NHeLP
NATIONAL HEALTH LAW PROGRAM

1444 I Street, NW
Suite 1105
Washington, DC 20005
Ph. (202) 289-7661
Fax (202) 289-7724
nhelpdc@healthlaw.org

HEALTH CARE REFUSALS AND CONTRACEPTION: UNDERMINING QUALITY CARE

Health care refusals and denials of care, sometimes referred to as "conscience" clauses, are proliferating in the United States based on ideological and political justifications that have no basis in medical standards of care. "Standards of care" are medical practices that are medically appropriate, and the services that any health care practitioner under the circumstances should be expected to render. Denials of care violate the essential principles of modern health care delivery: evidence-based practice, patient centeredness, and prevention. A recent report from the National Health Law Program ("NHeLP"), *Health Care Refusals: Undermining Quality Care for Women*, provides an extensive analysis of the adverse health care consequences for women when medicine is based on ideological beliefs instead of medical standards of care. NHeLP's report investigates and documents the extent to which these denials of care conflict with professionally developed and accepted medical standards of care for women's health, and analyzes the potential health consequences for patients. **The report concludes that refusal clauses and denials of medical care undermine standards of care by allowing or requiring health care professionals to abrogate their responsibility to deliver services and information that would otherwise be required by generally accepted practice guidelines and laws**.

Ideological restrictions occur at three levels: the individual health professional level, the institutional and health system level, and the political level. Refusal clauses are statutory or regulatory "opt out" provisions: they permit health professionals, personnel, and institutions to refuse to provide services that they would otherwise be required to provide under law or medical guidelines. Even more, these clauses shield health care providers and institutions from liability for the health consequences of their refusals on women. These clauses emerged as a way to allow individuals and institutions that receive federal funding to opt out of providing abortions or sterilizations. Recently, however, federal and state governments have proposed or enacted much broader refusal clauses, allowing health care personnel to refuse to participate in almost any health service with which they have an objection. For example, offering and providing emergency contraception ("EC"), which can prevent pregnancy if taken within 120 hours of unprotected sex, to survivors of sexual assault is the accepted medical standard of care.[1] Nevertheless, not all hospitals meet this standard. A number of states have enacted legislation to enforce the standard. At the same time, many of these "EC in the ER" bills include refusal clauses, which range from very narrow exceptions that include requirements for counseling and referral, to very expansive "opt out" provisions for both individual providers and institutions.

At the **institutional level**, the restrictions that have the greatest impact on access to care are those imposed by institutions controlled by religious entities. In particular, the Catholic health system has the

[1] *See e.g.*, Am. Coll. of Obstetricians & Gynecologists, Comm. on Healthcare for Underserved Women, Op. 499 (Aug. 2011), http://www.acog.org/Resources_And_Publications/Committee_Opinions/Committee_on_Health_Care_for_Underserved_Women/Sexual_Assault; Am. Coll. of Emergency Physicians, Policy Statement: Mgmt. of the Patient with the Complaint of Sexual Assault (reaffirmed Oct. 2008), http://www.acep.org/content.aspx?id=29562; Am. Med. Ass'n: Nat'l Advisory Council on Violence & Abuse, Policy Compendium H-75.985 (Aug. 2008), http://www.ama-ssn.org//resources/doc/violence/vio_policy_comp.pdf.

broadest religion-based health care restrictions. According to the Catholic Health Association, one in six Americans is seen in a Catholic hospital each year. Nearly 15% of all hospital beds are in Catholic hospitals, and in some states, more than 30% of the hospitals are Catholic. The U.S. Conference of Catholic Bishops has issued *The Ethical and Religious Directives for Catholic Health Care Services*, which governs all Catholic health institutions. The Directives specify a range of services that are prohibited, including abortion, contraception, sterilization, and most forms of assisted reproductive technology such as in vitro fertilization. The prohibitions extend to life-saving treatment for a pregnant woman. There are no exceptions to these prohibitions for rape, incest, the health or life of the person, medical necessity, or the informed decision of the patient. Other religious restrictions may apply at some Adventist and Mormon institutions. Physicians and other health care providers who work in these systems are prohibited from delivering the care they were trained to provide, even when they have no objection to—and want to provide—the service themselves.

At the **political level**, many restrictions on access to health care, particularly to reproductive health care, are enacted by federal and state legislatures and agencies. For example, several states prohibit insurance *coverage* of abortion unless the buyer has purchased a separate rider for abortion care. Other laws interfere with the doctor-patient relationship by requiring reproductive health providers to give women biased and/or inaccurate information, or by imposing restrictions such as medically unnecessary ultrasounds and unreasonable waiting periods, all of which are unrelated to health and safety. Laws also impose particular burdens on abortion clinics that are not imposed on other health facilities. These restrictions are driven by political ideology, electoral politics, and other political considerations that have nothing to do with evidence-based medicine. Indeed, these restrictions fly in the face of evidence-based medicine.

Informed consent is at the core of the individual's right to make his or her own decisions about medically appropriate health care. Some statutory refusal clauses allow providers to opt out of providing counseling, information, and referrals about services to which the provider has a personal objection. These clauses shield some providers from otherwise applicable legal and ethical mandates regarding informed consent, and the requirement to inform patients of all reasonable treatment options. Exacerbating the problem, neither individual providers nor hospitals are required to inform patients in advance of these restrictions. These laws thereby deprive patients of the complete and accurate information necessary for patients to give informed consent, and rob patients of their autonomy.

REFUSAL CLAUSES HAVE SERIOUS HEALTH CONSEQUENCES FOR WOMEN

There are many ways in which refusal clauses harm not only a woman's right to make her own reproductive decisions, but also her physical health. In the most grievous instances, a refusal clause can result in a woman's death.

Women take many factors into account when deciding whether or when to become pregnant, such as their age, educational goals, economic situation, the presence of a partner and/or other children, medical condition, mental health, and whether they are taking medications that are contra-indicated for pregnancy. Although there is near universal agreement in medical practice guidelines that women should be given information about and access to contraceptives to prevent unintended pregnancy, women face many barriers to contraceptive use, including institutional restrictions, physicians' personal objections, and pharmacists' refusals to fill prescriptions. Even when a woman suffers from a chronic medical condition that could jeopardize her life during a pregnancy, she may struggle to find birth control options. For example, millions of women live with common chronic conditions such as diabetes, heart disease, depression, obesity, and lupus which can lead to adverse birth outcomes or threaten maternal health if not under control and well managed during a pregnancy. Refusal clauses and denials of care operate to prevent women from obtaining complete and accurate contraceptive counseling, devices, and supplies.

A number of commonly prescribed pharmaceuticals such as certain anti-depressants, thyroid medications, and severe acne treatments are known to cause impairments in the developing fetus or to create adverse health conditions if a woman becomes pregnant while taking them. Approximately 11.7 million prescriptions for drugs the FDA has categorized as Pregnancy Classes D (there is evidence of fetal harm, but the potential may be acceptable despite the harm) or X (contraindicated in women who are or may become pregnant) are filled by significant numbers of women of reproductive age each year.[2] Pregnancy for women taking these drugs carries risk for maternal health and/or fetal health. Medical guidelines advise that women taking these drugs, who might also be at risk for pregnancy, use a reliable form of contraception to prevent pregnancy.[3]

Unintended pregnancy is also associated with maternal mortality and morbidity. The World Health Organization recommends that pregnancies should be spaced at least two years apart. Pregnancy spacing allows the woman's body to recover from the pregnancy. Further, if a woman becomes pregnant while breastfeeding, the health of both her baby and fetus may be compromised as her body shares nutrients between them. According to the American College of Obstetricians and Gynecologists ("ACOG"), women who become pregnant less than six months after their previous pregnancies are seventy percent more likely to have membranes rupture prematurely, and are at a significantly higher risk of other complications.[4] Family planning is a focus area of the Healthy People 2020 health promotion objectives set out by the United States Department of Health and Human Services. Healthy People 2020 aims to increase the proportion of intended pregnancies and to improve pregnancy spacing. Specific indicators of goal achievement include increasing: (1) intended pregnancies, (2) pregnancy spacing to 18 months, (3) the proportion of women at risk for unintended pregnancy who use contraceptives to 100 percent, and (4) the proportion of teens that use contraceptive methods that both prevent pregnancy and prevent sexually transmitted disease.

The burdens that refusal clauses impose fall disproportionately and most harshly on low-income women and low-income women of color. Low-income women and low-income women of color already experience severe health disparities in reproductive health, maternal health outcomes, and birth outcomes. Cardiovascular disease, lupus, and diabetes, for example, are chronic conditions that disproportionately impact women of color. The rate of diabetes is higher for women of color in all age groups. African American and Latina women have higher rates of hypertension, obesity, physical inactivity, and metabolic syndrome than do white women. The incidence of lupus is three times higher for African American women than for white women. Further, nearly one out of ten African American women and one in fourteen Latinas of reproductive age experience an unintended pregnancy each year. Low income women have unintended pregnancy rates that are more than five times the rate for women in the highest income level. Inaccessible and unaffordable contraceptive counseling and services contribute to these disparities.

Heart disease is the number one cause of death for women in the United States. The American College of Cardiology and the American Heart Association Task Force on Practice Guidelines issued specific

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[2] Ctrs. for Disease Control & Prevention, *Recommendations to Improve Preconception Health and Health Care— United States: A Report of the CDC/ATSDR Preconception Care Work Group and the Select Panel on Preconception Care*, Morbidity & Mortality Wkly Rep. 55 (April 21, 2006).

[3] David L. Eisenberg, et al., *Providing Contraception for Women Taking Potentially Teratogenic Medications: A Survey of Internal Medicine Physicians' Knowledge, Attitudes and Barriers*, 25 J. Gen. Internal Med. 291, 291-92 (2010).

[4] Am. Coll. of Obstetricians & Gynecologists, *Statement of the Am. Coll. of Obstetricians & Gynecologists to the U.S. Senate, Comm. on Health, Educ., Labor & Pensions, Pub. Health Subcomm. on Safe Motherhood* (April 25, 2002).

recommendations for management of women with valvular heart disease.[5] The task force concludes that individualized preconception management should provide the patient with information about contraception, as well as the maternal and fetal risks of pregnancy.

ACOG and the American Diabetes Association have developed practice guidelines for preconception care for women with pregestational diabetes. ACOG recommends that "[a]dequate maternal glucose control should be maintained near physiological levels before conception and throughout pregnancy to decrease the likelihood of spontaneous abortion, fetal malformation, fetal macrosomia [excessive birthweight], intrauterine fetal death, and neonatal morbidity."[6]According to the American Diabetes Association, planned pregnancies greatly facilitate diabetes care.[7] Their recommendations for women with childbearing potential who have diabetes include: (1) use of effective contraception at all times, unless the patient is in good metabolic control and actively trying to conceive, (2) counseling about the risk of fetal impairment associated with unplanned pregnancies and poor metabolic control, and (3) maintain blood glucose levels as close to normal as possible for at least two to three months prior to conception.

Contraception plays a similarly critical role in preparing a woman with lupus for pregnancy. Lupus is an auto-immune disorder of unknown etiology which can affect multiple parts of the body such as the skin, joints, blood, and kidneys with multiple end-organ involvement. Often labeled a "woman's disease," nine out of ten people with lupus are women. Women with lupus who become pregnant face particularly increased health risks. A large review of United States hospital data found the risk of maternal death for women with lupus is twenty times the risk of non-lupus pregnant women.[8] These women were three to seven times more likely to suffer from thrombosis, thrombocytopenia, infection, renal failure, hypertension, and preeclampsia. Women who suffer from moderate or severe organ involvement due to lupus are at significantly higher risk for developing complications during pregnancy, and medical guidelines applicable to chronic diseases apply to women with those co-morbidities. The National Institute of Arthritis and Musculoskeletal and Skin Diseases advises women to consider all of these factors when deciding to become pregnant or to carry a pregnancy to term.

CONCLUSION

The public expects health care decisions to be based on scientific evidence, the best clinical experience, and good economic policy. Health care refusals and denials of care, in contrast, are based on ideology and political justifications. Refusal clauses threaten to undermine the promise of the Affordable Care Act to ensure affordable, accessible, and quality care for women. All women should have access to the health care services they need based on their personal decisions and their medical condition. Employers, insurers, hospital corporations, and governments should not be allowed to use their ideological beliefs to discriminate against women.

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[5] Robert O. Bonow, et al., *Guidelines for the Management of Patients with Valvular Heart Disease*, Am. Coll. of Cardiology/Am. Heart Ass'n Task Force on Practice Guidelines (Comm. on Mgmt. of Patients with Valvular Heart Disease), 98 J. Am. Coll. of Cardiology 1949-1984 (Nov. 1998).

[6] Am. Coll. of Obstetricians & Gynecologists, *ACOG Practice Bulletin No. 60: Pregestational diabetes mellitus*, 115 Obstetrics & Gynecology 675 (2005).

[7] Am. Diabetes Ass'n, *Standards of Medical care in Diabetes-2006*, 29 Diabetes Care S4, S28 (2006).

[8] Megan E. B. Clowse, et al., *A National Study of the Complications of Lupus in Pregnancy*, 199 Am. J. Obstetricians & Gynecologists 127e.1, e.3-e.4 (Aug. 2008).