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# *Flashpoint* Informed Consent for Cesarean Section and Women's Rights

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Cesarean Section Safety & Quality in Low Resource Settings

Boston, July 2017

# Framing the Discussion

- Universal Rights of Childbearing women
- Non-consented “care” as mistreatment
- WHO Quality, Equity, Dignity Network
- Metrics
- Discussion points



A midwife holds the hand of a woman in labor at a hospital in Gusau, Nigeria. Photo by Karen Kasmauski/MCSP.

# Respectful Maternity Care Charter: Universal Rights of Childbearing Women

In seeking and receiving  
maternity care before,  
during and after childbirth:

**1** EVERY WOMAN HAS THE RIGHT TO  
**BE FREE FROM  
HARM AND ILL  
TREATMENT**  
NO ONE CAN PHYSICALLY  
ABUSE YOU

**2** EVERY WOMAN HAS THE RIGHT TO  
**INFORMATION, INFORMED  
CONSENT AND REFUSAL,  
AND RESPECT** FOR HER  
**CHOICES** AND  
PREFERENCES, INCLUDING  
**COMPANIONSHIP**  
DURING MATERNITY CARE  
NO ONE CAN FORCE YOU OR DO  
THINGS TO YOU WITHOUT YOUR  
KNOWLEDGE AND CONSENT

**3** EVERY WOMAN HAS THE RIGHT TO  
**PRIVACY AND  
CONFIDENTIALITY**  
NO ONE CAN EXPOSE YOU OR  
YOUR PERSONAL INFORMATION

**4** EVERY WOMAN HAS THE RIGHT TO  
**BE TREATED WITH  
DIGNITY AND  
RESPECT**  
NO ONE CAN HUMILIATE  
OR VERBALLY ABUSE YOU

All rights are grounded in established international human rights instruments, including the Universal Declaration of Human Rights; the Universal Declaration on Bioethics and Human Rights; the International Covenant on Economic, Social and Cultural Rights; the International Covenant on Civil and Political Rights; the Convention on the Elimination of All Forms of Discrimination Against Women; the Declaration of the Elimination of Violence Against Women; the Report of the Office of the United Nations High Commissioner for Human Rights on preventable maternal mortality and morbidity and human rights; and the United Nations Fourth World Conference on Women, Beijing. National instruments are also referenced if they make specific mention of childbearing women.

Safe Motherhood is more than the prevention of death and disability...It is respect for every woman's humanity, feelings, choices, and preferences.

**RESPECTFUL  
MATERNITY CARE:  
THE UNIVERSAL  
RIGHTS OF  
CHILDBEARING  
WOMEN**



**5** EVERY WOMAN HAS THE RIGHT TO  
**EQUALITY,  
FREEDOM**  
FROM DISCRIMINATION,  
AND **EQUITABLE CARE**  
NO ONE CAN DISCRIMINATE  
BECAUSE OF SOMETHING THEY  
DO NOT LIKE ABOUT YOU

**6** EVERY WOMAN HAS THE RIGHT TO  
**HEALTHCARE**  
AND TO THE **HIGHEST  
ATTAINABLE LEVEL  
OF HEALTH**  
NO ONE CAN PREVENT  
YOU FROM GETTING THE  
MATERNITY CARE YOU NEED

**7** EVERY WOMAN HAS THE RIGHT TO  
**LIBERTY, AUTONOMY,  
SELF-DETERMINATION,  
AND FREEDOM  
FROM COERCION**  
NO ONE CAN DETAIN YOU OR YOUR  
BABY WITHOUT LEGAL AUTHORITY

**Disrespect and abuse during  
maternity care are a violation of  
women's basic human rights.**



For more information visit:



World Health  
Organization

hrp.

## The prevention and elimination of disrespect and abuse during facility-based childbirth

### WHO statement

*Every woman has the right to the highest attainable standard of health, which includes the right to dignified, respectful health care.*



photo: UNICEF

*Many women experience disrespectful and abusive treatment during childbirth in facilities worldwide. Such treatment not only violates the rights of women to respectful care, but can also threaten their rights to life, health, bodily integrity, and freedom from discrimination. This statement calls for greater action, dialogue, research and advocacy on this important public health and human rights issue.*



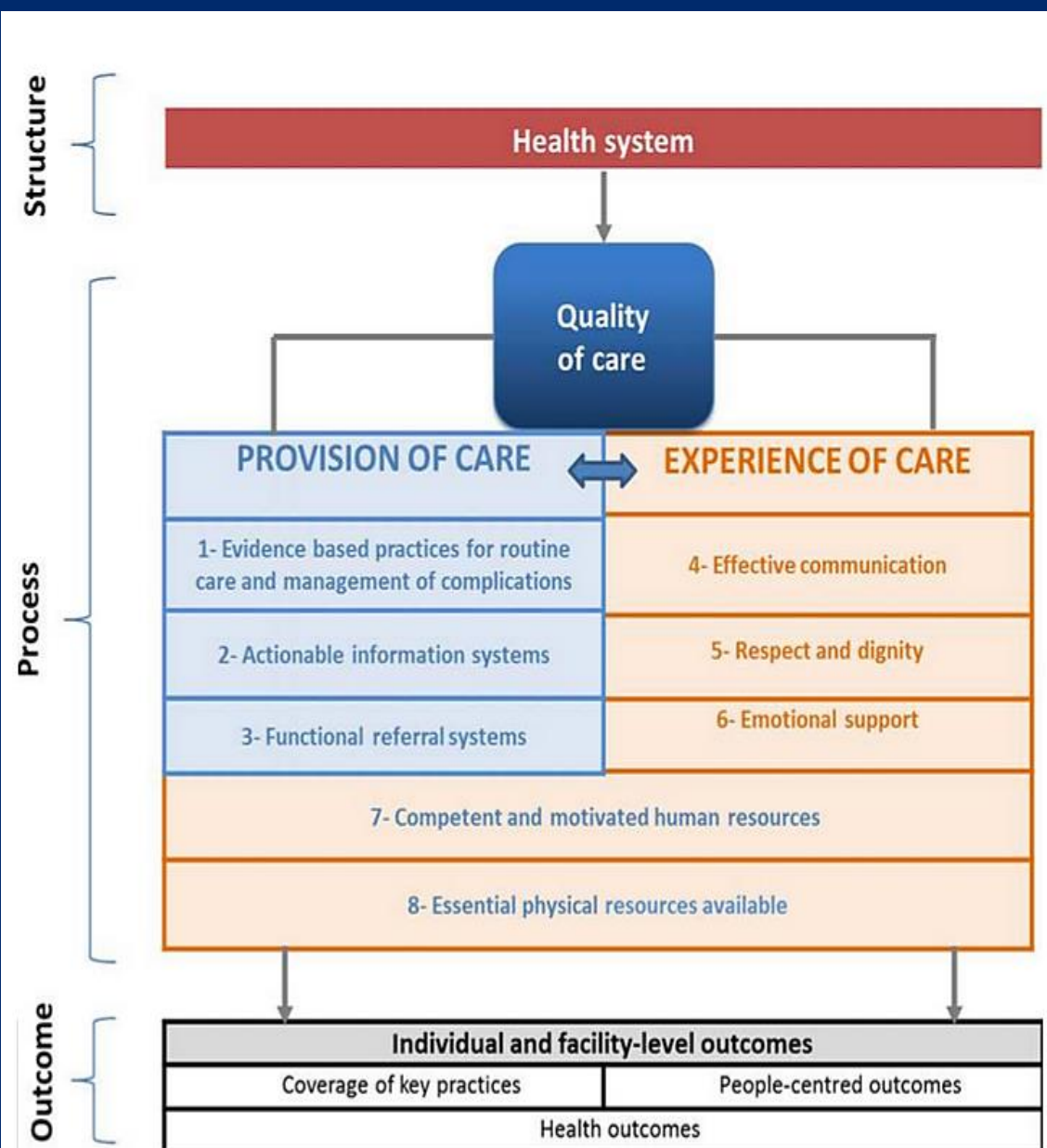
# The Mistreatment of Women during Childbirth in Health Facilities Globally: A Mixed-Methods Systematic Review

Meghan A. Bohren<sup>1,2\*</sup>, Joshua P. Vogel<sup>2</sup>, Erin C. Hunter<sup>3</sup>, Olha Lutsiv<sup>4</sup>, Suprita K. Makh<sup>5</sup>, João Paulo Souza<sup>6</sup>, Carolina Aguiar<sup>1</sup>, Fernando Saraiva Coneglian<sup>6</sup>, Alex Luíz Araújo Diniz<sup>6</sup>, Özge Tunçalp<sup>2</sup>, Dena Javadi<sup>3</sup>, Olufemi T. Oladapo<sup>2</sup>, Rajat Khosla<sup>2</sup>, Michelle J. Hindin<sup>1,2</sup>, A. Metin Gülmezoglu<sup>2</sup>

## ***Seven 3rd Order Mistreatment Themes Identified***

- Physical, Sexual, Verbal abuse (1-3)
- Stigma and discrimination (4)
- Failure to meet professional standards of care (5)
  - **Lack of informed consent process** – *only 3 citations*
    - Confidentiality breaches, neglect/abandonment
- Poor rapport between women and providers (6)
  - **Ineffective communication, loss of autonomy**
  - Lack of supportive care
- Health system conditions and constraints (7)

# WHO Quality of Care Framework for Facility Childbirth



# WHO QoC Standards 4 & 5 and RMC Charter Rights

WHO QoC Standard	RMC Charter Right
<p><u>Standard 4: Effective Communication</u></p> <p><b>-Communication &amp; information</b> responds to families' needs and preferences</p>	<p><b>-Right to information, informed consent/refusal, respect for choices,</b> including right to companionship of choice</p>
<p><u>Standard 5: Respect and dignity</u></p> <ul style="list-style-type: none"> <li>- Privacy</li> <li>- Confidentiality</li> <li>- <b>Informed choice and consent</b></li> <li>- No mistreatment - physical, verbal abuse, discrimination, neglect, detainment, extortion or denial of services</li> </ul>	<ul style="list-style-type: none"> <li>-Right to Dignity, Respect</li> <li>-Right to be free from harm and ill treatment</li> <li>-Right to Confidentiality and Privacy</li> <li>-<b>Right to....informed consent</b></li> <li>-Right to Equality, non-discrimination, equitable care</li> <li>- Right to timely healthcare and to highest attainable level of health</li> <li>-Liberty, <b>autonomy</b>, self -determination, and <b>freedom from coercion</b></li> </ul>

# WHO QoC Standards 4 & 5 Quality Measures:

## Illustrative measures adapted for C/S consent

- % [cesarean deliveries] in health facility that require **written consent** for which there is a **record of a woman's consent**
- % women undergoing [cesarean] who report that their permission was sought before [surgery] was performed
- Facility has accountability mechanisms for **redress** in event of violation of privacy, confidentiality or **consent**.
- % women who report they were given opportunity to discuss their **concerns and preferences**.
- Proportion of women who felt they were **adequately informed by care provider(s)** about care actions and decisions
- Women's knowledge/recall of [cesarean] counseling information
- % women who report that their **needs and preferences** were taken into account as part of [cesarean] decision-making



# **Tanzania RMC/Mistreatment Study**

## **Women's and Provider's Views about Consent**

*(Ratcliff, H., et al, 2016, BMC)*

### **% Women Agreeing with Statement (N=362)**

*“Any doctor, nurse or midwife who performs a test/procedure on me must ask my permission first and it is my right to refuse a procedure”*

- Baseline: 30% agreed
- Post-intervention: 58% agreed (Open Maternity Day)

### **% Providers agreeing with statement (N=76)**

*“It is safer to withhold information from less educated women who may not understand or become confused or distressed”*

- Baseline: 54% agreed
- Post-intervention: 45% (RMC workshop)

# Discussion Points - Informed Consent/Counseling

- **Client** and **provider perceptions, expectations** in LMICs?
- *Normalization* of **non**-consented “care” in some settings?
- Views of **women’s autonomy (gender)** (fetal “rights”)?
- **Policy** and **practice (and quality)** of counseling/consent?
- **Minimum elements of informed consent?** (indication, risks, benefits, options, prognosis if no intervention....)
- **Who** owns responsibility (elective/emergency)?
- **When** should counseling occur - ANC (trimester?), Labor (when?)

## Barriers & Facilitators to Informed Consent

<b>National policy &amp; Legal</b>	Regulatory frameworks, redress mechanisms
<b>Women &amp; families</b>	Low expectations, fear of providers, fear of care being withheld, power asymmetries, “normalization”
<b>Professional standards</b>	PSE, supervision, certification, enforcement mechanisms
<b>Health care workers</b>	Knowledge, Counseling competence/skills, personal views
<b>Work flow &amp; tools</b>	C/S counseling, consent - ANC, L&D (elective, emergent)
<b>HMIS</b>	Indicators, standardized forms, etc.

*Thank You*

# Mother's Autonomy in Decision Making (MADM)

## Validated Scale in Canada

Vedam, S. et al, PLOS, February 2017

### **Patient Questionnaire MADM Scale Items:**

- My [provider] asked me how involved in decision making I wanted to be
- My [provider] told me that there are different options for my maternity care
- My [provider] explained the advantages and disadvantages of the maternity care options
- My [provider] helped me understand all the information
- I was given enough time to thoroughly consider the different maternity care options
- I was able to choose what I considered to be the best care options
- My [provider] respected that choice

1. Response options are (1) Completely disagree; (2) Strongly disagree; (3) Somewhat disagree; (4) Somewhat agree; (5) Strongly agree; (6) Completely agree

# WHO Quality of Care Framework for Facility Childbirth (BJOG 2015)

