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Protecting Patients’ Rights When Health Providers Refuse Care

Recently, a great deal of public attention has been focused on what the Secretary of Health and Human Services has described as an urgent need to protect health providers who object to providing certain services or medical information because of their ethical or religious beliefs. As your council discusses this issue, I urge you to consider another imperative – protecting the rights of patients to receive accurate medical information and needed treatment in a timely manner. In a pluralistic society such as we have in the United States, public policy must carefully balance the needs and rights of all affected parties.

Let’s use an example to make this discussion very concrete:

*A 19-year-old rape victim – let’s call her Sally -- is brought to a hospital emergency department by the police. The physician who treats her numerous injuries – Let’s call him Dr. Brown -- omits any mention of the potential to prevent pregnancy from the rape by using emergency contraception, because he does not approve of it for religious reasons. Many hours later, Sally leaves the hospital without being informed about emergency contraception, or offered the medication. A friend takes her back to the college dorm where they live and Sally, exhausted, falls asleep for 24 hours. Because emergency contraception is the most effective when taken shortly after unprotected intercourse, Sally’s opportunity to prevent pregnancy has now been greatly diminished.*

What has just happened? Is this proper medical care? What are Sally’s rights? What are Dr. Brown’s? And, how should they be properly balanced?

The patient’s rights

Let’s start with Sally. After all, the patient is supposed to be the focus of what the health professions refer to as “patient-centered care.” Patient-centered care is not, as one presenter before this council seemed to suggest yesterday, the subjugation of a physician’s clinical judgment to the uninformed demands of a patient. It does not by any means turn the physician’s role into that of a technician responding to consumer demand. Instead, according to the Institute of Medicine, “patient-centered care is defined as health care that establishes a partnership among practitioners, patients and their families (when appropriate) to ensure that decisions respect patients’ wants, needs and preferences and
solicit patients’ input on the education and support they need to make decisions and participate in their own care.’

One of the central tenets of patients’ rights and “patient-centered care” is the right to informed consent. For a patient to make an informed decision about medical treatment, he or she must have knowledge of all potential treatment options, and their risks and benefits. George Annas, a bioethicist and professor of health law at the Boston University School of Public Health, has written that, “In the most important study of informed consent to date, the President’s Commission for the Study of Ethical Problems in Medicine concluded that informed consent has its foundations in law and is an ethical imperative as well. It also concluded that ‘ethically valid consent is a process of shared decision making based upon mutual respect and participation, not a ritual to be equated with reciting the contents of a form that details the risks of particular treatments.’ Its foundation is the fundamental recognition ‘that adults are entitled to accept or reject health care interventions on the basis of their own personal values and in furtherance of their own personal goals.’”

In this case, the rape victim has not been informed about an important potential treatment option – use of emergency contraception to prevent pregnancy. As it happens, Sally is one of the millions of American women of reproductive age who are not aware of EC. So, Sally has had no opportunity to consider this option or use her own moral, ethical or religious perspectives to decide whether she wishes to risk the chance of bearing the child of a rapist. Further, she has had no chance to discuss with her physician the potential medical complications of an unplanned pregnancy, in view of her existing medical conditions, which include diabetes.

Sally’s experience in the emergency department falls far short of what George Annas describes as the goal of the doctrine of informed consent: “to enhance and encourage a responsible patient-doctor partnership designed to share information and to provide the patient with the right to make the final decision about treatment.”

How could this violation of patients’ rights be corrected? The simplest method would be to require all hospital emergency department personnel, including Dr. Brown, to always offer EC to rape victims who are of reproductive age.

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Physicians’ rights and responsibilities
But now, let’s focus on Dr. Brown. A fundamentalist Christian, he believes that emergency contraception is the same thing as abortion, even though medical and scientific experts say that is untrue and the FDA has stated unequivocally that emergency contraception prevents pregnancy and does not cause an abortion.

Dr. Brown argues that requiring him to give emergency contraception to Sally would violate his religious beliefs. “I shouldn’t have to give up my religious freedom in order to be a doctor,” he says.

Let’s pause for a moment to consider whether personal beliefs that are unsupported by medical science should be considered valid reasons why a licensed medical professional should be permitted to refuse to provide needed medical care, especially in an emergency situation in a facility that serves the general public. There was discussion before this Council yesterday of how to deal with “erroneous” or “faulty” conscience claims, and whether a conscientious objection can be considered authentic even when it is based on misinformation. One could hope that Dr. Brown would be able to modify his position, when presented with accurate information about emergency contraception’s mechanism of action.

But what if he does not? How far should we allow Dr. Brown or one of his colleagues to go with conscientious objections? What if they are masking discriminatory views? If Dr. Brown also believes that AIDS is a just punishment from God for perverted behavior, should he be allowed to refuse to treat any patients with AIDS? What if one of his colleagues believes that under Islamic law, anyone who committed murder should be sentenced to death? Should he be permitted to refuse to treat suspected murderers who are brought to the emergency room for treatment of wounds suffered in the attack? Where should we draw the line between acceptable and unacceptable moral reasons for refusing to provide care? There are no easy answers here. Unfortunately, the Secretary of Health and Human Services’ new proposed regulation on provider conscience reflects none of this complexity and essentially treats all claims of health provider conscience as being equally deserving of government protection.

In the interests of moving our analysis along, however, let’s set that issue aside and see if there is a compromise we could arrive at that would permit Dr. Brown to refuse to give EC to Sally, while still ensuring that she gets the medication in a timely manner. What if we just require Dr. Brown to refer Sally to another physician or a nurse in the emergency department who could provide her the emergency contraception if she wishes to use it?

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6 See for example, 62 FR 8610-01
That, too, is unacceptable, Dr. Brown says, because it requires him to cooperate in helping the patient receive treatment he finds morally objectionable. “I cannot be implicated in any way in helping her commit an immoral act,” he states.

One could argue that Dr. Brown’s professional responsibilities to his patient should obligate him to provide Sally with at least a referral in such a situation. Indeed, the American Medical Association’s “Principles of Medical Ethics” states: “A physician shall, while caring for a patient, regard responsibility to the patient as paramount.”

But, under the proposed “Provider Conscience Regulation” issued by the U.S. Department of Health and Human Services (HHS) on August 26, 2008, no entity receiving federal funding (such as the hospital where Dr. Brown works) could require him to give Sally the medical information or referral she needs if he claims a religious objection. To attempt do so would be to “discriminate” against him, and could result in the loss of federal funding, according to the rule. Not a single other physician or nurse in the hospital could be required to step in and give Sally what she needs, if that health professional held the same views as Dr. Brown.

Moreover, HHS has proposed a very expansive definition of the term “assist in the performance of” to permit refusals for “participation in any activity with a reasonable connection to the objectionable procedure, including referrals, training and other arrangements for offending procedures.” Arguably, this definition would permit a pharmacy technician to refuse to stock emergency contraception in the hospital pharmacy, or a hospital purchasing agent to refuse to order it. Again, we face the question of where we should draw the line between acceptable and unacceptable refusals. The proposed HHS rule would seem to draw no line at all, instead allowing medical professionals and hospital personnel to use personal moral or religious beliefs to exempt themselves from any medical obligations to their patients.

Let’s consider another alternative – requiring the hospital to be responsible for ensuring that Sally’s rights as a patient are protected.

**Hospital responsibilities**

Arguably, the hospital *should already* be responsible for ensuring that Sally’s medical needs are met. In order to participate in the federal Medicare program, and to be reimbursed under the Medicaid program, hospitals must adhere to “Conditions of Participation.” These conditions are meant to ensure that patients’ rights are respected and they received medically appropriate care. For example, hospitals are required to:


9 42 C.F.R. § 482.13, 482.55 and 482.25
• “Honor a patient’s right to make informed decisions regarding his or her medical care.”
• “Meet the emergency needs of patients in accordance with acceptable standards of practice.”
• “Have pharmaceutical services that meet the needs of patients.”

One might also argue that the hospital is responsible under the provisions of the Emergency Medical Treatment and Active Labor Act (EMTALA). All hospitals that accept Medicare and Medicaid have a duty to screen and stabilize individuals who arrive at their emergency department requesting medical treatment, as mandated by EMTALA. Since a rape victim of reproductive age who was forced to have unprotected intercourse is in danger of becoming pregnant, it could be argued that in order to “stabilize” her condition, and prevent pregnancy, she should be offered emergency contraception. But since neither EMTALA nor the Medicaid/Medicare Conditions of Participation has yet been enforced to require the provision of EC to rape victims, a number of states have enacted so-called EC in the ER or Compassionate Care for Rape Victims laws. These statutes specifically require hospitals to offer emergency contraception to rape victims, or, at minimum, inform rape victims about the potential to use the medication to prevent pregnancy.

How should the hospital go about fulfilling these responsibilities for patients like Sally? Should administrators fire Dr. Brown and replace him with someone who will dispense EC to rape victims? No, that would not be the preferable way of dealing with this situation, because there are far less drastic options available.

Instead, the hospital could offer Dr. Brown a transfer out of the ER into another unit of the hospital where he would not be expected to dispense EC, and replace him in the ER with someone who has no objections to EC. Such an arrangement would be an example of a “reasonable accommodation” under Title VII of the Civil Rights Act of 1964, which requires employers to reasonably accommodate an employee’s religious beliefs or practices, unless doing so places an “undue hardship” on the employer’s business. This type of careful balancing of competing rights is a hallmark of American public policy.

But, Dr. Brown might argue that he is being discriminated against even by such a reasonable accommodation, because it removes him from the practice of emergency medicine, which he sees as his mission in life. The proposed HHS rule might give him ammunition to do so, because it lacks any attempt to balance his rights with the patients’ rights and the obligation of the hospital to serve its patients.

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11 11 states require hospitals to dispense emergency contraception on request to rape victims, while another four require hospitals to provide information about emergency contraception. State Policies in Brief: Emergency Contraception. The Guttmacher Institute, September 1, 2008. Available at http://www.guttmacher.org/statecenter/spibs/spib_EC.pdf
12 Provider Conscience Regulation, RIN0991-AB48
HHS Secretary Michael Leavitt, in a press conference to release the department’s proposed rule, went so far as to frame the issue this way: “Freedom of conscience is not to be surrendered upon issuance of a medical degree.”\(^{13}\) He told reporters, “This is about protecting the right of a physician to practice medicine according to his or her moral compass.”

Is there another solution? How about requiring the hospital to have a routine protocol of offering EC to all rape victims, and designating someone on each shift who does not object to EC to step in, inform the patient about EC and offer it? This surely would be somewhat cumbersome, and would require careful management of hospital staffing schedules. It also would require that Dr. Brown and any other hospital emergency department personnel who have objections to dispensing EC disclose those objections up front, so that hospital administrators can make appropriate scheduling decisions.

**Religious hospital claims to “conscience” rights**

But what if the hospital as an institution operates under a religious doctrine that expresses grave reservations about the use of emergency contraception? Let’s put Dr. Brown and Sally in the emergency department of St. Mary’s Roman Catholic Hospital. Like other Catholic hospitals, it is governed by the *Ethical and Religious Directives for Catholic Health Care Services* (ERDs).\(^{14}\) The ERDs offer this guidance about the use of emergency contraception at a Catholic hospital:

> A female who has been raped should be able to defend herself against a potential conception from the sexual assault. If, after appropriate testing, there is no evidence that conception has occurred already, she may be treated with medications that would prevent ovulation, sperm capacitation or fertilization. It is not permissible, however, to initiate or recommend treatments that have as their purpose or direct effect the removal, destruction or interference with the implantation of a fertilized ovum. (Directive 36)

There are no existing medical tests that can show within 72 hours of unprotected intercourse – the time frame in which EC is effective -- whether conception (fertilization) has occurred. A pregnancy test shows that a fertilized egg has become successfully implanted in the uterus, but such a blood or urine test cannot be performed until 6 to 12 days after ovulation.\(^{15}\)

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\(^{13}\) Associated Press, “HHS: Doctors can refuse to provide abortions,” August 21, 2008.


Given this difficulty, Catholic theologians, individual Bishops and administrators of Catholic hospitals have come up with a variety of ways of interpreting Directive 36. Some Catholic hospitals provide EC to all rape victims. Some administer a pregnancy test, even though such a test would only be able to detect a pregnancy that was established prior to the rape (and if the woman is already pregnant, she does not need EC). Some require the rape victim to undergo an ovulation test. If the test comes back positive, EC is denied because of the hypothetical possibility that there might be a fertilized egg in existence. Still other Catholic hospitals refuse to offer EC at all.

St. Mary’s Hospital, as it happens, is one of the Catholic hospitals that refuses to allow any dispensing of EC. Moreover, the hospital does not permit staff to even discuss EC with patients like Sally, citing another two of the ERDs:

“Free and informed consent requires that the person or person’s surrogate receive all reasonable information about the essential nature of the proposed treatment and its benefits; its risk, side-effects, consequences and cost; and any reasonable and morally legitimate alternatives, including no treatment at all (Directive 27, with emphasis added);

“The free and informed health care decision of the person or the person’s surrogate is to be followed so long as it does not contradict Catholic principles.” (Directive 28, with emphasis added).

Under a new state law taking effect in six months, St. Mary’s and all other hospitals in this state (including Catholic ones) will be required to offer EC to rape victims. Dr. Gray, a colleague of Dr. Brown’s in the emergency department, is happy about the new law, because he believes it is his professional and ethical obligation to serve the patient’s medical needs, and he wants to be able to offer EC to patients like Sally. He is upset about what he views as the hospital’s violation of his rights to use his own ethical beliefs and his medical training in deciding how to treat patients. (The proposed HHS regulation, it should be noted, does not seem to protect physicians like Dr. Gray, who wish to provide medical treatment, not refuse it, but are stymied by institutional religious restrictions.)

St. Mary’s, which opposed the new law, hopes to argue that since it considers emergency contraception to be an abortifacient, it cannot be compelled to obey the law.

17 A 2002 telephone survey of 597 Catholic hospital emergency departments found that only a small percentage of Catholic hospitals were routinely offering EC in an unrestricted manner to women who had been raped. Of the 23% of Catholic hospital emergency rooms that said they offered EC to rape survivors, only three percent offered it without restriction. The others required pregnancy tests (13%) or that the rape be reported to the police (.5%). Most significantly, the study found that 66% of Catholic hospital emergency rooms did not provide EC to rape survivors at all or had policies that are sufficiently unclear as to make provision of EC unlikely. Second Chance Denied: Emergency Contraception in Catholic Hospital Emergency Rooms Ibis Reproductive Health for Catholics for a Free Choice. 2002 http://www.catholicsforchoice.org/topics/healthcare/documents/2002secondchancedenied_001.pdf
Administrators of St. Mary’s plan to cite the proposed HHS rule which, in seeking to enforce compliance with a longstanding federal law allowing federally-funded hospitals to refuse to perform abortions or sterilizations, seems to leave the definition of abortion open to interpretation.

The regulation, as promulgated, dropped a definition of abortion that had appeared in an earlier draft that had attempted to conflate contraception with abortion by including anything that could interfere with a fertilized egg. But, as the Washington Post reported, supporters and critics alike agreed that the language remains broad enough to apply to contraceptives. HHS Secretary Leavitt, in response to reporters’ questions about the proposed rule, acknowledged that there was no definition of abortion and that some medical providers may want to “press the definition” and make the case that some forms of contraception are tantamount to abortion, according to the Wall Street Journal.

Does this mean that state health officials who try to enforce the new state law at St. Mary’s – in order to ensuring that all rape victims are offered emergency contraception -- might risk being found guilty of “discrimination” against St. Mary’s. Could the state lose all of its federal health funding as a result? Is that really the outcome we should be seeking in federal policy?

If St. Mary’s were to be successful in its claim, what would happen to rape victims who need emergency contraception? Should they be expected to go to drugstores to buy it, even though they have just suffered a traumatic attack, may have had their clothes torn and may have been robbed of their purses, their money and their car keys? What if the local pharmacy also objects to emergency contraception? The proposed HHS rule, which purports to be about protecting health providers from having to perform abortions and sterilizations, extends provider conscience protections to pharmacies (and also, it should be noted to a wide variety of other health care institutions, including nursing homes and dentists offices).

Should rape victims be expected to leave St. Mary’s and go to a different hospital, again in a traumatized state? What if St. Mary’s is the only local hospital? A national study conducted by my organization in 2002 revealed that there were 48 religiously-sponsored hospitals in the United States that were recognized by the federal government as being the sole providers of hospital care for a geographic region.

Conclusions
To hear HHS Secretary Leavitt and his colleagues tell it, the department’s regulatory might and funding power must be marshaled behind medical professionals in this country.

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18 The Church amendment (42 USC 300a-7).
who, they contend, are at serious risk of retaliation, firing or being forced to surrender their medical licenses for exercising their religious consciences. The department’s introduction to its proposed rule on provider conscience states, “There appears to be an attitude toward the health professions that health care professionals and institutions should be required to provide to assist in the provision of medicine or procedures to which they object, or else risk being subjected to discrimination.” The Department’s commentary, however, did not supply a single example of a health professional who actually had been discriminated against.

Secretary Levitt claimed at his press conference releasing the proposed regulation that “there is nothing in this rule that would in any way change a patient's right to a legal procedure” and that "this regulation does not limit patient access to health care.”

But, as the story of Sally, Dr. Brown and St. Mary’s Hospital has demonstrated, that would not be the case. In fact, the proposed HHS rule has the potential to seriously undermine the already fragile balance between providers’ rights and patients’ rights in the American health care system. It would tip the scales far over in the direction of objecting health providers, and leave patients at risk of going without needed medical information and care. It would allow providers’ personal moral beliefs to come before patients’ rights and would take American health care in the opposite direction from “patient-centered care.” To summarize, it would do so in the following ways:

- Allow health practitioners to violate a patient’s right to informed consent by refusing to tell the patient about those potential treatment options that the provider finds morally objectionable;
- Allow health practitioners to refuse to provide patients with any medical services or information a provider finds morally objectionable – even for reasons that are completely contrary to medical science. Because of the broad language of the proposed rule, it is entirely conceivable that this “refusal permission slip” could extend well beyond abortion and sterilization to potentially encompass contraception, emergency contraception, STD treatment, end-of-life decision-making and even refusal to treat patients whose lifestyles are objectionable to the provider;
- Further, permit health practitioners to refuse to provide the patient with a referral to another practitioner who would be willing to meet the patient’s needs;
- Obligate nearly 600,000 health care institutions (not just hospitals, but also insurance companies, pharmacies, dentist offices, nursing homes and other facilities) to “certify” that they do not discriminate against practitioners with moral objections to certain services, with no similar obligation to certify that patients’ medical needs will always be met;
- Leave these health care institutions in complete confusion about how they, as employers, must go about meeting the needs of these objecting health practitioners, since the proposed rule makes no reference to the types of reasonable accommodations that have been customary under the provision of Title VII of the Civil Rights Act of 1964;
- Invite religiously-affiliated health care institutions to file challenges to state laws, such as EC in the ER or Compassionate Care for Rape Victims Laws, which have been enacted by elected representatives of the people after careful weighing of religious freedom claims against the need to serve a public good of protecting the health needs of rape victims.

**Recommendations**

Clearly, the proposed HHS rule, as it has been promulgated, should be withdrawn. It is both unnecessary -- given the existence of underlying legal protections -- and overreaching in its broad interpretation of those existing statutes. I urge your council to so recommend to the Secretary of Health and Human Services.

But, I also recommend that your council consider ways in which public policy could more strongly protect patients’ rights and access to care, without unduly burdening individual health practitioners who have moral objections to providing certain medical services. What would be some ways of doing this?

- **Patients’ right to informed consent must be paramount.** Patients must be informed of all potential treatment options so that they are able to give fully informed consent, based on medical recommendations and the patient’s own ethical or religious beliefs. Compliance with fully-informed consent requirements should be a condition of institutional participation in Medicaid and Medicare programs. The existing informed consent language for those programs should be strengthened to explicitly state that information about treatment options may not be withheld from patients because of hospital ethical or religious policies or the objections of individual health practitioners. Individual health practitioners should be expected, at minimum, to refrain from expressing personal opinions about potential treatment options and to provide the patient with an immediate referral to another practitioner who will explain all of the potential treatment options and provide requested treatment.

- **Acute care hospitals and any other health facilities that are licensed to serve the general public and receive patients needing emergency care must be required to provide such care immediately.** When time-sensitive emergency care is needed -- such as for rape, an ectopic pregnancy or a miscarriage – a hospital must be required to provide it immediately on site. In such an instance, a hospital should not be permitted to refuse the care or attempt to send the patient elsewhere. The patient’s need for emergency care must take precedence. New or enhanced language under the Medicare and Medicaid conditions of participation should specify this requirement. In such situations, the health facility should attempt to accommodate any objecting individual practitioner on duty in the emergency room by substituting a non-objecting practitioner, provided that doing so will not delay or compromise the patient’s care. Anticipating such situations will enable a hospital to arrange staffing schedules accordingly.

- **The ability of non-objecting health practitioners to fulfill their duty to their patients must be safeguarded.** Physicians and other caregivers must be guaranteed the right to discuss all treatment options with patients, regardless of
whether those options are permitted at the hospital or other health facility, and must be able to assist patients in obtaining desired treatment at alternate facilities. It is unacceptable for hospitals that serve the general public and receive public funding to impose “gag orders” on physicians and other caregivers. Hospital policies must explicitly spell out protections of caregivers’ rights to discuss all treatment options with their patients. These protections must not be countermanded by conditioning admitting privileges or staff employment on caregivers’ adherence to religious or ethical policies of the institution.

- **When health institutions serving the general public have treatment restrictions based on religious or ethical principles, they should be expected to disclose those policies to patients and individual health providers.** Patients cannot make informed choices about where to seek treatment in non-emergency situations if they are unaware of service restrictions at certain institutions. For example, a woman who is delivering a baby and wishes to undergo a post-partum tubal ligation must be able to select a hospital that will permit this choice and avoid those hospitals that prohibit it. Similarly, a patient with a terminal disease who does not wish to be placed on artificial nutrition and hydration must be informed if a hospital will not honor such a choice. Disclosure of restrictive hospital policies should be carried out prior to admission, and repeated following admission in the event of a conflict between hospital policy and the patient’s desired course of medical treatment.

- **For non-emergency care, referrals to alternate practitioners or facilities must be made if treatment is being refused.** Referrals to alternate providers are essential to ensure that patients are fully able to exercise their right to pursue courses of treatment not offered at a particular health institution or by an individual practitioner. Acceptable referral practices must include providing the patient with the names, addresses and phone numbers of alternative providers; ensuring that the patient is able to travel to at least one of these other providers and has insurance coverage (including Medicaid) which will be accepted there. It should not be permissible medical practice to simply refuse treatment and send the patient away.

*The MergerWatch Project is a national initiative dedicated to protecting patients’ rights and access to care. The project, based in New York City, assists communities in securing such protections when religious and non-religious hospitals merge and in such other situations as when pharmacists or pharmacies refuse to dispense medications on religious grounds or when insurance companies or employers use religious doctrine to restrict coverage. To learn more about our work, visit our website at www.mergerwatch.org.*