



Article

The Mothers on Respect (MOR) index: measuring quality, safety, and human rights in childbirth



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ARTICLE INFO

Keywords:

Childbirth

Human rights

Participatory research

Psychometrics

Scale development

Respectful maternity care

Survey research

Provider–patient communication

ABSTRACT

Background: Abuse of human rights in childbirth are documented in low, middle and high resource countries. A systematic review across 34 countries by the WHO Research Group on the Treatment of Women During Childbirth concluded that there is no consensus at a global level on how disrespectful maternity care is measured. In British Columbia, a community-led participatory action research team developed a survey tool that assesses women's experiences with maternity care, including disrespect and discrimination.

Methods: A cross-sectional survey was completed by women of childbearing age from diverse communities across British Columbia. Several items (31/130) assessed characteristics of their communication with care providers. We assessed the psychometric properties of two versions of a scale (7 and 14 items), among women who described experiences with a single maternity provider ($n=2514$ experiences among 1672 women). We also calculated the proportion and selected characteristics of women who scored in the bottom 10th percentile (those who experienced the least respectful care).

Results: To demonstrate replicability, we report psychometric results separately for three samples of women (S1 and S2) ($n=2271$), (S3, $n=1613$). Analysis of item-to-total correlations and factor loadings indicated a single construct 14-item scale, which we named the Mothers on Respect index (MORI). Items in MORI assess the nature of respectful patient-provider interactions and their impact on a person's sense of comfort, behavior, and perceptions of racism or discrimination. The scale exhibited good internal consistency reliability. MORI-scores among these samples differed by socio-demographic profile, health status, experience with interventions and mode of birth, planned and actual place of birth, and type of provider.

Conclusion: The MOR index is a reliable, patient-informed quality and safety indicator that can be applied across jurisdictions to assess the nature of provider-patient relationships, and access to person-centered maternity care.

Body

Reports of disrespectful maternity care are emerging worldwide, despite protections against abusive treatment of women in health care settings as outlined in formal international Conventions on human rights (United Nations Commission on the Status of Women, 2016; Oviedo, 1997). Bowser and Hill's groundbreaking landscape analysis

(Bowser & Hill, 2010) provides an evidence-based definition of disrespect and abuse in childbirth which includes seven domains: “physical abuse, non-consented care, non-confidential care, non-dignified care (including verbal abuse), discrimination based on specific attributes, abandonment or denial of care, detention in facilities”. Bohren and colleagues, from the WHO Research Group on the Treatment of Women During Childbirth (Bohren et al., 2015) con-

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ducted a mixed methods systematic review of 65 studies across 34 countries and concluded that there is no consensus at a global level on how disrespectful maternity care is measured. Their review added the domains of “poor rapport between women and providers, including ineffective communication, lack of supportive care, and loss of autonomy”, to Bowser’s examples of abuse and disrespect in childbirth. Bohren et al.’s paper ends with an urgent call to develop “validated and reliable research tools to measure the mistreatment of women in childbirth.” (Bohren et al., 2015).

While others have begun to develop tools to measure disrespect and abuse in childbirth in low resource settings, no published instrument has been developed by service users, or validated via a large dataset of childbearing women. In this paper, we describe a person-centered research process to develop a new quality and safety instrument that measures respectful maternity care.

1.1. Disrespect and abuse in maternity care

Most of the emerging literature on respectful maternity care focuses on low-resource settings (Sheferaw, Mengesha, & Wase, 2016; Warren et al., 2013). However, women who give birth in hospitals in the United Kingdom, United States, and Australia have also reported poor care by staff, including unkind and coercive treatment, and the trivializing of physical complaints, preferences, and personal needs (Brown, 1994; Declercq, Sakala, Corry, Applebaum, & Herrlich, 2013; Fraser, 1999). In their qualitative study of women’s experiences of hospital-based birth, Baker et al. reported that over half of British women interviewed ($n=24$) commented on the negative attitudes and behaviors of midwives. Care providers were described as offensive, harsh, judgmental, insensitive, threatening, and abrupt (Baker & Precilla, 2005). At times, care providers treated women like children and intimidated them, which resulted in feelings of anger, inferiority, and resentment.

Lukasse et al. (2015) studied 6923 pregnant women in six European countries. They found that one in five pregnant women had experienced some form of abuse (e.g. being degraded, black mailed, insulted, or abused physically and/or emotionally) when receiving health services over her lifetime; and a history of abuse in healthcare was associated with increased fear of birth during pregnancy. Very little is known about the maternity care experiences of Canadian women. Published studies and reports are either outdated (Public Health Agency of Canada, 2009), focus only on vulnerable populations (Varcoe et al., 2013) or do not assess important dimensions of quality of care, i.e. maternity care free from abuse and disrespect (Reis, Deller, Carr, & Smith, 2012).

The WHO bulletin by Freedman et al. (2014) proposes a definition of disrespect and abuse as “interactions or facility conditions that local consensus deems to be humiliating or undignified and those interactions or conditions that are experienced as or intended to be humiliating or undignified”. They construct this phrase after considering multiple domains, including “Behavior that by local consensus constitutes disrespect and abuse”, “subjective experience”, “intentionality”....a woman’s “lived experience” and“deeper dynamics of power”.

Freedman also makes a distinction between normalized disrespect and abuse that women consider disrespect and abuse but providers do not, and behavior that women consider normal or acceptable but others consider disrespect and abuse. Among survey respondents in the Listening to Mothers Study III ($n=2400$), 30% of black and Hispanic primiparous women and 21% of white women who delivered in hospitals in the United States reported that they sometimes or always felt “treated poorly because of a difference of opinion with [their] caregivers about the right care for [herself or her] baby” (Declercq et al., 2013). In the same study, 25% of women who had experienced an induction of labor or a cesarean section felt pressured to accept those interventions, 59% of women who received episiotomies did not give consent at all, and 63% of women experiencing a primary Cesarean section and 47% of women who had a repeat CS reported that the

provider made the “final decision” about whether they would receive cesarean surgery (Declercq et al., 2013).

1.2. Loss of autonomy and maternal outcomes

The right to informed consent and refusal enshrines the human right to autonomy in most nations. The American Medical Association and the American College of Obstetricians and Gynecologists have affirmed that informed consent is a basic principle of law and ethics that physicians must honor (American Medical Association, 2006). In *Ternovszky v. Hungary*, the European Court of Human Rights recognized that women’s decisions about childbirth are an expression of personal autonomy and as such are protected by Article 8 Right to Private and Family life (European Court of Human Rights, 2014b). The ability to make those decisions, however, depends upon the woman having both adequate information and respect for her decision-making capacity.

The Baker study (Baker & Precilla, 2005) established that women had little control over the decision-making process during labor, had inadequate information about birth options, and received interventions that were contrary to their preferences (Baker & Precilla, 2005). In the Baker study, women desired more information about the benefits and risks of certain procedures. The study concluded that inadequate information and sense of loss of control both contributed to feelings of disrespect (Baker & Precilla, 2005).

Women’s reports of care indicate that interventions are routinely imposed on them without meaningful informed consent. These violations can range from securing consent on the basis of inaccurate information, coercion, or threats, to performing interventions in the absence of consent, either without telling or asking the patient before the intervention, or performing the intervention over the patient’s explicit non-consent, sometimes with violent force (Bowser & Hill, 2010). Poor treatment has been linked to postpartum depression, post-traumatic stress and fear of childbirth during subsequent pregnancies (Lukasse, Schroll, & Karro, 2015). Post-traumatic stress disorder (PTSD) can result from negative birth experiences, and is associated with lack of involvement in decision-making, perceptions of inadequate care and feeling powerless (Creedy, Shochet, & Horsfall, 2000; Soet, Brack, & Dilorio, 2003).

Hodnett (2002) conducted a systematic review of 137 studies of factors linked to women’s satisfaction with childbirth. She found that care provider attitudes and behaviours most strongly influenced women’s experiences, rather than women’s characteristics (e.g. socio-economic status, race), the physical environment and medical interventions. In the Changing Childbirth in BC participatory research project, 95% of women said it was “very important” or “important to lead decisions about their maternity care” and those who had low scores on the Mothers Autonomy in Decision Making (MADM) scale indicated inability to direct their care (Vedam et al., 2015, 2017). Research suggests that the fear of mistreatment and loss of autonomy during childbirth can be directly linked to women’s unwillingness to seek life-saving measures from skilled providers, thus reducing access to basic health human rights (Abuya et al., 2015; Bohren et al., 2015; Jackson, Dahlen, & Schmied, 2012). This current paper focuses on measuring the experience of respectful/disrespectful care as it is correlated with sense of autonomy in decision-making.

1.3. Measuring respectful care

Leading global health agencies are prioritizing person-centered, respectful maternity care (International Federation of Gynecology and Obstetrics, International Confederation of Midwives, White Ribbon Alliance, International Pediatric Association, & World Health Organization, 2015; National Institute for Health and Clinical Excellence, 2014; White Ribbon Alliance, 2015; World Health Organization, 2015). The World Health Organization Research Group

on the Treatment of Women During Childbirth hopes to address the scarcity of evidence on the incidence, scope and impacts of disrespectful care, and develop tools to assess the quality and safety implications of abuse of human rights in childbirth (Bohren et al., 2015).

In African hospital settings, there are reports of physical abuse, non-consented care, non-confidential care, non-dignified care, discrimination, abandonment, and detention in facilities, that present a major deterrent to seeking out maternity care at hospitals (Abuya et al., 2015; Okafor, Ugwu, & Obi, 2015; Warren et al., 2013). For example, Abuya et al. (2015) conducted exit interviews with 641 women who delivered at thirteen hospitals in Kenya. One in five women reported some experience of abuse or disrespect: 8.5% reported violations of confidentiality, 18% experienced non-dignified care, and 14% reported being abandoned or neglected. Four percent received care they did not consent to, 4% experienced physical abuse and 8% were detained at the hospital because of non-payment of fees. The prevalence of any disrespectful or abusive treatment during childbirth in a representative sample of new mothers from Tanzania was 19.5% when assessed via exit surveys before leaving the hospital and 28.2% at follow up (when a subsample of women was interviewed at home). The most common events that were reported were being ignored (14.2%), being shouted at (13.2%), and threats from hospital staff (11.5%). Five percent of women were slapped or pinched (Kruk, Kujawski, Mbaruku, Ramsey, Moyo, & Freedman, 2014). Women in Tanzania ($n=1388$) who experienced abuse/disrespect during childbirth were half as likely to want to return to the same facility to deliver their next child (Kujawski, MbarukuLynn, Freedman, Ramsey, Moyo & Kruk, 2015).

To date quantitative instruments to measure the incidence and characteristics of respectful maternity care are scarce. Vogel et al. (2015) propose to use their qualitative data about experiences with disrespectful and abusive care to inform the development of a quantitative measure specific to maternity care. In Norway one quantitative measure, the NorAQ scale (Swahnberg et al., 2003) measures lifetime history of abuse. The scale includes three items that measure 'Abuse in Healthcare'. The scale has been used with obstetric patients in Norway (Swahnberg et al., 2007) but does not specifically assess abuse during pregnancy and childbirth.

More recently, Sheferaw et al. (2016) described the development and psychometric testing of a 15 item scale that assesses respectful maternity care along four dimensions: friendly care, abuse-free care, timely care and discrimination-free care. Items were generated inductively, via in depth interviews with 8 postpartum women, pilot tested with 40 women, subjected to expert review and tested for reliability and validity by interviewing 509 women within 7 days of being discharged from hospitals and health centers in Addis Ababa, Ethiopia. Highly relevant to the Ethiopian context, the scale focused on the overall experience of care by health workers in a low resource institutional setting. It included items that describe situations that are rarely reported in high resource countries, such as being slapped by a care provider or being shouted at for not following care providers' instructions. Moreover, while in the process of developing the Ethiopian RMC scale extensive input was sought from women, the women did not select the key topics or design the items. This RMC scale focuses primarily on women's experiences of provider behavior during labour and birth, not on their ability to exercise autonomy without discrimination as they sought to participate as decision leaders over the course of maternity care.

In summary, there are few existing validated instruments that can be used to measure the extent and impact of respectful/disrespectful maternity care as affected by patient-provider communication. None have been developed by service users, or are appropriate for use as a quality and safety indicator across jurisdictions and settings. Our Changing Childbirth in BC and Giving Voice to Mothers studies responded to these gaps through a person-centered research process. This paper describes the resulting development and validation of a new scale, the Mothers on Respect Index (MORI) that measures women's

experiences when interacting with primary maternity care providers.

1. Methods

In 2012, our team was funded by the Vancouver Foundation to conduct a provincial community-led participatory action research (CBPR) project entitled "*Changing Childbirth in BC: Women exploring access to high quality maternity care.*" A diverse community of childbearing women worked alongside community partners (e.g. leaders from non-governmental service agencies) and university researchers to design a mixed-methods study of maternity care in British Columbia (BC). Recognizing diversity in their perspectives and lived experience, the group self-organized into four work groups to address the needs of immigrant and refugee women, formerly incarcerated women, women facing multiple social and economic barriers, as well as midwifery and physician service users from urban and rural settings.

A community consultation with 1333 women determined key areas for study, and preferred modes of data collection and survey distribution. Based on their recommendations, the team developed a cross-sectional online survey to assess *preferences for model of care, experiences of decision making and respectful care, and access to maternity care providers*. An extensive content validation process included a literature review, an expert panel review, and community specific modifications by work groups. The CBPR process resulted in creation of four population-specific versions of a one-hour online survey that collected data on socio-demographics, preferences for maternity care, the process of decision-making, access to maternity providers, and experiences of care during the childbearing cycle.

1.1. Item development

Our team included women from all the target populations, psychometric experts, clinicians with over 30 years of experience, psychologists and sociologists. All of them participated in literature review to identify items from existing surveys and scales (e.g. Listening to Mothers I, II, and III, Perceptions of Racism, AMDD) as well as in new item generation, and ongoing expert content validation of the survey as a whole.

To examine aspects of the provider-patient relationship, the community members prioritized items that measure experiences of comfort, coercion, discrimination and/or autonomy when in conversation with their maternity care providers. They selected items on childbirth care, respectful care, and decision making from the Listening to Mothers surveys (Declercq et al., 2013; Declercq, Sakala, Corry, Applebaum, & Risher, 2002; Declercq, Sakala, Corry, & Applebaum, 2006), adapted some validated items from other tools, and generated new items. Professional team members who were midwives, nurses, psychologists, physicians, and health care administrators, provided a few additional items (e.g., length of prenatal appointments, reasons for change of prenatal provider), but these were then further vetted and approved by the four community work groups.

Across all four versions of the final survey, there were 310 total items, including slightly different questions on branching pages for specific populations (e.g. modified items for pregnancies that ended in loss, past tense for multiparas, present tense for currently pregnant respondents), and population-specific items for each vulnerable group (ie. on incarceration or immigration). Individual respondents were presented with 130 common core items, 31 of which were about the decision making process and experiences of communication with providers. To determine if women's experiences with maternity care differed depending on socio-demographic characteristics, the survey also included questions about women's race/ethnicity, family income, immigration status, age and pregnancy complications and outcomes. Finally, women were asked who their primary maternity care provider during pregnancy was. Each item was automatically populated with the care provider type that the woman identified in response to the

statement: “The following answers describe my conversations or experiences with my: family doctor, obstetrician, midwife, health centre nurse or other.”

1.2. Sample

Following ethics approval from the University of British Columbia, the survey was distributed via professional organizations, social media, and posters in clinical offices throughout the province of British Columbia (BC). The cross-sectional survey was open to women of childbearing age and their family members in BC. Respondents ($n=4082$) from diverse socio-economic and cultural backgrounds provided survey data, including 2323 women with past childbirth experiences.

The community felt strongly that survey participants should be able to describe their maternity care experiences for up to two previous pregnancies and/or during a current pregnancy. Women who were cared for by more than one type of provider during pregnancy were able to report on experiences with each type of provider (obstetrician, midwife, family physician, health centre nurse). Hence, for the purposes of scale development, to avoid confounding by multiple observations from one woman, we limited our psychometric analysis to maternity experiences of women with a single provider during pregnancy ($n=2514$ experiences from 1672 women). We also excluded pregnancy experiences from other provinces and countries, and those where the primary care provider was a nurse or ‘other’ because they did not reflect the primary care provider model in Canada.

We report socio-demographic characteristics for study participants as they described themselves at the time of data collection. To demonstrate that findings are replicable, we report psychometric results separately for two samples (S1 and S2) ($n=2271$ experiences). Sample 1 included 1596 experiences, and Sample 2 included 675 experiences from women who reported on previous pregnancies. We did not include experiences from a subset of the 1672 women who were pregnant at the time of data collection ($n=243$ experiences) because some scale items asked about experiences during birth.

1.3. Data analysis

1.3.1. The Mothers on Respect index (MORi)

The survey included 14 items that measured aspects of patient-provider communication (see Table 1). Items 1–7 had three response options, and items 8–14 had 4 response options. We list these response options and how they were harmonized below. Initially, we evaluated the psychometrics of seven items that measure a woman's comfort when engaging with her primary maternity care provider over the course of her pregnancy (see items 1–7, Table 1). We examined the correlation between each scale item and the sum of all of the other items, to ensure that each individual item contributes to the same construct, and estimated internal reliability with Cronbach's alpha. We examined the factor structure of the seven-item scale via unweighted least squares factor analysis (no rotation) for both samples of women (S1 and S2) who had completed pregnancies (see Table 2). We only created scale scores for women who completed all 7 items, i.e. 849 women in sample 1, and 373 in sample 2. Higher scores indicate more respectful interactions with care providers.

We also considered the number of eigenvalues > 1 and screeplots (not shown here), when determining the factor structure of the scale. Factor loadings, item-to-total correlations, screeplots and number of Eigen values confirmed that all 7 items measure a single construct which we recognized as “respectful maternity care”. Because of the patient-driven development of the items, we named this scale the **Mothers on Respect index (MORi)**. Finally, we report the proportion and selected characteristics of women who scored in the bottom 10th percentile of the MORi, i.e. those who reported the least respectful care. For the purpose of analysis, women who checked one or more complications (from a pre-defined list) were grouped together.

Table 1
MORi – scale items.

| Overall while making decisions during my pregnancy I felt: | |
|---|---|
| 1 | Comfortable asking questions |
| 2 | Comfortable declining care that was offered |
| 3 | Comfortable accepting the options for care that my (midwife, doctor) recommended |
| 4 | Coerced into accepting the options my (midwife, doctor) suggested (reverse scored) ^a |
| 5 | I chose the care options that I received |
| 6 | My personal preferences were respected |
| 7 | My cultural preferences were respected |
| During a prenatal visit I held back from asking questions or discussing my concerns: | |
| 8 | Because my (midwife, doctor) seemed rushed (reverse scored) |
| 9 | Because I wanted maternity care that differed from what my (midwife, doctor) recommended (reverse scored) |
| 10 | Because I thought my (midwife, doctor) might think I was being difficult (reverse scored) |
| When I had my baby I felt that I was treated poorly by my (midwife, doctor): | |
| 11 | Because of my race, ethnicity, cultural background or language (reverse scored) |
| 12 | Because of my sexual orientation and/or gender identity (reverse scored) |
| 13 | Because of my health insurance (reverse scored) |
| 14 | Because of a difference in opinion with my caregivers about the right care for myself or my baby (reverse scored) |

^a This item was re-phrased when it was administered to the US sample. The word coerced was replaced with pushed.

1.3.2. MORi – Canada

Once we determined that the construct being measured was “respectful maternity care”, the team recognized that 7 additional items in the CCinBC survey also measured women's impressions and behavior related to being heard and respected during maternity care. However, during the survey construction phase, the community reviewers had selected different response options for these items. Hence, to evaluate these items for inclusion in a 14-item index, we recoded them to align all response options with the Y/N/NA options. For items 8–10 we recoded responses ‘Yes, once’ or ‘Yes, more than once’ into Yes, and ‘No’ and ‘Never’ into No. For items 11–14, we recoded responses from women who answered ‘Never’ into ‘No’ and responses from women who answered ‘Sometimes’, ‘Usually’ or ‘Always’ into ‘Yes’. We then added these additional 7 items to the MOR-1 index, for a total of 14 items (see Table 1). These 7 additional items were reverse-scored. Again, we only created scale scores for women who completed all 14 items, i.e. 833 women in sample 1, and 366 in sample 2. In a second phase of analysis, we confirmed that again higher scores indicate more respectful care, but that the 14-item scale evaluates 3 different dimensions of respectful care. The results of psychometric testing for both scale versions are discussed below.

1.3.3. MORi – USA

In the summer/fall of 2016, the first author collaborated with community leaders across the United States to adapt and formally content validate the survey instrument, through a similar community based participatory process, with women from communities of color and women who chose home birth (Vedam, Stoll, Jolicouer & Martin, 2016). The study, called Giving Voice to Mothers, collects information about maternity care experiences among a sample of women who gave birth within the past 5 years. The 14 item MORi scale with harmonized Likert response options, (ranging from 1 – strongly disagree to 6 – strongly agree) was embedded in this survey. Data collection for the US study will complete in December 2016. However, the high response rate to date provides a robust enough cohort to examine the reliability

Table 2
Corrected item-to-total correlations and factor loadings for the 14 item MORi.

| Items | Sample ^a | % who agreed with item | Corrected Item-to Total Correlations | Factor loadings |
|---|---------------------|------------------------|--------------------------------------|-----------------|
| Overall while making decisions during my pregnancy I felt: | | | | |
| 1 Comfortable asking questions | S1 | 92.7 | 0.64 | 0.70 |
| | S2 | 95.8 | 0.54 | – ^b |
| | S3 | 94.4 | 0.79 | 0.82 |
| 2 Comfortable declining care that was offered | S1 | 82.6 | 0.59 | 0.62 |
| | S2 | 92.1 | 0.62 | – ^b |
| | S3 | 88.1 | 0.79 | 0.82 |
| 3 Comfortable accepting the options for care that my (midwife, doctor) recommended | S1 | 91.1 | 0.71 | 0.79 |
| | S2 | 94.6 | 0.59 | – ^b |
| | S3 | 92.6 | 0.82 | 0.85 |
| 4 Coerced into accepting the options my (midwife, doctor) suggested | S1 | 12.7 | 0.48 | 0.52 |
| | S2 | 13.2 | 0.25 | – ^b |
| | S3 | 20.5 | 0.63 | 0.64 |
| 5 I chose the care options that I received | S1 | 86.4 | 0.56 | 0.63 |
| | S2 | 93.4 | 0.52 | – ^b |
| | S3 | 89.7 | 0.77 | 0.80 |
| 6 My personal preferences were respected | S1 | 90.0 | 0.73 | 0.80 |
| | S2 | 94.4 | 0.65 | – ^b |
| | S3 | 90.9 | 0.84 | 0.87 |
| 7 My cultural preferences were respected | S1 | 97.1 | 0.59 | 0.68 |
| | S2 | 98.0 | 0.50 | – ^b |
| | S3 | 94.7 | 0.75 | 0.79 |
| During a prenatal visit I held back from asking questions or discussing my concerns: | | | | |
| 8 Because my maternity care provider seemed rushed | S1 | 23.9 | 0.48 | 0.49 |
| | S2 | 16.0 | 0.42 | – ^b |
| | S3 | 12.5 | 0.68 | 0.69 |
| 9 Because I wanted maternity care that differed from what my maternity care provider recommended | S1 | 14.0 | 0.53 | 0.54 |
| | S2 | 10.4 | 0.55 | – ^b |
| | S3 | 11.2 | 0.79 | 0.81 |
| 10 Because I thought my maternity care provider might think you were being difficult | S1 | 18.7 | 0.55 | 0.57 |
| | S2 | 10.6 | 0.51 | – ^b |
| | S3 | 15.2 | 0.75 | 0.76 |
| When I had my baby I felt that I was treated poorly by my (midwife, doctor): | | | | |
| 11 Because of my race, ethnicity, cultural background or language | S1 | 1.4 | 0.30 | 0.36 |
| | S2 | 0.5 | 0.11 | – ^b |
| | S3 | 2.4 | 0.53 | 0.57 |
| 12 Because of my sexual orientation and/or gender identity | S1 | 0.3 | 0.19 | 0.25 |
| | S2 | 0 | – | – ^b |
| | S3 | 0.9 | 0.47 | 0.69 |
| 13 Because of my health insurance | S1 | 0.5 | 0.18 | 0.23 |
| | S2 | 0.5 | 0.13 | – ^b |
| | S3 | 3.6 | 0.52 | 0.56 |
| 14 Because of a difference in opinion with your caregivers about the right care for yourself or your baby | S1 | 10.5 | 0.54 | 0.57 |
| | S2 | 6.4 | 0.51 | – ^b |
| | S3 | 11.2 | 0.72 | 0.76 |

^a S1 refers to Canadian Sample 1; S2 refers to Canadian Sample 2 and S3 refers to the US sample.

^b Factor analytic results cannot be displayed for sample 2 because of 0 variance for item 12.

and construct validity of the measure in a more racially diverse sample. The US sample ($n=2357$ started surveys) included 58.3% Caucasian women, 11.2% Black women, 8.4% Hispanic/Latina women, 3.4% Native Alaskan, Native Hawaiian or other Pacific Islander women, and 18.7% of women who identified as Asian, African, other or biracial.

2. Results

2.1. Demographics

Participating women were 32.6 years old, on average. By linking postal codes to provincial data by health authority, we determined that our sample was closely matched to the socioeconomic, age, and geographic distribution profile of childbearing women in BC. Two-thirds of the 2514 care provider experiences reported were about care

by midwives (1723, 68.5%), and the rest about care by family physicians (500, 19.9%) and obstetricians (291, 11.6%). Nearly one in ten represented the experiences (243; 9.7%) of currently pregnant women.

Women were able to self-identify as recent immigrants or refugees, and/or describe multiple barriers (e.g. history of substance use, poverty, homelessness or incarceration). In total 75 (4.5%) women with these challenges completed the survey, and several more described their experiences during population-specific focus groups without completing the survey. Most women self-identified as White (92.5%), with the largest representation from minority groups being Chinese (1.6%) and First Nations, Inuit, or Métis (1.8%). Group socioeconomic characteristics included 8.2% women with family incomes < \$30,000 (CAD) and 10.2% with no post-secondary education.

The majority of the pregnancies were low risk; however, 10.2% of

women reported at least one medical or social risk factor (high blood pressure, diabetes, fetal growth problems, fetal status compromised, depression, lack of social support during pregnancy, or unstable housing). In addition, 18 women (1.1%) reported on experiences during twin pregnancies.

2.2. Item-to-total correlations and factor structure

Corrected item-to-total correlations for the 7 item MOR index exceeded 0.45 for all items in Sample 1, providing strong evidence that the scale is uni-dimensional, i.e. measures one underlying construct (Roberts & Yeager, 2004). Factor loadings for the MORi scale items ranged from 0.52 to 0.82 for Sample 1, and 0.21–0.76 for Sample 2 (see Table 2). For Sample 2, lower item-to-total correlations and factor loadings for item # 4 of the MOR index (*Overall while making decisions during my pregnancy/birth care I felt coerced into accepting the options my care provider suggested*) suggest that this item does not fit as well with the other scale items for women who had a previous pregnancy.

Corrected item-to-total correlations for the 14-item version of the scale ranged from 0.18 to 0.73 (S1). Factor analysis of the 14-item version of the scale revealed a three factor scale for Canadian sample 1, i.e. items 1–7 and 14 grouped together, as well as items 12 & 13 and items 8–10. Item 11 cross-loaded on factors 1 & 2. Evaluation of the items that loaded together reveal three logical domains that describe the participant's reactions to respectful/disrespectful care: sense of autonomy and comfort; modified behavior; and perceptions of discrimination. Because item 11 cross-loaded and 2 of the sub domains have less than 3 items (i.e. do not have the minimum number of items needed for a subscale), we elected to conceptualize the 14 item MORi as a unidimensional scale. Factor loadings for the Canadian and US samples are presented in Table 2. While a few lower factor loadings were observed with the Canadian sample (See MORi items 11–13), when administered to a more racially diverse sample of American women who gave birth in the last 5 years, we found factor loadings > .45 for MORi items, indicating a unidimensional scale. The harmonized response options and high relevance of some of the items to the US context (i.e. items about poor treatment as a result of race and health insurance status) likely explain differences in the Canadian and US factor analytic results.

2.3. Internal consistency reliability

In Canada, for the 7-item MOR index, Cronbach alphas were good for women in S1 (0.85) and S2 (0.76). Alpha could not be calculated for the subsample of currently pregnant women because of low response variance (i.e. almost all women choose 'yes' on all items). For the 14 item MOR index, Cronbach alphas were 0.85 (S1) and 0.80 (S2).

The Cronbach's alpha for the US sample ($n=1613$) was 0.94. Corrected item to total correlations ranged from 0.43–0.84. The unweighted least squares factor analysis showed that 13 items loaded above 0.55 on factor 1 and one item loaded above 0.45. Although two Eigenvalues were above 1 and the scree plot indicated either a one or two factor solution, given the high factor loadings on one factor and the overall low loadings on the second factor (ranging from – 0.04 to 0.50) we confirmed the 14 item MORi index as single construct scale.

2.4. MORi scores among women in BC

Descriptive analysis using scores for individual items on the MOR index showed that, in British Columbia, most women reported that their personal and cultural preferences were respected, and that they were comfortable asking questions while making decisions during pregnancy and birth. Fewer were comfortable declining care that was offered, and approximately 1 in 10 reported feeling *coerced* into accepting options their care provider suggested. Poor treatment

“because of a difference in opinion with their caregivers about the right care for themselves or their baby” was reported by 10.5% of women in sample 1 and 6.4% of women in sample 2. The most common reason women “held back from asking questions or discussing concerns” was the perception that care providers were rushed. Women reported that they also held back their questions and concerns because of differences in opinion with their care providers, and fear that the care provider “might think [she] was being difficult.” (see Table 2).

Women with self-reported risk factors (high blood pressure, diabetes, compromised fetal status, depression, lack of social support, or unstable housing) were more likely to score in the bottom 10th percentile of the MOR index, compared to women with no reported risk factors. Women who reported one or more of these medical or social risk factors during pregnancy were four times as likely to have low MORi scores (19.8% versus 5.2%). Similarly, women who were recent immigrants or refugees, or had a history of substance use, incarceration, poverty and/or homelessness, were more likely to have very low MORi scores, (13.5% versus 6.3%), compared to women who reported no barriers. In this BC population, poor treatment from care providers because of sexual orientation, race or women's insurance status was very rare. The likelihood of scoring in the bottom 10th percentile was similar for women of color versus white women (see Table 3).

Women who planned a home birth and gave birth at home were unlikely to score in the bottom 10th percentile of MORi, and they were least likely to report overall experiences of disrespectful care. However, 16.2% of women who needed to be transferred to hospital from a planned home birth reported very low MORi scores and were much more likely to score in the bottom 10th percentile of the MORi scale compared to women who gave birth at home (0.5%) or those who planned a hospital birth (8.8%).

Women under the care of midwives were the least likely to have low MORi scores (see Table 3). Women who reported on their experiences with midwives were also less likely to have low MORi scores; 3.6% of midwifery clients, compared to 15.3 % of women who saw family physicians during pregnancy and 21.6 % of women who saw obstet-

Table 3
MORi scores (7 item version), reported by selected indicators ($n=1672$).

| | <i>n</i> (%) | MORi scores 0–10th percentile <i>n</i> (%) |
|---|--------------|---|
| Self-reported pregnancy complications | 170 (10.2) | 19 (19.8) |
| Yes | 1502 (89.8) | 42 (5.2) |
| No | | |
| Place of birth^a | 928 (66.8) | 41 (8.8) |
| Planned hospital birth, delivered at hospital | 120 (8.6) | 12 (16.2) |
| Planned home birth, delivered at hospital | 308 (22.2) | 1 (0.5) |
| Planned home birth, delivered at home | | |
| Primary maternity provider | 288 (17.2) | 20 (15.3) |
| Family Physician | 179 (10.7) | 16 (21.6) |
| Obstetrician | 1205 (72.1) | 25 (3.6) |
| Midwives | | |
| Vulnerable status | 75 (4.5) | 7 (13.5) |
| Yes | 1597 (95.5) | 54 (6.3) |
| No | | |
| Race/ethnicity | 1296 (93.0) | 41 (5.6) |
| Self-identified as Caucasian | 97 (7.0) | 5 (7.9) |
| Self-identified as woman of color | | |
| CS | 97 (6.9) | 18 (38.3) |
| Yes, pressured into decision | 151 (10.7) | 5 (6.9) |
| Yes, not pressured | | |
| Induction | 112 (7.9) | 17 (27.9) |
| Yes, and pressured into it | 113 (8.0) | 4 (7.0) |
| Yes, and not pressured into it | | |

^a Not all place of birth options are listed.

tricians. Higher scores among women who saw midwives persisted regardless of birth setting; 3.1% of women who planned a home birth with midwives reported disrespectful experiences and 4.4% who planned a hospital birth. In contrast, 22% of women who planned a hospital birth reported experiences of disrespect when describing encounters with physician providers.

3. Discussion

Measuring respectful care over the childbearing cycle requires thoughtful assessment of several domains. We have constructed a reliable and validated instrument that assess the culture of dialogue in maternity care. The MOR index is a straightforward tool to measure the experience of respect during discussions with providers about maternity care options. The index captures a complex set of effects and interactions related to three domains within the experience of respectful maternity care: 1. a woman's sense of autonomy and comfort when accepting or declining care options, 2. evidence of the woman modifying her behavior as a result of fear of anticipated disrespect, and 3. perceived differential treatment as a result of a non-modifiable socio-demographic factor. The significance of the first two domains is supported by findings of Lukasse et al. (2015) that loss of agency and poor treatment leads to fear. The third dimension, differential treatment based on race, ethnicity or personal characteristics, measures the occurrence of violations related to stigma and discrimination as described by both Bowser and Bohren (Bohren et al., 2015; Bowser & Hill, 2010).

In 2012, the USAID Maternal Child Health Integrated Program commissioned a comprehensive report on the state of “respectful maternity care” (RMC) across low and high resource countries (Reis et al., 2012). The authors concluded “safe motherhood must be expanded beyond the prevention of morbidity or mortality to encompass respect for women's basic human rights, including respect for women's autonomy, dignity, feelings, choices, and preferences.” The report identified key areas of disrespect and abuse in each country and described the major challenges to improving conditions for women in Canada as, “limited political will, institutional commitments, and plans to implement RMC, lack of accountability of doctors and their dominance over maternity care, and lack of specific training related to RMC for nurses, ob-gyns, anesthetists, and pediatricians”.

In our provincial study, Changing Childbirth in BC, a diverse community of childbearing women concurred with the USAID report and global researchers when they identified respectful care and the process of decision-making as core topics for study. They decided to include strongly worded items to evaluate the extent of coercive behaviors among providers. There was an overwhelming response from women and their family members from many socio-economic & cultural backgrounds across the province; 4082 respondents (including 392 from vulnerable populations) provided survey data and over 1100 women wanted to participate in focus groups, confirming the importance and currency of these topics.

While overall the MORi scores reflect a respectful environment in BC, over 10% of women reported that they felt **coerced** into accepting options for care, across provider groups. Women who were cared for by midwives and those who planned home births had overall higher scores, signifying respectful care.

Women from vulnerable populations were more likely to score in the bottom 10th percentile of the MORi scale. This finding is consistent with reports on reduced access to high quality health care experienced among recent immigrants, refugees, incarcerated, street-entrenched and homeless individuals (Thomson, Dykes, Singh, Cawley, & Dey, 2013). Fear of disrespectful behavior in institutions has been identified in both low and high resource countries as a major deterrent to seeking out essential maternity care at hospitals (Abuya et al., 2015; Jackson, Dahlen, & Schmied, 2012; Symon, Winter, Donnan, & Kirkham, 2010). The MOR index could inform quality improvement initiatives

aimed at increasing adherence and access to skilled attendants, and/or life-saving measures, for vulnerable populations.

3.1. Measuring quality: shared decisions or disrespect?

Three of the MORi scale items that measure how a sense of respect affects patient behavior may provide some insight into differences in scores across providers. “Holding back their questions because of” a sense of time pressure implies that they were not able to adequately engage in a decision-making discussion with the provider. In the Canadian model of maternity care, the obstetrician is least likely to have the time during prenatal, labor or birth to develop a trusting relationship or engage in ongoing discussions about options for care. In contrast, Canadian midwives are mandated by regulatory language to initiate and engage clients in informed choice discussions. Accordingly, the time needed to revisit topics and facilitate the patient-directed evolution of a care plan is built into the payor model (fee per course of midwifery care). Family physicians may have limited time allotted to each prenatal visit but their model of care is inherently relationship-based, sometimes over several years. Family physicians also typically have a limited obstetric caseload, perhaps allowing them more time to be present with laboring patients. A focus on a shared decision making process is emerging in medical education and health institutions, and has been linked to evidence of quality care in midwife-led units (Ten Hoope-Bender et al., 2014; Sandall, Soltani, Gates, Shennan, & Devane, 2015).

Women who reported medical or social risk factors had lower MORi scores than women with no health concerns during pregnancy. This suggests that the experience of respect might interact with the need to engage in a decision making process with maternity providers. The MORi scores suggest that, in BC, women experienced disrespect when they had “differences of opinion around maternity care options” more commonly than discrimination based on non-modifiable characteristics (sexual orientation, race). Our findings also indicate that experiences of respectful care vary depending on how obstetric procedures are presented to women. Women who felt pressured into having an induction or Cesarean section were more likely to report disrespectful care, compared to women who had these procedures without an experience of pressure.

This finding is supported by the differences among women who had to change their planned place of birth. Transfer from home to hospital birth typically requires women to engage in a detailed decision making process around options for care. BC women had lower MORi scores when they had experienced transfer from home to hospital. Interestingly, women who had home births reported experiencing the most respectful care; they had the highest MORi scores of all women in both samples. This could be a compounding effect since only midwives attend home births in BC (and midwifery care was also associated with higher scores). The reduction in scores among women whose care was transferred across birth settings could reflect the multi-disciplinary nature of informed consent discussions or simply an increased need to engage in difficult conversations involving differences in opinions around the care plan (Vedam, Leeman, Cheyney, et al., 2014; Fox, Sheehan, & Homer, 2014; Cheyney, Everson, & Burcher, 2014).

Perceptions of disrespect may be dependent on woman's reactions to inherent provider-patient power dynamics, which are known to influence patient choices (Cheyney, 2008; Lindgren & Erlandsson, 2010; Lukasse 2012). A sense of disrespect may also be affected by a woman's self-image. In marginalized populations, women may not feel they can exercise their agency because of systematic erosion of self-confidence and self-worth. A woman's sense of disrespect can also be affected by institutionally sanctioned behaviors such as adhering to minimum standards for informed consent (signatures) instead of requiring a detailed informed decision making process, including adequate time to consider options, such as in the case of *Montgomery v. Lanarkshire Health Board* (United Kingdom

Supreme Court, 2015). The evidence suggests that the use of coercion and pressure significantly increases women's likelihood of receiving unnecessary surgeries. A 2014 study found that women who perceived pressure to have a Cesarean section were more than five times more likely to have one, more than six times more likely to have one with no medical basis, and nearly seven times more likely to have an unplanned cesarean (Jou, Kozhimannil, Johnson, & Sakala, 2015).

The items included in both versions of MORi address common priorities described in patient-oriented outcomes research about quality maternity care. (Canadian Institute for Health Research, 2016). Due to the simple nature of the questions may be easily applied in low, middle, and high resource settings. Shared-decision making has been associated with reducing the unnecessary obstetric interventions that occur in all regions (Sandall et al., 2015; Hodnett et al., 2012). Research on provider attitudes in Australia revealed that while doctors and midwives supported a pregnant woman's right to make autonomous decisions, these same providers believed that under certain circumstances a pregnant woman's autonomy could be overridden for the safety of the baby (Kruske, Young, Jenkinson, & Catchlove, 2013). It is at this interface where refusal of unnecessary care may also provoke disrespectful behavior and create conflict. Thus, the items of the MORi could be used to conduct baseline measurements and post-intervention effects of respectful care in quality initiatives aimed to reduce obstetric interventions.

3.1.1. Respect as a component of patient safety

Effective reform requires an understanding of the components of care that affect patient experience and concepts of safety. The MORi enlists the user in evaluating the process of decision making and its effects, and so could help to clarify and normalize expectations for respectful interactions within the patient-provider dynamic. The dimensions of respect that Freedman et al. (2014) describe as being important to women include “behavior that by local consensus constitutes disrespect and abuse”, “intentionality” and....a woman's “lived experience” of the “deeper dynamics of power”. Women in North America report that relationship-based care that provides ample time for shared decision-making, increases their sense of safety and self-determination, facilitates family involvement, and allows for greater cultural congruency (Cheyney, 2008; Lothian, 2013). MORi can measure differences between their expected and actual interactions during maternity care discussions with providers. Interestingly our community process of RMC scale development in a high resource country also elicited the same four domains that are important during labour and birth women in a low resource country (Sheferaw et al., 2016): friendly care, abuse-free care, timely care and discrimination-free care. However, MORi measures these dimensions specifically as they relate to women's experience of decision making over the course of pregnancy, childbirth and postpartum care.

Vulnerable populations may particularly benefit from a model that supports informed decision making and strong provider-patient relationships. (McRae et al., 2016; Scupholme, Paine, Lang, Kumar, & DeJoseph, 1994). Finally, efforts to reduce unnecessary cesarean section rates may be facilitated by applying the MORi as a simple quantitative measure to evaluate of informed consent and refusal conversations in obstetric practice.

While numerous professional organizations and health systems have endorsed respectful, person-centered care as a key component of safe care, to our knowledge no official body is actually using a validated tool to measure and follow respectful care over time in high or middle resource countries. If incorporated as a routine quality and safety measure at the antenatal clinic or hospital level, this tool could help clarify the confusion providers often exhibit over the conflict between patient rights and their own perceived professional responsibilities concerning pregnant persons (Kruske et al., 2013). As well, implementation of the MORi at the hospital level could support more women to make more informed decisions by comparing respectful treatment

across birth facilities.

3.2. Implications for human rights in childbirth

Abuses of human rights in childbirth are documented by several high profile legal cases in low, middle and high resource countries. A case brought before the Jharkhand High Court in India, Kalyani Meena v. Union of India & Ors, addressed the overwhelming number of preventable deaths of women who die either in pregnancy or childbirth as a result of human rights violations. In Konovalova v. Russia, the European Court of Human Rights upheld a woman's claim that her treatment during childbirth was inhuman and degrading, and violated her right to privacy (European Court of Human Rights, 2014a). In Dubska v. the Czech Republic, Ms. Dubska argues for access to home birth in response to mistreatment and abuse prevalent in Czech Hospitals, including “the arrogant, intimidating, disrespectful and patronizing behaviour on the part of the hospital staff and the lack of privacy” (European Court of Human Rights Strasbourg, 2014). A recent UK case, Montgomery v. Lanarkshire, emphasized the necessity of providing adequate information in order to ensure safe decision making consistent with the dignity of patients (United Kingdom Supreme Court, 2015). A 2005 US civil case, Meador v. Stahler and Gheridian, awarded damages for a medically unnecessary cesarean (Chalidze, 2009; Middlesex Superior Court, 1993). This judgment cited that her provider misrepresented medical risks, ignored her express wishes, and compelled her to agree to the procedure. Similarly, in 2014, in Rinat Dray v Staten Island University Hospital et al. (Supreme Court of the State of New York, 2014), Ms. Dray contends she was subjected to a forced cesarean section, and the supporting briefs detail dozens of U.S. women's accounts of similar abuses at the hands of birth care providers, including threats, bullying, belittling, coercion, and dehumanizing treatment.

Legal scholars and global health professionals cite both individual and community-level factors that normalize these behaviors among institutional staff. These include lack of standards and accountability, scarcity of legal and ethical recourses or sanctions, ineffective leadership, and lack of resources to support reform through evaluation and training of care providers (Chalidze, 2009). When seeking redress for violations of their rights, women could use MORi scores to quantify care received, and support petitions for rights to autonomy, self-determination, privacy and freedom from inhuman and degrading treatment. In both legal and practice settings, the tool can be used to assess and provide context for assessing individual complaints. If used to evaluate care on a population level, MORi scores have the potential to serve as a clear standard for care received in various settings, ultimately informing patient driven policy changes with respect to informed consent and access to options for care.

Finally, the mode of development through extensive community input from diverse service users allows them to define the most important aspects of care that protect their human rights. Our research directly addresses the expressed community concern about lack of access to a maternity care model that prioritizes relationship-based care, patient-led decision making, and respectful maternity care across disenfranchised communities. It also enhances the applicability of this tool to examinations of women's experiences of respectful maternity care across low, middle, and high resource countries. This method of community led, participatory research generates authentic patient-oriented outcomes (Canadian Institute for Health Research, 2016) and may assist in informing and health professional education and health systems policy.

4. Limitations

The binary response format (Yes, No) of our initial MORi scale resulted in low response variance. A six point Likert response format may be more effective at capturing nuanced reactions to complex

personal interactions. Accordingly, we administered the 14 item MORi scale with the harmonized 6 point Likert response format to a large sample of mothers from communities of color who have given birth within the past 5 years in the United States. The improved internal consistency reliability, and factor structure of the 14-item scale in this diverse population, suggests that the multi-dimensional scale is stable.

The 14 item MORi can be used to quantify women's sense of disrespect and dismissal especially when engaging in conversations with providers. It does not measure incidence or impact of other types of abusive behavior (shouting, scolding, slapping, coercive procedures) which have been noted widely in the global context, and are measured by Sheferaw's tool. Noting this deficit the community members in the Giving Voice to Mothers study added validated items with harmonized Likert type responses to their own survey. Preliminary results (Vedam, Stoll & Declercq, 2016) indicate significant differences among populations in the rate and severity of these experienced behaviours. It may be advisable to evaluate psychometric properties of an expanded MORi that includes those additional items.

Results from the subgroup analysis of women who scored in the bottom 10th percentile on the MORi should be interpreted with caution, for subgroups < 20 women. Participants were likely highly motivated as they voluntarily completed a long online survey, hence, their experiences may not be representative of the entire BC maternity population.

5. Conclusion

Our method of community led, participatory research generated authentic patient-directed items for inclusion in a new validated scale that assesses women's experience of respect and ability for self-determination in maternity care. The MOR index may assist institutions and individual providers to evaluate the psychosocial impact of informed consent processes, as well as patient perceptions of discrimination and poor treatment. MORi scores could be used as a concrete indicator to inform institutional quality improvement initiatives, and health systems policy reform. The MOR index could also be used by patients to evaluate provider-patient interactions with learners and thus inform health professional education curricula, in patient oriented outcomes maternity care research, and by clinicians who desire to engage patients in continuous quality improvement in their practice settings. Application of this new quality and safety indicator may improve access to a maternity care model that prioritizes relationship-based, person-centered care.

Author contributions

Conceived and designed the study: SV KS GJ CCinBC SC. Gathered the data: SV KS GJ KM CCinBC SC. Analyzed the data: SV KS NR GJ KM CCinBC SC. Contributed materials/analysis tools: SV KS GJ KM NR HHK ZMV. Wrote the paper: SV KS NR ZMV HHK GJ KM. Reviewed/edited/approved: SV KS NR HHK ZMV KS GJ CCinBC SC.

Acknowledgements

From 2012–2014, Vancouver Foundation provided an operating grant (UNR12-0701) which supported the design, data collection, and quantitative analysis phases of our provincial community-led participatory action research (CBPR) project entitled “*Changing Childbirth in BC: Women exploring access to high quality maternity care.*” We would like to thank our community partners including leaders of the Immigrant Services Society of BC, Midwives Association of British Columbia, Womenin2Healing, Access Midwifery, Strathcona Midwifery Collective, and Pomegranate Clinic, for their remarkable support of the diverse group of mothers as ongoing partners in the Steering Council. We are also grateful to academic colleagues from Public Health, Obstetrics, and Midwifery, and the Women's Health Research

Institute for providing training and support for the community members. We are in awe of the persistence and perseverance of work group leaders Lorna McRae, Mo Korchinski, Anna Tashlykova, Raquel Velasquez, and Nora Timmerman who liaised with community members. Thank you to Barbara Karlen, Research Coordinator, who continues to patiently support all aspects of community engagement and knowledge translation. Most of all we thank the women and families of British Columbia whose frankness and commitment to improving maternity care immeasurably contributed to the drafting and testing of a patient-responsive scale.

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