COMMUNICATING WITH DYING PATIENTS: INFORMED CONSENT, PHYSICIAN FIRST AMENDMENT RIGHTS, AND STATE REGULATION IN THE UNITED STATES

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Summary
The right of competent adults to determine what is done to their bodies is a central tenet of U.S. medical-legal doctrine. This right emanates, in part, from the common law doctrine of “informed consent.” In overseeing the practice of medicine, U.S. states have regulated physician-patient communications through tort law concepts, including negligence (i.e., malpractice). Recently, some states have enacted legislation directly regulating the patient-physician dialogue in particular clinical settings. A controversial example is California’s “Terminal Patients’ Right to Know End-of-Life Options Act,” enacted in 2008. This paper addresses whether a physician who objects to an otherwise-legal, end-of-life medical option has a First Amendment right to refuse to abide by the California statute’s mandate to provide information and counseling to a terminally ill patient about that option or refer the patient to another provider. Based on analysis of judicial precedents, this paper concludes the California’s statute does not violate First Amendment rights.

1. THE COMMON LAW DOCTRINE OF INFORMED CONSENT

Patient autonomy—the right of competent adults to determine what is done to their bodies—is a central tenet of U.S. medical-legal doctrine. This right emanates, in part, from the principles of autonomy and self-determination that underlie the consensual nature of the physician-patient relationship. (Furrow 2000). Physicians are familiar with this concept in the context of the ethical and legal doctrine of “informed consent.” According to the American Medical Association (AMA), “informed consent” is the “process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention.” (AMA 2010). The AMA goes on to explain as follows:

The patient’s right of self-decision can be effectively exercised only if the patient possesses enough information to enable an informed choice. The patient should make his or her own determination about treatment. The physician's obligation is to present the medical facts accurately to the patient or to the individual responsible for the patient’s care and to make recommendations for management in accordance with good medical practice. The physician has an ethical obligation to help the patient make choices from among the therapeutic alternatives consistent with good medical practice. Informed consent is a basic policy in both ethics and law that physicians must honor. . . . (AMA 2010).
In overseeing the practice of medicine, U.S. states have long regulated physician-patient communications through common law tort concepts. In its early form, a cause of action for a lack of informed consent was characterized as an action for assault and battery based on the idea that an unconsented to medical treatment involved an unauthorized touching. (Furrow 2000; Paterick 2008). As the doctrine of informed consent evolved overtime, U.S. courts came to recognize that treating a patient without first providing the patient with adequate information regarding the nature of the proposed treatment and its risks, as well as available alternatives and their risks, constitutes professional negligence (i.e., malpractice). (Furrow 2000; Paterick 2008). In the majority of U.S. jurisdictions, the physician is required to provide such information to the patient as would be provided by a reasonable physician under similar circumstances as established through expert testimony. (Furrow 2000; Paterick 2008). A strong minority of states applies a “prudent patient” standard requiring physicians to provide the information that they would reasonably expect a patient would want in the situation. (Paterick 2008). Where informed consent issues arise, the claim usually involves an alleged failure by the physician to provide the patient with sufficient information about proposed treatments. As a result, physicians are routinely held liable for failing to speak, e.g., not providing material information about available alternative treatments.

2. STATE LEGISLATION AND PHYSICIAN-PATIENT COMMUNICATIONS

While the informed consent doctrine has been developed in the U.S. primarily by the courts, some states have articulated the general informed consent standard by statute. (Paterick 2008). Furthermore, several states have adopted statutes setting out required informed consent disclosures in particular clinical situations. (Furrow 2000). In most instances such state statutes have not raised concerns among health care professionals. However, in recent years some state legislatures have begun to regulate the content and process of communications between physicians and patients in sensitive treatment settings. Some of this legislation has engendered dispute.

2.1 ABORTION AND STATE CONSENT STATUTES

The most notable situation in which state legislatures have enacted statutes designed to regulate and control the physician-patient dialogue is in the context of a woman’s decision to undergo an abortion. Such statutes tend to reflect the state’s “pro-life” public policy. For example, South Dakota adopted a statute in 2006 requiring that, before performing an abortion, a physician inform the woman, in writing, that she is terminating the life of “a whole, separate, unique living human being” and that she risks “depression and related psychological distress,” including suicide, if she undergoes an abortion. (South Dakota 2009). Another recent example of a state’s effort to regulate physician-patient communications in the abortion context is a law passed in 2010 by the Oklahoma legislature specifying that a physician who withholds information about possible defects in a fetus from the woman, in order to avoid the risk that she will abort the fetus, may not be held liable for damages in a wrongful life or wrongful birth action. (Oklahoma 2010).

Critics of such statutes argue that they improperly interfere with communications between patients and physicians, either by requiring the physician to communicate certain legislatively-prescribed information to the patient regardless of its accuracy or efficacy, or by
permitting the physician to withhold relevant information from the patient. (Post 2007; Lazzarini 2008). In fact, the enforcement of the South Dakota statute was initially blocked by the federal trial court on the basis that it unconstitutionally compelled speech by physicians in violation of the First Amendment to the U.S. Constitution. The U.S. Court of Appeals for the Eighth Circuit in Planned Parenthood Minnesota v. Rounds later vacated the lower court’s injunction, rejecting this constitutional argument. (Planned Parenthood Minnesota 2008).

2.2 COMMUNICATING WITH DYING PATIENTS—THE CALIFORNIA RIGHT TO KNOW ACT

Another clinical context in which state legislation has been enacted to regulate the physician-patient dialogue involves terminally ill patients. In 2008, the California Assembly passed the “Terminal Patients’ Right to Know End-of-Life Options Act.” (California 2009). With this statute, the state legislature sought to ensure that dying patients receive, upon request, full information and counseling regarding legal end-of-life options. This statute, however, has proven to be very controversial, seen by some critics as “a veiled attempt at assisted suicide.”

The Right to Know Act’s basic requirement is that, “When a health care provider makes a diagnosis that a patient has a terminal illness, the health care provider shall, upon the patient’s request, provide the patient with comprehensive information and counseling regarding legal end-of-life care options. . . .” (California 2009). Under the Act, “health care provider” includes among others “an attending physician and surgeon.” The Act specifies that “comprehensive information” includes, but is not limited to, the availability of hospice care; the patient’s prognosis with and without continued disease-targeted treatment; and the patient’s right to refuse/withdraw life-sustaining treatment, to continue disease-targeted treatment, with or without palliative care, to comprehensive palliative care as well as other clinical treatments useful for dying patients, and to provide written health care instructions such as an advance directive. “Counseling” includes, but is not limited to, discussions about available treatment options and the outcomes for the patient and family, based on the interests of the patient. If the patient requests information on the costs of treatment options, including the availability of and eligibility for insurance coverage, the Act requires that the patient be referred to the appropriate entity for this information. If the provider does not wish to comply with the patient’s request for the information specified in the Act, he or she must refer or transfer the patient to another health care provider who will provide the requested information and furnish the patient with information on how to affect such a transfer. (California 2009).

Initially, one may ask why this Act would generate much controversy. On its face, it appears to be simply an “informed consent” statute for terminally ill patients. Given established common law informed consent standards, which would seemingly require physicians to always provide complete and honest information and counseling to their terminal patients, one might see the Act as unnecessary and perhaps unwise, but not controversial. And yet, it has been. Insight as to why this controversy developed may be gained by looking at the background of and perceived “purpose” for the Act.

In its legislative findings, the California Assembly expressed concerns about the “lack of communication between health care providers and their terminally ill patients.” (California 2009). The findings observe that the “lack of information and poor adherence to [terminal] patient choices can result in ‘bad deaths’ that cause needless physical and psychological suffering. . . [These] problems are complicated by social issues, such as cultural and religious pressures. . . .” (California 2009). In this regard, the Assembly specifically cited a “recent
survey” finding that providers who object to certain practices are less likely to believe they are obligated to present all options to their patients and refer them to other providers, if necessary.

The survey referenced by the California Assembly, “Religion, Conscience, and Controversial Clinical Practices” by Curlin and others appeared in the *New England Journal of Medicine* in 2007. (Curlin 2007). Surveyed physicians were asked to respond yes, no, or undecided to three questions as follows:

If a patient requests a legal medical procedure, but the patient's physician objects to the procedure for religious or moral reasons, would it be ethical for the physician to plainly describe to the patient why he or she objects to the requested procedure?

Does the physician have an obligation to present all possible options to the patient, including information about obtaining the requested procedure?

Does the physician have an obligation to refer the patient to someone who does not object to the requested procedure?

The survey found that many physicians do not consider themselves obligated to disclose information about [14%] or refer patients for [29%] legal, but morally controversial, medical procedures. Physicians who were more religious (as measured by either attendance at religious services or intrinsic religiosity) were less likely to believe that they must present all options to their patients or refer them to someone who does not object to the requested procedure. The surveyed physicians were specifically asked about their ethical views on several controversial clinical practices. This included whether they had religious or moral objections to so-called “terminal sedation” of terminally ill patients. Seventeen percent of the responding physicians objected to this practice and indicated that they would not discuss this as an option with their patients.

What is terminal or palliative sedation? As discussed by one commentator,

Terminal or palliative sedation consists of sedating a patient who is close to death to the point of unconsciousness to relieve symptoms that are intractable despite aggressive symptom-specific treatments, and maintaining this condition until the patient dies. Typically, artificial hydration and nutrition are withheld, as they no longer offer any benefit to the patient and may cause adverse effects. (Taylor 2003).

The ethics and legality of palliative sedation have been extensively discussed and debated. An opinion from the AMA’s Council on Ethical and Judicial Affairs provides that:

Palliative sedation . . . is an intervention of last resort to reduce severe, refractory pain or other distressing clinical symptoms that do not respond to aggressive symptom-specific palliation. It is an accepted and appropriate component of end-of-life care under specific, relatively rare circumstances. When symptoms cannot be diminished through all other means of palliation . . . it is the ethical obligation of a physician to offer palliative sedation to unconsciousness as an option for the relief of intractable symptoms. (AMA Council).
Regarding palliative sedation from a legal perspective, in her concurring opinion in *Washington v. Glucksberg*, U.S. Supreme Court Justice Sandra Day O’Connor stated that, “a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death.” (Washington 1997). Justice Souter echoed this view in his opinion as well.

Despite such medical and legal recognition given to palliative sedation as an appropriate form of end-of-life care, as reflected in the 2007 Curlin study (and others), a substantial number of physicians find this clinical alternative morally and religiously objectionable. As such, these physicians would simply decline to discuss it with patients as an available option.

Against this backdrop, the Act, as initially introduced in the California Assembly, specifically named among the treatment options to be included in a health care provider’s discussion with a terminally ill patient, “palliative sedation” and another controversial end-of-life option, “voluntary stopping eating and drinking” or VSED. During the enactment process, the language referencing these specific treatment options was modified and eventually deleted. Still, the legislative intent behind the Act seems clear. When asked by their patients about end-of-life care, the Act requires that physicians (and other providers), discuss and counsel them about all legal end-of-life care options, even some that a substantial number of physicians view as morally or religiously objectionable and which they would not otherwise discuss with their patients. It is this tension that has engendered the controversy concerning California’s Right to Know Act, leading to the argument that the Act violates physician rights under the First Amendment to the U.S. Constitution.

### 3. THE FIRST AMENDMENT AND THE RIGHT TO KNOW ACT

The First Amendment, which, as interpreted by the U.S. Supreme Court, applies to both the federal and state governments, provides, in relevant part, that, “Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof; or abridging the freedom of speech . . . .” (U.S. Constitution) With regard to the California Right to Know Act, two First Amendment issues arise: one involving the free exercise of religion; and the other involving free speech rights of physicians.

#### 3.1 RELIGIOUS FREEDOM AND THE RIGHT TO KNOW ACT

As to religious freedom, the initial question to consider is the appropriate constitutional standard to apply to state-imposed restrictions on the “free exercise” of religion in the context of the professional practice of medicine. The touchstone ruling regarding the free exercise clause and state law is the U.S. Supreme Court’s 1990 decision in *Employment Division v. Smith*. (Employment Division 1990). This case involved the use of an illegal drug, peyote, as part of a religious ceremony. Two devotees of the religion where dismissed from their jobs for their use of the drug during a religious ceremony and then denied unemployment compensation by the state because their employment had been terminated for “misconduct.”

The issue for the Court in *Smith* was whether the state law criminalizing the use of peyote, with no exception for religious purposes, violated the First Amendment’s free exercise clause. In rejecting this claim, Justice Scalia wrote for the Court stating, “the right of free exercise does not relieve an individual of the obligation to comply with a ‘valid and neutral
law of general applicability on the ground that the law proscribes (or prescribes) conduct that
his religion prescribes (or proscribes)” (Employment Division 1990). The state law at issue
in Smith, criminalizing the use of peyote was religiously neutral and generally applicable and
therefore did not violate any First Amendment free exercise rights. In its analysis, the Court in
Smith applied the “rational basis” test to assess the constitutionality of the state law. Under
this test, a state law is constitutional so long as it is rationally related to a legitimate
governmental interest. The statute in Smith met this test.

Using the Smith standard, the question to ask about California’s Right to Know Act is
whether it is religiously neutral and generally applicable. If so, the Act does not infringe
improperly on religious freedom under the First Amendment so long as it meets the rational
basis test.

Because the language of the Act never specifically mentions religion, except to note in
the findings provision that the problem of poor communications between physicians and
terminally ill patients can be “complicated by . . . cultural and religious pressures,” the Act is
religiously neutral on its face. Furthermore, any argument that, despite its language, the
purpose of the Act is to “target” physicians with religious objections to certain forms of end of
life care seems weak. The Act is broadly designed to address what the state legislature
identified as a general problem—poor physician-patient communications regarding end-of-life
medical care. Although the Act acknowledges that cultural and religious views of health care
providers, as well as patients and their families contribute to this problem, it hardly can be
said that the Right to Know Act is targeted at religious views or practices. Certainly the Act is
generally applicable as it applies to any “health care provider” including physicians, nurses,
and physician assistants. Finally, given the Act’s purpose to ensure adequate physician-patient
communications at the end of life, the Act clearly meets the rational basis test.

3.2 FREE SPEECH AND THE RIGHT TO KNOW ACT

In addition to the “free exercise” clause, the First Amendment also protects “freedom
of speech.” The type of speech at issue under the Right to Know Act is “professional speech,”
that is speech by health care professionals uttered in the course of rendering professional
services to patients. Although some health care providers may argue that, by compelling them
to discuss with patients treatment alternatives that they view as morally or religiously
objectionable, the Act inappropriately infringes on their free speech rights, the sort of speech
addressed by the Act is properly subject to state regulation.

The practice of medicine, like the practice of any other profession, requires speech.
Physicians must talk with their patients. As part of its authority to regulate medical practice as
a profession, the state has the power to regulate physician-patient communications. As
discussed earlier, physicians are routinely held liable for malpractice by courts for speaking or
failing to speak with patients.

U.S. Supreme Court precedent is not entirely clear regarding the standard of review
applicable to a state’s regulation of professional speech. Nevertheless, if the speech involves a
“personal nexus between professional and client” then, looking to Justice White’s concurring
opinion in 1985 in Lowe v. Securities and Exchange Commission, the speaker is “properly
viewed as engaging in the practice of a profession” and regulation is treated as economic
regulation subject to rational basis review requiring only that the governmental action be
“rationally related” to a “legitimate” government interest. (Lowe 1985). In this context, the
critical Supreme Court decision is Planned Parenthood of Southeastern Pennsylvania v.
Casey. (Planned Parenthood 1992). In this 1992 case, physicians asserted a First Amendment
right not to provide state-mandated information about the risks of abortion to patients considering that procedure. Upholding the state statute, the Court stated as follows:

To be sure, the physician’s First Amendment rights not to speak are implicated, but only as part of the practice of medicine, subject to reasonable licensing and regulation by the State. We see no constitutional infirmity in the requirement that the physician provide the information mandated by the State here. (Planned Parenthood 1992).

The Right to Know Act requires physicians to provide information and counseling, when asked by a patient, about legal end-of-life medical treatment options—speech consistent with a physician’s “traditional role” and “necessary to the proper functioning” of the physician-patient relationship. Thus, following Casey, the Act should be upheld in the face of a free speech challenge if it is “rationally related” to a “legitimate” government interest. As discussed in the context of the free exercise clause, the Act surely meets this test. California certainly has a legitimate interest in seeing to it that terminally ill patients are fully informed about their legal treatment options as death approaches. By mandating that health care providers caring for dying patients provide this information, the Act appears rationally related to the attainment of this interest.

3.3 THE RIGHT TO KNOW ACT UNDER A STRICT SCRUTINY STANDARD

An additional First Amendment claim might be raised regarding the Right to Know Act. In dictum appearing in Justice Scalia’s opinion in Employment Division v. Smith, he suggests that, in First Amendment cases involving a “hybrid situation” where the contested law implicates both free speech and free exercise rights, it may be appropriate to require that the law pass the more rigorous strict scrutiny test in order to be upheld as constitutional. (Employment Division 1990). The Right to Know Act could be characterized as involving such a “hybrid situation” and thus subject to strict scrutiny.

As explained by the Supreme Court in 1993 in Church of Lukumi Babalu Aye, Inc. v. City of Hialeah, to pass strict scrutiny, a law must satisfy a two-prong test. (Lukumi 1993). First, the law must be supported by a compelling state interest. Second, it must be narrowly tailored to meet that interest. As to the Right to Know Act, the state’s interest in assuring that patients who ask receive complete information about their legal end-of-life treatment options is a compelling one. The Act is narrowly tailored to meet this purpose. The Act only applies where patients have asked about their end-of-life treatment options. Further, the Act directs a physician who objects to fully discussing any legal options with a patient to refer the patient to another health care provider who will provide the information and counseling required under the Act. Finally, nothing in the Act precludes a physician from discussing with a patient who has asked about available treatment options, the social, cultural, moral, or religious issues involved in any particular form of end-of-life care.

The “hybrid situation” line of analysis is an unsettled area of First Amendment law. The lower federal courts have shown little inclination to utilize it. In any event, as noted, there is a strong argument that the Right to Know Act would still prevail even if measured by strict scrutiny criteria.
4. THE RIGHT TO KNOW ACT AND THE FEDERAL PROVIDER CONSCIENCE REGULATION

Recognizing the limited First Amendment protections offered to health care providers who have moral or religious concerns regarding medical procedures, many states have enacted so-called “right of conscience” statutes. Such statutes permit health care providers to refuse to participate in procedures that they might view as morally or religiously objectionable without risking criminal, civil, or administrative sanctions. The scope of coverage of such law varies widely from state to state. They may shield individual health care providers such as physicians, as well as hospitals and other health care facilities, from having to participate in a variety of medical procedures from abortions to human cloning to withdrawal of life sustaining treatment, where to do so would be against their religious or moral beliefs. (Swartz 2006).

While generally an area of state concern, at the federal level, a variety of laws have been enacted over the years to protect the rights of health care professionals and institutions who refuse to participate in particular health care services to which they may object for religious, moral, ethical, or other reasons. (Parr 2009). In late 2008, as President George Bush’s term in office was coming to a close, the U.S. Department of Health and Human Services (HHS) adopted a federal “provider conscience regulation” that became effective on January 20, 2009, immediately before President Obama took office. (Provider Conscience Regulation 2008). This regulation was intended to ensure that, in the delivery of health care services, recipients of federal funds do not require individual providers who have religious or moral objections to engage in practices in violation of these existing federal laws. However, the provider conscience regulation went farther than existing federal law in terms of who is protected and what medical services are covered. (Parr 2009).

This rule, which caused a great deal of concern among many health care providers and provider organizations such as the AMA, was rescinded by President Obama at the outset of his administration. (Sorrel 2009). While most of the controversy regarding the rule focused on its effect on access to abortion and contraceptive services, it would have impacted end-of-life care as well. (Lee 2009). In fact, upon analysis, the rule if implemented could have effectively nullified the California Right to Know Act.

As adopted, the rule specified that covered entities, including any state receiving federal money for health care services, could not, “require any individual to perform or assist in the performance of any part of a health service program . . . funded by [HHS] if such service or activity would be contrary to his religious beliefs or moral convictions.” (Provider Conscience Regulation 2008). As defined in the rule, “assist in the performance” meant “to participate in any activity with a reasonable connection to a procedure, health service or health service program . . . so long as the individual involved is a part of the workforce of a Department-funded entity [including] counseling, referral, training, and other arrangements for the procedure, health service, or research activity.” Arguably this rule would have impacted the Right to Know Act. For example, if California (which receives money for medical services from HHS) disciplined a physician who violated the Act by refusing to respond to a patient’s request and provide counseling and referral for palliative sedation because of personal religious or moral objections, this could result in a complaint to the federal Office of Civil Rights and jeopardize the state’s federal funding for medical services.

During the comment period preceding adoption of this rule, comments filed with HHS argued that the rule would disrupt requirements that providers obtain informed consent from patients. (Provider Conscience Regulation 2008). These comments explained that informed
consent requires providers to furnish patients with information about all treatment options, including those to which they object because of their conscience. In response HHS acknowledged that “informed consent is crucial to the provision of quality health care services.” Nevertheless, HHS “found no evidence” that federal and state conscience rules “disrupt the informed consent process between providers and patients.” HHS suggested that the provider-patient relationship can best be served by early and open discussion of conscience issues, including objections providers may have to certain services or procedures. (Provider Conscience Regulation 2008).

Comments filed with HHS also argued that a health care provider unwilling to offer a certain service should be required to give the patient a referral for the service to another provider. HHS responded that, “[f]or many health care providers . . . referral means assisting in the performance of objectionable procedures or services . . . and would violate their consciences.” HHS concluded, “Federal law recognizes and protects the conscience rights of individuals and entities when it comes to referral for certain objectionable services.” (Provider Conscience Regulation 2008).

As explained above, immediately after taking office in 2009, President Obama initiated the rescission process for this HHS “conscience” rule. Thus, the fears concerning its impact on end-of-life care for terminally ill patients never materialized.

5. CONCLUSION

Looking to the famous words of Justice Cardozo in his 1914 opinion in Schloendorff v. Society of New York Hospital, the essence of the informed consent doctrine is respect for the individual patient and the “right to determine what shall be done with his [or her] own body. . . .” (Schloendorff 1914). Recognizing the particular significance of this right for terminally ill patients, the California Assembly enacted the “Terminal Patients’ Right to Know End-of-Life Options Act” in 2008. The Act represents an important public policy statement by the legislature to address inadequate physician-patient communications at the end of life. While the Act has generated some dispute by requiring that health care providers, upon request by a patient, furnish information and counseling about all legally available treatment alternatives for a patient, even some the provider might find religiously or morally unacceptable, the Right to Know Act should withstand any First Amendment challenge in terms of free religious exercise and free speech rights.

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