

Medical Ethics Committees in Israel: Implementing the Israel Patient Rights Act and Terminating Life-Sustaining Treatment

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The Israeli Patient Rights Act, passed by the Knesset in 1996, establishes statutory ethics committees with the express purpose of overriding a competent patient's decision to refuse medical treatment.*

The ethics committee is a legally sanctioned administrative body authorized to act in the court's stead when a patient rejects life-saving treatment. In the original draft of the law, refusals of this nature were referred to the local courts for adjudication. However, the final legislation provides for a professional committee of physicians, jurists, psychologists and ethicists to decide if and when to honor a patient's request to refuse care.

This legislation is unprecedented in several respects. First, it is probably the only example of legislation designed to override a patient's right to informed consent and to treat one against one's will. Informed consent reflects a patient's right to receive adequate information in order to decide the kind of treatment one needs. Consent is meaningless, however, without the concomitant right to refuse treatment; in fact no other Western nation will allow a patient to be treated without permission. This has been standard medical practice for at

least thirty years. Second, the law does not address the long-standing debate over withdrawing and withholding treatment. It only indirectly refers to a patient's right to *refuse* treatment. If we are going to follow Anglo-American precedent and extend this to include the right to withdraw or discontinue treatment then the law requires re-interpretation. Finally, the law is unabashedly paternalistic, wreaking havoc on "progressive" interpretations of autonomy that respect a patient's absolute right to accept or refuse treatment.

Implementing the Act: Some Practical Problems

The statutory ethics committee will convene following a physician's request to treat a competent patient who refuses treatment. If the committee finds that a patient has been properly informed *and* treatment will bring significant improvement *and* the patient is likely to give his consent after treatment then he may be treated in spite of his informed refusal (IPRA, 1996, paragraph 15). Obviously, this leads to a number of practical and ethical difficulties.

First, there are no clear guidelines whether patients may be represented by legal counsel or whether they have the right to appeal. Off hand, the answer should be "yes," but no means are

offered to protect or publicize these rights. The committee's decision is usually carried out immediately and in most cases neither the patient nor his family is in any position to react with any degree of vigor and intelligence. Second, the law explicitly allows patients to appoint surrogate decision makers. While this greatly facilitates decision making by maintaining respect for a patient's autonomy when one is no longer competent, little has been done to inform patients of this right. Patients should be encouraged to choose a surrogate no later than when they enter the hospital. This will expedite decision making at a later date. Finally, committees must consider how to publicize their decisions. Although the Ministry of Health has not offered clear guidelines, there is no question that ethics committees function in a normative *and* statutory capacity. Their findings provide both ethical and legal guidelines for hospital personnel confronting similarly complex and vexing moral biomedical dilemmas.

If all this sounds very paternalistic, it is. The IPRA stakes out a position regarding the patient-doctor relationship that is considerably more conservative than policy in most other democratic nations. In doing so it forces us to rethink many accepted axioms regarding patient autonomy and rights while, at the same time, allowing interdisciplinary statutory ethics committees to help shape Israeli bioethical culture. Two cases exemplify these claims.

* The ethics committee is also authorized to consider other issues such as a physician's request to withhold medical information from a patient for therapeutic reasons. This will not be discussed here.

IPRA = Israel Patient Rights Act

Two case studies

In the first case, an elderly patient suffered complications following hernia surgery and was placed on a respirator. He is described as "strong" but the staff is unable to wean him from the respirator and after two months a tracheostomy is recommended. The patient, however, refused consent and the ethics committee was asked to authorize treatment.

It is instructive to see how the case was handled in the Israeli context and how it might have been handled in an American one. The American position emphasizes the absolute need for informed consent. If the patient understands his condition and the benefits (and costs) of treatment, then his decision must be respected even if it is detrimental to his health. In this case, the intensive care unit staff (confirmed by subsequent psychiatric examination) had no doubts that the patient understood the state of his health, understood the proposed procedure, understood that he could die and still the patient refused treatment. In fact, he expended considerable energy trying to pull out his tubes. Under these circumstances the American bioethicists I consulted with were unequivocal. Wrote one, "if he does not want the vent anymore and understands that he will die without it, then by all means revisit it after a few days and if he hasn't changed his mind, start a morphine drip and take out the tube and give him some privacy, comfort and dignity with which to die."

For reasons of law this option is problematic in Israel (see below). But it is precluded for moral reasons as well. When told he could die, the patient just waived off the doctors as if to say, "So what." It was impossible to really know what his motives were. Was he tired of being old, of being sick, or just fed up after nearly two months of staring at the ceiling? While we don't know the patient's motives we do have good reason to believe that surgery in this case is straightforward and beneficial. We also know that the patient will keep trying to pull out his tubes. We also know that the moral inclinations of the

physicians will not allow them to disconnect their patient and let him die. This does not mean that they oppose all instances of termination of life support. These physicians have seen enough futile cases. This is just not one of them. Under these circumstances the IPRA's ethics committees provide a useful palliative for overdoses of autonomy, a significant improvement over the American model.

But what if the case is futile and/or the patient's motives clear? Here the ethics committee can serve to expand the scope of patient rights. In another case, an elderly patient was intubated as he suffered from end-state systems failure. In spite of aggressive treatment the staff felt death was imminent. This prognosis was relayed to the family who asked to disconnect the patient from life support. The ethics committee denied the family's request for two reasons. First, the family had no legal standing before the committee, and second, the law does not allow treatment to be withdrawn. Here, I think the committee erred and missed a chance to have a significant impact on hospital policy, patients' rights and emerging bioethical norms in Israel.

Patients' rights and surrogate decision making

Although the IPRA allows a patient to execute a power of attorney and appoint a surrogate decision maker, this right is rarely exercised. The purpose of the provision is to allow a competent patient to authorize another party, usually a spouse or family member, to consent to medical care on the patient's behalf. A power of attorney is not a living will; the patient need not leave specific instructions (although he may do so). Instead the patient appoints someone else to make medical decisions on his behalf.

Most often, surrogate decisions are taken when the patient is unconscious or otherwise incompetent. Under the provisions of the IPRA, a surrogate decision maker may also refuse to consent to a medical procedure, in which case the attending physician may appeal to the ethics committee for permission to treat the patient over the surrogate's objec-

tion. Under these circumstances a family can have standing before an ethics committee, and in the case above the family would have been within its rights to object to certain forms of treatment on behalf of the dying patient.

The fiduciary responsibility required of surrogate decision makers was discussed at length in the United States in 1983 [1] and in American courts in 1985 [2]. The American recommendations are problematic in Israel for two reasons. First, American guidelines stipulate that surrogates must first consider a patient's wishes, wishes that may be expressed explicitly in writing or indirectly derived from a patient's known attitudes and beliefs. This guideline speaks directly to the overriding respect most American bioethicists have for patient autonomy and self-determination. In fact, respect for a patient's wishes supersedes the patient's best interest. The surrogate only considers a patient's best interest when his wishes are not known. Clearly this is problematic in the Israeli context if only because the IPRA places best interests ahead of patient autonomy. Deciding between the two is the province of the ethics committee. Thus any surrogate decision-making process is ultimately subject to review by the ethics committee. This should help retain the balance between patient interest and patient autonomy, which some argue has become distorted in the United States [3].

A more difficult problem is posed by the definition of "best interests." The American guidelines push well beyond acceptable practice in Israel and give significant weight to pain, suffering and inferior quality of life over considerations of extended life. In the case cited above, the New Jersey Supreme Court set guidelines allowing surrogates to discontinue food and fluids to permanently disabled patients who were neither unconscious nor terminally ill, a practice confirmed by dozens of subsequent cases [2,4]. The current climate in Israel is far more constrained and we still have yet to decide whether to allow terminally ill patients to withdraw treatment, much less consider the case of

those who are permanently unconscious or disabled.

Pushing the envelope: withdrawing and withholding treatment

In most Western nations today, there is no moral or legal difference between withdrawing and withholding treatment. The argument moves in several directions at once, beginning with a competent patient's right to refuse treatment and ending with an incompetent patient's right to withdraw treatment that includes life-sustaining technology as well as basic care. Assuming a patient has a right to refuse any treatment on the grounds that any treatment against his will is an actionable battery, the issue moves rapidly to a discussion of the distinction between withholding and withdrawing treatment, between a patient's right to refuse a treatment and his right to stop a treatment that has been started. Space does not permit full elaboration of this debate but the basic arguments can be listed as follows:

- **The logical argument.** There is no logical or practical difference between refusing treatment and refusing to continue treatment. No treatment is continuous: IVs must be changed, antibiotics must be administered, ventilator-dependent patients must be suctioned, etc. At each of these points, in the very least, a patient who has the right to refuse treatment also has the right to refuse further treatment. This extends to any kind of treatment regardless of the patient's condition.
- **The argument from causation.** Patients disconnected from life support die of their underlying illness and not as the result of a physician action. This argument was generally acceptable when patients were moribund, i.e., when death was imminent. It has been expanded in recent years to include patients who are terminally ill (although not in danger of imminent death) or permanently unconscious on the same grounds.
- **Consequentialist arguments.** Unable

to withdraw treatment, physicians will be reluctant to commence certain kinds of care. While life-supporting care may be beneficial, its use is outweighed by the possibility that it cannot be withdrawn later once it is determined that it is merely sustaining death and, possibly, contributing to pain and suffering as well. This argument figures strongly in recent Israeli court rulings that reject the distinction between withholding and withdrawing care.

- **Patient's best interests.** In some cases patients are better off dead than sustained on life support. While some argue that proper pain management belies this argument, quality of life may be considered by patients or their surrogates.
- **Futility.** In many cases continued care of permanently unconscious and/or disabled patients is futile, i.e., it offers only a very low probability of any significant recovery. Physicians have no obligation to provide futile treatment and may discontinue care without moral or legal culpability.

While these arguments may be extended to non-terminally ill patients who are permanently unconscious or disabled and/or to termination of food and fluids, it remains for us, in Israel, to still deal with the simplest of these cases – namely, the right of a terminally ill competent patient, or his surrogate, to withdraw life-sustaining care. Until this basic question is considered there is no room to deal with the more complicated issues of withdrawing technologically advanced treatment or basic care from permanently unconscious or disabled patients. As we deliberate this basic question we must also ask whether the courts or committees are the most appropriate forum.

Committees or courts?

In the case described above, the ethics committee largely agreed that withdrawal of treatment is prohibited. Not only is this incorrect from the perspective of Western bioethics, it does not fully reflect the present-day situation in Israel

where these norms remain in a state of flux. Given the ethical arguments cited above (together with American legal precedent), Israeli courts have slowly recognized a patient's right to withdraw treatment. The right is not as expansive as it is in the U.S. This stems in part from our desire to define an Israeli ethos in terms of a Jewish-democratic state, one that grants overriding consideration to the sanctity of life. In this context, sanctity of life, as I have noted elsewhere [5], is not only a religious norm but reflects the need of many Jews to persevere in the face of historical catastrophe, as well as succeed in the Zionist endeavor that was so much its offspring. The major Israeli Supreme Court decisions that weighed the question of end-of-life treatment have consistently tried to frame their arguments in terms of the norms incumbent upon a Jewish-democratic state. While this synthesis is not always successful, these decisions necessarily frame the discussion for discontinuing care. As a result, it is doubtful, for example, whether the right to refuse or withdraw treatment can be fully exercised by parents on behalf of their children [6,7] or by patients who are not terminally ill [8].

Nevertheless, two district judges, Judge Sirota and Telgam, have ruled that there is no legal distinction between withdrawing and withholding life support when a patient is terminally ill [9,10]. These rulings closely parallel American precedent, as democratic norms gain some measure of ascendancy over Jewish values. Absent Supreme Court rulings on these limited cases, statutory committees – and ethics committees are no exception – may adopt the decisions of district courts when they make their rulings. Under current circumstances ethics committees may allow a patient's request to terminate life support. If that patient is represented by a surrogate decision maker, that person may also elect to terminate care.

Instituting these changes requires more diligence on the part of physicians and hospital ethics committees. Currently, few hospitals have set up ethics committees as required by law, perhaps

under the assumption that these committees will interfere with physician-patient decision making. This is mistaken, for deliberative forums like ethics committees are preferable to the courts as a decision-making mechanism. Law courts are by nature adversarial. One side wins and the other loses in what is often a zero sum game. A statutory committee, on the other hand, represents a mixture of interdisciplinary views. Its role is to consider conflicting viewpoints and reach a consensus that satisfies the majority of interests.

Active ethics committees fulfil several crucial functions as we confront dilemmas posed by contemporary biomedicine. First, they should encourage hospitals to obtain powers of attorney for healthcare from patients. This assures respect for patient autonomy while granting surrogate decision makers the necessary standing to refuse treatment. Second, ethics committees can directly confront the question of terminating end-of-life care. To do this, physicians and patients must be persuaded to bring cases of termination of care for discussion. Statutory ethics committees can and should use their authority to approve requests for withdrawing life-sustaining treatment when patients are

terminally ill. Finally, ethics committees need to become more active among physicians and hospital staff by inspiring debate on other ethical issues of concern. Rapid technological change makes it impossible to avoid many hard questions. Under these circumstances, the purpose of the committee is not to provide ready answers but to offer an interdisciplinary venue to clarify and help resolve issues through debate and discussion. To accomplish this goal ethics committees need not wait to be consulted but may raise their profile by conducting ad hoc discussions in wards where difficult ethical problems arise. In this way, deliberative forums like ethics committees can serve as the focal point for generating new ways of thinking and new norms of biomedical practice in Israel today.

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