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# COMMENTARY

# THE DENIAL OF ABORTION CARE INFORMATION, REFERRALS, AND SERVICES UNDERMINES QUALITY CARE FOR U.S. WOMEN

Tracy A. Weitz, PhD, MPA<sup>a,\*</sup>, and Susan Berke Fogel, JD<sup>b</sup>

<sup>a</sup>Advancing New Standards in Reproductive Health (ANSIRH), Bixby Center for Global Reproductive Health; Department of Obstetrics, Gynecology and Reproductive Sciences; University of California, San Francisco, California <sup>b</sup>National Health Law Program, Los Angeles, California

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n September 9, 2009, President Barack Obama spoke before a joint session of Congress on the imminent need for health care reform. In his speech, he addressed the contested social issue of abortion in two ways: by reaffirming the ongoing exclusion of abortion from federal health care financing and supporting health care providers' right to opt out of providing health care they find objectionable. "I want to clear up—under our plan, no federal dollars will be used to fund abortions, and federal conscience laws will remain in place" (Obama, 2009). His acceptance of the right to deny health care for ideological reasons directly contradicts the expectation most Americans share—that the care they receive will be consistent with the highest standards of scientific evidence, based on individual patient need, and with the goal of maximizing health and wellness.

This commentary provides a brief investigation into this contradiction by providing a new way of thinking about health care denials using the same yardsticks employed to assess health care quality more generally: the adherence to evidence-based standards of care, a commitment to patient centeredness, and focus on prevention of poor health outcomes (Institute of Medicine Committee on Quality of Health Care in America,

E-mail: weitzt@obgyn.ucsf.edu.

2001). The contents of this commentary are drawn from a report to be released by the National Health Law Program, *Health Care Refusals: Undermining Quality Care for Women* (Fogel & Weitz, 2009). Although the full report addresses broader needs for care related to pregnancy prevention, pregnancy termination, fertility achievement, and healthy sexuality, this commentary is limited to a few standards of care that necessitate abortion as a health care option for women.

# Allowances for Denials of Information, Referral, and/or Services

Allowances for the denial of information, referral and/ or services manifest in three ways: 1) refusal clauses, often called "conscience clauses," in which institutions and individuals are shielded from liability for failing to provide health services, counseling, and/or referrals because the individual or institution has an objection to the service; 2) institutional prohibitions in which institutions override physician-patient decision making and prohibit the provision of certain services in their facilities, refuse to cover those services in their insurance products, or otherwise restrict services that meet evidence-based standards of care; and 3) political restrictions, including those laws and regulations that are enacted based on political ideology or electoral politics and mandate how health care must be delivered, where and how it can be delivered, or what care is covered by health care payers.

Refusal clauses, first passed soon after the *Roe v. Wade* (1973) decision and now in existence in almost every state, were initially limited to the right of physicians to opt out of performing abortions and sterilizations

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<sup>\*</sup> Correspondence to: Tracy Weitz, PhD, MPA, Director, Advancing New Standards in Reproductive Health (ANSIRH), Bixby Center for Global Reproductive Health, Assistant Professor, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California, San Francisco, 1330 Broadway St., Ste 1100, Oakland, CA 94612; Phone: 510-986-8939.

(Church Amendment 42 U.S.C. § 300a et seq.). Newer refusal clauses allow a wider range of medical personnel, facilities, and health insurers to refuse to participate in any service to which they have an objection on religious, moral, or ethical grounds. A Mississippi statute limits the steps that a facility that offers the service can take to overcome the refusal by framing the issue as one of "discrimination" against the refusing individual. Under this law, a hospital clerk can refuse to admit a patient for a service to which the clerk objects (Miss. Code Ann. §§ 41-41-215 [Enacted 1998; Last Amended 1999], Miss. Code Ann. §§ 41-107-1 [Enacted 2004]).

The broadest institutional prohibitions are those imposed by Catholic health systems which control 15% of the hospital beds in the United States, serving one in six Americans in need of health care annually (The Catholic Health Association of the United States, 2009). Catholic health systems, hospitals, clinics, and managed care organizations are governed by the Ethical and Religious Directives for Catholic Health Care Services (The Religious Directives), promulgated by the U.S. Conference of Catholic Bishops. The directives present "a theological basis for the Catholic health care ministry" (United States Conference of Catholic Bishops, 2001). Health care professionals must agree to abide by the directives to obtain admitting privileges at Catholic hospitals or to lease offices in medical buildings; other health care workers are contractually bound by them as a condition of employment. The Religious Directives specify a range of services that are prohibited including abortion, contraceptives, sterilization, and most forms of assisted reproductive technology, such as in vitro fertilization, and impose limits on information that can be given to patients.

One of the most significant political restrictions is the Hyde Amendment, first passed in 1976 and every year thereafter, which prohibits the use of federal Medicaid dollars to pay for abortions (Consolidated Appropriations Act, 2008, Pub. L. No. 110-161, §§ 507-508, 121 Stat. 1844, 2208-2209 [2007]). Currently, only 17 states use their own funds to provide coverage for low-income women's abortion care, leaving Medicaid-eligible women in 33 states without financial coverage (Guttmacher Institute, 2009). The Balanced Budget Act of 1997 contains a broad refusal clause that essentially allows managed care organizations that serve the Medicaid population to impose their own gag rules by opting out of providing or reimbursing for a counseling or referral service, if the organization objects to the provision of such service on moral or religious grounds (Balanced Budget Act of 1997, Pub. Law No. 105-33, 111 Stat. 251, 295). In December 2008, under former President George W. Bush, the Department of Health and Human Services issued final regulations that would expand the legal protections afforded to a wide range of participants in the health care workforce including volunteers, framing any limitation on refusals as "discrimination" (Ensuring that Department of Health and Human Services Funds Do Not Support Coercive or Discriminatory Policies or Practices in Violation of Federal Law, 73 Fed. Reg. 78071 [Dec. 19, 2008] [codified at 45 C.F.R. Pt. 88]). In March 2009, President Obama issued a proposed regulation to rescind the HHS regulations (Rescission of the Regulation Entitled "Ensuring That Department of Health and Human Services Funds Do Not Support Coercive or Discriminatory Policies or Practices in Violation of Federal Law," 74 Fed. Reg. 10207 [March 10, 2009] [to be codified at 45 CFR Pt 88]).

# **Defining Standards of Care**

Standards of care are defined as the practices that are medically necessary and the services that any practitioner under any circumstances should be expected to render (Mulrow & Lohr, 2001). Standards of care statements are created to indicate the level of clinical practice endorsed by scientists and clinicians and grounded in evidence from investigations of a particular area of practice. Unlike "best practices," which focus on the highest level of care a patient can receive, standards of care establish a baseline of professionally agreed-upon practices. Generally, standards are based on large quantities of evidence from empirical studies (e.g., data generated from studies of practice or clinical trials), but clinicians' experiences in practice may also form the basis for evolving standards when no systematic evidence exists to guide care. Although the phrase "standard of care" is also used in the medical liability context to assess liability, standards of care in this analysis are discussed in the context of what care patients should expect given the prevailing medical knowledge.

# Delineating Health Conditions for Which Access to Abortion is the Standard of Care

Although most often associated with factors related to an unintended pregnancy, abortion care is also needed for women with medical or fetal complications associated with a wanted or intended pregnancy. Medical standards developed by the American College of Obstetricians and Gynecologists (ACOG), the American Academy of Pediatrics (AAP), the American College of Cardiology/American Heart Association (ACC/AHA), the European Society of Cardiology (ESC), and the Cochrane Collaboration all recognize the importance of access to abortion as a component of quality health care. Universally, these practice guidelines place that decision about whether to have an abortion in the hands of the patient. They charge the physician with giving the patient full and complete medical information about her treatment options.

### Example 1: Cardiovascular disease

There are some cardiac conditions in which the physiologic changes brought about in pregnancy are poorly tolerated. The Task Force on the Management of Cardiovascular Diseases during Pregnancy of the ESC is clear on the importance of abortion as an option for some high-risk patients: "Pregnancy is not recommended. If pregnancy occurs, termination should be advised as the risks to the mother are high" (Task Force on the Management of Cardiovascular Diseases During Pregnancy of the European Society of Cardiology, 2003:764). The guidelines from the ACC/AHA concur that pregnancy should be avoided altogether or terminated if a woman has cyanotic congenital heart disease, Eisenmenger syndrome, or severe pulmonary hypertension (Warnes et al., 2008). Additionally, because Marfan syndrome can cause spontaneous dissection or rupture of the aorta, the most feared cardiovascular complications associated with pregnancy, the guidelines recommend pregnancy termination if a woman's aortic root enlargement is greater than set limits (Warnes et al., 2008).

# Example 2: Premature rupture of membranes

Premature rupture of the membranes occurs when the amniotic membranes surrounding a pregnancy rupture before the pregnancy has reached term (at 37 weeks). Mid-trimester premature rupture of the membranes occurs between 16 and 26 weeks gestation and complicates approximately 1% of all pregnancies in this stage and can cause severe bleeding and infection (ACOG, 2007). Maternal sepsis, an infection of the body that involves all major organ systems, is a rare, but very serious complication; if left untreated or diagnosed too late, can be fatal. Risks to the fetus include infection and neurologic impairment (ACOG, 2007).

Because of the poor survival rates for fetuses at less than 24 weeks' gestation, clinical guidelines locate the focus on safeguarding the health and well-being of the pregnant woman (Kilpatrick et al., 1997). The ACOG/ AAP Guidelines for Perinatal Care recognizes that some women will elect induction of labor with no expectation of fetal survival (i.e., to undergo an abortion). Consequently, the guidelines strongly advise that women whose fetuses are pre-viable (less than 24 weeks) should be counseled by an obstetrician and a pediatrician to understand the maternal health risks and the low likelihood of delivering a healthy infant (AAP, ACOG, & March of Dimes Birth Defects Foundation, 2007). ACOG practice guidelines require that the pregnant woman should be counseled about all the risks and benefits of continuing her pregnancy without intervention (ACOG, 2007).

### Example 3: Preeclampsia and eclampsia

Preeclampsia and eclampsia are serious and related pregnancy complications, responsible for 17% of

maternal deaths in the United States (ACOG, 2002). In the United States, preeclampsia complicates almost 4% of live births, and eclampsia, an additional 2 of every 1,000 live births (Centers for Disease Control and Prevention, 2009). The cause of these conditions is unknown and the rate of pregnancy related morbidity from severe preeclampsia is increasing (Berg, Mackay, Qin, & Callaghan, 2009). Significant racial disparities exist in rates of and complications associated with these diagnoses (Mackay, Berg, & Atrash, 2001). Preeclampsia and eclampsia can affect the kidney, liver, and brain of the pregnant woman. If left untreated, it can lead to long-term health problems and even death of the fetus and/or the pregnant woman (National Institutes of Health Eunice Kennedy Shriver National Institutes of Child Health and Human Development, 2006).

The Cochrane Review explains that the only treatment of preeclampsia and eclampsia is delivery of the pregnancy (Churchill & Duley, 2002). The ACOG/AAP guidelines state that the risks to the woman from persistent severe preeclampsia are such that delivery (abortion) is usually suggested regardless of fetal age or potential for survival, taking into consideration factors such as severity of preeclampsia, gestational age, maternal condition, fetal condition, and prospect for fetal survival (AAP et al., 2007). Expectant management should only be considered for those women remote from term who have mild preeclampsia (ACOG, 2002).

#### Conclusion

Under refusal clauses, individual physicians, nurses, and other personnel can refuse to provide services, refer to alternative providers, or even inform women that abortion is a treatment option for their health condition. This undermines the standard of care in two ways: first, by interfering with patients receiving complete medically accurate and unbiased information about their treatment options; and second, by inhibiting the ability of patients to access medically appropriate care. Shielded by refusal laws, physicians can opt not to follow the standard of care for women for whom abortion is one alternative. Institutional prohibitions further extend these effects. For example, the directives explicitly state that abortion is never permitted (United States Conference of Catholic Bishops, 2001) and even when the abortion is intended to protect the health of the pregnant woman, or to save her life, abortion is prohibited (O'Donnell, 1996). Thus, even if the treating physician is willing to perform the abortion, she or he may be prohibited from doing so based on the beliefs or religious ownership of the organization that employs, houses, or funds her or him. Political restrictions exacerbate the effect on quality in secular facilities where state laws prohibit the provision of abortion in facilities receiving state funds.

The Institute of Medicine's influential Crossing the Quality Chasm report (2001) identifies the new paradigms of evidence-based medicine and patient-centered care as explicit means for achieving better health outcomes among individual patients and the U.S. population. Complementing these approaches is the commitment to prevention that has moved from public health to mainstream medicine. As this brief analysis shows, quality of care is undermined when a full range of medically appropriate services are not available to patients because institutions or individuals object to providing a particular service based on religious doctrine or ideology. Contrary to the trends in modern health care delivery, health care refusals and institutional denials of care grounded in personal and religious beliefs rather than scientific evidence negate evidence-based practice, patient-centered care, and prevention. They take women's reproductive health backward to the discredited model of paternalistic health care where treatment decisions are made by physicians and health systems regardless of patient needs and preferences, and they negate patients' capacity to make informed decisions. Health care reform efforts should not continue to allow women to receive lower quality care and should instead mandate that the standard of care be met for all patients regardless of where and from whom they obtain their care.

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### **Author Descriptions**

Tracy Weitz, PhD, MPA, is the Director of the Advancing New Standards in Reproductive Health (ANSIRH) program of the Bixby Center for Global Reproductive Health and Assistant Professor in the Department of Obstetrics, Gynecology and Reproductive Sciences, both at the University of California, San Francisco (UCSF). ANSIRH's mission is to ensure

that reproductive health care and policy are grounded in evidence.

Susan Berke Fogel, JD, is a public interest lawyer who directs the Reproductive Health projects for the National Health Law Program, a non-profit law firm work-

ing for health justice for low income people, people of color, immigrants and people with disabilities. Her work focuses on health systems change to support the right and ability of low income women and low income women of color to achieve their reproductive desires.