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Legal and policy lessons from the Schiavo case: Is our right to choose the medical care we want seriously at risk?

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ABSTRACT

The article explores the individual patient's right to refuse, withdraw, or insist on medical treatment where there is conflict over these issues involving health care personnel or institutions, family members, legal requirements, or third parties concerned with public policy or religious/ideological/political interests. Issues of physician assistance in dying and medical futility are considered. The basis and the current legal status of these rights is examined, and it is concluded that threats to the autonomy of patients, to the privacy of the doctor/patient relationship, and to the quality of medical care should be taken seriously by individuals, medical practitioners, and others concerned with developing and maintaining reasonable, effective, and ethical health care policy.

KEYWORDS: Law and ethics, End-of-life decisions, Withdrawing or withholding care, Living wills, Terri Schiavo, Ethics committees, Medical futility

INTRODUCTION

In 1990, a medical tragedy befell Theresa Schiavo and her family. Between 2003 and 2005, this private tragedy became a national political and cultural spectacle that included overwrought behavior by the Florida State Legislature and governor, the United States Congress, the President of the United States, and interest groups, media outlets, and religious leaders of every stripe. It was not America's finest hour, but there are lessons to be learned from it. In a 2-day meeting of physicians, nurses, and social workers in October, 2005—just 6 months after Theresa Schiavo was allowed to die—more than 100 professionals explored some of these lessons in the cold light of academic and professional study. Two of the authors of this article led and participated in discussions of the legal and policy lessons that might be drawn from the Schiavo conflict and are joined in this article by a third in presenting some of these lessons.

The requirement of obtaining informed consent to medical treatment and the right of the individual to refuse or to withdraw even life-sustaining medical care have become so commonplace in medical practice, training, and administration that we might assume that they are fixed legal doctrines on which we all can depend. In a May 2005 commentary in *JAMA*, Georgetown law professor Lawrence Gostin wrote:

> Federal and state courts have reached a broad consensus on matters of death and dying. . . . So too has there been substantial consensus in the bioethics literature. Courts and scholars have affirmed a person's right to refuse life-sustaining treatment and concluded that this right remains intact even if the person is no longer able to speak for herself. (Gostin, 2005, p. 2403)

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Professor Gostin points out in his thoughtful *JAMA* article that this assumed consensus may not have survived the polarizing political and cultural battles that characterized the Terri Schiavo case. He suggests, moreover, that our ability to think clearly and creatively about end-of-life issues may have been a casualty of these ideological battles, and he attempts to rekindle the careful reflections that end-of-life issues require. As the personal tragedy of the Schiavo and Schindler families played out in the courts, legislatures, streets, and media of the nation, numerous very important issues beyond whether a legally appointed surrogate can cause the withdrawal of nutrition and hydration from a patient in a persistent vegetative state were raised. Many of these issues have received renewed scholarly and professional attention by commentators since then. (Noah, 2004)

Rather than considering in detail any of these individual medical/legal/policy issues, we have tried to draw a broader lesson from the Schiavo case. This article examines the more general set of questions: (1) How strong are the legal foundations of a patient's right to refuse, withdraw, or insist upon medical treatment where there is a conflict involving health care personnel or institutions, family members, or third parties? We conclude that the legal status of patient autonomy is more tenuous than the assumed clinical/ethical consensus suggests. (2) To what extent might ongoing challenges to those rights undermine the relationship of clinicians and patients and significantly undermine the quality of palliative care in general and end-of-life care in particular? We suggest that considerable work needs to be done to secure and defend rights that have been assumed for nearly a generation, and that clinicians in particular have a stake in this struggle and a unique opportunity to affect its outcome.

LIBERTY, PRIVACY, AND THE PRINCIPLE OF INDIVIDUAL AUTONOMY

The core principle of the requirement of informed consent, of the right to refuse treatment, and of the ability to get access to appropriate treatment and palliative care could be called individual autonomy, personal liberty, or privacy. However labeled, this principle—which also lies at the heart of our most important freedoms in other spheres of life—acknowledges the historical importance of the individual in American culture, in relation to the power of the state and as the primary building block of voluntary relationships and communities. To appreciate the nature and importance of the autonomy principle in the area of health care, consider the following expressions of its judicial and philosophical recognition from Supreme Court Justices O'Connor and Stevens and from philosopher Ronald Dworkin:

> At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State. (*Planned Parenthood v. Casey*, 1992, p. 851)

> Our duty, and the concomitant freedom, to come to terms with the conditions of our own mortality . . . are essential incidents of the unalienable rights to life and liberty endowed us by our Creator. . . . [N]ot much may be said with confidence about death unless it is said from faith, and that alone is reason enough to protect the freedom to conform choices about death to individual conscience. We may also, however, justly assume that death is not life's simple opposite, or its necessary terminus, but rather its completion. Our ethical tradition has long regarded an appreciation of mortality as essential to understanding life's significance. It may, in fact, be impossible to live for anything without being prepared to die for something. (*Cruzan v. Director, Missouri Department of Health*, 1990, p. 343)

> So we have that reason of beneficence, as well as reasons of autonomy, why the state should not impose some uniform, general view by way of sovereign law but should encourage people to make provision for their future care themselves, as best they can, and why if they have made no provision the law should so far as possible leave the decisions in the hands of their relatives or other people close to them whose sense of their best interests—shaped by intimate knowledge of everything that makes up where their best interests lie—is likely to be much sounder than some universal, theoretical, abstract judgment born in the stony halls where interest groups maneuver and political deals are done. (Dworkin, 1994, p. 213)

INFORMED CONSENT AND THE RIGHT TO REFUSE CARE

As these quotations demonstrate, the principle of patient autonomy is rooted in the most basic ideas of individual freedom in a democratic society. An individual's right to make decisions regarding medical treatment can be traced to Anglo-American common law, which held that a "battery" existed for any unconsented touching. This has been carried forward into the statutory definitions of both crimes and torts in many states. American case law formally recognized such a right relevant to medical care in the 1914 case of *Schloendorff v. Society of New York Hospital*, in which Justice Cardozo articulated the right of bodily integrity in the context of medical care:

> The root premise is the concept, fundamental in American jurisprudence, that, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body. . . ." True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each. (*Canterbury v. Spence*, 1972, p. 780)

The basic requirement, that physicians get patients' permission to proceed with a particular course of treatment prior to initiating that treatment, evolved during the 20th century to require not only voluntary choice, but also that physicians disclose to patients the diagnosis, the recommended treatment, the risks attendant upon that treatment, its likelihood of success, and alternative treatments that might entail different rates of success or risks. As a result, the expectations of patients, health care providers, and hospital administrators have grown to encompass the process of informed consent for a very wide range of procedures and treatments.

The common law and statutory right to refuse care is the logical corollary of the requirement of informed consent, and violation of these rights may incur liability in civil and/or criminal courts. Early in American jurisprudence, courts recognized the right of an autonomous individual to refuse medical treatment, including the ruling that, "every human being of adult years and sound mind has a right to determine what shall be done with his own body" (*Schloendorff v. The Society of the New York Hospital*, 1914, p. 129). As recently as 2001, commentators described the right of competent adults to refuse care as virtually settled law (Meisel, 1998; Berg et al., 2001).

The right to refuse or to withdraw unwanted medical treatment has been found to be grounded in the United States Constitution as well as in tort law (*Vitek v. Jones*, 1980; *Washington v. Harper*, 1990). Clearly, the idea that "a competent person has a constitutionally protected liberty interest in refusing unwanted treatment" reflects the fundamental importance of the right to control what is done to one's own body and to make decisions that lie at the heart of how we define ourselves and how we understand the meaning of our lives (*Cruzan v. Director, Missouri Department of Health*, 1990). These constitutional rights are not, of course, absolute; and when they become the stuff of conflict among health care providers, family members, and others, the courts have been called upon to define the "state interests" that should be balanced against the asserted constitutional right to refuse or withdraw treatment. These state interests have been held to include the protection of life, maintenance of the ethical integrity of the medical profession, protection of innocent third parties and of vulnerable persons, and the prevention of suicide (Arons, 2004).

Defining and applying a constitutional right to refuse or withdraw treatment becomes even more complex when the person asserting that right is doing so on behalf of a patient who is not in fact autonomous—that is, a patient who is not able to make or articulate decisions because of that patient's medical condition. In *Cruzan v. Director, Missouri Department of Health*—a case with significant legal and medical similarities to the Schiavo case, but without the family conflict over withdrawal of life support—Nancy Cruzan's parents and coguardians sought a court order to direct the hospital to withdraw artificial feeding and hydration. Their daughter had been in a persistent vegetative state since an automobile accident and had no chance of recovery (*Cruzan v. Director, Missouri Department of Health*, 1990). Two parts of the Court's ruling in *Cruzan* are particularly important to our consideration of the legal status of the right to refuse or withdraw medical treatment. First, the Court's majority indicated that "for purposes of this case, we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition" (*Cruzan v. Director, Missouri Department of Health*, 1990, p. 280). Note that the Court makes an *assumption* for this particular case rather than a *ruling* on a principle that would have to apply to future cases, and that this assumption is stated in terms of competent patients. Because the majority also declined to assume this right to be "fundamental," the case can hardly be regarded as a rock-solid protection for the constitutional right to be free of unwanted medical treatment. Nevertheless, the Court goes on to make the very significant decision that the right to refuse life-saving treatment continued to apply to Nancy Cruzan even after she became legally incompetent.

The second important part of the decision for our evaluation is that because Cruzan had no advance directive and because of the alleged difficulty of determining what her wishes actually were when she was legally competent, the Court approved of Missouri's very tough standard for the proof that her family had to meet in its contention that she did not want to be sustained by artificial feeding and hydration. As the dissenters in *Cruzan* pointed out, by allowing the state of Missouri to require clear and convincing evidence of a patient's wish to *discontinue* life support, but not of a wish to *continue* life support, the Supreme Court abandoned the search for accuracy in decision making and simply made it much more difficult to assert the right to refuse treatment for incompetent patients.

Thus the Supreme Court concluded that the State's asserted interest in this matter—the protection of life—outweighed the interests of Ms. Cruzan and her guardians to exercise her constitutional rights. The *Cruzan* ruling allows us to conclude that the right to refuse life-prolonging medical treatment belongs to both autonomous and nonautonomous individuals, but that states are permitted—in the name of protecting a right to life—to place significant restrictions on the free exercise of the right to refuse treatment.

One way to secure the requirement of informed consent and the right to refuse or withdraw unwanted medical treatment for patients who lack decisional capacity is through the use of advance directives. All states have adopted some form of legal advance directive that individuals may use to direct their health care choices if they become incompetent. Forty-seven states and the District of Columbia authorize living wills to instruct caregivers on a patient's care (Bryan, 2003/2004). The only states that do not authorize living wills are Massachusetts, Michigan, and New York, and each of these has adopted another form of advance directive, usually a health care proxy or durable power of attorney. Many states authorize both forms of advance directives. There are several problems with the authorization and use of advance directives, however.

Despite the publicity surrounding informed-consent and right-to-refuse-treatment cases such as *Cruzan* and *Schiavo*, studies show that most people, even those with terminal illnesses, have not executed advance directives. Not only are there disparities among ethnic groups, but one 2002 study showed that only 15%–20% of the general population has an advance directive (Bryan, 2003/2004). The low proportion of execution of advance directives may be due to the difficulty inherent in thinking about severe illness when one is healthy, the fact that doctors are rarely compensated for the time it would take to meet with patients to discuss advance directives, or even a general denial of death in American culture.

In addition to their lack of use for these reasons, advance directives have their own limitations. State statutes creating advance directives are sometimes ambiguous and often limit the circumstances in which they can be used, for example, by prohibiting their use to withdrawal of life-support except where the patient is diagnosed as terminally ill. Because the advance directive arguably is a tool for exercising a constitutionally protected liberty right, it is possible that such state law limitations could be found to violate the Due Process Clause of the Fourteenth Amendment (Arons, 2004). When there is no valid and effective advance directive in place, most states have statutes designating which family members have priority in making health care decisions for incompetent patients.

Living wills themselves are also under attack, both for what they lack and for what they try to accomplish. The President's Commission on Bioethics issued a report in September 2005, "Taking Care: Ethical Caregiving in Our Aging Society," in which the following statement, among others, was made:

> Not only are living wills unlikely to achieve their own stated goals, but those goals themselves are open to question. Living wills make autonomy and self-determination the primary values at a time of life when one is no longer autonomous or self-determining, and when what one needs is loyal and loving care. This paradox is at the heart of the trouble with this approach to caregiving. (The President's Council on Bioethics, 2005)

PHYSICIAN ASSISTANCE IN DYING AND THE PUTATIVE RIGHT TO PALLIATIVE CARE

In 1997, the Supreme Court ruled that states may criminalize physician-assisted suicide without violating the Constitution's protections of liberty or privacy (*Washington v. Glucksberg*, 1997). The Court unanimously ruled against the claimed constitutional right to a physician's help in actively hastening even an imminent death from incurable and painful disease. It did so in spite of the argument made in the companion case of *Vacco v. Quill* that terminally ill persons on life support are already constitutionally entitled to a physician's active aid not only in withdrawing life support but in easing the pain, agitation, and other suffering that follows such withdrawal (*Vacco v. Quill*, 1997). The Court distinguished these cases from those in which prescription of lethal drugs was the aid requested by terminally ill patients not on life support but equally suffering. It based the distinction on two things: the difference in the doctor's *intent* in withdrawing life support from the intent in prescribing a lethal dosage and whether the *cause* of the patient's death would be the disease or the prescribed medication. Whether this legal distinction has any medical significance is a question for clinicians.

States are still free to enact physician-assisted suicide laws, as the Court's opinion in *Glucksberg* said would be appropriate in our federal system and as the recent decision in *Gonzales v. Oregon* (2006) reaffirms. Perhaps the most interesting aspect of the *Glucksberg* case however—and certainly the most significant for our assessment of the status of the autonomy principle in health care—is the number of comments made by the justices in *Glucksberg* about a possible right to adequate pain management. In his *New England Journal of Medicine* article, "The Supreme Court Speaks: Not Assisted Suicide but a Constitutional Right to Palliative Care," law professor Robert Burt analyzes the six opinions written in the unanimous *Glucksberg* decision and makes a convincing argument that five of the justices then on the Court might have been willing to find a right to palliative care in the Constitution if state law were to be used to prevent a patient suffering extreme pain from receiving adequate pain management even if that hastened the patient's death (Burt, 1997).

This constitutional analysis opens up a promising area of work for those concerned with the quality of end-of-life and other palliative care, including defining what might be included in a putative right to palliative care, how to ground this care in the autonomy principle, and the practical mechanisms by which a judicial or legislatively created right to palliative care could be reasonably assured (Weinman, 2003; National Consensus Project for Quality Palliative Care, 2004). But just as the right to refuse treatment is tenuous and under attack from some quarters, the as-yet-undeveloped right to palliative care has its enemies as well. The best example is the case of *Gonzales v. Oregon* decided by the Supreme Court in mid-January of 2006. During the late 1990s some members of Congress made two attempts to adopt legislation that would, in effect, have overturned Oregon's Death with Dignity Act under which a terminally ill, legally competent patient could get prescriptions from a physician for medication that the patient could take to hasten death. Although the Oregon law contains strict conditions under which this physician-assisted suicide can be made available and although the Oregon law was twice adopted by the voters of the state, some in Congress viewed it as threatening to their moral code. The congressional action failed to pass, as did the attempt to get Attorney General Janet Reno to ban the prescription of Controlled Substance Act (CSA) Schedule II substances when made with the intention of hastening death.

In 2001, U.S. Attorney General John Ashcroft did what his predecessor and the Congress had failed to do. He issued a directive prohibiting the prescription, dispensation, or administration of Schedule II, federally controlled substances to assist suicide, claiming that he had the power under the CSA to determine what constituted a "legitimate medical purpose." This directive would allow the Drug Enforcement Agency to revoke federal prescription privileges of those doctors operating under the Oregon Death with Dignity Act.

The Attorney General's action was challenged by the State of Oregon in a case then titled *Oregon v. Ashcroft*. The Bush administration policy was rebuffed by the federal district court and by the Ninth Circuit Court of Appeals and Attorney General Gonzales appealed to the U.S. Supreme Court in 2005, causing the name of the case to become *Gonzales v. Oregon*. A coalition of "medical associations and societies; pain, palliative care, and elder care associations; and distinguished individual pain, palliative and elder care professionals" filed an amicus brief at several levels of the litigation arguing that the Attorney General's directive had a "chilling effect" on the practice of pain management and palliative care everywhere in the country. This argument also appeared in a January 2006 *New England Journal of Medicine* article, "The Big Chill—Inserting the DEA into End-of-Life Care" (Quill & Meir, 2006). In one amicus brief, filed by "physicians, and professors who address issues of medical ethics in their work," the argument was made that the Attorney General's claimed power under the CSA could interfere with end-of-life medical care including palliative care and refusals of treatment:

> [M]any states now, by statute, permit doctors to prescribe sedation sufficient to ensure that a terminally ill patient does not feel pain or experience suffering, even if there is a risk that enough medication to quell the pain or suffering will also be lethal. The expansive powers claimed by the Attorney General would permit him to conclude

> that such uses of controlled substances are outside of "the course of professional practice or do not serve a "legitimate medical purpose. . ." Controlled substances are also commonly prescribed to relieve pain in terminally ill patients who have chosen to refuse further life-sustaining care. If the Attorney General opposes such a patient's right to refuse care, as his filing in the *Schiavo* case suggests, he could effectively prevent the exercise of this right by threatening to revoke the license of any physician prescribing controlled substances to ease the pain of a patient who rejects further life-sustaining support. (Brief for Margaret P. Battin et al. as Amici Curiae (2004).)

On January 17, 2006, the Supreme Court ruled 6–3 in favor of the State of Oregon and affirmed the lower court holdings that the CSA does not give the Attorney General the power he claimed to regulate the practice of medicine in Oregon or elsewhere. The Court's opinion upholds the Death with Dignity Act against this particular attack; but it deals only with narrow statutory considerations and barely mentions the problem that arises when the federal government uses the political process to dictate what constitutes legitimate pain management or palliative care by clinicians:

Under the Government's theory, moreover, the medical judgments the Attorney General could make are not limited to physician-assisted suicide. Were this argument accepted, he could decide whether any particular drug may be used for any particular purpose, or indeed whether a physician who administers any controversial treatment could be deregistered. This would occur, under the Government's view, despite the statute's express limitation of the Attorney General's authority. . . . (*Gonzales v. Oregon*, 2006)

The Oregon case presented an opportunity for some justices to further articulate the idea of a right to palliative care such as was suggested in the Burt article on *Glucksberg* (Burt, 1997). But that opportunity was not taken, and the idea of a right to adequate pain management and other forms of palliative care remain in need of further clinical study and of policy and legal development. Also remaining is the attack on the Oregon law in particular and on the practice of pain management and palliative care in general. Congress may try again to amend the CSA. Other cases may be brought before an increasingly conservative federal judiciary. Other political strategies might be employed to bring the autonomy principle and the doctor/patient relationship under increased government control.

MEDICAL FUTILITY

One of this article's authors (Z.L.) has observed, as chair of an acute care hospital's clinical ethics committee, that although end-of-life cases still occupy as much time and attention of ethics committees as they have over the last 30 years, the focus of those cases has changed. Recently, it seems as if the most common focus of these deliberations has shifted away from efforts by family members to persuade physicians and health care institutions to *allow* withdrawal of life-sustaining care of the seriously or terminally ill and toward efforts by families trying to *prevent* withdrawal of treatment regarded as not medically beneficial by medical staff (sometimes called "futile" care). These conflicts have spawned extended debate in the medical literature on the concept of "medical futility" and have led to the development of institutional policies, state laws, and a number of legal cases (Faber-Langendoen, 1991; Callahan, 1993; Waisel & Truog, 1995; Gillon, 1997; Helft et al., 2000). The Schiavo case can be viewed from both perspectives—as an effort to withdraw unwanted medical treatment by one side of the family and as an effort to continue futile medical treatment by the other.

In general, it seems to us that the cases increasingly likely to create conflict are those in which families want "everything done," even when the professionals involved doubt that the treatments will benefit the patient. One possible explanation for an increased focus on requests for "futile care" could be that some portion of the public has—for moral, ideological, or even political reasons—become more vocal and more willing to challenge the judgment of physicians or families regardless of the merits of those judgments about the "best" course of treatment. In addition, disability rights activists have raised objections in some specific cases and opposed withdrawal of care more widely in the media, pointing out that the public attitude toward disabled persons and the issue of quality of life has often been discriminatory and inhumane (Frank, 2006; Not Dead Yet, 2005). Since the events in the Schiavo case, it has become apparent that any end-of-life case has the potential to become contentious. But in general, when patients, families, and caregivers agree on what is best for the patient (or what the patient would want), there is rarely legal trouble.

Patients or families claiming a right to care that their physicians consider unwise or futile may base their claims on a number of strongly held beliefs that highlight some of the weaknesses of the current approaches to dealing with medical futility. First, families pressing to continue care may share common ground in the area of patient autonomy with those seeking withdrawal of life support. In such a case, a family might argue that the patient wanted/wants all measures possible taken to sustain life, regardless of the likelihood of recovery. If autonomy is to be meaningful, they might add, it must include some provision for ensuring even "futile" desired care and privileging the wishes of the patient/family over those of the caregivers. This is a familiar ethical dilemma for clinicians, a conflict between autonomy and beneficence, which, in the area of refusal or withdrawal of care for competent patients, has generally been decided in favor of patient autonomy. (Berg et al., 2001)

Other arguments for continuing "futile care" are religious faith or religious doctrine. Faith and doctrine may state independent claims. First, the faithful may argue that their strong belief in God makes miracles possible even in the face of a grim prognosis. Second, some adherents argue that their particular religion values (or requires) sustaining life in any form. Additionally, patients or families may strongly believe that the physician's quality of life evaluation should not be used to support terminating life support, as those judgments are inherently subjective and cannot take the place of the patient's or family's evaluation of the patient's quality of life. This latter view may be strongly supported by persons with disabilities or activists supportive of disability rights, who believe that any argument that supports withdrawal of care based on quality of life considerations presents a slippery slope that endangers all the disabled by valuing their lives less than those of the able-bodied.

These arguments deserve consideration and are unlikely to be satisfied by one-size-fits-all solutions. Currently, proposed solutions for handling questions of medical futility include: clearly defining *futility*, creating effective institutional processes to resolve questions of "futile care," adopting state statutes to empower physicians or hospitals to act, and using courts to resolve the question on a case-by-case basis.

None of these proposed solutions has worked particularly well in practice. For example, defining *futility* has run up against the problem that everyone cannot agree on a common definition in theory, much less in practice, because medicine's inability to precisely predict the outcome of any single intervention looms large (Truog et al., 1998). Attempts to define *futility* are ripe for disagreement as to what constitutes "benefit" to the patient, who establishes the goals of therapy, or who determines what level of statistical likelihood is used.

Various organizations and institutions have tried to establish their own medical futility policies. In 1991 the American Medical Association stated that physicians do not have to get consent for do not resuscitate orders when cardiopulmonary resuscitation (CPR) is futile (American Medical Association, 1991). The Cardiac Care Committees and Subcommittees, American Heart Association (1992, p. 2283) asserted that physicians may stop or withhold resuscitation in the following circumstances: (1) basic life support and advanced life support have been tried and have failed, (2) there is no physiologic benefit due to deterioration of vital functions, or (3) no similar patients have survived after CPR (reported in well-designed studies). Similarly, the Society of Critical Care Medicine (1990) determined that providing intensive care for patients in PVS is generally a misuse of resources.

Clearly policies cannot and do not resolve all cases of futile care and sometimes tend to sidestep the central issues. Some endorse a narrow definition of *futility* that will leave many of the difficult end-of-life cases unsolved (Cardiac Care Committees and Subcommittees, American Heart Association, 1992, p. 2283) whereas others appear to dodge the issue by using the undefined term *futile* in the policy itself (Council of Ethical and Judicial Affairs, 1991). Although arguments for conserving resources may elicit substantial support, they are actually based on a much more complex determination of quality of life and "appropriate use of resources" that deserves independent debate.

Some states, such as Texas, have adopted statutes that authorize physicians and hospitals to terminate care determined to be futile for the patient (Texas Advance Directives Act, 1999). Although these statutes may provide a legal process to terminate care, absolve physicians from liability for terminating care, and create some protections for patients (notification, a second physician's opinion, waiting period, and an opportunity to seek a transfer of care to another institution), they do not resolve the core issues: differing views of what constitutes benefit to a patient and who should be able to determine that.

Critics of the Texas law, for example, have noted that in at least some cases that law appears to disadvantage poor, minority patients who are least well equipped to find alternative sources of care (Hopper, 2005). Recently, a hospital in Plano, Texas, used the law to end treatment of a terminally ill but conscious woman with no insurance and little money. She was an African immigrant and wanted to remain on life support until relatives could arrive from overseas. Against her family's wishes she was unplugged from a ventilator and she suffocated in front of her family, who had been unable to find a hospital that would accept her for care (Frank, 2006). Although it may be too soon to judge the overall worth or fairness of futility statutes, the concerns already raised suggest that these statutes, at least, are not ideal solutions.

When questions of medical futility have reached the courts, those courts have split as to when to allow doctors to override the treatment decisions of a patient or his or her surrogate. Although there is no clear trend among all the cases, many cases have been resolved in favor of patients'/families' requests for continuing care, even where the patient was unconscious, moribund, and died soon after the case was decided (*In re: Conservatorship of Wanglie*, 1991; *In re: Jane Doe*, 1992; *In the Matter of Baby K*, 1994; *In re: Finn*, 1995; *Velez v. Bethune*, 1995). It is noteworthy that in the absence of statutes empowering physicians and hospitals to terminate care, some courts have held for physicians/hospitals that had allowed life support to be withdrawn against the family's wishes. In general, courts have been reluctant to hold physicians or hospitals liable for deaths where care was stopped, perhaps showing that from a hospital's perspective, in the area of medical futility, "it is always easier to ask for forgiveness than it is to get permission" (*Gilgunn v. Massachusetts General Hospital*, 1995; Kolata, 1995; *Causey v. St. Francis Medical Center*, 1998).

CONCLUSION

Over the past quarter century, substantial progress has been made in establishing the autonomy principle in health care through developments in medical practice, training, and administration, through legal and policy decisions, and through efforts to protect the privacy of the relationship between doctor and patient. Informed consent, the right to refuse unwanted medical treatment, and the availability of advance directives have all become part of the underlying assumptions of the health care system. Important work is being done in finding ways to deal with the problem of medical futility, and recently the beginnings of a right to palliative care have found their way into clinical literature and judicial opinions.

But an examination of the legal status of these accomplishments shows that even those expressions of autonomy that we take most for granted are secured by a somewhat tenuous web of statutory and constitutional law. Furthermore, public struggles over private tragedies such as those that befell the Schiavo family have demonstrated a sometimes overbearing intensity of moral conviction and a frightening willingness to impose a single ideological or religious code upon the most intimate, complex, and emotionally sensitive decisions that any individual, family, or health care provider can be called on to make. These realities should serve as a warning that individual liberty and quality palliative care are at risk in the polarizing culture wars that increasingly put ideology above science and political agendas above individual autonomy and the privacy of the doctor/patient relationship.

By heeding this warning, clinicians can find uniquely important opportunities to lend their expertise and realistic assessments of the issues to those professional associations, legal advocates, health care policy experts, legislators, and judges who are working toward protecting and advancing the principles of autonomy and humaneness in end-of-life and palliative care.

Applications of the autonomy principle to health care over the past 25 years have demonstrated, as Justice John Paul Stevens wrote in *Cruzan*, that "Our duty, and the concomitant freedom, to come to terms with the conditions of our own mortality . . . are essential incidents of the unalienable rights to life and liberty endowed us by our Creator" (*Cruzan v. Director, Missouri Department of Health*, 1990, p. 343). These are private matters for the individual patient, the family, and the health care provider to decide. Precisely because we all feel so strongly about the ethical, emotional, and spiritual consequences of these individual decisions, they are not proper subjects for decision by what philosopher Ronald Dworkin has called a "universal, theoretical, abstract judgment born in the stony halls where interest groups maneuver and political deals are done" (Dworkin, 1994, p. 213).

Protecting and enhancing the privacy of end-of-life care decisions are essential not only to individual patients, their physicians, and families, but to the very idea of individual liberty in a constitutional democracy. As Justice Robert Jackson wrote in 1943:

> The very purpose of a Bill of Rights was to withdraw certain subjects from the vicissitudes of political controversy, to place them beyond the reach of majorities and officials and to establish them as legal principles to be applied by the courts. One's right to life, liberty, and property, to free speech, a free press, freedom of worship and assembly, and other fundamental rights may not be submitted to vote; they depend on the outcome of no elections. (*West Virginia State Board of Education v. Barnette*, 1943, p. 638)

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