

The Psychological Structure of Patient Autonomy

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The patient's right to informed consent is grudgingly acknowledged by medical professionals, firmly established in law, and brandished as a shibboleth by most bioethicists. But questions remain concerning genuine patient autonomy, and the doctrine of informed consent offers inadequate answers. In addition to the continuing controversy over what counts as "informed," the passive acquiescence implied by "consent" seems a pale shadow of genuine autonomy.^{1,2}

Autonomy is not the mysterious power that philosophers and theologians sometimes suggest, but neither is it mere consent. Autonomous choice-making requires two essential psychological elements: an internal locus of control and a sense of competent self-efficacy. When patient autonomy is understood in terms of internal locus of control and self-efficacy, then autonomy is neither a philosophical quandary nor an imposition from the judicial system. Focus on the psychological structure explains the therapeutic value of autonomous choice-making, offers a better standard for *informed* choices, and shows why respect for autonomy is part of sound scientific medicine.

The first requirement for exercising autonomy is a sense of internal—rather than external—control; or as Rotter³ christened it, an "internal locus-of-control."^{4,5,6,7,8} Those with an internal locus of control believe that their life's course is basically up to them. With an *external* locus of control I believe there is little or nothing I can do to influence events in my life. The onset of illness, recovery from disease, career success or failure, and the quality of my personal relationships are not under my control. My life is manipulated by powerful others, or perhaps by fortune or fate. (One can be an external about some areas of life, such as health,^{9,10,11} and internal in other areas. And although locus of control is a stable personality trait, it can change under environmental influences.^{12,13})

Internal locus of control is vital for autonomy. If I feel that what happens is not really up to me then I have no motive to improve my health, speed my recovery, or even make choices. Like a child turning a toy steering wheel, my choices don't control anything. Thus an internal locus of control is necessary for autonomy; but it is not sufficient.¹⁴ Some episodes of strong internal control are not enriching experiences of autonomy. Suppose that midway through a pleasant flight the pilot hands you the controls, opens the hatch, and hits the silk. You—with your strong internal locus of control—believe that it is up to you whether you land safely or plunge into fiery disaster. But you are not enjoying an opportunity for autonomous decisionmaking. To the contrary, internal though you are, you would much prefer to hand the controls over to an experienced pilot: all the buttons and switches and dials and pedals are confusing and frightening, and this is not an exercise of autonomy.

The situation of a strongly internal patient is too often analogous to that of the involuntary pilot. It's no good having a strong sense of internal control linked with a weak sense of competence. Psychologists have examined the essential sense of *effective* control under the rubric of "self-efficacy."^{15,16,17} Self-efficacy involves the perception of competence to activate some behavioral process; or more broadly, a sense of having the ability to successfully carry out a task and achieve a result. If you perceive a project as beyond your effective powers, then you are disinclined to make the attempt.¹⁸ If you undertake a task despite a weak sense of self-efficacy, then you give up sooner when confronting difficulties, whereas those with a strong sense of self-efficacy persevere.^{19,20,21,22,23,24} When a patient is reluctant to take the controls and make her own choices, it may be because she is profoundly passive and suffers from learned helplessness;^{25,26} or because she has an external locus of control and believes that she cannot influence her own health. But it may also be a case in which a strongly internal patient feels incompetent to exercise the control she would prefer to have (confidence in producing a desired outcome requires both internal locus of control and positive sense of self-efficacy).^{27,28,29,30,31,32} In such situations, the stress of exercising incompetent control may be worse than having others in control.

Rather than assuming that the patient does not want to exercise control, we must first help the patient become comfortable in her (initially alien) surroundings, inform the patient concerning available options, and empower the patient with sufficient knowledge to exercise *confident* (self-efficacious) control. (Recent surveys³³ indicate many patients would rather *not* make their own medical decisions, preferring to let their physicians decide for them. But given that the surveys do not factor in the patients' level of self-efficacy, it is impossible to determine whether the reluctance to exercise control is a genuine preference or merely an absence of confidence.) If patients really are externals, or profoundly passive, it can be difficult to develop their capacity for confident autonomous behavior. But internal incompetents—patients who believe control is up to them, and who wish to exercise control, but who feel incompetent in this confusing situation—should not be confused with patients who view themselves and their world as under the external control of powerful others or chance. The importance of that point is shown by research carried out by Woodward and Wallston.³⁴ They studied 116 adults ranging in age from 20 to 99 years and found that older adults typically wanted less control over healthcare decisions than did younger persons. However, when a measure of health self-efficacy was factored in (a measure of the degree of confidence in one's ability to make and control healthcare decisions), the difference was greatly reduced. Thus the difference in desire for control was not directly the result of age but instead stemmed from differences in perceived health self-efficacy: older people felt less competent to make healthcare decisions. Perhaps, then, what many older people really want is the information and support and encouragement to *effectively* control their own healthcare decisions; but in the absence of self-efficacy, they prefer less control to control without competence.

When the perceived competence (self-efficacy) element of autonomy is ignored, then an internal locus of control may appear a mixed good. Some studies show that patients who exert control have better therapeutic results, whereas other studies indicate that strongly internal patients suffer negative effects from high levels of stress. But the negative effects are not from having an internal locus of control; instead, they result from patients with strong internal locus of control

suffering loss of self-efficacy. That is indeed a stress-provoking situation: the task is really up to me, and success or failure is under my control, but I lack the ability or knowledge or competence to succeed. Imagine yourself stranded in a fine crystal shop with 30 typically rambunctious 4-year-olds. That is a stress-provoking scenario under any circumstances; but if you regard the situation as being—for better or worse—under your control (though obviously beyond any mortal's powers of self-efficacy), that is significantly more stressful than believing the future of the crystal is in the hands of fate.

The double autonomy requirement of self-efficacy *and* internal locus of control has been demonstrated by a number of medical studies. In a study of smokers attempting to overcome their habit, Chambliss and Murray³⁵ gave subjects pills (actually placebos) to help them stop smoking. Later the experimental (self-efficacy) group was informed that the pill was in fact a placebo and that their success in stopping smoking had been their own doing, not pharmaceutically induced; the comparison group continued to believe that they were receiving an effective smoking-cessation medication. At the conclusion of the study, there was no difference in results between the informed (self-efficacious) group and the placebo (uninformed, non-self-efficacious) group when comparing those with an external locus of control; but when internals in the self-efficacious group were compared to internals in the non-self-efficacious group, the researchers found that stronger self-efficacy made a positive contribution to successfully quitting smoking. Thus self-efficacy combined with internal locus of control promoted treatment success; self-efficacy without internal locus of control contributed little or nothing.

Similar results were found in a study of patients with chronic obstructive pulmonary disease.³⁶ Patients with an *external* health locus of control showed no relation between self-efficacy beliefs and health outcome: external patients with strong self-efficacy fared no better than those with weak self-efficacy beliefs. In contrast, among strong internal health locus of control patients, those with positive self-efficacy beliefs fared much better than did internals who lacked confidence in their own self-efficacy: internals with high self-efficacy beliefs tolerated exercise better, had greater energy and endurance, and enjoyed better overall health. So, internal locus of control and self-efficacy are both essential elements of effective patient autonomy, and good medical therapy requires protecting and nurturing both. Dumping control on patients with no concern for their self-efficacy is an act of cruel negligence that provides only a frustrating semblance of autonomy.

If patients lack self-efficacy then a strong internal locus of control may be counterproductive rather than contributing to healthy autonomy. There is another situation in which strongly internal patients face difficulties: in adjustment to highly controlled environments, like those too often encountered in hospitals and long-term care facilities. Futile efforts to exert control create a sense of helplessness,³⁷ as individuals attribute the control failure to their own incapacity. Felton and Kahana³⁸ found that in homes for the aged, residents with a strongly external locus of control adjusted better than did strong internals. A study of older patients admitted to acute-care hospitals³⁹ found similar results: internals perceived that they were under greater constraint, whereas externals perceived less constraint and made an easier adjustment to the hospital environment. These results are interesting, though hardly surprising. But what's the moral of the story?

Some may say it shows the value of being external rather than internal. And there is some truth to that. If you are sent to prison, or enslaved, or confined in a very authoritarian long-term care facility, or stuck in a traditionally paternalistic hospital, then you will probably adjust better with an external locus of control.^{40,41} But rather than shaping passive persons to fit oppressive environments, surely it is better to arrange the care environment to encourage autonomy exercise by those with a strong, self-confident internal locus of control and aid those with weaker autonomy resources (externals, or patients suffering from diminished perceptions of self-efficacy) in developing effective autonomy. In retirement homes with few constraints on residents, internals are significantly more likely than are externals to adjust well.⁴² That is in line with what happens in most settings: internals (except in unusually coercive environments) are typically more successful in adjusting to and functioning in their environments.

A strong internal locus of control is salutary for patients and residents;^{43,44} but that salutary effect can be reversed in the absence of a strong sense of self-efficacy, or in an oppressive setting that punishes independence. And there is another closely related situation in which a strong healthy internal locus of control can become harmful: when control is lost.

One study showing the debilitating results of loss of control occurred almost inadvertently, as the aftereffect of an earlier research project. Residents in a long-term care facility had been divided into experimental and comparison groups. Both groups received visits from area college students, but the experimental group controlled the time and scheduling of the visits, whereas the comparison group did not. The study⁴⁵ clearly demonstrated the benefits of exercising control. But a follow-up study⁴⁶ revealed disturbing and unanticipated results. After the initial study ended and the visits stopped, members of the experimental group—rather than enjoying continued long-term benefits from having exercised control—experienced greater depression than did the comparison group that had lacked control. The researchers concluded that when the visits from the students abruptly ended, this made clear to the residents their profound lack of control over their living environment; and the effects on those who had enjoyed a stronger sense of control were more severe than on those with less control. These results are consistent with animal studies showing that loss of control has more severe effects, both psychologically and physiologically, than does consistent absence of control;⁴⁷ and they are also consistent with other studies of older individuals indicating that negative changes in control have worse effects than does the stable absence of control.^{48,49,50}

Along similar lines, rheumatoid arthritis patients with a strong sense of internal control typically do better than patients with an external locus of control and weaker self-efficacy. But when the course of the disease becomes more severe, and is clearly unmanageable, then the strong internals suffer worse effects and less positive mood.^{51,52} Perhaps it is better to have loved and lost than never to have loved at all; but the opposite seems to be the case when dealing with control.

This poses a quandary. The solution in the nursing-home case is comparatively simple: it is therapeutically important to promote patients' sense of control, and it is doubly important not to destroy that enhanced sense of control, and caregivers must promote and *sustain* an autonomy-enhancing environment as a basic element of conscientious professional therapy. But the rheumatoid-arthritis sufferers are another matter: when progression of the

disease is uncontrollable, it is a terrible impossibility to prevent the progressive debilitation and obvious loss of control.

One solution is the stoic one: don't get your hopes up. But that would mean losing the genuine benefits of a sense of autonomous control, including benefits for patients whose disease does not follow such a debilitating course. A better way to deal with uncontrollable disease is by focusing on what *can* be controlled. If the patient can't control the outcome, instead empower the patient to control, so far as possible, the immediate environment, her own behavior, and the disease symptoms (including the level of pain, or the endurance of pain). Such control may seem like a pyrrhic victory if the progress of the disease itself cannot be checked; but in fact the control may be very important to the well-being of the patient, enabling her to cope more effectively with her disease, avoid depression, and live—or die—with greater equanimity.

For example, Parkinson's disease is a chronic, progressive, and incurable neurological disease. Even with the best management, functioning is impaired and complications increase. But whereas the inexorable march of the disease cannot be checked and the patient inevitably experiences loss of control over long-term health, there are important ways of preserving a sense of control. A study by Margaret Wallhagen and Meryl Brod found that having a sense of significant control over disease symptoms has a strong positive effect on patient well-being. In fact, perceived control over symptoms has a greater influence over patient well-being than do beliefs concerning ability to control the disease itself. As Wallhagen and Brod state:

Data from the current study suggest that more specific, situational beliefs about one's ability to control the symptoms that are experienced on a daily basis have a greater influence on well-being than more global, long-term beliefs about one's ability to control the progression of the disease.⁵³

So symptom control may be even more important to patient well-being than control over ultimate outcome.

But there are times when even symptom control is difficult: when disease overmatches the resources of the patient and caregivers and medical science. When options are exhausted and efforts at control are obviously futile, that can be profoundly debilitating. As indicated by the studies cited above, the effects can be even more devastating for those who have previously enjoyed a strong positive sense of competent control. But that bleakest of situations should be very rare if caregivers are attuned to the importance of preserving and enhancing the patient's opportunities for choice and control. If the course of disease is not under the control of the patient (and sometimes even symptom control is beyond the power of medicine), there remain important opportunities for patients to exercise control: control over information about their disease, control over much of their environment (when visitors are admitted, what the patient wears and eats and reads and watches), and control over end-of-life plans. As control over one area of life—one's health status—waned, it may be somewhat balanced by the waxing of control elsewhere. If all treatments fail, it remains important for the patient to have a sense that she had an effective part in those treatments and decisions concerning them. It is frustrating to try, and fail; it is more frustrating to want to try, and be kept out of the game.

Shelley Taylor's research^{54,55} found results that confirm the importance of control over other aspects of life when control over one's disease is impossible. As noted earlier, some studies indicate that when patients with a strong sense of control experience loss of control, then their suffering is greater; in seeming contrast, Taylor found that when cancer patients with strong internal control beliefs had those beliefs disconfirmed—through the dreaded recurrence of cancer, for example—they dealt with that disappointment *more* successfully than did those with a weaker sense of effective control:

people who believed they understood the cause of their cancer, believed they could control it, or believed they were handling it well, and who then discover their beliefs are untrue, are not worse off for having thought so. In fact, they may be better off.⁵⁶

The key was that instead of losing all sense of effective control, strong self-controlled patients shifted their control emphasis to something they *could* control: if not their disease, then their reaction to it, or the choice to spend their remaining time on something of special importance, or even their leave-taking.

When facing unfavorable prognoses and an absence of effective treatment, there remain important domains in which the patient can exercise competent control. One of the most significant is control over information, including control over information concerning the disease prognosis. Information is important and beneficial for patients in the full range of treatment and illness situations. Karen Dennis found that information was vital to the well-being and sense of control of a diverse patient population:

The importance of information was a repeated theme in the original and replication studies. Understanding one's diagnosis, treatment, and the lifestyle implications of the disease process were central to patients' cognitive control and the crux of the information imperative.⁵⁷

Having knowledge of the expected course of the disease—even when, perhaps especially when, that course is profoundly unpromising—is much better than being constantly surprised by further debilitating changes. When patients have knowledge, then the disease developments *confirm* their expectations rather than taking them unawares, and the knowledgeable patient can adjust more effectively and experience a stronger sense of control over the situation. When such information is withheld from patients, they not only lose the benefits of perceived control but are also likely to find themselves locked in an oppressive atmosphere of secrecy: they know something is going on and sense that all is not well, and they feel isolated behind walls of deceit. That isolation is exacerbated by the distancing and abandonment that typically accompany attempts to "keep the patient in the dark."⁵⁸

Information is an important element of autonomous control; but unless the patient has confidence and competence to understand, it provokes stress rather than providing comfort. Overwhelming a patient with information that she cannot assimilate is not a means of empowering the patient.⁵⁹ Rather than helpful usable knowledge, the information becomes one more noise in a bewildering cacophony. Thus it is not surprising that in many cases patients report wanting to receive less information and preferring that someone else take control and make their treatment decisions. In situations in which we feel helpless and befuddled, additional uncontrollable stimuli are not reassuring.

It may also be frustrating to receive extensive information when one is powerless to act on it. Information without effective avenues of behavior may increase a patient's sense of internal locus of control and responsibility for her treatment and recovery; but that sense of control may cause stress and frustration unless the patient has the means to effectively exercise the control and apply the information (exercise self-efficacy). A study by Cromwell, Butterfield, Brayfield, and Curry⁶⁰ found that patients who were given high levels of information together with effective opportunities to participate in their own treatment (through activating their own cardiac monitors to obtain EKG tracings and having mild exercises to perform) were discharged earlier from both CCU and the hospital. Patients receiving high levels of information but who had no effective means of treatment participation took much longer to recover sufficiently for discharge from the CCU and from the hospital. (As noted earlier, participation need not be effective in controlling the course of the disease; but there must be opportunities to make choices and exercise control over important elements of treatment, palliative care, and daily activities.)⁶¹

In sum, a vital element of sound patient care is attentiveness to the patient's capacities and opportunities to exercise competent, confident, autonomous control. It is all too easy for even well-intentioned caregivers to undercut the patient's opportunities for control and undermine the patient's confidence in her ability to exercise effective control. If the basic rule of medicine is "First, do no harm," then the harm done to patient autonomy by paternalistic medical environments and overcontrolling caregivers must be scrupulously avoided. Beyond that "do no harm" minimum, caregivers must understand the basic health benefits of autonomy as well as its complex psychological structure. Conscientious professional caregivers should strengthen the patient's sense of internal control, enhance the patient's sense of competent self-efficacy, and—especially when the progression of illness deprives the patient of many areas of effective control—establish a supportive and comfortable environment that maximizes the remaining opportunities for confident control.

Notes

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