

Who Decides – the Patient, the Physician or the Rabbi?*

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I am deeply honored to have been invited to give this second annual Jakobovits Memorial Lecture. I first met the Rav as a young physician who attended his biweekly shiurim at the Fifth Avenue Synagogue. He was my teacher, guide and personal friend for over four decades.

As you all know, it was he who coined the term “Jewish Medical Ethics” which has taken firm hold throughout the world. The Rav directed this term, as well as the field, towards at least two audiences; one to the observant Jewish physicians and patients who wanted guidance on how to conduct themselves in the face of serious ethical and halachic medical dilemmas. But no less important to the Rav was the message to the world at large, which was, of course, under no particular obligation to follow Jewish norms. But the Rav felt that we, as Jews individually, and as a collective, had an important message to the world – אור לגויים, a unique, divinely inspired message which the Rav so ably articulated at every opportunity and for which he was so respected and admired.

Tonight I will try to discuss a subject of fundamental importance to medical ethics, no matter in what area, and to examine with you the basic principles and the subtle differences and similarities between the Jewish approach and that of the secular western world.

When we encounter life and death medical decisions involving a competent patient facing an ethical dilemma, who decides – the patient, the physician or the rabbi? I have deliberately posed the question in its most simplistic and attention-getting format. Obviously in no system is the decision really an either/or matter.

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The last half of the 20th century brought about many major changes in the field of medicine, aside from the obvious impressive scientific and technological advances in medical practice. Among more dramatic processes has been the change from “physician-centered medicine” to “patient-centered medicine.”¹

This change means that no longer is the physician the sole arbiter of what should happen to a patient. No longer does the physician, with his expertise, solely determine the course of treatment. Rather the patient’s wants and not merely his/her needs, have assumed major importance, and often have become the decisive factors in what actually occurs. In the field of secular bioethics, there has emerged a relative consensus about the so-called four principles; which are almost always cited in the analysis of most bioethical dilemmas: autonomy, beneficence, non-maleficence and justice; all allegedly carry significant weight but in practice, particularly in the Western courts of law, and in the western bioethical literature, autonomy usually prevails.

The factors that have pushed autonomy to the top of the priority list among ethical values, especially in the United States,² and perhaps somewhat less in the UK, are varied and complex. In essence, the changes are a continuation and accentuation of a process that began with the French revolution and the so-called period of Enlightenment. In some respects, autonomy reflects a flight from authority, whether it be political, religious or medical. In its most extreme form, autonomy can justify suicide as the ultimate expression of doing one’s own thing: indeed, suicide has been removed from the list of crimes in many Western countries, and assisted suicide is becoming increasingly accepted in some societies. But even without going to that extreme, Western court systems are virtually unanimous in insisting on informed consent before any treatment to a competent patient. A violation of this requirement subjects one to both civil and criminal action in most Western countries.

Robert Veatch, one of the more ardent exponents of autonomy, has stated categorically³ that he knows of no cases in

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1. Laine C., Davidoff F., (1996) “Patient-centered medicine – a professional evolution.” *JAMA* 275; 152-156.
 2. Wolpe P.R., “The triumph of autonomy in American bioethics: a sociological view” in DeVreis R., Subedi J. – *Bioethics and Society*, Prentice-Hall (1998): pp 38-59.
 3. Veatch R.M., (1996) “Which grounds for overriding autonomy are legitimate?” *Hastings Center Report* 26; 42-43.

which patient welfare is so weighty that it could outweigh autonomy. He claimed that “no competent patient in the United States has ever been forced to undergo medical treatment for his or her own good. No matter how tragic, autonomy should always win if its only competitor is the paternalistic form of beneficence.”

If one now asks where does the halacha stand with respect to autonomy, to the almost absolute secular requirement for informed consent, it would seem, on the face of it, that here we have a direct confrontation, a head-on collision, between the halacha and secular bioethics. This is certainly the prevalent point of view. But let us examine the issue in greater detail.

Before we get to the actual decision-process of the halacha, it is important first to call attention to two fundamental dichotomies between the contrasting world views under question – that between the Torah viewpoint and the prevailing Western secular philosophy.

First, there is the contrast between a philosophy of rights and one of duties.

These fundamental differences have been emphasized by the Rav and have been elaborated in considerable detail in the academic legal literature by two outstanding Jewish jurists, the first, the late Prof. Silberg,⁴ senior judge of the Israeli Supreme Court and subsequently by the late Robert Cover, a young law professor at Yale Law School.⁵

The concept of rights is a product of Western thought since the Enlightenment. It does not exist in its modern form in the Jewish tradition. Yet, paradoxically, the development of the concept of human rights is a product of the Jewish tradition, as was pointed out so eloquently in a recent article by Chief Rabbi Jonathan Sacks prior to the Durban conference on racism. But there is a catch – in the Jewish tradition, the child has no right to education, but the father and/or the community have a duty to provide education, and so on for many recognized human rights.

Every right, if it is to have serious meaning, must impose a corollary duty on someone. The question is then logically asked – “Well, what difference does it make if we express the same notion as a right or as a duty?”

4. Silberg M., (1961) “Law and morals in Jewish jurisprudence.” *Harvard Law Review* 75; 306-331.

5. Cover R., (1998) “Obligation: a Jewish jurisprudence of the social order,” *J. Law and Religion* 5; 65-74.

To this, I would ask you to think of a citizen who gets up in the morning aware of all the rights to which he/she is entitled. Rarely will the person at the end of the day achieve all his rights and he will thus suffer some degree of frustration. Compare that citizen to one who arises in the morning faced with an array of duties which he has to fulfill. At the end of the day, he too will inevitably fall short. But compare a society of individuals who are frustrated by what they have not received to one composed of people who have not carried out all that they should have.

To quote the famous sentence of the late President Kennedy's inaugural address "Ask not what your country can do for you. Ask what you can do for your country."

How does this relate to our topic?

In the field of medicine, the secular world does not recognize a duty to care for one's health, or to seek medical care. A corollary of this hiatus is that one may not impose treatment on a competent person against his/her will, unless that person threatens the welfare of the public. One has but to witness the tragic psychiatric cases freezing to death in the streets of large metropolitan areas in the West, to appreciate the consequences of the denial of the duty for self-care, the almost absolute right to do one's own thing even if it leads to degradation and death and the unwillingness to impose treatment on those unfortunate souls. In many Western countries, there is also no duty imposed on a physician to give medical care, even in emergencies. In halacha, the duty to render medical care is unequivocal – derived from a variety of texts including the requirement for return of lost property (והשבות לו), the admonition against standing idly by your friend's blood (לא תעמוד על דם רעך), and other sources. The duty to care for one's own health and body by consulting a physician while not as unequivocal perhaps, is nevertheless currently accepted virtually unanimously in the halacha. Paradoxically, while this duty to care for one's health would seem to preclude the need to obtain the patient's consent if he/she is obligated to obtain care, it may well provide an interesting opening for a more nuanced view on the subject, to which I will return later.

A second major philosophical difference between the Jewish and the secular world view relates to the ownership of the body. In the secular world view, a competent person clearly has full rights over his/her body. Certainly, one does not have to give an

accounting to anyone for how he/she treats their body. In Jewish thought, the human being does not have absolute rights over his body. Like everything else in the world, the body is the property of the Almighty. We are but stewards or guardians of someone else's property, as it were. To quote Maimonides:⁶ "A person's soul is not his property, but rather property of Holy one, blessed is He." Does this, as some have said, remove all rights from a person to determine what will be done to him? The answer is no, but clearly, limitations are set by the owner of the body, the Almighty, as to the boundaries of authority granted to the user. It is somewhat like renting a car or an apartment – to be used, but not abused, in accord with the rental contract.

Maimonides in his *Mishneh Torah*⁷ makes the following statement:

The rabbis prohibited many things because of danger to life. And anyone who transgresses these, saying 'I'll endanger myself, and what concern is it to others' or 'what do such things matter to me,' we inflict *makkot mardut* (rabbinically ordained lashes) upon him.

This is certainly a clear and unequivocal statement which not only forbids dangerous behavior but actually punishes it. This is a view clearly incompatible with modern day-views on autonomy. For those who might argue that fines for not wearing seat-belts conceivably could be considered in the same category, I would point out that the justification in the West for these laws is not primarily protection of the individual but rather because of the economic and social consequences of the injury.

Now what about the forcing of treatment on a non-consenting patient?

Rabbi Yaakov Emden, an 18th century Jewish scholar, wrote⁸ with respect to an individual who refused therapy on Shabbat, that he may be forced, and I quote –

in the case of an illness or wound which is exposed and about which the physician has certain knowledge and clear recognition and deals with a proven medication, it is certain that we always, in every matter and manner, impose therapy on a patient who refuses in the face of danger, because the physician has been

6. Maimonides, *Mishneh Torah Hilchot Rotzeah* 1; 4.

7. Maimonides, *Mishneh Torah Hilchot Rotzeah* 11; 4-5.

8. Rabbi Jacob Emden, *Mor u-Ketzi'ah, Orach Hayim* 328.

granted permission (by the Almighty) to cure, for example, to do surgery, to open abscesses, and to splint a limb, even to amputate a limb in order to rescue the individual from death. In all such cases, we perform the surgery and even against the will of the patient because of life-saving. We ignore his will if he doesn't want to suffer and prefers death to life, but we even amputate a full limb if this is necessary to save his life and we do all that is necessary for saving of life against the will of the patient. This obligation is incumbent on every individual because of the command to not stand idly by your friend's blood. And the decision does not depend on the opinion of the patient and he doesn't have the right to commit suicide.

Now what could be clearer than the above? The rabbi instructs the physician to ignore the patients' wishes, even amputate his leg. But it is not at all that simple. Perhaps in classic cases, for example, of someone who has severed a major artery and is in danger of bleeding to death, I am sure that there would not be a single halachic authority who would disagree with the premise that one may stop the bleeding by pressure on the artery, even against the patient's expressed will.

But even in the original response by Rabbi Emden, there are clear reservations. It's like the fine print in your insurance contract. The asterisks, which often are no less important than the text, may determine what actually happens when you have to file a claim. I will return to the reservations of Rabbi Emden shortly.

I will now quote a relatively young Talmudic scholar of modern times who seems to have reached opposite conclusions. The late Rabbi Shilo Raphael, in a discussion of the subject about a decade ago,⁹ came to the conclusion that we do not impose treatment on a non-consenting patient. He combined a triad of arguments, each of which, on its own, perhaps would have been inadequate to support his conclusion, but the three together he claimed are sufficient.

On the one hand, he quotes Nachmanides who has a particular view that does not mandate every patient to seek treatment but permits some particularly righteous ones to rely on the Lord. And

9. Raphael S., (5752) "*Kefiyat tippul refui al holeh*," in *Torah She'ba'al Peh*, 33rd conference, 74-81. Reprinted in his *Mishkan Shilo*, pp. 212-222 (Mossad Harav Kook, Jerusalem, 1995).

indeed, there are precedents among some great rabbis who actually refused treatment and relied on prayer. This view is a distinct minority view but nevertheless exists and is not to be lightly dismissed. The second point that he invokes is another minority view that man is not totally denied ownership over his body. And finally, he raises the third point that in any event, in order to enforce performance of a mitzvah under which mandate coercion is indicated, one needs a formal court of three judges, perhaps even a court not just of laymen, but of experts. Combining the minority views that one does not have to seek medical care, that one is owner of ones body and the need for a court in order to impose therapy, Rabbi Raphael concludes that imposition of therapy is essentially not acceptable in current times. He then quotes rulings by the late Rabbis Feinstein and Auerbach, who in specific cases, opposed imposition of certain therapy on patients.

What indeed are the criteria that can perhaps help us in our halachic decision making? If we go back to the original responsum of Rabbi Emden, to the reservations that he expressed some 250 years ago, we can perhaps begin a reasoned and balanced approach to what seem to be two non-compatible viewpoints. He states

We impose therapy upon him only if he wishes to avoid a proven treatment suggested by an expert, where the patient refuses because he does not wish to violate the Sabbath, but if he refuses treatment because he does not regard the treatments as effective, even in his own personal opinion and certainly if he has support by a single other physician, we do not impose treatment. Certainly, if he is afraid that the treatment that is recommended by the physician may harm him, one may not impose therapy even during a weekday and certainly not on the Sabbath.

What then are the criteria suggested by Rabbi Emden in our analysis of individual situations?

The first differentiation described by Rabbi Emden, reflecting the medical knowledge of the time, was between external diseases, whose treatment was established, and internal diseases: He states: "And for drugs made from medications that the patient swallows for some hidden ailment of internal organs, and even the physician himself does not know them certainly, but by estimation, and tries drugs that he himself is in doubt about, then certainly blessed is he

who always avoids them and does not depend on human physicians and their medications and leaves matters to the reliable healer who heals free of charge.” This distinction between external lesions or those which are man-made and those which are internal or spontaneously appearing diseases, had been cited by Ibn Ezra many years earlier in an attempt to rule that only in the case of the former is there an obligation to take medical therapy.

But if we try to project these views into modern terminology and current conditions, it is difficult to sustain the differentiation between external lesions and internal diseases in its literal sense. What is being argued, I believe, is the degree to which the diagnosis and the therapy are proven. Therapy may be imposed only if the diagnosis and treatment are relatively certain. Today, with the watchword of the term “evidence-based medicine,” one would say that the first criterion for the possibility of imposition of therapy is the quality of the evidence both diagnostically and therapeutically. If there are significant questions about the diagnosis and the treatment, then the patient’s opinion is given significant weight.

It is worth pointing out that too many of us physicians are often guilty of over-confidence and arrogance in presenting diagnostic and therapeutic options to patients, far beyond what the real evidence can sustain. Certainly, before considering coercion or even psychological pressuring of a patient, a small dose of humility for the physician would do no harm.

Interesting in this regard is the decision reached just a few years ago by the late Rabbi Haim David Halevy¹⁰ in a well publicized case of a teenager who had a lymphoma and refused chemotherapy, wishing to rely on homeopathy. Rabbi Halevy specifically cited Rabbi Emden’s reservations about internal diseases under which he considered the lymphoma to fall, therefore precluding coercion. In addition, to the chagrin of many others, rabbis as well as physicians, he did not reject alternative medicine. One may take exception to the particular ruling and as to whether the principles relied upon were properly applied in this case. But the principles were, first uncertainty about the effectiveness of the proposed therapy, especially in the judgment of the patient, and the patient’s right to prefer another form of therapy.

The second factor to be considered beyond the efficacy of the

10. Halevy H.D., *Aseh Lekha Rav* 5:52-53.

treatment is the danger involved in the treatment.

There is considerable discussion in the halachic literature about undergoing surgery which may have a significant immediate risk for the sake of a greater chance of long-term survival. The halachic terms, used are short-term life (חיי שעה) and long-term life (חיי עולם). The consensus is that one may risk a חיי שעה for חיי עולם, but one is under no obligation to do so and one certainly may not force a patient to take this risk. Here, there is unanimity by two of the greatest modern halachic decisors. Rabbi Shlomo Zalman Auerbach was presented with a case of a blind diabetic with one leg who developed gangrene of that leg, which, according to the physicians, necessitated amputation to save his life. The patient refused, citing fear of the pain and suffering resulting from the operation plus the unwillingness to remain a double amputee. Rabbi Auerbach decided¹¹ that he was not to be coerced and not even to be forcefully persuaded. Similarly, Rabbi Moshe Feinstein ruled¹² that one should not impose risky treatment on a competent adult who refuses to consent to treatment. Rabbi Feinstein, who was willing to allow a competent patient to undergo dangerous surgery even for a small chance of success, was unwilling to force a patient to undergo surgery which has only minimal risk.

Again, here in the face of any significant risk, patient consent is essential, even according to the halacha. The patient's consent does count and may not be ignored. When dealing with actual coercion, Rabbi Feinstein has two responses which add another important dimension to be weighed. With respect to forcing a patient to take a particular medication essential for treatment, Rabbi Feinstein indicates that this is theoretically permitted were there total consensus among the physicians that such treatment is essential. But he adds a reservation, a proviso, that the patient is not frightened by the prospect of physical coercion, because the fright or the stress of coercion itself may present a danger to the patient. And Rabbi Feinstein adds that in the case of an adult, who refuses medication, the physician should weigh very carefully the risk of coercion against the benefit of treatment before deciding on a course of coercion. He also states that in all probability, an adult coerced into treatment may not benefit from such treatment.

11. Abraham A., (1982) *Nishmat Avraham to Yoreh De'ah* 339; 4 p. 246.

12. Feinstein M., *Teshuvot Igrot Moshe, Hoshen Mishpat* 2, #73.

In a second responsum¹³ Rabbi Feinstein discusses force-feeding patients. In general, the halacha regards food in a category that differs from medical treatment. Whereas under certain conditions, withdrawal of medications or treatment may sometimes be sanctioned, the withdrawal of food is generally regarded as equivalent to murder and is not permitted under any circumstances. Yet, when the question of forced feeding on an adult was posed, Rabbi Feinstein stated:

But to actually restrain a patient and force-feed him, one should not do this to a competent adult who does not want to eat, especially if the patient thinks that the food is not good for him. Even if the physician thinks he should be fed and the food is beneficial for him, because if a person thinks that the food is not good for him, the eating may be dangerous to the patient if he does not heed his request. The physician should try to influence him to follow medical instructions, but if unsuccessful, one can do nothing about it.

Here, we have another important element, the subjective feeling of the patient taken into account, expressed not at all in terms of autonomy, but in terms, if you will, of beneficence. Overriding the patient's expressed decision, says the rabbi, will not benefit the patient and may harm him. Thus, we may arrive at the same conclusion either via autonomy or via beneficence.

But even if we accept the idea that under the halacha one may coerce a patient to accept treatment, the question is then logically posed, "who is authorized by Jewish law to coerce a patient?" A number of rabbis, including Rabbi Shilo Raphael, have discussed coercion under the rubric of the Jewish law that one may force someone to perform his religious obligations. If this is the route by which we proceed, then the authority for such coercion is granted only to a legally constituted Beth Din, a court of three halachic experts. But still more problematic is the generally accepted ruling that authority for coercion for mitzvah performance does not exist at all nowadays. Thus, this entire discussion becomes really theoretical only, if the basis is the coercion to perform a mitzvah.

However, I suggest that one may perhaps look at the issue not so much from the obligation of the patient and his coercion to

13. Feinstein M., *Teshuvot Igrot Moshe, Hoshen Mishpat 2, #74.*

fulfill a mitzvah, but rather on the obligation of the physician to save someone's life. One does not need a Beth Din to sanction such action and this may provide the opening for a possibility of coercion. As we have just seen, while theoretically one does not need consent, because both the physician and patient have clear obligations for life-saving treatment, in the realities of daily life in medicine, rarely are treatments 100% certain; even rarer are treatments without risk – and when questions of efficacy and risk/benefit consideration are involved, as they usually are, the patient's consent is essential, according to the halacha, as well.

More recently, the late Benjamin Freedman, an orthodox Jewish professor of philosophy and bioethics in Montreal, has tried to put an even stronger emphasis on informed consent from a specifically Jewish point of view, not as a "right" in the secular sense, but as a duty incumbent on the patient.¹⁴ He emphasized the duty of the individual as a guardian or steward of his/her body and health in terms of a *shomer*. If someone places an object in my custody and asks me to watch for him, the *shomer* (watchman) undertakes very serious obligations. According to the Jewish tradition each of us has been given our body for safekeeping by the Almighty. This is a more valuable possession than any material goods and therefore one may not be casual or careless about it. When a physician proposes a treatment to a patient, the patient is obligated, if he is a conscientious *shomer* of his own body, to investigate the physician's proposal thoroughly. In spite of all the great and impressive achievements of medicine as a whole, not all physicians are equally competent or equally conscientious, and all too often, their recommendations are far from being deeply thought out. Therefore, it is incumbent on the patient to question, to investigate and then to weigh the proposal. Furthermore, we recognize in medicine that patients with identical diseases differ one from another. It is not always the physician in his infinite knowledge that has all the answers.

The Talmud too recognizes that in some situations the individual patient may really feel and judge better than the physician what suits his particular need. There is an expression הלב יודע מרת נפשו (the heart understands the bitterness of its soul) which means that the patient often has better insight into his/her

14. Freedman B. (1999) *Duty and Healing: Foundations of a Jewish Bioethic*, Routledge, New York, pp. 139-142.

problem than any outsider, even if the outsider is a physician. Under certain conditions the patient's self-described and self-prescribed needs override even the opinion of medical experts.

Thus, it is incumbent on the Jewish physician not merely to tell the patient what he recommends and then act as if the patient's consent is irrelevant, because the patient is not obligated halachically to accept a medical recommendation as *Torah min Hashamayim* (Torah from heaven). The physician does not only have an obligation to obtain consent, but has a responsibility to provide the patient with all the information that a conscientious *shomer* needs to carry out his God-given responsibility fully.

This is an interesting and somewhat original emphasis on informed consent from a Jewish point of view.

We have thus come a long way from the simplistic view that consent plays no role in the halachic view of medical treatment.

I would now like to get to a practical modern day narrative of some real cases to see how they play out or perhaps should play out. My focus will be the tension between autonomy and paternalism or, as a colleague of mine more correctly refers to it, parentalism, since mothers, especially the proverbial over-protective Jewish mother, often have a no less dominating role than fathers. Who makes, or should make critical decisions?

I will begin with an incident described in the *Journal of Medical Ethics* in the UK some three years ago by Dr. Brian Hurwitz.¹⁵ He wrote of an elderly widow who had developed a huge basal cell carcinoma of the umbilicus which had grown, become ulcerated and infected. This condition was relatively easily curable by simple radiotherapy, with virtually no side effects. But the patient adamantly refused to visit the clinic to accept treatment, apparently because of a fear of hospitals. The care of this lady at home was consuming home nursing resources and had forced the son to quit his job in order to take care of the mother. Dr. Hurwitz's colleagues who had been caring for this elderly lady had made their peace with the situation. But when Dr. Hurwitz came on the scene, he decided to ignore the patient's refusal of therapy, ordered her to attend the hospital clinic and had her taken by ambulance to the hospital for treatment, over her stated objections. The lesion was treated with complete success. Dr. Hurwitz in his article agonizes over his

15. Hurwitz B., (1998) "Pressuring Mrs. Thomas to accept treatment: a case history." *J. Med. Ethics* 24;320-321.

success. He asks: "Did I apply undue pressure upon Mrs. Thomas?" Interestingly enough, and a sign of the times, Dr. Hurwitz, in discussing the motivation for his actions, places less emphasis on the obvious benefit for the patient and focuses rather on his responsibility towards the community nursing staff, and other patients in the region, "not to allow scarce and valued resources to be consumed by a futile and irrational treatment strategy."

In other words, in spite of the clinical success of his actions, this conscientious physician is not certain that he acted properly. One also gets the impression that were it not for the considerations of resources, and the impact on the son and others, he might not have imposed his will on the patient.

As a disciple of Western bioethics Dr. Hurwitz's hesitation is indeed justified, because of the dominant priority assigned to autonomy in the list of bioethical values.

As an American by birth and training in the North American spirit of individualism and civil rights, I applaud the contribution of autonomy to the practice of medicine. It has greatly enriched the tapestry of medicine, has made it more sensitive to patient needs and desires, has tempered the often arrogant and insensitive parentalism which has unfortunately characterized medicine for much of its long history. This traditional "physician knows best attitude" coupled with the sudden plethora of new and modern technology, often applied mindlessly and cruelly to patients, appropriately spawned a patients' revolution which led to the triumph of autonomy, and to patient empowerment. But I maintain that the pendulum has swung too far in the direction of autonomy to an extent not compatible with the Jewish tradition and that a redressing of the balance for the good of the patient is in order. Dr. Hurwitz should be congratulated on his act, even had he not conserved community resources, but had acted only for the patient's good. Indeed I published an article to that effect in the *Journal of Medical Ethics*.¹⁶

Israeli medicine, too, is undergoing a major evolution or revolution in the area under discussion. I recently reviewed¹⁷ the process of patient empowerment in Israel over the past half century. Israeli medicine has its roots solidly in Middle and Eastern

16. Glick S.M. (2000) "The morality of coercion." *J. Med. Ethics* 26;393-395.

17. Glick S.M. (1998) "Patient empowerment in Israel." *Medicine and Law* 19; 78-83 (Hebrew).

Europe. There the physician was completely dominant in the physician-patient dyad – a model exemplified vividly by the physician in Tolstoy’s “The Death of Ivan Ilyich.” And the Israeli courts in their decisions in the 1950’s and 1960’s accepted this model. But as part of our Americanization, along with MacDonal’d’s and Pizza Hut and other great contributions of American culture, Israeli courts, legislation and practice have moved much closer to the American autonomy model – but not quite all the way, and it is this difference that I want to discuss.

Another story – this one from my own department of medicine.¹⁸ I was sitting in my office minding my own business one morning when the head nurse came in with a high ranking officer from the prison service informing me that a prisoner had just been admitted to my department. He was one of a group of hunger strikers whose condition had deteriorated to the point of danger to his life. Since this was a most unusual and delicate situation, I decided that rather than have the junior house officer proceed immediately to the admission history-taking and physical examination as is usually the case, I would meet with the prisoner first in person to discuss the issues. He was a pleasant, articulate young man in his 20s who had the usual appearance of a *haredi* Jew, with a beard, *peyot* and a large *kippah*. He was engaged in reading a religious tract.

After a few pleasantries, I explained that he had been sent to the hospital to be fed, even against his will. I pointed out that I was under two sets of orders to feed him, one from the legally constituted Israeli court and the other from a divine edict that commands me not to let a fellow human being die if such an event can be prevented. He responded quite calmly, firstly that he rejected the authority of the court, since he regarded it as part of the corrupt system against which his protest was directed. With respect to the divine edict, he pointed out that his *rav* had instructed him that there are situations in which one is commanded by this same divine authority to sacrifice one’s life for a greater cause. He indicated that he would not be dissuaded from this firmly held position.

I indicated that we had the will and the ability to feed him even against his will and that it would be much more pleasant for all

18. Glick S.M. (1997) “Unlimited human autonomy a cultural bias?” *New Eng. J. Med.* 336; 954-956.

concerned if he did not resist being fed through a nasogastric tube. He asked for time to think it over, then questioned the nature of the nutriments which he would be given – whether they would meet his particularly stringent kosher standards. After assurances that this was so, he then asked to deposit with me a statement addressed to me, with copies to a variety of media and public officials, stating that he was being fed against his express wishes and that when justice would ultimately triumph, I would have to bear the legal and criminal consequences. When this was accomplished, he offered no resistance and accepted tube feeding “under protest.”

The Israeli district judge in his order¹⁹ to have the prisoner fed, summarized the issue clearly “when there is direct conflict between human life and human dignity, human life must be given priority.”

The decision by this Israeli court based on the Jewish tradition stands in striking contrast to a situation in Turkey in which at least 40 hunger strikers have died: to previous political hunger strikes in Ireland and South Africa; and to the generally accepted position of Western bioethicists, as reflected in the Tokyo Declaration. I am convinced that my particular hunger striker was ultimately pleased with the turn of events. He received the necessary attention, yet he was prevented from dying by a superior power. In essence, he was able to have his cake and eat it too.

This decision is also in keeping with a 1985 Israeli Supreme Court decision²⁰ in which the court ordered surgery on a non-consenting patient to remove bags of illegal heroin that he had swallowed to save his life in case the bags ruptured in his stomach. This court decision was, and still is, criticized widely by civil rights advocates.

When, a decade later, and after years of discussion, Israel was ready to pass a patient’s rights law, eventually enacted in 1996,²¹ the subject of autonomy came under discussion. Much of the law was relatively non-controversial, but one clause in the original bill created considerable debate. It required that informed consent be obtained before treatment as in most Western countries, and it spelled out in considerable detail the information to be provided to the patient. The legislators were faced with a major dilemma,

19. State of Israel vs. Rahamim Gibli, originating motion 829\ 26A; 1996.

20. Kurtam V., State of Israel, Israeli Supreme Court (1986) AP 480/85 (527/85).

21. Patients’ Rights Law 1996 – Laws of State of Israel. Jerusalem, Israel Government Printing Office, 1996:327.

however: what to do when a patient refuses a treatment that is clearly lifesaving. The government's chief legal counsel convened a meeting of about thirty physicians, philosophers, lawyers and clergy to discuss this issue. The civil libertarians in the group, of course, took the standard Western position – namely, that under no circumstances could therapy be rendered against the will of a competent patient, unless the patient's illness threatened the welfare of others, as in the case of certain communicable diseases.

But others in the group would not accept this position. The rabbis, of course, opted for sanctity of life being supreme. One of Israel's leading philosopher-ethicists stated dramatically:

I simply am incapable of standing idly by and watching while someone lies on the railroad tracks waiting for an approaching train in order to commit suicide, without making an effort to prevent that person's death, even against the person's will." The final compromise, a bit unusual by any standard, permits a competent patient to be treated against his or her expressed will if the legally constituted hospital ethics committee is convinced that there is "reason to believe that after receiving the treatment, the patient will give.... retroactive consent.

This compromise might legitimately be seen as a bit of Talmudic *pilpul* to justify physicians' parentalism and disregard of patients' wishes.

I must confess that my initial reaction to this compromise was quite negative. But as a result of a particular case which was brought to my attention and as a result of further consideration, I have become convinced of the wisdom of this approach. Not too long ago, a young, otherwise healthy Bedouin man was admitted to an Israeli hospital with pneumococcal pneumonia, an eminently treatable disease in his age group. He got into serious respiratory difficulty, to the extent that intubation and assisted ventilation was unquestionably indicated as a lifesaving, albeit temporary, step. He however, adamantly refused, in spite of all attempts, including family members and interpreters, to persuade him to consent. His physicians did not take advantage of the clause in the law permitting the possible imposition of treatment in this cases, but accepted the patient's refusal and treated him without intubation. The patient died.

Ironically a recent article²² in the *New Yorker Magazine* by a physician described an almost identical case in the United States, with an opposite and surprising ending. A man, in his late thirties, with bacterial pneumonia, in serious respiratory distress, refused intubation in spite of all efforts to persuade him. The physicians, in this case, also honored his refusal, but immediately upon the patients' loss of consciousness intubated him, attached him to a respirator and sedated him. When his condition improved, some 24 hours later, the sedation was stopped, and the tube removed. The patient's first words were "Thank you."

The Israeli patient's death would be considered perfectly acceptable by many Western ethicists. But I would disagree strongly, and consider the death an unnecessary and preventable tragedy. Here was a patient, acutely ill, with a curable disease. The physicians were not dealing with a patient who was suffering from a terminal illness, who was looking forward to death as a salvation. This patient, while technically and legally competent, obviously feared the intubation. But had his life been saved by several hours of mechanical respiration, he, his wife and young children, would undoubtedly have been eternally grateful to the physician who had the courage to act decisively. Under Israeli law, such a step would have been perfectly legal. But the Western influence of autonomy, reigning supreme, influenced this man's physicians to accept his tragic choice. The American physicians, who actually violated American legal and ethical norms, I believe acted appropriately, in accord with the spirit of the Israeli law.

I believe that more careful examination of the specific cases, is indicated, applying a more nuanced approach to terms such as competence and autonomy. If competence is regarded as an all-or-none phenomenon and autonomy as an absolute trump over all other values, obviously the Israeli law is unethical. But in evaluating a specific case, in the tradition of classical Jewish responsa, the details are critical.

The degree of competence of patients, all of whom are certified as "competent" by a psychiatrist, may vary from patient to patient, and many acutely ill competent patients have been shown to have

22. Gawande A. (1999) "Whose body is it, anyway." *New Yorker Magazine*, October 4, 84-91.

serious impairments of judgment.²³ Autonomy is predicated on a rational determination, free of coercion; not just coercion by a physician, but also by the overall circumstances. The reasoned, repeated, well thought-out decision by a chronically ill cancer patient should clearly be given greater weight than a hasty decision by an acutely ill, frightened patient, although technically competent. Is not fear coercive and does its presence permit real autonomy?

In June of this year there appeared a report in the *Annals of Internal Medicine* which demonstrated that sick patients have serious impairments of judgment and that their performance on several Piagetian tasks of judgment was similar to that of children younger than 10 years of age. Dare we let a person die on the basis of a lack of consent by such a patient?

The ethics committee is charged with weighing the quality of the competence of the patient, the degree of his/her autonomy, the potential for risk and suffering in the procedure, the likelihood of its success, the danger of refusal and the likelihood of the patient's subsequent reversal of his earlier refusal. If, on balance, the scales tip toward imposing treatment on a currently unwilling patient, they may so decide.

This "escape clause" is not intended for frequent or routine use. Far from it; and as the case of the Bedouin patient indicates, it may be underused. But when the magnitude of the beneficence is huge, and the weight of the autonomy consideration weak, why not let beneficence "override" autonomy?

One should also ask the question whether autonomy is an end in itself or merely a means to an end. If it is merely means to an end, it may be foregone for a greater good. Autonomy is of no value to a dead person. By permitting a patient to die avoidably, when it is virtually certain that were he saved against his present protest, he would be grateful, one is granting that person his short term "autonomous" wish while depriving him of his/her long term autonomy. The Israeli Law's line of reasoning is similar to that of John Stuart Mill, the philosopher champion of autonomy who regarded freedom as the end. Therefore, he refused to permit an individual to sell himself into slavery, because he thereby misuses his autonomy to deprive himself of freedom, which is the ultimate

23. Cassell E.J., Leon A.C., Kaufman S.G., (2001) "Preliminary evidence of impaired thinking in sick patients." *Ann. Int. Med.* 134; 1120-1123.

raison d'être of autonomy. With respect to slavery Western countries all seem to accept that reasoning and do not allow even competent autonomous individuals to sell themselves into slavery.

Similarly if the ethics committee errs in coercing the patient who subsequently persists in his/her withholding consent, the patient's autonomy has indeed been violated, which is not to be taken lightly. On the other hand, if the ethics committee errs in the other direction and permits the patient to die, in a situation where the patient might, in retrospect, have wanted to live, the damage would seem to be infinitely greater; there is no reversal of death.

What is it about Israeli society that prevents it from accepting the total triumph of autonomy over beneficence, aside from the East European paternalistic roots of Israeli medicine and the old socialistic ethos of the central authority which knows best what is good for the citizen?

The first of these factors is the emphasis on the value of human life in the Jewish tradition. Virtually all the religious imperatives and restrictions are overridden when there is a threat to human life.

This philosophy has been expanded and popularized by Rav Jakobovits over and over again in terms of what he has referred to as the infinite value of human life. While this is ultimately a religious value, even secular Israel is deeply rooted in this culture, and in times of stress, people tend to gravitate towards tradition.

A second major factor that results in occasional imposition of treatment even on unwilling patients, is the strong communitarian ethic, which characterizes Israeli society. Virtually every Israeli Jew feels part of a community because of a shared historic experience, a collective solidarity and a whole variety of other reasons.

The classic Talmudic statement: "all Jews are responsible for each other," and perhaps for each other's needs as well, expresses it well. No man is an island. An individual's death is not just his or her private and personal affair only, but diminishes the entire community. If a near and dear one of mine were headed deliberately and voluntarily for an obvious disaster, I could not be indifferent about it, and would undoubtedly intervene.

In many ways, perhaps the entire country is still a family – a big family, but a family just the same. Families have distinct advantages as well as disadvantages. In a family people care about you. On the other hand, you must give up some measure of autonomy and privacy. Your affairs and your welfare are everybody's concern,

even to an annoying degree. Certainly, your protective Jewish mother will want to make sure you stay healthy and live to 120 years. She certainly will do everything to prevent you from dying.

Therefore, autonomy does not reign supreme, and human life is given a higher priority than in the West.

The trauma of the Holocaust also contributes in a major way to the ethos of Israel. Rightly or wrongly, it affects any discussion about euthanasia and any deliberate taking of human life, even that of criminals. But a no less relevant dimension is that the Holocaust is often remembered in terms of the failure of the nations of the world to take action to prevent the death of others. The Israeli aversion to indifference may be a national neurosis, but we have come by it honestly.

It is interesting that in talking about patients, we hear a great deal about the importance of autonomy. But when physicians themselves are ill, they are not such great advocates of autonomy for themselves. In an editorial review²⁴ of their experience in writing the book “When Doctors get Sick,” Spiro and Mandell state the following: “The accounts of sick doctors rise doubts about some popular ethical concerns such as autonomy or parentalism..... Autonomy find little favor with sick doctors who are mostly relieved when another physician takes over their case.... They suggest that a judicious parentalism may be in order.”

Let us return now to the title of my talk – who decides? Whereas the secular world has made a complete turnabout from physician-centered medicine in which the physician had the almost exclusive rights of decision making, to patient-centered medicine where the patient now has all the decision-making power, the ideal Jewish system introduces a third participant – the rabbi who represents the religious and ethical norms. Each of the participants has a clear role – indeed a series of duties, rather than rights.

The physician has the medical and scientific knowledge and he/she has a duty to put it fully at the disposal of his/her patient. The patient has a duty to himself to obtain all the information to match it with his own gut feelings, fears and understanding of his own needs. And the third participant, the rabbi, should give halachic guidance and pastoral support to the patient and physician in their critical decision-making process, and to bring to bear the

24. Spiro H.M., Mandell H.N., (1998) “When doctors get sick.” *Ann. Int. Med.* 128; 152-154.

external values of the Jewish tradition. In most complex cases none of the three has the absolute decision-making power. By listening to each other with an open mind, by discussing all the ramifications of the decision-making process it is hoped that the decision will bring relief and cure to the patient, and will be medically and ethically and halachically proper.

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