

# What do women say?

### **TOO MUCH, TOO SOON**

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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)

The Mother's Autonomy in Decision Making (MADM) scale: Patient-led development and psychometric testing of a new instrument to evaluate experience of maternity care. *PLOS ONE, 2017*. http://dx.doi.org/10.1371/journal.pone.0171804.

The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth Social Science and Medicine: Population Health, 2017. <u>http://dx.doi.org/10.1016/j.ssmph.2017.01.005</u>

**Patient-led decision making: measuring autonomy and respect in Canadian maternity care**. Journal of Obstetrics and Gynaecology Canada (JOGC), 2016-05-01, 38(5):501.

### 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

n=2915	n (%)
It is very important or important to me that I lead the decisions about my pregnancy, birth and baby care	2766 (95.0)
It is very important to me that I lead the decisions	2018 (69.3)
It is very important or important to me that my doctor or midwife guides the decisions	1392 (47.8)
It is not very important to me that that I lead the decisions	11 (0.4)

#### 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 maternityCP recommended a cesarean while I was in labour
- Other

### MADM:

### Mothers Autonomy in Decision Making scale

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

(Vedam t al., PLOS ONE 2017)





### The Mothers On Respect (MOR) index

Vedam et al. SSM Population Health 2017

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

## Interventions and Respect



Feeling Pressured



## Poor treatment reported, regardless of provider type

**Pressure** =



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

### Autonomy and Respect by Race and SES









### 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



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#### Integration and mode of delivery

N= 51 (states + DC)

%	Correlational coefficient *
Spontaneous Vaginal Delivery	0.402**
Vaginal birth after Cesarean	0.330*
Cesarean section	- 0.278*

a Spearman's rho, \* p < 0.05, \*\* p < 0.01



Key Findings



"....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."

"...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 <u>Care</u>

"...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