

PATIENT AUTONOMY NATURALIZED

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ABSTRACT Traditional informed consent often promotes passive acquiescence rather than active exercise of autonomy. A more natural biologically based model of autonomy is needed, a model that both recognizes the biological roots and therapeutic benefits of active confident choices among real alternatives, and offers substantive guidelines for promoting patient autonomy. A biological model of patient autonomy explains the value of information to patients, outlines the circumstances under which patients make effective choices, and suggests complementary roles for patients and professional caregivers.

MEDICAL CAREGIVERS OFTEN REGARD patient autonomy as a nuisance that must be tolerated for ethical and legal reasons, and recently some have argued for reduced emphasis on autonomy (Callahan 1996; Schneider 1995). Medical ambivalence toward autonomy is hardly surprising. Traditional accounts represent autonomy as a power of mysterious or even miraculous uncaused choice that transcends environmental influences, and such accounts are a difficult fit with empirical medical science. But genuine autonomy, stripped of the philosophical accretions, is not only compatible with medical science but a valuable contributor to sound therapy.

Therapeutically valuable patient autonomy does not require the mysteries of miraculous uncaused choices. Instead, the appropriate medical model of patient autonomy is biologically based. Keeping options open and alternative paths

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available is of basic value to many animals (Bronikowski and Altmann 1996; Caro and Bateson 1986; Kavanau 1967), including humans. Following a single foraging path decreases opportunities for discovering new food sources and increases vulnerability to predators. We live in a changing world in which food sources appear and disappear, favored hypotheses sometimes lead to success but other times to failure, some treatment plans work and others are abandoned, and formerly safe swift paths are blocked by predators or highway construction. In our world it is valuable to have options available, and animals that favor open alternatives are more likely to survive and pass that preference to their offspring. There is nothing esoteric about our need for autonomy: it is a creation of biological evolution, not philosophy.

Genuine autonomy requires options available within our actual environment, options chosen on the basis of our conditioned preferences and changing circumstances; not mysterious alternatives that transcend all causal and environmental influences. This natural biological view of autonomy, with its mundane alternatives, has special value in the medical environment. As noted by Perlmutter, Monty, and Chan (1986): "The exercise of choice is of special significance in environments that are normally inhospitable to the perception of control (i.e., hospitals, nursing homes, etc.) because it can decrease morbidity and possibly even sustain life itself" (p. 113).

The weakened patient is particularly vulnerable to becoming dependent and passive (Lidz, Appelbaum, and Meisel 1988). When others make decisions for us (what to eat, what to wear, when to take our medications), the lesson learned is that we are incompetent to make decisions for ourselves. And the standard process of gaining "informed consent" may exacerbate the problem. Medical professionals sometimes present "medical information" in confusing and intimidating "one-way language that conveys inadequacy along with (and often instead of) information to the patient" (Press 1984, p. 58), followed by "doctor's orders" given with all the trappings of powerful authority. As Stanley Milgram (1974) has demonstrated, orders from authority figures can be a powerful controlling force even for healthy persons. In obtaining "informed consent" the physician may offer "the only reasonable" path, and the "informed" patient passively acquiesces (Jones 1990, p. 399). "Do you have any questions?" may seem to the patient a combination of "Do you accept your fate?" and "Do you acknowledge my authority?"

Thus instead of promoting genuine patient autonomy, the current process of gaining informed consent may subtly shape patient passivity, a passivity that threatens both physical and psychological well-being. Depriving animals—including human animals—of choices has debilitating effects that are well known to biological and psychological researchers (Seligman 1975). In cancer patients, a sense of helplessness and lack of control is a strong predictor of recurrence of cancer as well as cancer death (Anderson, Kiecolt-Glaser, and Glaser 1994; Greer, Morris, and Pettingale 1979); and higher levels of helplessness are also associated with greater metastatic spread of cancer (Jensen 1987). A con-

trolled study of the institutionalized elderly found that residents who had greater opportunity to make simple choices and exercise control enjoyed substantially better health and a significantly lower mortality rate (Langer and Rodin 1976; similar results were obtained by Mercer and Kane 1979).

There are four specific ways that passivity and helplessness negatively impact patients: passivity promotes psychological depression, slows recovery (including inhibition of patients' rehabilitation efforts), exacerbates pain, and weakens the immune system. Consider first the psychological factors: a serious problem in its own right, depression is a frequent and debilitating accompaniment of physical illness. It is well established that patients (and nonpatients) who have a greater sense of being in control and making their own choices are less likely to suffer depression (Cromwell et al. 1977; Devins et al. 1982; Kugler et al. 1994). In a study of patients with early breast cancer, Morris and Royale (1988) found that patients who were given a choice of treatment options and had a sense of being in control of their treatment suffered less anxiety and depression in the months following their surgery. Even in the worst of circumstances—such as cancer patients who cannot effectively control the course of their disease—those having a strong sense of personal control suffer less depression and make more effective adjustments. In a revealing study, a group of researchers headed by Suzanne C. Thompson (1993) examined 71 cancer patients. After controlling for differences in physical status and social circumstances, the results indicated that patients who felt that they could make effective choices and exercise some control suffered less depression and adjusted better; these results applied not only to patients whose cancer treatment was more effective, but also to those for whom treatment was less successful. When the progression of the cancer was causing severe physical limitations, those patients who had a stronger sense of perceived control still coped better psychologically.

A second result of passivity is slower recovery (Brody et al. 1989). In a study of patients hospitalized after suffering acute myocardial infarction, the control group received routine information and standard care (that is, the control patients were essentially passive recipients of information and care). The experimental group received more detailed explanations concerning the causes of myocardial infarction and its treatment and were able to participate in monitoring and treating their condition: patients had cardiac monitors and could take EKG tracings whenever they wished to check on their symptoms and were taught mild exercises they could perform as they chose. The patients with greater control were able to leave the hospital earlier than their more passive comparison group (Cromwell et al. 1977). A study of patients undergoing heart bypass surgery found that “greater perceived control and an orientation toward behavioral involvement in health care were both reliably and independently associated with quicker hospital release following surgery” (Mahler and Kulik 1990, p. 748). Closely related to swifter recovery is another benefit: autonomous patients exhibit greater perseverance in effective rehabilitation (Eisenthal et al. 1979;

Kanfer and Grimm 1978; Rokke, Tomhave, and Jovic 1999), are less likely to be in “noncompliance” with their therapy programs (Rodin 1982; Taylor 1982; Wallston 1993), and more often engage in healthy living practices (Scheier and Carver 1992).

The third reason for encouraging active involvement and autonomous control is the important area of pain control, where the value of autonomous patient control over choices is perhaps most obvious. The widespread use of patient-controlled analgesia may have originated in the need to reduce demands on nursing personnel, but the benefits for frustrated patients have been profound. An alien hospital environment combined with the stress of illness can threaten the autonomy of the most resilient patients, and that threat is intensified when patients wait helplessly and passively for pain relief that is manifestly outside their control. Self-administering of pain medication offers patients an opportunity for control that is not only more efficient but also more effective. Rather than patients making excessive use of analgesics, studies indicate that patients who self-administer their analgesia require significantly less medication to achieve relief than do patients whose narcotics are dispensed by the nursing staff (Hill et al. 1990).

It is not surprising that self-administering pain-relief medication works well. Numerous studies have shown that when subjects believe they can control noxious or aversive stimuli they suffer less anticipatory distress, endure pain more easily, experience less stress, and recover from the experience more quickly (Bowers 1968; Langer, Janis, and Wolfer 1975; Staub, Tursky, and Schwartz 1971); a sense of helplessness makes the pain experience more severe (Reesor and Craig 1987). The importance of pain management for patient well-being may be obvious, but its importance goes well beyond the obvious: anxious patients who experience greater sensitivity to pain face increased surgical risks because they require higher levels of anesthesia (Williams et al. 1975).

The fourth and final therapeutic reason for avoiding patient passivity is that passivity weakens the immune system and leaves the patient more vulnerable to opportunistic infection (Bandura et al. 1988; Rodin 1986; Schorr and Rodin 1982), while perception of control has positive immunological effects (Wiedenfeld et al. 1990).

Passivity contributes to depression, slows recovery, exacerbates pain, and weakens resistance; thus for solid therapeutic reasons, patients need real options and sufficient information to make their own informed choices. How much information does that require? Enough for the patient to weigh options and make confident choices. Ideally, that will include information concerning several viable options. (Even in the grimmest scenario, there may be choices concerning do not resuscitate orders, hospice or hospital care, stopping or continuing tube feeding.) But the community of medical caregivers must appreciate the full significance of the information given. Details concerning a proposed treatment plan are not enough. As Lidz, Appelbaum, and Meisel (1998) note: “Sometimes physicians will ask if patients have any questions, or patients may ask on their

own initiative, but these are typically brief and focus on details of compliance rather than choice of treatment” (p. 1387). Respect for genuine biological autonomy requires much richer information: information that enables patients to maintain options and explore alternatives.

Knowledge is our most efficient means of examining options and trying new paths. Information on alternatives empowers the patient to make autonomous choices among alternatives and vastly expands the alternatives that can be tried through informed imagination. We may consider several alternatives, rejecting the path lined with quicksand without placing ourselves at risk. In like manner, with adequate information we can consider and reject the therapy options with debilitating side effects or ineffectual results, and without directly experiencing the ill effects. But though we reject these options, having them available to consider remains valuable. We have a deep healthy inclination to consider alternatives and explore options; and alternatives are salubrious and desirable whether we are hospital patients, practicing physicians, or foraging animals.

Medical practitioners typically tailor information toward the treatment the professional regards as optimum. Following extensive observations of the informed consent process at a large New England hospital, Cathy J. Jones (1990) concluded: “From my observations, many physicians disclose to patients the benefits and to a lesser extent the risk elements of proposed medical treatments. There is little or no discussion, however, of alternatives” (p. 399). But information crafted to channel a patient along a single path may seem coercive rather than autonomy-enhancing. Patients need open options; that some of them are less than optimal does not mean they have no value. In most medical procedures there are real alternatives. As Jay Katz (1987) notes, “choice among a variety of medical options has become an integral part of the practice of modern medicine” (p. 224). And those options are multiplied as we consider questions of how aggressive a patient may wish to be in treating a particular problem, what goal the patient has in treatment or rehabilitation, which side effects the patient regards as more or less tolerable, what sorts of palliative measures the patient desires. Medical professionals may be tempted to omit mention of some viable treatment options, but denying patients significant choices—even if the physician obtains “informed consent” for the favored treatment plan—denies the patient the basic benefits of autonomy.

There may be occasions when one treatment program is so superior that it seems better to block other options—cases when medical professionals legitimately believe that the alternatives offer less effective therapy, and perhaps lead to disaster or death. In such circumstances it is tempting to close off all options and push the patient down the medically optimal single path. This may be narrowly rational but it is not biologically sound. It ignores the fact that we are not purely rational animals, and that we derive profound psychological and biological benefits from open alternatives.

Patients’ choices may have irreversibly bad consequences: the patient, for

example, who suffers a debilitating stroke because he refuses the optimum option of medication. Such results are unfortunate, even tragic, but they do not invalidate the value of autonomous choices among alternatives. If patients have adequate information concerning their options and are supported in making their own choices, there are likely to be *fewer* tragically bad choices, not more. Patients may “irrationally” resist a treatment plan because they are strongly inclined to keep an option open; and since no alternatives are offered, the only option available is resistance. If patients feel in control of the decision, and believe that supportive caregivers are providing information that empowers them to make their own choices, then the problem of “willfully perverse” choices will be ameliorated, not exacerbated (see Rodin 1982, p. 62; Taylor 1982, pp. 118–19). Furthermore, choice-making patients are more likely to persist in following difficult treatment regimens, a point made by Kenneth Wallston (1993) in discussing treatment of arthritis patients:

allow patients to participate in as many treatment decisions as possible, including allowing them to choose which treatment(s) they will receive. When a patient chooses a course of action, he or she is more likely to own it, and to stick with it even if the beneficial results are not immediately apparent. With a condition such as arthritis there are often many treatment alternatives with approximately equal degrees of objective efficacy. Informing the patient about these alternatives and allowing the patient to choose from among them should heighten his or her sense of control and may, in fact, play a key role in whether or not the treatment actually does have a beneficial effect. (p. 292)

Patients with choices are not driven to resist treatment (noncompliance) as their only option. Instead, making treatment choices enlists patients’ participation in their own treatment programs, and thus reduces noncompliance. Consider the patient who says: “I have to endure this treatment; I have no alternative, and no choice; it is dictated by my physicians and my circumstances.” Now compare her with the patient who resolves: “I shall succeed with this treatment and rehabilitation, because I choose to follow this path.” The path traveled may be the same in both instances, but the fortitude and enthusiasm and degree of success are likely to be quite different.

If physicians regard themselves as benevolent authorities and “good” patients as passive followers of doctors’ orders, then willful “noncompliance” must be either a challenge to physician authority or evidence of patient incompetence. At best such noncompliance is regarded as an impediment to good medical treatment. But medical sociologists see it differently. From his studies of patients with chronic illnesses, Peter Conrad (1987) concludes that patients often use “noncompliance” as an effort of self-regulation. Rather than perverse “disobedience to doctors’ orders,” Conrad suggests that noncompliance “is better seen as an aspect of people’s struggles not to let an illness take undue control of their lives” (p. 17). Noncompliance is then one way of striving to be in control of one’s ill-

ness, rather than controlled by it, a way of making choices and keeping options open when chronic illness is threatening to force the patient along a single narrow path.

The “noncompliant” patient’s desire for control is basically healthy. As Eli Glogow (1973) noted, “The ‘bad patient’ gets better quicker.” That is, the patient who is uncooperative, complaining, and demanding recovers more quickly than the patient who is quiet, passive, and acquiescent. Glogow suggests that often “those we think of as good patients are persons who follow medical instructions for the wrong reasons, namely, feelings of powerlessness,” while the noncompliant “bad patients” often “ignore medical advice for the right reasons, that is, because they have a sense of independence and have options open to them” (p. 74).

When caregivers act as benevolent dictators, patients may perceive them as alien authorities issuing “orders,” orders that threaten an autonomy already besieged by illness or injury. If medical professionals appreciate the vital therapeutic contribution of patient autonomy and self-regulation, caregivers can foster genuine patient autonomy. Patients would then regard caregivers as allies in the struggle to maintain independence in the face of illness, and nurses and physicians could support patients in making autonomous active choices that are also medically sound. At that point it would be more appropriate to speak of a “therapeutic alliance” (Zola 1981) between caregivers and patients rather than patient “compliance” with doctors’ orders.

“Informed consent” undergoes significant changes when autonomy is integrated into effective therapy. Instead of passive acquiescence to a recommended (or “ordered”) treatment, patients make active choices. But while autonomy does require that the patient have choices, that does not imply a mind-numbing and choice-defeating thicket of alternatives. Patients desire open options, not paralysis by so much information and so many alternatives that they cannot meaningfully make any choice at all. The key point is that choices are themselves important, and are a biological desideratum that good medical practice should strive to preserve and strengthen.

Some patients do not want to make choices (as documented by Schneider 1994, 1995). But that should be cause for alarm, not complacency. Lacking self-confidence, fearing loss of support if they push to make their own choices, concerned that their questions and choices may appear stupid, and intimidated by a strange new environment, patients may give up and resign themselves to their fate or their orders. They prefer passive acquiescence to the frightening prospect of making important choices in ignorance and incompetence. But what such patients may really want—and what extensive research shows is in their best medical interest—is sufficient information and support to make their own confident choices (see Woodward and Wallston 1987).

Obviously there are times when patient choices are less important. The comatose patient needs beneficent care, not considered options; and the trauma unit is no place for lengthy deliberation over alternatives. Furthermore, some patients

may be so profoundly passive and dependent that significant choice-making will yield more stress than benefit. Patients also may vary significantly in their need for choices: for some, choosing a physician may suffice. But these special circumstances do not justify the general curtailment of patient choice and control.

The therapeutic goal is not merely to give information but to empower the patient to choose among options with a sense of intelligent control. In contrast to mysterious transcendent autonomy, biological autonomy focuses on the patient's choosing *environment*: an environment that must contain genuine options and confidence-enhancing information and social support. Autonomy operates in an environment that caregivers can understand and enhance through empirical research in biology and psychology. Promoting genuine autonomy is not easy, but it is a vital part of sound scientific medical therapy.

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