Effects*

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Informed consent has passed through three stages. The first *paternalistic* stage lasted for many centuries: The doctor's diagnosis and healing arts were kept secret, and informing patients was regarded as professionally and ethically wrong. Second came the *legal* stage, when the right of patients to make informed decisions concerning their own treatment was imposed by the courts and reluctantly tolerated by medical professionals. The third informed consent stage emerged more recently: the *general therapy* stage. The therapeutic benefits of informed consent have been well established, and informed consent is widely recognized as an important element in sound medical practice. When patients are effectively informed and can exert knowledgeable control over their own treatment decisions and therapy processes, that enhances recovery,<sup>1</sup> strengthens the immune system,<sup>2</sup> promotes better pain tolerance,<sup>3</sup> prevents depression,<sup>4</sup> and encourages patient cooperation and fortitude in treatment, rehabilitation, and preventative procedures.<sup>5</sup> As the medical community has absorbed greater knowledge of this research, informed consent has been recognized as both ethically essential and *therapeutically* sound: the hallmark of the current *general therapy* stage of informed consent.

The widespread ethical and therapeutic acceptance of informed consent is a positive development, but there are dangers. Like many positive therapeutic processes, informed consent can cause harm if administered carelessly. Informed consent is a valuable element of medical therapy, and good medical therapy is not a one-size-fits-all procedure. The question of what a "reasonable person" would want to know is no more helpful than asking whether a generic "reasonable person" would benefit from penicillin. To gain the full benefits of informed consent and avoid potential harms, conscientious medical professionals must move beyond the *general therapy* stage of informed consent to an *individual therapy* level of informed consent, in which—like other elements of good medical therapy—informed consent is tailored to the individual patient. Conscientious medical professionals are already accustomed to offering information in a vocabulary and at a level of discourse appropriate to the patient's background and understanding. The fourth stage of *individual* therapy informed consent makes additional requirements on the informed consent process. Those requirements entail examining some important psychological characteristics of individual patients, along three distinct but related dimensions.

First, physicians must determine what *coping style*<sup>6</sup> the patient employs: a *monitoring* style, in which the patient copes by gaining as much information as

possible and trying to anticipate and understand everything that will happen, with no surprises, or a *blunting* style of coping, in which the patient copes by trying to avoid thinking about a painful or distressing situation. The monitoring patient facing chemotherapy wants to know as much as possible about the treatment, all side effects, what the treatment process involves, what is involved in each step, what to anticipate; the blunting patient prefers not to think about it, giving the entire process as little attention as possible. An early study along these lines<sup>7</sup> found that active (monitoring) patients recovered from surgery more swiftly if they received detailed information, whereas such information slowed recovery for patients who coped by means of blunting. Other studies<sup>8</sup> have found similar results.

Dealing effectively with patient coping styles is an important but challenging process. It is complicated by the fact that the blunting style involves problems of its own. Monitors are more likely to take positive steps toward health promotion and disease detection,<sup>9</sup> and a blunting style may have direct negative effects on physical health.<sup>10</sup> Crisson and Keefe<sup>11</sup> found that chronic pain patients who employed a “diverting attention” or blunting style of coping suffered greater anxiety, more obsessive-compulsive symptoms, and increased depression, they were more likely to catastrophize their situation, and they avoided taking active steps to cope with their pain, and they themselves reported that “their coping strategies were not very effective in controlling and decreasing pain.” Patients adopting an avoidance (blunting) coping style experience greater psychological distress<sup>12</sup> and poorer psychological adjustment to illness.<sup>13</sup> Positive results for those using the monitoring coping style are widely confirmed.<sup>14</sup> Patients who are blunters may need help in finding more effective means of coping, and they may well desire and request such help if they realize that other coping styles are possible. In that case, active intervention—by a psychotherapist—is no more a violation of autonomy than is active intervention to assist a smoker who expresses a desire to stop. Thus the physician legitimately could describe the problems associated with blunting, just as the physician might point out the problems associated with smoking. What the patient chooses to do with that information is, of course, up to the patient. When patients choose not to modify their less than optimum coping style (and such modifications are not an easy process), the physician must consider that important factor in providing individualized information to the patient. Furthermore, it is very important that physicians know which of their patients are blunters, so that they can be alert for signs of depression (just as knowledge of a patient’s smoking habit should alert the physician to check for various diseases associated with smoking).

Individualized informed consent requires screening patients to determine whether they employ a blunting style of coping: a coping style that makes some kinds of information potentially harmful to the patient. The best informed consent process with a blunting patient will be very different from the process that would occur with a patient who is an active monitor.<sup>15</sup> In particular, patients who are blunters should have *control* over what information is, and is *not*, provided; and physicians should guard against reciting a standard detailed description of the proposed therapy and the experiences associated with it, instead prefacing each part of the description with a question concerning whether the patient wants this particular item of information or perhaps

giving the information in written form with clear headings so the patient can easily skip sections she does not wish to read. Honoring a patient's *own choice* to control the flow and detail of information provided is an enhancement, rather than a violation, of patient autonomy.

Careless use of informed consent, without adequate attention to the individual needs of the particular patient, may undermine a patient's preferred coping style. That is the first problem with general therapy "one-size-fits-all" informed consent, and the first reason to move toward a model of individual therapy informed consent. The second danger concerns the *locus of control*<sup>16</sup> orientation of patients. Is this patient strongly *internal*, believing that what happens to her is largely under her own control, or strongly *external*, believing that most of what happens is outside her control and influence? For those having an external locus of control, a further distinction is important: between patients who believe that important events are under the control of *fate* or chance and that there is little anyone can do to control them, and patients who believe that important events are largely controlled by *powerful others* (who may exercise benevolent control for the benefit of the patient). Research indicates that an internal locus of control is associated with both better psychological adjustment as well as better general health and health behavior; but unless the patient is experiencing severe problems from this external locus of control and desires to change—and that would call for specialized psychotherapy—then it is hardly the physician's right to modify such a deep orientation, which may well be associated with personal convictions about fatalism or free will or God. Unsolicited intervention to reshape a patient's locus of control would be much more intrusive than unsolicited intervention to prevent a patient from smoking.

It is very important that the physician recognize the locus of control of her patient when tailoring the informed consent process to fit the therapeutic needs of the individual patient. If a strongly external patient feels that medical professionals are placing the decisionmaking weight on his shoulders, though he can't effectively exert control, that will be very frightening. Furthermore, it is important to go further with patients who are external, and determine whether they believe control of events is set by fate or chance or instead by powerful others. In the right circumstances—when patients are confident of the expertise and good will of their physicians—externals who believe in control by powerful others fare almost as well as internals. It is obviously of great importance that such a patient regard his physician as strong, highly competent, and committed to the patient's welfare. This does not mean that the physician must pretend to knowledge of nonexistent medical certainties, much less that the physician should make false promises or cover up risks; but with externals who believe that control is in the hands of powerful others, the physician is justified in offering a stronger and more confident recommendation that "in my considered opinion, and with my many years of experience with cases like yours," this specific course of treatment is best.

When dealing with external patients who believe that control rests with powerful others, Howard Brody's *transparency* standard<sup>17</sup> for informed consent may prove useful. Brody proposes that physicians should make transparent to their patients the reasoning process followed in making a treatment recommendation: the alternatives the physician considered and the relevant advantages and disadvantages that led to the physician's conclusion. Ideally, the physician's

disclosure would lead to questions by the patient, which the physician would answer fully. For strongly internal patients, Brody's model may be too passive: The doctor is making the decision and deliberating about it, and my basic role as patient is merely to acquiesce. But with externals who believe that control primarily is exerted by powerful others, Brody's transparency standard might be a perfect fit. The physician is saying to the external patient: This is how I reasoned, this is why I believe that this is the best course for you, and I will use all my skill and resources to reach the best possible result. The external patient observes that the physician is offering careful and wise advice, and the physician is obviously taking time and effort to think through the process to the best treatment procedure possible; and so here is a wise powerful other who has my interests in mind and at heart. This does *not* imply—as Brody himself emphasizes—that the patient's right to make an informed final choice may be compromised in any way. But if we are to respect the patient's individuality and personal orientation, then it is essential that we frame the informed consent process in the way that works best for that patient and allows the patient to comfortably and confidently exercise her autonomous right to make her own decisions. Under the *general* therapy model of informed consent, we might suppose that if the transparency model is acceptable as a standard of informed consent then it must be optimum for all patients. On the model of *individual* therapy informed consent we can recognize that the transparency model is a good fit for some patients, but not for all.

The first danger from the general therapy informed consent model is the danger of undercutting the patient's preferred coping method; second is the danger of imposing a frightening decisionmaking burden on an external patient who believes that he cannot control such vital decisions. The third danger concerns strongly *internal* patients, who believe that what happens is really up to them and under their control. Patients with an internal locus of control generally do better—in recovery, positive health behavior, avoidance of depression—than do externals. There are, however, some important exceptions. The problems emerge for internal patients who have a weak sense of perceived *self-efficacy*. Self-efficacy<sup>18</sup> concerns the patient's level of confidence that she can effectively handle the tasks that confront her or understand the material she is supposed to understand or be successful in her efforts to follow a treatment program: in short, that she has (or lacks) competence. Perceived self-efficacy may be domain specific; that is, I might be highly self-efficacious in most areas of my life yet have low perceived self-efficacy in managing my own medical care and making wise medical decisions. Furthermore, my perceived self-efficacy is *not* the same as my actual ability. I may have a high sense of mathematical self-efficacy despite being lousy at mathematics or be quite competent at mathematics while still being convinced that "I just can't do math."

Making competent choices for myself is satisfying and healthy, but making important choices while feeling painfully inadequate is stressful and even terrifying. Thus the third danger of general therapy informed consent is the danger to an internal patient who—because of her weak sense of self-efficacy—is wrongly characterized as an external, and thus "chooses" not to exercise the full range of control that (with adequate support and information and confidence) the patient prefers to exercise and would benefit from exercising.<sup>19</sup>

The fourth danger is closely connected with the third. It is unfortunate to be deprived of desired effective control because of one's sense of incompetence and low self-efficacy; it is still worse to feel that one *is* in control and that what happens is unavoidably in one's own hands, but one is incompetent to exercise that control intelligently and effectively.<sup>20</sup> Consider a patient who is strongly internal (who believes that what happens depends largely on her own choices and behavior) and who normally thrives in exercising control and making decisions. But this patient is overwhelmed by an alien hospital environment and befuddled by information she finds impossible to comprehend: Perhaps the vocabulary is unfamiliar or the patient understands the words but lacks a framework that would invest them with significance or too many options overwhelm the patient's capacity for intelligent comparison. The patient—feeling a very inadequate sense of health self-efficacy—prefers to have the physician make the decisions in this frightening context (though the optimum situation for this patient is adequate understanding that may strengthen the patient's sense of health self-efficacy and enable the patient to exercise effective control). If the physician simply makes the decision for the patient, we have the third problem: an internal patient who wants to exercise control and would benefit from doing so, but who lacks the confidence to do so effectively. But suppose the physician refuses to make a treatment recommendation for the patient, instead thrusting the responsibility back on the patient's uneasy and self-efficacy challenged shoulders: "No, this is an important decision that you must make for yourself." The physician is striving to honor the patient's autonomous right to make her own decisions, but the result for the patient is the worst of all possible worlds: This very important decision is entirely under my control, but I cannot exercise that control effectively and intelligently. Increased patient participation is generally positive; but only if the patient has enough information, in a form that the patient can actually use and control, *and* the patient has a sufficiently robust sense of self-efficacy to welcome the opportunity for active participation.

It is essential to provide patients with sufficient information, in a form they can understand, but it is also important to keep in mind that even when patients have such information they may not feel confident to make decisions. Strengthening or restoring a patient's sense of health self-efficacy is not always an easy task: Anyone who has tried to tutor a bright and capable student who lacks an adequate sense of mathematical self-efficacy will appreciate the challenges. If the patient's perceived self-efficacy can be strengthened, then the patient's autonomy as well as the patient's therapeutic success is significantly enhanced. As patients gain more information and experience success in making decisions and managing their own care, they may gradually gain a stronger sense of health self-efficacy.<sup>21</sup> But although development of stronger perceived self-efficacy is a worthy goal, it is important to recognize that not all patients have reached that goal. If I start from a low level of health self-efficacy, I may *stay* at that level even after I have gained considerable knowledge of how to effectively manage my own healthcare. Thus a patient low in self-efficacy may still find it terrifying to make medical decisions on her own, even when she is well informed and in fact quite capable of making good decisions. If we are to respect the autonomy of the individual patient, with her own distinctive capacities, concerns, and fears, then we must be prepared to help patients who

are low in health self-efficacy enhance their sense of confident self-efficacy; but we must not treat all patients as if they are equal in health self-efficacy. That does not imply that we should give such patients less information, hide things from them, or deprive them of their opportunity to make informed choices. But it does imply that with such patients we should not simply set out a daunting range of options and wait for them to make their own choices. Patients with weak self-efficacy require more support throughout the decisionmaking process, and physicians might well adopt something closer to the transparency process—including the physician's own recommendation—in helping such patients reach a decision with which they are comfortable and confident.

Informed consent is a basic requirement for dealing ethically with patients: a requirement mandated by the obligation to honor the autonomous choice-making capacities of patients. But informed consent is also a positive element of good therapy; as such, it should be handled with caution and tailored to the individual patient. Individual therapy informed consent requires medical professionals to recognize the salient psychological characteristics that are key determinants of appropriate informed consent practices (coping style, locus of control, and level of self-efficacy) and shape decisions concerning informed consent procedures to the relevant characteristics of individual patients. None of that justifies forgoing or compromising the patient's basic right of informed consent. But honoring that right—and achieving the best ethical *and* therapeutic results—requires honoring the *individuality* of the patient.

Determining the relevant psychological characteristics of patients is a significant task, but by no means an impossible one. There are relatively short tests available that can be given to patients, perhaps as part of their admission profile. For coping style, brief available tests include the Threatening Medical Situations Inventory (TMSI)<sup>22</sup> and the Monitor-Blunter Style Scale (MBSS).<sup>23</sup> “The feasibility of administering a brief test of coping style before instruction and employing the results to tailor instruction to the patient's coping style”<sup>24</sup> has been successfully tested. For locus of control, the Multidimensional Health Locus of Control Scale<sup>25</sup> is the most widely used for determining locus of control in relation to health issues. For self-efficacy, the generalized self-efficacy (GSE) scale<sup>26</sup> is standard, whereas specialists working with narrower specialties might prefer one of the many specific self-efficacy measures. No combined test is currently available, but psychologists could devise a simple and reasonably brief questionnaire (by combining existing tests) that would provide an adequate profile of these important patient characteristics. If physicians occasionally require the aid of psychologists in interpreting such test results, that would lead to improved therapy as well as to opportunities for physicians to become more knowledgeable concerning key psychological traits of their patients. Online scoring and interpretation could make the process swift and manageable.

Patients with an internal locus of control, a monitoring style of coping, and a strong sense of self-efficacy are the patients most likely to benefit from a rich, full, informative discussion of prognosis, treatment options, and likely outcomes. Such patients are also most likely to make good use of the opportunity to exercise choice and control in selecting a program of treatment and following that treatment program as full partners with their health professionals. At the other end of the spectrum is the patient who favors a blunting style of coping, has an external (even fatalistic) locus of control, and suffers from a weak sense

of self-efficacy—perhaps an especially weak sense of health self-efficacy. We might well conclude that the latter patient enjoys considerably less autonomy than does the former. It would still be wrong, both ethically and therapeutically, to treat the latter patient paternalistically. First, paternalistic treatment violates the patient's autonomy. A patient with a weak sense of self-efficacy and an external locus of control has only minimal autonomy, true enough; but respect for autonomy is not limited to those with the richest autonomy resources. Second, such paternalistic treatment will solidify the problematic perspectives. Medical professionals do not have the right to change the personalities of people against their wishes, even for their own good; but neither should they adopt policies that exacerbate problematic psychological characteristics. A weak sense of control, combined with weak self-efficacy, causes problems: It is associated with depression, compromised immune function, slower recovery, and poor health behavior. Treating such patients paternalistically—not respecting them as persons who have their own values and are still autonomous (even if not as robustly autonomous as some others)—is likely to entrench those unfortunate characteristics and make a bad situation worse. When physicians recognize the relevant psychological characteristics of their patients, that makes it possible for patients to gain the knowledge that is most appropriate for their needs and interests and enables patients to make judgments—or at the very least, freely acquiesce in the considered judgment of a respected and trusted physician—and thereby exercise genuine informed consent; and respect for limited autonomy may be one way of enlarging and strengthening autonomy. Thus even patients with very weak psychological resources can and should practice giving informed consent. Third, involving the patient of limited autonomy resources in a rudimentary and nonthreatening exercise of autonomy may be a means of preventing that patient from sliding into deeper learned helplessness,<sup>27</sup> with all of its severe psychological and physical consequences. Obviously that will not be enough to transform weak autonomy into a richer and stronger and more resourceful autonomy; but at least it's a step in the right direction, rather than a push in the wrong.

Informed consent is fundamentally the recognition of the autonomous patient's right to make her own decisions concerning medical treatment. But informed consent is also a positive therapeutic resource when used correctly and a significant source of potential harm when handled carelessly. Having recognized both the ethical and therapeutic importance of informed consent, the medical community must now invest the care and thought required to gain the benefits and avoid the perils of informed consent. Those in health psychology have an opportunity to make relevant psychological research readily accessible to practicing physicians and to devise tests that can be easily administered and adequately understood by physicians who are learning to deal with the vitally important psychological dimensions of treatment that is therapeutically sound and ethically legitimate.

## Notes

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