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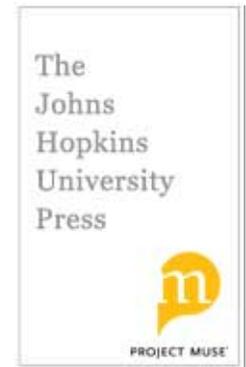
The New Israeli Law on the Care of the Terminally Ill:
conceptual innovations waiting for implementation

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THE NEW ISRAELI LAW ON THE CARE OF THE TERMINALLY ILL

*conceptual innovations waiting
for implementation*

Y. MICHAEL BARILAN

ABSTRACT Israel has recently enacted a law on the care of terminally ill patients. This law, the Patient Nearing Death Act, is the first of its kind in the world. The law divides terminally ill patients—upon their own wishes—into two separate groups: “those who wish their lives be prolonged,” and those who do not. Doctors will have to abide by elaborate advanced directives and take into account various sources of information on the presumed wishes of the patient. The law sanctions discontinuation of mechanical ventilation should it become a “cyclical” rather than “continuous” therapy, a provision that has implications for the use of the already available paraPAC ventilators. The law exposes gaps in modern Judaism between the religious law and the attitudes of the observant population with regard to medical ethics.

IN DECEMBER 2005, following five years of public and parliamentary deliberations, the Israeli Parliament (Knesset) enacted the Patient Nearing Death Act (Knesset 2005). This law has been endorsed by both liberals and religious conservatives, groups that elsewhere have not reached consensus on the regulation of the end of life. Although a few countries have laws on euthanasia, the new Israeli law is the first law worldwide whose scope is the regulation of medical care at

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the end of life. The new law contains novel concepts and approaches to the care of the terminally ill, all inspired by *halakhah* (rabbinic or Jewish religious law). Although Israel is a secular country whose legal code derives from British common law and is independent of—and sometimes opposed to—rabbinic law, lawmakers wish to take Jewish law and values into account, particularly in regulating sensitive issues such as health care. Besides, although always a minority, the religious parties in the Knesset have managed to thwart legislation that significantly offended religious values. This paper will survey this new law, devoting special attention to some of its novel aspects, and will also discuss some of the topics deliberated in the process of legislation.

HISTORICAL BACKGROUND AND A SYNOPSIS OF THE PATIENT NEARING DEATH ACT

Until the enactment of the 1996 Patient's Rights Act (Knesset 1996), medical care in Israel—with the exception of abortion—was subjected only to the “reasonable physician standard,” and there were no laws that directly governed medical practice. Disagreements between religious and secular representatives in the Knesset regarding a section on “the right to death with dignity” resulted in the omission of end-of-life issues from that law. This omission, however, cried out for attention, as patients kept petitioning the courts for permission to refuse and even stop “life-saving” medical care. In 2000, the Minister of Health appointed a public committee, headed by Rabbi Dr. Avraham Steinberg, to draft a law dedicated to end-of-life issues and based on the broadest possible consensus. In 2002, the Steinberg Committee published its report, which served as the basis for the final law (see Barilan 2003, 2004; Ravitsky 2005).

At a practical level, the new Israeli law divides terminal patients into five categories: those who wish to die and forgo medical treatments; those who wish to go on living and to receive standard medical care; those who wish for life-maintaining care even “beyond accepted practice”; those who do not have, or have not expressed, any wish regarding their medical care; and incapacitated patients such as minors.

The law requires doctors to inform terminal patients about their condition and to make patients classify themselves as either “those who wish their lives be prolonged” or as those who do not. Basic care such as nutrition, hydration, and oxygen will be given to all, but more advanced medical therapy may be withheld from the latter group, following the patients' wishes: if the latter are documented by specially prepared advanced directives, the doctors will have the duty to comply. The new law is not part of the criminal code. Violators of the law are liable to civil suits as well as to disciplinary measures by the Ministry of Health, the Israeli Medical Association, and their direct employers.

The law declares that a typical person wants to live, and that in the absence of evidence to the contrary, he or she should receive life-prolonging medical

treatment. The presumption is reversed, however, when life expectancy has shrunk to less than two weeks, “a plurality of vital systems are failing,” and the patient is suffering significantly. Only when all of these conditions obtain is it assumed that the typical person does not wish for more than palliative treatment.

CONCEPTUAL FRAMEWORK

Possibly as a result of the bitter and sterile 1996 debate on the “right to death with dignity,” the word *dignity* does not appear in the new law. Its preamble delineates three fundamental values: the “sanctity of life,” the “autonomy of human will,” and the “importance of quality of life.” Correspondingly, decisions are to follow only the “medical condition of the patient, his or her wishes and the degree of suffering.”

Two key terms in discussions on end-of-life ethics—*sanctity of life* and *death with dignity*—do not exist in traditional rabbinic Judaism. Contemporary rabbinic Judaism, and consequently the new Israeli law, has imported the term *sanctity of life* but not *death with dignity*. One reason for this difference might be the centrality of the “sacred” in religion and the strong vitalistic trends within Jewish philosophy and mysticism (Weingarten 2004).

Rabbinic law (as opposed to secular Israeli law) is duty-based rather than value-based. The relevant duties regarding patients are the duty to save life and the duty to return lost goods. The good in question is health. According to Jewish law, when a terminal patient wishes to end his agony and die, killing is not a violation of interpersonal duties. Rather, prolongation of life may be considered as “delaying death,” which is a serious violation of the duty of neighborly love. However, the *religious prohibition* (duties to God only) on homicide obtains regardless of each person’s wishes. For this reason, especially in the context of the relief of suffering, when the “lost good” of health cannot be returned and life could be saved only temporarily, the rabbis feel committed morally to the welfare of the patient, even at the price of bending religious law and stretching it in the most lenient way possible.

Moreover, since every person is bound by the duty of neighborly love, and since the rabbis accept the notion that extreme and irremediable suffering can make life intolerable, whenever Jewish law deems passive euthanasia as *permissible*, this act becomes an ipso facto *duty* incumbent on anyone who can help, within the limits of the prohibitions on homicide.

On the other hand, if a person wants to go on living, both religious interpersonal duties and duties to God forbid any action or omission of action that might shorten his or her life. Indeed, in opposition to the Catholic and utilitarian traditions, considerations of justice with regard to the prudential use of health resources has not been applied to medical treatments (Bleich 1996). Indeed, the new Israeli law invests terminal patients who wish to live with unprecedented powers to receive medical care.

Many Israeli doctors subscribe to Hippocratic ethics and object to any form of discontinuation of life-support. It is evident, however, that the presence of positive religious duty of such a fundamental character, to interfere on behalf of terminal patients who suffer, prevailed upon the rabbis and pushed them in the direction of the “right to choose death with dignity” camp. The latter has supported the law as well, even though the liberal jargon of a “right to die” and “death with dignity” are absent from the law.

SCOPE AND PRINCIPLES

The jurisdiction of the Steinberg Committee was limited to “terminal patients,” which the committee defined as a life expectancy of less than six months. This definition was based on the fact that a majority of references in the clinical and bioethical literature use this time span. From a legal point of view, the homicide of a person whose life expectancy is less than a year—a person referred to as *terefa* in Hebrew—is a lesser offense than the homicide of an ordinary person. Although from moral and theological standpoints, the murder of the vulnerable is no less abhorrent than any other murder, the legal differentiation between *terefa* and all other persons might help those *terefa* who wish to die (Sinclair 2003, chap. 5). Restricting the definition of terminal illness to a life expectancy of less than six months places the special arrangements accommodating patients who wish to die on the “safe side” of Jewish law and human error in prognostication (Lamont and Christakis 2001). As far as I know, the two-week period mentioned earlier has no basis in Jewish tradition and law.

The focus on terminal illness at the expense of extreme disability leaves out many patients, possibly the hard core of those struggling to end their own lives. The subjects of milestone cases on the right to die—Quinlan, Cruzan, Bouvia, Sampedro, and Schiavo, for example—were not expected to die imminently when the legal battles over the discontinuation of their care took place. Ironically, therefore, the new law offers escape from agony and from dependence on life support only to those whose sufferings are, in any event, about to end. Some jurists worried that the new law might even harm non-terminal patients on life support, or with other forms of extreme debility and dependence, by excluding them from processes that restrict medical care. I believe, however, that the new law will encourage the courts to be even more receptive to other suffering patients whose plight is similar to those covered by the law.

Ethics committees will have the power of arbitration whenever someone contests a particular policy of end-of-life care. Any person worried about the well-being or just treatment of a terminal patient may appeal to the committee, and maximal life-sustaining treatment will be given until the committee issues a ruling.

The 1996 Patient’s Rights Act mandated ethics committees in every public hospital; for various political and technical reasons, however, the vast majority of

those committees have never convened. The new law chose not to rely on the existing system, but to have its own special committees. It is not clear at all why the 2005 legislators had faith in the function of a new set of ethics committees. Additionally, setting the affairs of dying patients apart from all others is a dangerous precedent that might spill over into other sectors of healthcare. The value of human solidarity embodied in a national health care system is incompatible with advocates of certain groups of patients, such as those with breast cancer or juvenile-onset diabetes, who promote their own special laws, nominating dedicated committees and bypassing the National Committee for the Health Basket, whose mandate is to allocate public medical funds, distributing them justly among all those who need medical care.

ADVANCE DIRECTIVES

The 1996 Patient's Rights Act declares that a patient has a right to receive all of the information on his or her condition, but it does not specifically require doctors to take action when patients remain silent and do not try to exercise this right. Under the new law, doctors must elicit and document the genuine wishes of the patient. It is hard to see how this can be done without the latter being duly informed. Moreover, the new law demands that the doctors periodically reassess the wishes of their patients and make sure they have not changed their minds. All of these communications must be properly recorded in the patient's chart. It will be impossible to camouflage omissions in patient information, since lack of documentation in the chart regarding a terminal patient's wishes is in itself a violation of the law.

I believe this legal duty will alter the habits of disclosure in Israeli medicine. Many—perhaps most—doctors tend to collude with family members who plead that “bad diagnoses” be withheld from an ailing and aged parent. Many doctors hold back information from patients deemed “unfit” for processing it.

When healthy patients anticipating a medical crisis that might leave them incapacitated write advance directives, a nurse or a doctor must sign the directive, testifying that the patient has received the appropriate explanations on medical issues such as mechanical ventilation or dialysis. The official forms of advanced directives are quite elaborate, allowing patients to choose from a menu of possible treatments which ones they wish to have (e.g., “amputation of fingers”) and which not (e.g., “blood transfusions”).

While patients' advocates might worry about excessive bureaucracy stymieing the preparation of advance directives, the law offers some remedy for this concern. It declares that, although advance directives that fail to meet all the formal criteria of the law—attestation by doctor or nurse, as well as renewal every five years—are not strictly binding, doctors have a duty to “take into consideration” such directives “in the process of recovering the authentic wishes of a patient.”

**BALANCED RESPECT FOR NO-TREATMENT
AND FOR VITALISTIC TREATMENT**

Similar to the development of end-of-life ethics and legislation in the West, the Israeli law was enacted following litigation initiated by patients or by patients' refusal to receive life-saving or life-sustaining care. However, the new law calls for a balanced attitude, vouchsafing the rights of terminal patients to receive life-saving and life-sustaining care, even against the standards of medical practice, with the exception of procedures that doctors find likely to be "significantly harmful to the patient or others." Thus, the law avoids the problem of futility by instituting the patient's right to receive any medical care to be found in the arsenals of Israeli biomedicine, as long as it aims at the prolongation of life, is "not harmful," and is within the limits of the "standard regulations of the Israeli healthcare system." Unfortunately, the law is not all that clear at this point. What it seems to say is that patients have the right to insist on reasonable treatments (antibiotics for fever, platelet transfusions for low platelet count, etc.), even when doctors believe it is unlikely to benefit this particular patient, but not to receive care which has no basis in the standards of good clinical practice (radiation to a tumor that is not radiosensitive). The Steinberg Committee considered a not-uncommon situation, in which relatives of patients insist on broad-spectrum antibiotics, while infection control specialists oppose the futile use of antibiotics that are likely to result in the spread of resistant bacteria. Does the new law preclude this practice as "significantly harmful"? Time will tell.

Not only does the section on the right to life-saving care "beyond standard" constitute an unprecedented intrusion into medical jurisdiction in a manner far exceeding the standards of the strictest and most vitalistic streams of Jewish law and tradition, it also creates some strange paradoxes.

Despite the law's explicit commitment to a "balanced" approach towards terminal patients who wish to die and those who wish to go on living, the legally and morally laden word *right* is used only with regard to access to care beyond standard life-prolonging means. Moreover, as far as I know, nowhere else in the history of rights there has been a claim-right (a right to receive action, for example, a right to receive certain kind of health care) for an action that is beyond standard (see Barilan and Brusa, n.d.).

Suppose we do wish to incorporate a claim-right to beyond-standard care—does it make sense to grant such a right to terminal patients, as opposed to other patients, and to life-prolonging care, as opposed to palliation? The 1996 Patient's Right Act does not grant *curable* patients the right to receive care that is above the minimum level of service provided then by the largest health insurance in the country, but the new law grants *hopeless* patients the right to receive care that is outside the standards of medical practice. If there is some logic in fighting for life against all odds, it is only when the patient is still curable and in good shape, not when he or she is by definition terminal.

Although Jewish law demands extra efforts for the relief of suffering even more than for saving life (Bar Ilan and Barilan 2005), the Patient Nearing Death Act does not acknowledge a right to extraordinary palliative care. The law specifically requires that palliation be given, subject to the patient's wishes, even if it carries with it a "reasonable risk" to his or her life. Palliative medicine is not yet recognized as an independent discipline in Israel. Accordingly, the lawmakers could not incorporate the right of dying patients to consult dedicated palliators: there would be no standard for defining who is a "palliator" and who is not. Due to monetary considerations, hospice care is not mentioned in the Steinberg Report or in the new law (see Aminoff 2007). It took a great deal of effort to replace *accepted* with *appropriate* in the section describing the kind of palliative care to which terminal patients are entitled. In view of concerns over the uneven standards of palliative care across the country and the inchoate state of professional palliation in Israel, even this minor change is promising with regard to increased awareness of and investment in palliative medicine in Israel.

The Steinberg Report recognizes the rights of patients, particularly those whose condition confines them to an institution, to receive "alternative" treatments at their own discretion and expense. The Israeli Medical Association objected to any mention of "alternative medicine"—a huge domain of practice, to date utterly unregulated in Israel—in the law. On the other hand, since some public hospitals and healthcare insurers run alternative medicine clinics for a fee, denying such care to terminal patients, who have an explicit right to futile care, verges on hypocrisy. The compromise that was finally reached refers to a right to arrange and to pay for "additional actions which the patient or his family believe necessary," subject to the safety of other patients and other institutional regulations.

INCAPACITATED PATIENTS, MINORS, AND PREMATURE NEONATES

In the case of incapacitated patients who were once competent (above the age of 17 and mentally healthy), the law requires that "reasonable efforts" be made to find out what their wishes were, whether in the form of legally valid advance directives or other documents and testimonies. In the absence of helpful and reliable information and in the case of children, retarded persons, and other wards that could never have had rational wishes of their own, the doctors and the guardian need the approval of a special ethics committee in order to make no-treatment decisions. This restriction was instituted in order to doubly protect the life of the most vulnerable.

The law goes further in recognizing the standing of mature minors, stating that such a minor has a right to participate in medical decisions if he or she is fully informed and the caring physician finds him or her mature enough to deliberate the issue at stake. Doctors have a duty to fully inform a minor patient whenever he or she can understand the information and the doctor is "con-

vinced that receiving it is not likely to harm physical or mental health.” This wording ignores the wishes and opinions of the parents—the natural guardians of the minor patient—thus disregarding or even sabotaging the “pediatric triangle” that is the conceptual, legal, and moral framework of medical care for children. More significantly, there is no evidence whatsoever that medical information, as ominous as it might be, is harmful to either adults or children who want to be informed of their illness. Rather, although it has been well established that withholding information from pediatric patients who request it is detrimental to their well-being and coping capacity, many doctors still shun truthful discussions with minors on their health situation (Claflin and Barabarin 1991; Fallowfield and Jenkins 2004). In rabbinic law, the age of majority is 12 for girls and 13 for boys. Caretakers who abide by the Jewish tradition are not likely to find justification for withholding information from adolescents or for making paternalistic decisions for them.

The new law does not consider premature neonates as a separate category. This creates an unexpected legal paradox that is in line neither with the motivation to empower patients who would rather die than live, nor with Jewish tradition. According to the common law inherited from the British mandate of Palestine, premature neonates are considered legal persons. As a result, their end-of-life care will be governed by the new Israeli law—which is based on the Jewish law of care for all patients *except* for premature babies. Jewish law is relatively undemanding with regard to the duty to save the lives of premature infants. According to premodern rabbinic sources, premature and sick babies who are less than one month old and whose chances of survival are less than 50% may be allowed to die rather than risk a life marred by serious suffering. Contemporary rabbis set the lower limit of mandatory care to a survival probability of 10%. From a legal point of view, discontinuation of life support for premature infants who have never been independent of it and who, if they survive, are likely to have miserable lives, is much simpler than avoidance of care for ordinary terminal patients (Barilan 2006, pp. 282–84).

SCOPE OF PERMITTED AND FORBIDDEN ACTIONS

The popular press has presented the new law as the “Euthanasia Law,” and some hasty journalists have attempted to get access to the first patient who would be “executed” according to the new law. Nothing is further from the truth. The law specifically prohibits any act that shortens or even aims at shortening life. Only avoidance of medical treatments may be permitted.

The permission to stand idle and withhold therapy is explicitly limited to conditions “related to the terminal illness.” In certain situations, this distinction sounds intuitively sensible: in its absence, paramedics might not try to save the life of a terminal patient who was hit in a car accident. In other situations, this distinction appears quite strange. Think of two terminal patients who are suffering from gas-

trointestinal bleeding, both of whom are already classified as patients who do not wish their lives be prolonged. It seems that according to the law, the patient with fatal liver cirrhosis and bleeding varices will be left to die, while the patient with brain cancer and a coincidentally bleeding peptic ulcer will be treated with blood transfusions and invasive gastroscopy. Even more perplexing would be questions such as whether hyponatremia is “related” to heart failure or not.

Since the Jewish tradition regards the mental trauma produced by confrontation as life-threatening to vulnerable patients, the law does not allow coercion or verbal confrontation with a patient; instead, it requires that caretakers make a “reasonable effort” to “persuade the patient to receive basic care such as nutrition, hydration, and oxygen, even by artificial means.” But when he or she is unaware of the transgression of his or her will and cannot be traumatized by confrontation and insult, the value of life is given the upper hand. Caretakers must administer basic care to incapacitated patients, even if they have specifically wished otherwise. This is the only major point on which the religious and the secular groups could not reach an agreement, and the former prevailed. Jewish religious law does not recognize a right to refuse basic life-sustaining care. However, since Jewish law defines death as loss of respiration, dependence on respiratory support often counts as a hindrance to death rather than a life-sustaining measure. Because hindering death is regarded as wrongful, rabbinic attitude to irreversible mechanical ventilation has always been either ambivalent or negative, thus setting permanent mechanical ventilation apart from all other forms of medical or nursing care.

Another feature of Jewish religious law is the distinction between basic care and medical treatment. Basic care is routine, serving the fundamental needs of the body; it is a stable regimen of care that does not require frequent modifications by professionals and to which the patient is habituated. For example, if a patient is dependent on a fixed schedule of feeding by a nasogastric tube and insulin injections, and these treatments have become distress-free habits of his or her existence, their discontinuation, even by acts of omission, may amount to the commission of homicide (Feinstein 1985, mark 74).

DISCONTINUING LIFE SUPPORT

Leading Orthodox rabbis have ruled that patients may refuse mechanical ventilation that is likely to become irreversible. Some rabbis have even written that disconnecting such patients from respirators is a religious duty of neighborly love (Firrer 1984, pp. 219–25; Israeli 1965, mark 32b). In order to accommodate other opinions, however, the Steinberg Committee recommended that timers be installed on respirators and be reset routinely unless the patient does not wish to go on living. In such cases, life support will run down without anybody taking an active action.

Since respirators with timers do not yet exist, the law incorporates their pos-

sible development by distinguishing between “cyclical” and “continuous” life support. Hemodialysis, which is typically carried out in sessions of a few hours a few times a week, is paradigmatic of cyclical therapy; the sessions start and end at specific times. Mechanical ventilation as we know it is continuous; without it, many patients cannot survive more than a few minutes. With the clock-machines in mind, the law declares that, if a certain life-sustaining continuous therapy becomes cyclical, it may be stopped by means of omitting its renewal.

Observant Jews often employ timers in order to render an action legally indirect. This, however, is done in purely religious contexts, such as the observance of the Sabbath. Direct interference with medical care and in ways that might even compromise its safety is a novelty.

For the sake of implementing the timers, the Ministry of Health has appointed a special subcommittee, headed by Rabbi Dr. Raphael Halperin, the bioethical advisor to the Minister of Health and a practicing gynecologist. Preliminary sketches have been made on the basis of an apparatus that supplied gas for stoves in tenement apartments in post-World War II Britain. Tenants would insert coins in a special slot whenever they wished their home gas supply to be renewed. A request has recently been issued for the design and construction of pilot machines for initial testing.

One concern with the timers was about possible division, and consequently discrimination, between patients on regular machines and patients on timers. For this reason, the intent of the law was to make all Israeli respirators timer-dependent. Alas, I cannot see how it would be ethically possible to undermine a key safety feature of life support—its immunity to accidents, such as power failure—for the sake of a subgroup of terminal patients. If, however, we wish to transform mechanical ventilation into a kind of cyclical care, no invention is needed. For the purpose of transferring patients from one place to another, hospitals employ portable respirators (paraPAC machines), whose mechanical energy is derived from the pressure within the oxygen tank. All that is needed to help patients die without performing an act of commission is to switch from a regular respirator to a portable one and wait until the oxygen runs out. Although some conservatives may have hoped to bury the idea of disconnecting patients from respirators until a futuristic design matures, the paraPAC option has the potential to transform Israeli society into the first one to sanction an easy and fast procedure of disconnecting terminal patients who wish to die from life support. Whereas even jurisdictions that legalize active euthanasia insist on exhaustive evaluation of the patient, the alternatives available, and the authenticity of his or her wish for death, the Israeli law empowers every competent patient with expected survival of less than six months to stop life-sustaining mechanical ventilation by means of articulated refusal or an advance directive. This could be done even against the best judgment of all of his or her doctors and other experts, caregivers, and close family members. In the absence of psychosis, neither severe depression nor lack of attempts of a few days of adjustment to life support can prevail against an

explicit refusal to replenish the oxygen tank (or resetting the clock in a clock-machine), even if the patient was connected to the paraPac machine merely for the sake of transfer from one place of the hospital to another.

Despite considerable attempts to promote the value of life at the end of life, and despite explicit prohibition on euthanasia, this new law makes Israel the only country in the world in which patients may force their caregivers to allow them to die from cessation of life support and without any attempt at consultation, reevaluation, or palliation. To date, all forms of proposed or legally permissible disconnection from life support have required the collusion of at least some doctors who find the decision clinically and ethically acceptable. The new law empowers patient autonomy to such a degree so as to allow him or her to dictate sensitive aspects of medical care, without having obtained support from any other person, lay and professional alike.

It does not cost much to die; staying alive in spite of terminal illness requires effort. Therefore, a genuine empowerment of those who wish to go on living necessitates the allocation of appropriate resources. To me, the worst possible scenario would be for patients to choose to discontinue life support for want of good palliation; in this case, a death wish would be a result of inadequate care, no less than of the disease itself. What is needed in order to promote the values of life, well-being, and dignity is to help patients carry the burden of disease in ways that *make* them want to live and to find meaning in life.

Another worry is that patients on timer-ventilators might abuse their right to die in order to make friends, family members, and the caring team comply with all sorts of whims at the threat of discontinuation of life support. Who would accept a responsibility for the death of a person under one's care?

THE SLIPPERY SLOPE: THE SEPARATION OF SUICIDE FROM EUTHANASIA

Worries about "slippery slopes" always loom over debates on end-of-life care. One slippery slope leads from the death of those who wish to die to the death of those who do not. The history of the German euthanasia movement before and during World War II is often invoked in this context. Another slippery slope is that leading from justifiable death (e.g., refractory and severe medical suffering) to motivations for death that are deemed morally controversial and even stupid (e.g., romantic love).

One way to look at the new Israeli law is through some developments in rabbinic thought that serve as safeguards against loss of control of the ethics of death. A strict rabbinic distinction exists between acts of commission and acts of omission. We have seen, though, that omission of daily necessities of life, such as food and drink, may be considered as acts of commission as well. This does not allow for any form of death through neglect.

The Bible and premodern rabbinic literature, from the time of the Talmud

until the 19th century, contain numerous stories of commendable or tolerated suicide. King Saul asked a servant to help him die, and medieval Jewish parents slaughtered their own children in order to protect them from forced baptism by riotous mobs (I Samuel 31:1–6; Goldstein 1982; Yovel 2000, pp. 159–72; Zohar 1997, pp. 54ff). These were extreme circumstances indeed—but a book attributed to one of the leading authorities of Jewish law, the 14th-century Spanish Rabbi Asher ben Yechiel, takes a much more permissive view, arguing that only “philosophical [stoic?] suicide,” self-destruction out of contempt for life, is prohibited. But in the face of “unbearable physical or mental suffering . . . it is doubtless that suicide [literally, taking one’s life in hand] is not forbidden” (De Molina 1793, mark 345). This book has been controversial from the day of its publication, as many rabbis and scholars suspect that it is a forgery. Nonetheless, 19th-century rabbis developed this line of thinking on suicide and wrote that suicide as a means to escape terrible suffering is pardonable. Some even wrote that it is forbidden to take an active action and rescue a person thus committing suicide (Babd 1988, p.138; Firrer 1984; Halevi-Epstein 1937, p. 149; Perla 1914, pp. 340–47).

Probably because other authorities ruled that “suicide, even due to suffering, is murder” (Sofer 1865, mark 69), modern rabbinic discourse on end-of-life care and disconnecting life support has abandoned the argument of suicide due to agony. Modern rabbis tend to ignore the discussions on suicide and instead focus on the theme of irreversible mechanical ventilation being a hindrance to death that must be removed, rather than being considered life support at all (Sinclair 2003, chap. 5). Distancing the moral, legal, and theological problem of suicide from end-of-life care, setting mechanical ventilation apart from all other forms of medical care, and distinguishing between medical care and nursing, as Jewish and Israeli law do, create legal and ethical buffers that enable policies of no-treatment and of discontinuation of life support for a well-defined group of people.

JUDAISM AND THE LAW

Since the time of St. Paul, Western culture has referred to Judaism as a religion that is first and foremost bound by a commitment to its set of laws, the *halakhah*. Some critics of the timer-ventilators see this concept as a manifestation of excessive legalism that avoids the heart of the ethical problem. However, withdrawal of life support and other key bioethical issues might shed a different light on Judaism and on the relationship between the law and other aspects of religion.

The historian of religion Gavin Langmuir (1990) makes an important distinction between religiosity and formal religion. Religiosity is a psychosocial phenomenon of attitudes and emotions, whereas formal religion is a partial codification of religiosity and its transfer into social systems of power and meanings. Religiosity stems from the personal, is often spontaneous, is loaded with emotion, and is tuned to the mystical. Formal religion is manifested by means such

as legal systems, catechisms, and sacred texts, and is the product of an elite class that shapes the religion based on its own sense of religiosity, as well as theological and political considerations. Sometimes the elite give shape and structure to popular voices; at other times they strive to educate the people and direct their religiosity. Consequently, in the name of the same creed, religiosity and formal religion often oppose as well as balance each other, resulting in a dialectical process of historical evolution. Formal texts and laws are easily amenable to critical analysis, and academicians who study religion are likely to grant greater weight to those producing those texts. This situation might create a serious bias in the study of religious medical ethics, particularly by those holding ethics to be mainly a rational system. Pious laypeople, on the other hand, tend to conceive their own religious law through a biased prism of their personal religiosity.

For example, many devout Jews, influenced by their own perception of what religious law is *likely to be* and also by *kabbalah* (mysticism and folk religion), insist on maximum care even for irreversibly and profoundly comatose patients. Consequently, a comprehensive view of Jewish medical ethics must incorporate these trends within *halakhic* discourse. From such a perspective, legal trickery such as the clock-ventilators may be seen as a way to make a synthetic resolution of legalism and spirituality, so as to make values prevail, in this case the prominence of “neighborly love” in both Jewish law and spirituality.

Langmuir’s theory about the dialectical interaction between religion and religiosity is also borne out by a brief examination of the relationship between Jewish attitudes regarding organ donation and elective abortion. At least one of these practices—organ donation—has not yet become widely accepted. Rabbis have repeatedly ruled in favor of organ donations from patients whose hearts are no longer beating; at least one rabbi encourages altruistic donation of kidneys from living volunteers (Aviner 2004).¹ But the rate of organ donation in Israel, even of organs whose removal is not implicated in the timing of death, such as corneas, is painfully low. Patients and families, even those whose daily lifestyle is far from observant, express their opposition to donation in religious terms, such as a worry about the relationship between the burial of an intact body and the well-being of the soul.

Rabbinic laws on elective abortion count among the most lenient in the history of human ideas and laws. However, the Israeli counterpart to the pro-life movement is a wholly religious organization, supported by prominent rabbis. Religious activists and leaders who are not experts on religious law (for example, hassidic rebbes) fight vehemently against elective abortion of almost any kind. The situation has reached such an absurdity that a leading rabbi recently

¹The rabbinic world is divided on the question of brain death, as well as on whether this diagnosis should be entrusted to doctors-only committees. The official position of the Chief Rabbinate of Israel is that a rabbi or similar religious representative should participate in the deliberation on brain death.

published an article in the popular press, reminding women that they might be allowed to abort fetuses with Down's syndrome and similar disabilities (Melamed 2002).² In a telephone conversation with me, that rabbi expressed a worry that mistaken piety might bring about a situation in which only religious families have retarded children, and that fear of problematic pregnancies might dissuade women in the twilight years of their fertility from begetting children.

These gaps between formal law and religiosity may be looked at through two different understandings of "the law." The Patriarchs of the Church distinguished between laws as "commandments" (such as the Pharisaic "laws of Moses") and laws as "counsels," as preached by Jesus and the Church (Brague, 2007 pp. 68–70, 231–37). The latter may better be conceptualized less formally, yet within narrative structures and even nonverbal paragons of virtue. In opposition to universalized codes of formal law, counsel has been associated with the intimacies of friendship, with holistic prudential considerations, and with deeper personal values such as love. The Christian vocabulary of counsel is rooted in the parable of the Good Samaritan and with supererogation and grace. In the rabbinic tradition, however, the dialectical relationship between formal law and religiosity-inspired counsel may create situations in which formal law is more permissive than personal religiosity (abortion), situations in which formal law is manipulatively mitigated by compassion with the sufferers (terminal care), and situations in which formal law and religious sensibilities on questions of right and wrong remain in unresolved frustrating disagreement (organ donation).

Although Israel's Patient Nearing Death Act is not a religious law, parts of it are under the sway of religious law and others are imbued with popular religiosity. It reflects a live dynamics inside religious society and between religion and state. Nevertheless, many elements in the law express for the first time liberal values and trends, such as the introduction of advance directives and a right of the suffering to choose death over life. It seems to me that the new law and the processes of deliberations leading to its enactment bear promise regarding the possibility of dialogues between religion and liberal values as well as of dialogues between formal religion and popular religious sentiments.

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²On this controversy and on abortion in Jewish law in general, see Barilan (n.d.) and Schiff (2002).

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