What do women say?

TOO MUCH, TOO SOON

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Woodrow Wilson International Center For Scholars
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Person-Centered Research

- Changing Childbirth in BC (N 3400/3167)
- Giving Voice to Mothers (N 2800)
- Maternity Care Experience Study - Hungary (N1267)
- Access and Integration of Midwifery Mapping Study (AIMMs)

http://dx.doi.org/10.1371/journal.pone.0171804

http://dx.doi.org/10.1016/j.ssmph.2017.01.005

Community Based Participatory Research

Steering groups of people of childbearing age from different cultural and socio-economic backgrounds

Four work groups and 35 communities:

- Women who have been incarcerated
- Immigrants and refugees
- Experienced homelessness, poverty and/or other barriers
- Communities of color
- Women who planned community birth
Study Topics

- Access to care
- Preferences for care
- Experiences with maternity care
  - Decision-making
- Knowledge of midwifery
## Preferences For Care – Leading Decisions

<table>
<thead>
<tr>
<th></th>
<th>n=2915</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is very important or important to me that I lead the decisions about my pregnancy, birth and baby care</td>
<td>2766</td>
<td>95.0</td>
</tr>
<tr>
<td>It is very important to me that I lead the decisions</td>
<td>2018</td>
<td>69.3</td>
</tr>
<tr>
<td>It is very important or important to me that my doctor or midwife guides the decisions</td>
<td>1392</td>
<td>47.8</td>
</tr>
<tr>
<td>It is not very important to me that that I lead the decisions</td>
<td>11</td>
<td>0.4</td>
</tr>
</tbody>
</table>
Who made the decision to have a CS?

- Mine, I decided I wanted the cesarean before I went into labour
- Mine, I asked for the cesarean while I was in labour
- My maternity CP recommended a cesarean before I went into labour
- My maternity CP recommended a cesarean while I was in labour
- Other
# MADM:
Mothers Autonomy in Decision Making scale

<table>
<thead>
<tr>
<th>Please describe your experiences with decision making during your pregnancy, labour and/or birth. (select one option for each)</th>
<th>Completely Disagree</th>
<th>Strongly Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Strongly Agree</th>
<th>Completely Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My doctor or midwife asked me how involved in decision making I wanted to be</td>
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<tr>
<td>My doctor or midwife told me that there are different options for my maternity care</td>
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<tr>
<td>My doctor or midwife explained the advantages/disadvantages of the maternity care options</td>
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<tr>
<td>My doctor or midwife helped me understand all the information</td>
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<tr>
<td>I was given enough time to thoroughly consider the different care options</td>
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<tr>
<td>I was able to choose what I considered to be the best care options</td>
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<td>My doctor or midwife respected my choices</td>
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</tbody>
</table>

(Vedam et al., PLOS ONE 2017)
<table>
<thead>
<tr>
<th>Overall while making decisions during my pregnancy/birth:</th>
<th>Completely Disagree</th>
<th>Strongly Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Strongly Agree</th>
<th>Completely Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Felt Comfortable asking questions</td>
<td></td>
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<tr>
<td>I Felt Comfortable declining care that was offered</td>
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<tr>
<td>I Felt Comfortable accepting the options for care that my provider recommended</td>
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<tr>
<td>I Felt Coerced into accepting the options my provider suggested (reverse scored)</td>
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<td>I chose the care options that I received</td>
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<tr>
<td>My personal preferences were respected</td>
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<td>My cultural preferences were respected</td>
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<td>I felt that I had enough time during prenatal visits.</td>
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<tr>
<td>I felt that I was treated poorly by my maternity care provider because of</td>
<td>Completely Disagree</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
<td>Strongly Agree</td>
<td>Completely Agree</td>
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<tr>
<td>My race, ethnicity, cultural background or language</td>
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<td>My sexual orientation and/or gender identity</td>
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<td>My type of health insurance or lack of insurance</td>
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<td>A difference in opinion with my caregivers about the right care for myself or my baby</td>
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<tr>
<td>I held back from asking questions or discussing my concerns because</td>
<td>Completely Disagree</td>
<td>Strongly Disagree</td>
<td>Somewhat Disagree</td>
<td>Somewhat Agree</td>
<td>Strongly Agree</td>
<td>Completely Agree</td>
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<tr>
<td>My maternity care provider seemed rushed</td>
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<td>I wanted maternity care that differed from what my maternity care provider recommended</td>
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<tr>
<td>I thought my maternity care provider might think I was being difficult</td>
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<tr>
<td>I felt discriminated against</td>
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<tr>
<td>I felt my maternity care provider didn’t value my opinion</td>
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<td>I felt they didn’t explain in lay terms</td>
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</tbody>
</table>
Interventions and Respect

2 in 5
38% felt pressured to do have C/S

54% felt pressured to have induction

MORi Scores
Spontaneous Vaginal Delivery
Instrumental Vaginal Delivery
C-section

C-Section
Induction
Feeling Pressured

Poor treatment reported, regardless of provider type

Pressure =

- Respect
- Autonomy
Difference of Opinion with providers

Women held back their questions if they wanted different care because they were worried about poor treatment.

Lower MADM and MORi scores
Interventions:

- **C-section (N=600)**: 41%
- **Vaginal birth with forceps or vacuum (N=600)**: 2%
- **Induced birth (N=600)**: 27%
- **Episiotomy if vaginal birth (N=354)**: 70%
- **Epidural if vaginal birth (N=354)**: 10%

Episiotomy for vaginal birth (N=354):
- Yes: 70%
- No: 29%
- Do not remember: 2%

Consent for episiotomy (N=247):
- With consent: 63%
- Did not ask permission: 32%
- I refused the episiotomy but they still did it: 4%
- Do not remember if they asked permission: 1%
Autonomy and Respect by Race and SES

Respect and Autonomy in decision-making by Race and SES: MADM Scores

Respect and Autonomy in decision-making by Race and SES: MOR-I Scores
Autonomy

Provider Type Influences Autonomy
Place of Birth

MORi scores lower with hospital births than home births.
Midwifery clients report consistently respectful treatment across settings.
Women Need Time

Higher MADM scores with more TIME to process information
Integration and mode of delivery

N = 51 (states + DC)

<table>
<thead>
<tr>
<th></th>
<th>Correlational coefficient *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spontaneous Vaginal Delivery</td>
<td>0.402**</td>
</tr>
<tr>
<td>Vaginal birth after Cesarean</td>
<td>0.330*</td>
</tr>
<tr>
<td>Cesarean section</td>
<td>-0.278*</td>
</tr>
</tbody>
</table>

* Spearman’s rho, * p < 0.05, ** p < 0.01
Key Findings

Integration
Density
Access

=

INTerventions

VBAC
“….they made an anatomy scan in the third trimester sound like a good idea while I was trying to decide if I wanted to decline because of my fear of them wanting to tell me my baby was 'big' and wanting to induce. I didn't decline the scan and that's what happened. The maternal fetal medicine doctor told me I was going to be induced at 39 weeks. No talk of risks or alternatives. Told me. Then proceeded to tell me that I wouldn't want my baby to die by waiting.”
“At my most recent birth I had a nurse tell me, when I said I wanted to go home and come back to try the induction the next day, that she had a patient do that and the baby was a stillborn. She did this when I was alone in the room and my husband was returning with my parents.”

“My midwife always seemed rushed and I felt stupid for asking questions. She told me I was anxious.”
Women’s Voices

“…one doctor in particular was AWFUL. He bullied me, tried scare tactics, ganged up on me by showing up with a team of four to convince me to do what he wanted, etc. It made my labor unnecessarily stressful. I will avoid the hospital at all costs in any future pregnancy unless absolutely necessary.”
Person-Centered Outcomes Care

“...healthcare organisations, healthcare providers and policy-makers actively working with consumers to ensure that health information, systems and services meet their needs.”

Australian Commission on Safety and Quality