The Standards of Care Project: Health Care Refusals as Violations of Standards of Care

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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



National Health Law Program (NHeLP)

- The National Health Law Program is a national public interest law firm that seeks to improve health care for America's working and unemployed poor, minorities, the elderly and people with disabilities. NHeLP serves legal services programs, community-based organizations, the private bar, providers and individuals who work to preserve a health care safety net for the millions of uninsured or underinsured low-income people.
- NHeLP believes that health is a human right



The Standards of Care Project: Goals

To investigate and document whether and to what extent denials of health care and information conflict with professionallydeveloped, accepted medical standards of care, and to analyze the potential medical and health consequences for patients.



Project Team

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- University of California, San Francisco
 - Tracy Weitz, PhD, MPA
- Public Interest Media Group
 - Susan Lamontagne

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Overall Project Design

- Analyze medical practice guidelines and compare with refusal clauses and denials of care
- Provide a new framework for talking about the findings of the report
- Disseminate the findings to the health care professional community



The Need for a Standards of Care Analysis

- Refusal clauses are proliferating
 - 2007: 11 states proposed broad refusal clauses
- Individuals who refuse are more organized and more vocal
 - Self Magazine poll: 1 in 20 respondents reported their doctors had refused to treat them based on moral, ethical, or religious reasons
- Religiously-controlled health systems are expanding
- Great risk that Health Reform proposals will institutionalize refusal clauses and denials of care
 - Major players refusing to discuss reproductive health
 - Religiously-controlled providers are "at the table"



Current Framework for "Conscience 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
- Promotes the issue as a philosophical debate without tangible impact
- The patient and her health are invisible



Health Care is Unique

- Information and services do not take place in an open marketplace
- Practicing medicine, providing nursing care, or distributing drugs without a license are forbidden by law
- Patients can only obtain certain care from professionals who are given that privilege by the state
- Provider-patient relationship is inherently unequal



Trends in Health Care

- Evidence-based practice
- Patient-centered
- Prevention oriented
- Transforming the provider-patient relationship to optimize health, broadly defined as a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity



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 standard of scientific evidence, based on individual patient need, with fully informed consent, and with the goal of maximizing wellness



A New 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
- Health care denials are understood as violations of the standard of care rather than as moral contests



Methodology

- Review medical practice guidelines from major national medical associations and other recognized sources
 - ACOG, AMA, ACC, ADA AAP
 - Cochrane Review
 - CDC, WHO, IOM
- Review major recognized sources on religious and ideological restrictions
 - U.S. Conference of Catholic Bishops
 - National Recognized theologians
 - Catholic Medical Association
- Review major national experts on refusal clauses and restrictions on care



Sources of Restrictions

• 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 that providers can offer
- Political Restrictions
 - Governmental actions that restrict access to, or prohibit provision of services that would otherwise be required



Individuals Refusals

- Statutes and/or regulations that allow health provider to opt out of providing information or services that would otherwise be required
- Shield from liability
- Expansion and proliferation of refusals
 - 1970's abortion and sterilization
 - 2000's any provider can refusal any service



Individual Refusals

- Abortion, sterilization, family planning (state employees), contraception
- 46 states allow some providers to refuse to provide abortions
- 43 states allow institutions to refuse to provide abortions
- 4 states have broad refusal clauses
 - Mississippi: any provider can refuse to participate in any service



Institutional Restrictions

- Prohibit certain services in their facilities, health plans, medical office buildings
- Require adherence to restrictions as a condition of employment or contract
- Restrictions based on ideology, personal belief; not related to evidence or patient need



Institutional Restrictions

- Adventist, Baptist, Morman
- Ethical and Religious Directives for Catholic Health Care Services
 - Prohibitions on abortion, contraception, artificial reproduction
 - No exceptions for patient need, health or life of the patient or the fetus
- Past two decades, growth of religiously controlled health systems
 - 16% of patient beds in U.S. in Catholic hospitals
 - One in six Americans is treated in a Catholic hospital each year

Political Restrictions

- Government actions that restrict access to, or prohibit provision of services
 - Hyde amendment prohibits federal funding for abortions except rape, incest, save life of women
 - \$176 billion for abstinence only programs that are not effective
 - Targeted Restrictions on Abortion Providers (TRAP)
 - Mississippi: must have ultrasound equipment and provide ultrasound prior to abortion
 - Prohibition on private insurance coverage of abortion except to save life of woman
 - Idaho, Kentucky, Missouri, South Dakota



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

