Flashpoint
Informed Consent for Cesarean Section and Women’s Rights

Kathleen Hill
Cesarean Section Safety & Quality in Low Resource Settings
Boston, July 2017
• Universal Rights of Childbearing women
• Non-consented “care” as mistreatment
• WHO Quality, Equity, Dignity Network
• Metrics
• Discussion points
Respectful Maternity Care Charter:
Universal Rights of Childbearing Women

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.

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.
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.

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.
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

Source: BJOG 2015
<table>
<thead>
<tr>
<th>WHO QoC Standard</th>
<th>RMC Charter Right</th>
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<tbody>
<tr>
<td><strong>Standard 4: Effective Communication</strong></td>
<td>-Right to information, informed consent/refusal, respect for choices, including right to companionship of choice</td>
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<td>-Communication &amp; information responds to families’ needs and preferences</td>
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<tr>
<td><strong>Standard 5: Respect and dignity</strong></td>
<td>-Right to Dignity, Respect</td>
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<tr>
<td>-Privacy</td>
<td>-Right to be free from harm and ill treatment</td>
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<tr>
<td>-Confidentiality</td>
<td>-Right to Confidentiality and Privacy</td>
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<tr>
<td><strong>Informed choice and consent</strong></td>
<td>-Right to...informed consent</td>
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<tr>
<td>-No mistreatment - physical, verbal abuse, discrimination, neglect, detainment, extortion or denial of services</td>
<td>-Right to Equality, non-discrimination, equitable care</td>
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<td></td>
<td>- Right to timely healthcare and to highest attainable level of health</td>
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<td></td>
<td>-Liberty, <strong>autonomy</strong>, self-determination, and freedom from coercion</td>
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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
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**

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

Structure

Health system

Quality of Care

PROVISION OF CARE

1- Evidence based practices for routine care and management of complications
2- Actionable information systems
3- Functional referral systems

EXPERIENCE OF CARE

4- Effective communication
5- Respect and dignity
6- Emotional support

7- Competent and motivated human resources
8- Essential physical resources available

Process

Individual and facility-level outcomes

Coverage of key practices
People-centred outcomes
Health outcomes

Outcome