

The Alchemy of Informed Consent Revisited

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First, let me thank Dr. Adrienne McEvoy and the other planners of this conference for inviting me to participate. A retired philosopher does not have as ready a cachet for intellectual interactions with fellow philosophers as one still employed in the profession, and the chances for stimulating conversation that an event such as this conference offers is a welcome respite from the solitude of my study.

Second, let me offer an apology for not having a handout for this talk. I do have a website that contains most of my talks and published papers, as well as various other ravings collected over thirty-plus years of ruminating, and you are each welcome to visit it and acquire for your own reading pleasure or other legitimate purposes (such as composing refutations of my foolish views) such copies as you may require. Just don't steal my ideas and misrepresent them as your own! The address is <http://www.richard-t-hull.com>. This paper should be posted there within the month.

This talk is an expansion of two papers that I have previously published: *Informed Consent: Patient's Right or Patient's Duty*,¹ and "The Alchemy of Informed Consent"²; but it also explores other themes that have occupied me from time to time since the late 1970s as Dr. McEvoy has indicated. I decided on this occasion to expand on those themes in the light of the recent media coverage of the case of Terri Schiavo, the 41-year-old woman who had been in a persistent vegetative state for some fifteen years and who was allowed to die in Florida just this past week. The case is still in the news, and one effect of its publicity has been that literally tens of thousands of Americans have logged onto websites that offer generic advance directives, presumably to download and execute them as indications of their wishes about medical treatments and nutrition and hydration provision should they ever fall into an irreversible, vegetative state.

Whether this upswing in public attention to advance directives arises from an aesthetic urge, a self-interested concern, or a genuine moral sense we may wish to explore in the discussion. But I want to lay out a general account of why patients should be regarded as having strong moral obligations as patients, obligations that extend far beyond paying their medical bills (if they can), showing up on time for their doctors' appointments, and following their doctor's orders. I want to see if I can establish a set of moral obligations to physicians and, in this extension of the earlier papers, to family members that center around the giving of informed consent to treatment options, including the options of no treatment.

In 1998, lawyer-bioethicist Carl Schneider published a work with Oxford University Press titled *The Practice of Autonomy: Patients, Doctors and Medical Decisions*.³ I was asked to write a reaction to the book for a forum focus of the *Journal of Clinical Ethics*. Part of this reaction was a reprise of arguments I had given in 1985 at a conference here in Mansfield and published that year; part was an extension of that argument to attempt a resolution of the question, How can a physician engage in the kinds of modern medicine that are so actively invasive of patients and still live within the Hippocratic Oath's admonition, *Primum non nocere*, First of all, do no harm?

Schneider's book is, from one perspective, curiously incomplete. The wishes and interests of patients are detailed in all their rich variety. The benefits and disbenefits of the new organizations of medicine are characterized honestly and fairly. But, the complaints of physicians about patient suspicion and squeamishness are brushed off, relatively speaking, as the natural outcome of those forces that impinge on the patient. To be fair and balanced, docs deserve a better representation in this court of bioethics.

In his rush to counter tendencies in bioethics to woodenly apply ethical principles with situationally sensitive characterizations of the plights of patients, the full range of reasons for the principles of bioethics as regards the duties of patients in the context of medical decision-making and of the moral needs of physicians is not fully explored. Schneider devotes less than a page to such duties and needs, and any full reconsideration of the relations between physicians and patients, if it is to hope for success, has to address this dimension of the issues with equal sensitivity.

The space is not adequate, even if the author were, for my providing such a complete set of considerations. Rather, I hope to establish that there is a legitimate set of further observations involved in patient responsibility to be considered by bioethics from the point of view of physicians, and to indicate just what some of those issues are. In what follows, I give an argument that appears to support something like mandatory autonomy. I am not sure whether I personally would endorse it. Rather, I intend it as a foil to stimulate further exploration of the issues raised in Schneider's work.

(1) *Physicians have a duty not to commit battery on their patients.* This truism, part of the rationale for such rules as the requirement of informed consent for treatment, has long been recognized from the patient's point of view. That is, since an unconsented touching is a battery under the law, apart from exceptional, emergency situations where consent is presumed physicians need their patients' consent in order to ply their craft. Absent such consent, surgery becomes stabbing, chemotherapy becomes poisoning, and urological examinations become sexual assaults. Nor is the defense of good intentions a sufficient excusing factor. The consent of the patient is recognized in the law as essential, and the provision of unwanted medical care is not excused by the benevolent intentions of the provider.

(2) *Therefore, physicians have a right not to commit a battery on their patients.* Although sounding odd, this follows directly from the duty mentioned in the first observation, together with the general moral principle that "ought implies can." Any individual having a duty to do something has a right to do it, in that such a right at least involves a right against others who might place obstacles in the way of satisfying that duty. For example, if a divorced father has a duty to visit with his or her child regularly, he has a right that the child be available for such visitations. Sometimes such rights imply obligations on the part of others not merely not to interfere but actually to provide material elements necessary to doing one's duty. If I have a duty to repay you the \$500 I borrowed, and I have sufficient funds in my bank account, I have a right to extract that money necessary to pay off my loan, and that right is one against my bank to assist in my withdrawal.

(3) *What keeps a physician's touching of a patient from being a battery is the patient's consent.* We would no doubt want to qualify this claim for children and other persons lacking capacity, but the arrangements made in such cases are designed to have appropriate (not just any) decision-makers act on behalf of those incapable of competent self-determination. Generally, it is the consent of the patient that keeps a physician's touching from crossing the line of battery and assault.

(4) *Therefore, physicians have a right to the consent of their patients to the acts that constitute the physicians' treatment.* This is not an absolute right to consent; physicians are not some special class of individuals who practice by divine right. Rather, the practice of medicine is a privilege extended by the patient, and the extension of such privilege is normally through the consent of the patient or the patient's representative or guardian. In the case of emergency treatment, where the patient's life hangs in the balance and no advance directive is evident, consent is presumed for such time as the patient's life is in the balance and no due representative of the patient can be consulted.

(5) *Therefore, patients have a duty to give consent to the acts that constitute their physicians' treatments.* I do not mean this duty to be construed as absolute. Cruzan has taught us that, in the public morality of this society, a patient may refuse treatment, even if it is life-sustaining, such refusal being finally determinative of the responsibilities and rights of involved physicians. Rather, when patients seek treatment by physicians, it is the consent of those patients to whatever treatment is provided that gives physicians what they need in order to avoid battering or assaulting their patients in providing that treatment.

We are at a critical juncture in the argument. For, it might seem that a patient can give blanket consent to whatever the physician thinks best, and thereby shift the material burden of deciding on a treatment onto the physician. (Schneider contemplates such a practice and regards it rather benignly, noting that it is a common expression of patients' wishes and acknowledging that physicians meet such a stance with mixed feelings, but offering no principled argument against allowing such a shift.)

Let us assume that it makes sense to say that a patient has consented to a treatment regimen, using language like "Whatever you think best, doctor," even when the patient doesn't know what the doctor does think best in the situation. What, if anything, is authorized by such an act of speech?

I can envision three possible responses. (1) The patient might be said to have *authorized anything the physician thinks best*. In that case, nothing the physician does and "thinks best" would constitute a battery: the physician might sterilize the patient in thinking it best the patient not have any more children, or the physician might remove a healthy kidney in thinking it best another patient receive a transplanted organ. Or, (2) the patient might be said to have *authorized any standard medical procedure typically employed for patients with the particular problems this patient has*. Under such a conception (which I suspect Schneider would countenance under his notion of "Guidelines"), a naive or incautious Jehovah's witness would have unknowingly authorized a transfusion, and one who believes in certain versions of bodily resurrection might unknowingly consent to amputation and incineration of the amputated limb. Or, (3) the patient who attempts to consent without knowledge *hasn't really consented to anything at all*.

The consequences of (1) and (2) are unacceptable. (1) is wholly unacceptable on the face of it; (2) is unacceptable in a society characterized by an enormous diversity of beliefs about bodily matters as a rule of procedure when physician and patient do not come into the medical situation with fully consonant values and beliefs. That leaves us with (3). And the consequence of (3) is this:

(6) *Patients who seek to give consent that is not knowing consent fail in their duty to their physicians: consent must be informed.*

For a long time I thought that the upshot of this was a kind of negotiation that needed to go on between the patient who was reluctant to make substantive decisions about his or her care and the physician who undertook treatment of that patient. One might still argue that physicians, while they have the theoretical right to insist on their patient's informed consent as a condition of treatment, routinely can and often should excuse patients from such an obligation. All I have

shown, it can be objected, is that patients have no *right* to waive informed consent and remain blissfully ignorant; physicians may, and out of decency probably should, extend the *privilege* to give blanket, uninformed consent out of respect for their squeamishness or their sense of being overwhelmed by their condition. After all, isn't the treatment situation somewhat analogous to a contract? Each party brings his or her terms to the table, and if a set of those terms are found to be acceptable to everyone, the bargain is struck. And if a part of that bargain is the "do whatever you think best, Doctor" attitude of the patient, and the physician is willing to assume the burden, where's the harm?

It has occurred to me, however, that physicians have another source of obligations besides the wishes of and agreements with their patients. Every physician takes, upon admission to the profession, the Hippocratic Oath. While some elements have fallen by the wayside in recent decades, one has remained central: Above All, Do No Harm. As medicine is now recognized in what is effectively the Social Contract, it is still largely a self-regulating profession that enjoys the privileges of monopoly and high status in exchange for adhering to the standards it has set itself and publicly proclaims.

It is an interesting historical fact that the informed consent doctrine emerged as medicine moved from a relatively passive art in which achieving a correct diagnosis of the patient's condition and prognosis of the patient's likely medical future was the goal, to an admixture of art and science in which the causes of ill health are dealt with aggressively. The Hippocratic injunction, more fully "to help, or at least to do no harm," has perhaps never been more apt than in this time of chemotherapy, cardio-pulmonary resuscitation, surgery, radiotherapy, and gene therapy.

What is it that keeps these invasions of our persons, our bodies, our minds, our germ cells and somatic cells, from being harms? They indeed are harms if performed by enemy soldiers, criminals, terrorists. They are arguably harms even if competently performed by medical personnel if done so without our knowledge and consent, direct or through a proxy. It is the knowledgeable consent, the assent, the agreement of the patient to such invasions that transforms them from harms into treatments, and that converts the resultant scars, deformities, and functional losses from injuries into unfortunate consequences. This, if you will, is the alchemy of informed consent.

So, the final element in the case for informed consent being a patient's duty to the physician is in place. Informed consent to treatment is needed by the physician and surgeon, needed as a crucial element in the preservation of the physician's oath. The practice of modern medicine can avoid harm only with the informed, knowledgeable, freely given consent of the patient. Hence the final principle:

(7) Physicians need informed consent if their practice is to remain consistent with the Hippocratic Oath. That need is not satisfied if either patients or physicians waive their respective rights as regards informed consent. Hence, physicians have an absolute duty to obtain informed consent to invasive procedures; patients have a duty, consistent with their capacities, either to give informed consent or to refuse treatment. They may not morally opt for blanket consent

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In correspondence, Carl Schneider has raised with me the fundamental question he raises in his book, that of the practicality of principlist ethics. "How capable are patients of meeting the standards you set for them? How capable are doctors (etc.) of helping them do so in any satisfactory way?" Behind his questions is a seemingly irrefutable argument against my position, an argument that turns on the dictum, "Ought implies Can." If my requirements of patients and physicians are

not capable of being met, that is, if neither “Can” meet my requirements, then neither “Ought “ to meet them: the requirements are hollow and do not express duties at all. Is there any way to view such duty-claims other than in a way that they fall to the limitations of humans imbedded in their lives and struggles?

Ironically, Schneider has provided a direction in which to think about these difficulties. He suggests nearly a dozen courtesies that physicians would do well to adopt as measures that would ease the experiences of their patients and foster a better, less confrontational atmosphere in which the pursuit of healing can better occur. My suggestion is that Schneider’s task is incomplete until a similar list of “courtesies” is commended to the patient and the patient’s family. Such a list would be a step in the direction of countering bioethics’ position that informed consent is (only) a right of the patient against the physician. The suspicions besetting medicine call for recognition that the obligations of the physician-patient relationship are not one-sided, but that physicians have rights and patients responsibilities too, so that they may come together in recognition of duties owed to one another.

I suppose that my “requirements” should be taken as descriptive of the ideal. Do any physicians never do harm? I suspect even pathologists cannot evade the charge. Ought they to do no harm? To say that they ought may not imply that they can, but rather that they should strive mightily to avoid harming their patients. Should patients be expected to meet these standards? Even if they are not able, there is something more noble about a patient who recognizes that to ask another to undertake the task of healing is to ask a great deal, and who struggles, despite relative ignorance, fear, pain, and despair, to give the physician the forgiveness of informed consent, as compared with the patient who treats the physician as a servo-mechanism and simply commands, “Physician, heal myself!”

The Extension of the Alchemy to Advance Directives

The Schiavo case helps us refocus this paper’s central mission: to remind us of the duties and obligations we have as patients.

We each are potential Teri Schiavos. We each have the potential of a medical condition that renders us incapable of performing our dutiful participation in our own health care. Whether as the result of engaging in bulimic practices in an effort to control weight, as Schiavo did, or drug abuse, or accident, or high fever, or cardiac arrest, any one of us could end up in a persistent vegetative state. So what responsibilities do we have as regards these possibilities?

If her husband, Michael, is to be believed, Teri told him, in the kind of private and personal communication between husband and wife that often occurs in good marriages, that she did not want to be kept alive if ever in an irreversible coma or persistent vegetative state. If her parents, the Schindlers, are to be believed, she never made such a declaration of her wishes. Her care givers, thus confronted with a familial conflict having the character of “he says, they say”, and not in possession of an independent, written declaration of her wishes in an advance directive, continued to provide her with care for some 17 years, during the later stages of which the matter was repeatedly referred to the courts as the insistence of both husband and parents took on the tone of increasingly hostile legal action. How shall we analyze and understand this situation in terms of Teri’s dispatch of her obligations to caregivers, husband, and parents? What moral lessons can we learn that will provide us with guidance in our own lives?

Recall that part of what I have called the alchemy of informed consent – the ability of thoroughly informed consent to transform culpable harms into nonculpable misfortunes – is a

recognition that physicians are owed relief and forgiveness in advance for what they do to us in trying to heal us. That duty to give informed consent is a duty to the physician—an by extension to all our providers of health care—to relieve them of responsibility for inflicting on us what we would subsequently find unacceptable.

Reflect as well on the wider role that consent plays in our social relations. What is rape but unconsented to sex? What is theft but unconsented to appropriation of our property? What is the morally relevant difference between being stabbed by a stranger in a dark alley and one's body being laid open with a scalpel by a surgeon? Whatever else may be involved in the arena of the agent's intentions, a central difference is the presence in the one case of consent that authorizes the invasion of one's person and knowingly accepts the consequences, and the absence in the other case of such authorization. Even in the difficult case of an individual who voluntarily has sexual intercourse only later to discover that she has acquired as the result a case of AIDS., when the male partner knew of his HIV+ status, we are inclined to say that she was harmed culpably because her consent wasn't informed of the risks of infection that were so much higher in this particular encounter. One recent court has charged a HIV+ male with murder for knowingly transmitting this deadly virus.

It appears, therefore, that informed consent plays a wide and important role in our social relations. Consider, then, the Schiavo case from this broad perspective. How does informed consent impact on our obligations to physicians and family as regards the terrible possibilities of persistent vegetative states?

In the first place, when we leave a health care provider in the dark about our wishes in such possible situations we impose on that provider and the system of provision of, and payment for, medical care a terrible moral burden. Confronted with an irreversible persistent vegetative state, the physician knows she cannot restore us to even a marginally productive and satisfying life. The physician is thus confronted with allocation questions: what resources are owed to the patient who cannot recover a meaningful life, as opposed to those patients whose lives have a good chance of healthful restoration. Physicians and hospitals deal all the time with triage and allocation of resources questions. The patient who has neglected to have conversations and clarifications of that patient's wishes under such tragic circumstances imposes the burden of attempting to discern those wishes on caregivers, who must agonize with the moral and legal burdens of determining, if they can, what those wishes would be.

In the second place, even the patient who has had "the conversation" about such tragic circumstances with a loved one – perhaps a child or a spouse, perhaps a close friend or minister – where the conversation has not been adequately documented, places on that loved one the burden of convincing others of the accuracy of such expressions. Teri Schiavo did, it is reported, have that conversation with her husband. But, his report was disbelieved by her parents, in part because of their suspicion that he had financial motives and in part because, they aver, she never expressed a wish not to be kept alive to them. We may well understand her reluctance; we may sympathize with her apparent attempt to provide an adequate indication through intimate conversations with her husband; but that she failed to provide an adequate and independent record of her wishes in a written advance directive materially contributed to the legal, moral, and psychological conflict that has been the subject of such intense public attention in recent weeks and months. She failed to anticipate the potential for conflict between her husband and her parents, and did nothing to forestall it.

Let me emphasize that this is not a condemnation of Teri Schiavo. I am prepared, as I think all of her family members are prepared, to forgive her both the failure to provide a relevant

advance directive and even her self-abusive behavior in acting bilemically in her attempt to control her weight by inducing emesis. Rather, I am offering an analysis of what happened, what could have been done but wasn't, as a way of drawing a moral lesson from her tragic life's end.

From the perspective of her parents and their supporters, withholding nutrition and hydration from Teri was murderous, the starving of their daughter, making her die of thirst. It was the imposition of a terrible, morally culpable harm.

But from her husband's perspective, assuming he correctly reported his wife's wishes as regards her situation, withholding nutrition and hydration was not a harm, or at least was not a culpable harm, but the recognition of her right of self-determination. Her informed dissent to further treatment not only made its withholding not a harm, had they been provided against her wishes, nutrition and hydration would have been harms.

So what are our duties as regards advance directives? I conclude that we owe our health care providers and our loved ones relief in advance of the burdens of making decisions about our care in the absence of our participation. Any person of majority in this audience who has not grappled with the questions of what he or she would want done if unable at the time to participate in medical decision making, and communicated the results of that sober reflection effectively to relevant others, is failing in his or her obligations: to health care providers, to loved ones, even to society generally.

So let me end with a plea: Learn from this tragedy. Go to your physician, campus health services, the internet, the library and investigate various possible advance directives. Decide whether you would want various modes of treatment or not under various situations of temporary or permanent incapacitation. Execute appropriate documents and give copies to everyone affected by those wishes: parents, spouses, children, family attorneys, regular physicians. Be prepared to present such documents when hospitalized.

In so doing, you take responsibility for decisions affecting your own welfare, you remove the burden of such decisions from others, and you act in such a way that the alchemy of informed consent, if it doesn't make gold out of lead, will at least make morally culpable harms into what they should be: "mere" tragedies and misfortunes.

NOTES

1. Richard T. Hull, "Informed Consent: Patient's Right or Patient's Duty?" *Journal of Medicine and Philosophy*, 10 (1985): 183-197.
2. Richard T. Hull, "The Alchemy of Informed Consent," *The Journal of Clinical Ethics*, 13, no 1 (Spring 2002): 63-65.
3. Carl Schneider, *The Practice of Autonomy: Patients, Doctors and Medical Decisions* (New York: Oxford University Press, 1998).