



# Health Care Refusals: Undermining Quality of Care

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*“Securing Health Rights for Those in Need”*

# Welcome to *Communications Connection*



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# Overview

- Description of the Standards of Care Project and project goals
- A framework for analyzing refusal clauses and denial of care
  - Standards of Care
  - Refusal Clauses and Denials of Care
- Examples of how health care denials undermine the quality of care for women
- Recommendations for new ways of talking about health care refusals

# The Standards of Care Project: Restrictions on Women's Health

**Goal:** To develop a new communications framework for addressing refusal clauses and denials of care by:

1. investigating and documenting whether and to what extent denials of health care and information conflict with professionally-developed, accepted medical standards of care, and
2. analyzing the potential medical and health consequences on patients.

# Project Team

- National Health Law Program (NHeLP)
  - Susan Berke Fogel, JD
    - Former NHeLP team members: Lourdes Rivera, JD and Jamie Brooks, JD
- University of California, San Francisco (ANSIRH)
  - Tracy Weitz, PhD, MPA
- Communications support
  - Susan Lamontagne and Adrienne Verrilli, Public Interest Media Group
  - Margaret Conway, Conway Strategic



# Advisory Board

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# Refusal Clauses and Denials of Care

- Individual refusals
  - Statutory or regulatory
  - Shields provider from liability for failure to provide services or information that would otherwise be required
- Institutional restrictions
  - Religious, political, or financial
  - Restricts services and information that patients can obtain
  - Prohibits providers from delivering care in accordance with their professional medical judgment

# Refusal Clauses

## Allow Substandard Care

- Refusal clauses give permission to providers or institutions to opt-out of meeting accepted medical standards of care
- Refusal clauses shield individual providers and institutions from liability for their failure to deliver care that meets accepted medical practice
  - Malpractice
  - Licensing
  - Medical Board review
- **Regardless of health outcome**

# What are Standards of Care?

- The practices that are medically necessary and services that any practitioner under any circumstances should be expected to render
- Requires that all health care professionals provide information and care consistent with the highest standards of scientific evidence, based on individual patient need, and with the goal of maximizing wellness

# Current Framework for Analyzing Refusal Clauses

- Seen as conflict between provider rights of conscience vs. patient's right to exercise autonomy
- Dialogue about refusal clauses is polarized in pro-choice/anti-choice argument about abortion
- Institutional restrictions are narrowly framed as a debate about abortion
- Promotes the issue as a philosophical debate without tangible impact
- The patient and her health are invisible

# Standards of Care: A Framework for Analyzing Refusal Clauses and Denials

- Denials of care should be measured with same yardstick used to assess health care quality generally: evidence-based, patient-centered, and prevention
- Denials of care and information should be evaluated in terms of real health consequences for patients

# Standards of Care: A Framework for Analyzing Refusal Clauses and Denials

- A patient's health should always come first
  - Health care should be guided by evidence and medicine, not religious or personal beliefs
  - A patient should always be able to trust and expect quality care
  - A patient should be able to trust that her doctor's information and treatment recommendations are based on what's best for her, not on her doctor's personal beliefs
- Refusal clauses put a patient's health at risk
  - Not part of quality care
  - Legal permission to provide care that does not meet accepted practice standards
- Health care denials are understood as violations of the standard of care rather than as moral contests

# What Standards of Care are Violated by Allowing Refusals and Restrictions?

- Reproductive and Sexual Health
  - Pregnancy Prevention
  - Pregnancy Termination
  - Pregnancy Attainment
  - Healthy Sexuality
- Other Areas of Concern
  - End-of-life issues (not included in report due to a current lack of established standards)

# Pregnancy Prevention and the Management of Chronic Conditions

Epilepsy

Acne

Lupus

Depression

Cardiovascular Disease

Diabetes

Obesity

# Pregestational Diabetes

- **Condition**

- 8 million women in the US have diabetes
- 1.85 million women are affected with pregestational diabetes

- **Consequences**

- Failure to manage glucose during pregnancy = complications for the health of the pregnant woman and her developing fetus
  - increased risk of hypoglycemia, blindness (from acute acceleration of diabetic retinopathy), renal failure (from diabetic nephropathy), complications from chronic hypertension, life-threatening complications from coronary heart disease, diabetic ketoacidosis, and diabetic nephropathy

# Standards of Care: Diabetes

- The American College of Obstetricians and Gynecologists (ACOG) and the American Diabetes Association (ADA) have practice guidelines for the preconception care for women with pregestational diabetes
- The ADA recommends that all women with diabetes and childbearing potential be educated about the need for glucose control before pregnancy and should participate in family planning
- The ADA recommends that the standard of care for diabetic women with childbearing potential includes:
  - education about the risk of fetal malformations associated with unplanned pregnancies and poor metabolic control; and
  - use of effective contraception at all times, unless the patient is in good metabolic control and actively trying to conceive.
  - Maintain blood glucose levels as close to normal as possible for at least two to three months prior to conception

# Pregnancy Termination

Ectopic Pregnancy

Premature Rupture of Membranes

Preeclampsia / Eclampsia / HELLP Syndrome

Chronic Conditions (CVD, Lupus, etc)

Emergent Conditions

Use of Teratogenic Medications

# Ectopic Pregnancy

- Condition
  - Non-viable but “living” pregnancy develops outside the uterus
- Consequences of substandard care
  - Rupture, internal bleeding
  - Death of the pregnant woman
  - Infertility

# Standards of Care: Ectopic Pregnancy

- 3 treatment options to be determined by individual clinical presentation and patient preference for intervention and future fertility (ACOG / RCOG)
  - Surgical removal of portion of tube with pregnancy
  - Surgical removal pregnancy only (laparoscopy)
  - Medication to dissolve pregnancy

# Ex. of Ectopic Care Denials

- Individual
  - Physician refusal to treat ectopic due to presence of heart beat
- Politically-driven
  - Bans on abortions in public hospitals
- Institutional
  - ERDs
    - Analyze ectopic pregnancy treatment within context of prohibition on abortion
    - Can not perform “direct” abortion
    - Can perform some interventions under principle of “double effect,” i.e salpingectomy (removal of tube)

# More Evidence Developing

- Foster, Dennis, and Smith (2009) Poster at the National Abortion Federation Meeting
  - Random sample of 69 hospitals with emergency departments after stratifying for geographic region, facility type, regulatory environment, and size
  - Physicians reported multiple cases where patients were discharged to other facilities or where medication management of the ectopic pregnancy was prohibited

# Premature Rupture of Membranes

- Condition (PROM)
  - Amniotic membranes rupture pre-term
  - < 24 weeks: only 30% fetuses survive
- Consequences
  - Infection, rare maternal sepsis
  - Severe bleeding, aka hemorrhage
  - Infertility
  - Death
  - Reduced fetal neurologic functioning

# Standards of Care: PROM

- ACOG and AAP standard of care
  - Balance risk to woman v potential for fetal survival
  - Ob/Gyn must counsel about risks, and woman must decide whether to abort or attempt to continue pregnancy
- Refusal or denial of care
  - no counseling on risks
  - refusal to terminate
  - hospital/clinician makes the decision instead of the patient

Freedman, L. R., Landy, U., & Steinauer, J. (2008). When there's a heartbeat: miscarriage management in Catholic-owned hospitals. *Am J Public Health, 98(10), 1774-1778.*

“I’ll never forget this; ... I’m on call when [the patient] gets septic and she’s septic to the point that I’m pushing pressors on labor and delivery trying to keep her blood pressure up and I have her on a cooling blanket because she’s 106 degrees. And I needed to get everything out. And so I put the ultrasound machine on and there was still a heartbeat and [the ethics committee] wouldn’t let me because there was still a heartbeat. This woman is dying before our eyes...”

# What Can You Do?

- Understand what a refusal clause really is:
  - Release from liability for not providing services a provider is otherwise obligated to perform
  - By definition they demonstrate that they are a violation of the standard of care
  - Different from the exercise of professional judgment not to provide or perform services for which the clinician is evaluated within the framework of the standard of care.

# Message Compass

- ***Patient's health* is the positive value** that provides the underpinning of this message.
  - It must be front and center in all discussions.
- **Talk about “a patient’s health” not just women’s health.**
  - This does two things: reminds the listener that this is about any patient, not just a subset or specialty (i.e., women’s health); and narrows the listener’s thinking to individual circumstances, not a huge population which can overwhelm or invoke stereotypes.

# Message Compass Con't

- **Illustrate the impact of refusal clauses.**
  - Use real examples to illustrate the real and negative impact they can have on a patient's health. Use stories and examples to bring this to life.
- **Use “refusal” or “denial” -- as in “refusal clauses,” “refusal bills,” “provider refusals” or “health care denials.”**
  - Avoid using “conscience clause” which is our opponents' preferred phrasing.

# Other Recommendations

- Distinguish between individuals who deny care and institutions that prohibit clinicians from offering the standard of care even when they want (denials of care).
- Remember “Standard of care” is a medical term which is probably not commonly understood outside the medical professions or related legal and policy experts, so be cautious in its use.
  - Alternatives are “health standards,” or “medical standard of care” or just “accepted practice.”

# BE ACTIVE IN THE HEALTH CARE REFORM DEBATES AND DISCUSSIONS

- May be naive to believe that if we don't bring up contraception and abortion neither will "they"
- We are at significant risk of expanding the scope of denials of care
- Find novel ways to compromise
- Rely on other published opinions about how to limit refusals

# ACOG Statement

The Limits of Conscientious Refusal in Reproductive Medicine. Committee Opinion No 385. Washington, DC: American College of Obstetricians and Gynecologists; Nov. 2007.

“Although respect for conscience is important, conscientious refusals should be limited if they constitute an imposition of religious or moral beliefs on patients, negatively affect a patient’s health, are based on scientific misinformation, or create or reinforce racial or socioeconomic inequalities.”

# ACOG Recommendations

- Give patients prior notice of moral commitments and provide accurate unbiased information about RH
- Refer patients in a timely manner to a doctor that can provide the service
- Provide medically indicated services in an emergency when referral is impossible or might affect physical or emotional health
- Practice close to a physician who will provide legal services and ensure that referral processes are in place

# Implications

- Begin a dialogue about refusal clauses in the framework of standards of care
- Consider health consequences when hospitals merge
- Consider health consequences when refusal clauses are proposed
- Raise concerns about institutionalizing refusal clauses in health reform

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