birth place lab

Giving Voice to Mothers:

A national survey of the experiences of care during and after pregnancy and childbirth in the US

This community led research study was funded by the Transforming Birth Fund through the New Hampshire Charitable Foundation. We are indebted to the community partners who worked with the Birth Place Lab to develop this survey.

BACKGROUND

The need for the Giving Voice to Mothers-US study arose at Home Birth Summit III (HBS), in September 2014. Delegates noted that the only studies conducted to date in the US on maternal experience in pregnancy in childbirth were the Listening to Mothers surveys (LTM I,II,III). The LTM studies captured information on a nationally representative sample of women who planned hospital births only. Given the documented health disparities in communities of color in the United States (US) and the lack of information (despite increasing uptake) about women who plan community births (home and birth center), the HBS Research and Community Engagement Task Forces collaborated to design studies focussed on these communities. The team decided to use patient-centered, community based methods to conduct the study, based on the previous work in the Birth Place Lab led Changing Childbirth in British Columbia survey.

A multi-stakeholder, national Steering Council, including service users, clinicians, and community specific service providers convened to select topics and review validated measures. Service users from the target communities (i.e. women of color and women planning a community birth) were involved throughout the process including defining the survey topics, selecting the questions, rating each survey item for relevance, importance and clarity, recruiting respondents, identifying the key outcomes for analysis, informing and conducting the analyses, and interpreting the results. The final survey tool examined access to and experience of care, including respect, autonomy, and mistreatment when interacting with health care providers over the course of pregnancy, childbirth, postpartum and newborn care. It also explored links between behaviors, options for care, and decisions and indicators of racism and discrimination during healthcare encounters, and factors that support community and individual resilience.

We targeted recruitment of women from communities of color (Black, Indigenous, Hispanic/Latina), and those who planned a community birth, to make sure that we captured information on unique topics that are most relevant to these communities, and so that we collected enough data from these previously underrepresented groups. The results of the survey demonstrate that there is much to be done to improve access to high quality experiences of childbearing and newborn care especially among people of color, and those who choose to give birth in a community setting.

In 2016, the World Health Organization issued new Standards for Improving Quality of Maternal and Newborn Care, to evaluate “the extent to which health care services provided to individuals and patient populations improve desired health outcomes and [are] safe, effective, timely, efficient, equitable and people-centred”. The WHO standards emphasize that outcomes of high quality care include experiences of autonomy, respect, dignity, emotional support, and a patient-led, informed decision-making process. We hope that everyone working with childbearing communities will utilize the results to improve health outcomes in their own settings. We also aim to work with communities to increase awareness of these results amongst childbearing people

to allow them to understand their rights and expectations for safe, quality maternity care.

ACKNOWLEDGEMENTS

We are extremely grateful to all the people across the United States who took the time to share their experiences of maternity care, and in particular the community members who helped improve the survey by sharing their knowledge during the content validation process.

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Giving Voice to Mothers in the US: Experiences of care among people of color and in community settings for birth

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To access the full report and related resources:
www.birthplacelab.org/givingvoicetomothersreport

For support interpreting or using this report please complete the contact form at this link: https://www.birthplacelab.org/contact-us/ or email: birthplace.lab@ubc.ca

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EXECUTIVE SUMMARY

We received responses from 2700 women from across the United States. The majority of participants (56%) were between the ages of 31 and 39 when they gave birth; 14% were pregnant at the time of data collection. Most were born in the US (90%), and spoke English at home, and 80% had completed post-secondary education. All 50 states are represented in the survey, but the largest proportion of respondents were from New York State (29%); California (8%), Washington (5%), and Texas (4%). One third reported family incomes less than $50,000 per year. 15 % self-identified as Black, 10 % as Hispanic, 3% as Indigenous and 5% as Asian, and 66% as white.

The majority of participants received prenatal care from midwives (71%), followed by obstetricians (26%) and others, including family physicians (2%). Fewer women of color had prenatal care by midwives (55% Black vs 76% white). Half of respondents gave birth in their homes or a freestanding birth center, and half in a hospital. Fewer women of color (30% Black vs 55% white) had a planned community birth. Close to 14 % of women had a Cesarean birth, with variation by race (19% Black vs 12% white). Half of women paid for maternity care via private insurance, and 14% had some coverage from Medicaid/CHIP.

Preferences for care

Women identified what is important to them during maternity and newborn care. The following factors were rated as important or very important by more than 90% of women: having a trusting relationship with their the care provider, having a doctor or midwife who is a good match for what they value and want for pregnancy and birth care, not being separated from baby after birth, having enough time to ask questions and discuss options for care, having support people of their choice present for labor and birth, knowing the midwife/doctor who will care for them during birth, choice of birth place (home, birth center or hospital) and leading decisions about pregnancy, birth and baby care. Having access to pain relief and having their doctor or midwife lead decisions around care were cited least frequently.

Inequitable access to high quality maternity care

Two thirds of women reported that midwives were most directly involved in their prenatal care. Women of color were less likely to report having access to midwifery care compared to white women. Black women were least likely to access midwifery care. Women of color were also less likely to receive continuity of care; they were less likely to have the doctor or midwife who provided the majority of prenatal care attend their birth. Most Black women reported that it was very important or important to them to have continuity of care (i.e. only one doctor or midwife throughout pregnancy and birth), yet they were the least likely to report continuity of care.

Black women were the most likely to report that they want to lead decisions around their pregnancy, birth and baby care, yet they reported the lowest scores for autonomy in decision-making and had the least access to models of care that support decision-making.

Similarly, 95% of Black women said it was important or very important to them to have enough time to ask questions and discuss options for care, yet they were the most likely to have very short prenatal appointments (10-15 minutes), on average.

Access to preferred care

One in seven women agreed or strongly agreed with the statement *'Finding a midwife or doctor who shared my heritage, race, ethnic or cultural background was important to me'*, with large variations across racial groups: 46% of Black women, 9% of white women, 25% of Latina women, 13% of Asian women and 25% of Indigenous women agreed with the statement.

Of the women who said it was important to them to find a health care provider from their heritage, race, ethnic or cultural background, 69% of Black women, 4% of white women, and 49% of Latina women had difficulty locating a doctor or midwife from their heritage, race, or cultural background.

High Unmet Need for Social Services

Over half of respondents reported on barriers to optimal health during pregnancy. Depression, inability to meet financial obligations, concerns about health insurance, and not enough support from family and friends were the most common problems noted. Respondents reported receiving assistance from providers with smoking cessation, but almost no help for those who needed other important resources and referrals. These unmet needs include: nutrition counseling, IPV/safe housing, mental health, depression, and navigating the social safety programs.

Black and Indigenous women checked more than twice as many social determinants of health as white women (1.5 and 1.7 vs 0.7 for white women). Black and Indigenous women reported 2-3 times more unmet need for mental health services than white women.

Community birth

The most common reasons why women planned a community birth were: control over my childbirth experiences, comfortable, peaceful environment, low intervention options for care, to avoid disturbance of my labor, to avoid having to fight for my desired birthing experience, to avoid a cesarean section, safety, confidence in my own body, better for baby, to avoid separation from my baby, to avoid hospital policies and procedures and to avoid time limits. Each of these reasons was cited by more than 90% of women who planned a community birth.

Over 80% of those who planned community births felt judged or criticized for their choice of birth place; women most commonly felt judged or criticized by the public, friends, in laws, healthcare providers, parents and work colleagues.

Continuity of care was disrupted for many women who transferred to the hospital: one third reported that their midwife was not able to stay with them after transfer, and 15% said that their midwife did not provide care after hospital discharge.

High unmet demand for doula support among Black and Indigenous women

We defined a doula as a *"person who usually stays with a woman throughout labor and birth to provide emotional support, comfort measures, and information."* Of the women who did not have a doula during labor/birth two fifths would have liked to have had the care of a doula during their most recent birth. Preferences for doulas varied by race, with high demand among Black (59%), Latina (62%), and Indigenous women (55%) and lower demand among Asian (39%) and white women (34%).

Disparities in mistreatment during pregnancy and birth

One in six women reported one or more types of mistreatment, most commonly healthcare providers shouting and scolding them (9%), or threatening to withhold treatment or to force them to accept treatment they did not want (8%). Physical abuse and personal information being shared without consent were reported by few women.

Indigenous women were the most likely to report experiencing at least one form of mistreatment by healthcare providers (34%), followed by Latina (25%) and Black women (23%). Women who identified as white were least likely to report that they experienced any of the mistreatment indicators (14%). Differences in mistreatment by race were pronounced for some indicators. For example, twice as many Hispanic and Indigenous women as compared to white women reported that health care providers shouted at or scolded them. Likewise, Black women, Latina women, Asian, and Indigenous women were twice as likely as white women to report that a health care provider ignored them, refused their request for help, or failed to respond to requests for help in a reasonable amount of time.

Half of respondents declined care at some point during their labor/birth, over 90% of them reported that they declined because they "thought it was not necessary". One third of women who had an episiotomy were not asked by care providers what they wanted before the procedure was done. Black and Asian women were most likely to report not being consulted before an episiotomy.

Proportions of women of color and white women who declined care were similar (52% of women of color versus 54% of white women). Women of color were more likely to report that their care providers performed the procedure anyway, against their will (5% Black vs 2% white). White women were more likely to report that their care provider accepted their decision to decline care (86% white vs 78% Black).

Privacy, dignity, and respect

Most respondents rated their overall sense of privacy, dignity, and respect as very good or excellent; however there were notable differences by race, place of birth, and type of provider. Care in community settings and by midwives was associated with greater respect, privacy, and dignity. Women of color reported lower overall rates of respect,

privacy and dignity, compared to white women and Indigenous women were most likely to report poor respect, dignity and privacy.

Pressure to have or to avoid interventions

Women were asked if they experienced pressure to have or to avoid interventions, tests or procedures from healthcare providers. The most common procedure that women felt pressured into was continuous fetal monitoring (24%), followed by medications to start or speed up labor (13%), a Cesarean (11%) and an epidural (7%) . Women of color were more likely to report feeling pressured into all of the listed interventions and procedures, compared to white women.

Autonomy in decision-making

The Mothers Autonomy in Decision-Making (MADM) scale is comprised of seven items that assess the degree that maternity care providers respect and facilitate the ability of women to lead decisions about their care.

Women of color (especially Black women), young women, less experienced mothers (those pregnant for the first or second time) and those with low SES, pregnancy or social risks were more likely to report low autonomy in decision-making. Having a midwife as their prenatal care provider, having a home birth and a vaginal birth were all linked to higher autonomy. Autonomy was more likely to be compromised for women who had obstetricians as their primary prenatal care providers, those who gave birth at the hospital and women who experienced an emergency caesarean or instrumental vaginal birth. Women who were induced, those who were transferred from the community to the hospital, and women who reported newborn health problems were also more likely to report low autonomy.

Health and Safety during pregnancy

The GVtM survey included several items that assessed health and safety concerns that childbearing women might experience. The four most commonly cited sources of worry were experiences of being pregnant and giving birth, peace of mind/stress/mental health, children’s health and access to women’s health services. Black and Indigenous women were most likely to voice concerns about their experiences of being pregnant and giving birth and were also more likely to worry about safety at home, stress, and access to affordable housing and healthy food. For example, one in two Black and Indigenous women noted that they were worried about their mental health and stress levels, compared to one in three white and Asian women.

When asked how often participants felt safe in their neighborhood during pregnancy, white and Asian women were most likely to respond that they felt safe every day of the week. In contrast, 9% of Black women and 7% of Indigenous women felt unsafe some or all of the time during their last pregnancy. Over 30% of Black participants reported daily stress related to violence against their family or community.

Postpartum experiences

Most women (86%) reported skin- to-skin contact immediately after birth – i.e. their baby's naked body against their skin with no clothing, blanket or diaper between mother and baby the first time they held their baby. The proportion of women who reported skin to skin contact varied by type of intrapartum care provider and place of birth: skin to skin contact was reported by 97% of women who gave birth in the community with a midwife, 87% of women who gave birth at a hospital with a midwife, and 69% of women who gave birth at the hospital with a doctor.

Over two thirds of women reported getting help with breastfeeding initiation from their maternity care provider: 89% of women who gave birth in the community with a midwife, 65% of women who gave birth at a hospital with a midwife, and 43% of women who gave birth at the hospital with a doctor.

CONCLUSIONS

The Giving Voice to Mothers- US study is the first to use indicators developed by service users to describe experience of childbearing care among communities of color and those who plan to give birth in homes and birth centers in the US. Adverse experiences of care occur more frequently when birth occurs in hospitals, and among those with social, economic or health challenges. Loss of autonomy, disrespect, and mistreatment is exacerbated when women encounter unexpected interventions, and or disagree with their providers about the right care for themselves or their babies. Our findings suggest that women of color are at higher risk of experiencing all types of mistreatment, loss of autonomy, discrimination, and lack of access to their preferred care. Childbearing people of color in this study were also more likely to report reduced access to and unmet needs for critical health and social services, relying more on their own community and family resources to support their resilience and well-being.

In this study of care in a high resource country, physical abuse was uncommon, but verbal abuse and failure to respond to requests for help were common; and rights to information and autonomy were not reflected in actual experiences of card. While the overall rates of mistreatment are lower among the GVtM participants than is reported in low resource settings, they are still unacceptably high for a country that places high value on patient autonomy, gender and race equity, human rights, and resources for health professional education.

Having a vaginal birth, giving birth at home or in a freestanding birth center, and having a midwife as the primary prenatal provider increased access to optimal experiences of care and reduced mistreatment. Importantly, more than half of our sample had planned community births. Since less than 2% of all childbearing women in the US give birth in community settings, the rate of mistreatment (30%) among women in our study who gave birth in a hospital is likely a better estimate of the true rate of mistreatment during childbirth among US women.