Declined care and discrimination during the childbirth hospitalization

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ARTICLE INFO

Keywords:
U.S.
Childbirth
Discrimination
Women of color
Patient-provider interaction

ABSTRACT

Many studies have documented poorer patient-provider interactions among people of color compared to Whites, including lower-quality patient-provider communication, less involvement in decision making, and higher chances of perceived discrimination in healthcare encounters. In maternity care, where overuse of medical interventions such as cesarean delivery is a concern, women may try to exert agency by declining procedures. However, declining procedures may brand these women as uncooperative or non-compliant patients. The potential consequences of this are likely worse for women of color, who already expend more effort to manage their image during healthcare encounters in order to avoid stereotypes (e.g. the “angry Black woman”). Using a national sample of women who gave birth in U.S. hospitals in 2011–2012, we examined the relationship between declining procedures and discrimination during the childbirth hospitalization. We found that women who reported having declined care for themselves or their infant during the childbirth hospitalization were more likely to report “poor treatment” based on race and ethnicity, insurance status or having a difference of opinion with a healthcare provider. Moreover, the increase in odds of perceived discrimination due to a difference of opinion with a healthcare provider was significantly larger in magnitude for Black women compared to White women. These results suggest that in the context of childbirth care, women pay a penalty for exhibiting behavior that may be perceived as uncooperative, and this penalty may be greater for Black women.

1. Introduction

Many studies have documented poorer patient-provider interactions among people of color compared to Whites (Attanasio et al., 2018; Bertakis and Azari, 2011; Ghods et al., 2008; Hausmann et al., 2008; Martin et al., 2013; Ratanawongsa et al., 2010; Street et al., 2007; Weeck-Maldonado et al., 2013; White-Means and Osmani, 2017). In maternity care, where overuse of medical interventions such as cesarean delivery is a concern (American College of Obstetricians and Gynecologists, 2014; Committee on Obstetric Practice, 2017; MacDorman et al., 2008; Molina et al., 2015; Queenan, 2011; Ye et al., 2016), women may try to exert agency by declining procedures. (We acknowledge that not all birthing people identify as women. Throughout the manuscript we use the terminology of “women” and “mothers” for consistency with the survey data source used in the analysis and the literature cited.) However, declining procedures may result in these women being viewed as uncooperative or non-compliant patients (Kotaska, 2017; Morton et al., 2018). The potential consequences of this are likely worse for women of color, who already expend more effort to manage their image during healthcare encounters in order to avoid stereotypes (e.g. the “angry Black woman”) (Malat et al., 2006; McLemore et al., 2018). Using a national sample of women who gave birth in United States (U.S.) hospitals in 2011–2012, we sought to examine the relationship between declining procedures and discrimination during the childbirth hospitalization.

1.1. The patient-provider relationship

Over the last two decades, patient-centered care has been held up as the ideal model of patient-provider interaction in all types of healthcare; the implementation of patient-centered care is now recognized as an integral component of care quality (Committee on Quality of Health Care in America, 2001; Epstein et al., 2010). In an approach consistent with patient-centered care, clinicians respect and take into account individual patients’ preferences and values, and involve patients in decision-making (Berwick, 2009; Committee on Quality of Health Care in America, 2001; Rathert et al., 2013). Along with this shift toward patient-centered care, patients are increasingly viewed as consumers (Boyer and Lutfey, 2010; Lupton, 1997; Potter and McKinlay, 2005). In this model, healthcare providers are charged with providing adequate information to patients to enable them to make decisions that best fit their preferences, while patients are charged with active involvement in
making decisions about their treatment and following through to implement treatment plans (Potter and McKinlay, 2005).

These changes in expectations for patient-provider relationships and consumerist patient behavior are evident in the context of maternity care as well as in healthcare more generally. Theoretically, pregnant women may be particularly well positioned to act as consumers compared to patients in other medical domains; in many areas of healthcare, the vulnerability of a sick patient, who is seeking out health care services based on need rather than want, may have a limited ability to act as a consumer (Benoit et al., 2010; Zadoroznyj, 2001). Pregnant women, in contrast, are able to anticipate an “acute” episode of care (giving birth) within a known time frame, and may be in a less susceptible position when seeking out prenatal care, and therefore more able to choose a provider that fulfills certain desired criteria (Lazarus, 2017). Indeed, women have historically fought to be treated as consumers in birth and to make birth safer, advocating for giving birth in hospitals rather than at home in the first few decades of the 20th century (whether or not this improved safety at the time), for access to anesthesia, and then for the option to be “awake and aware” and to have partners present in labor and delivery after abuses were exposed in the 1950s (Leavitt, 1986; Schultz, 1958; Simonds et al., 2007).

However, women’s ability to behave in a consumerist manner is constrained by social factors; for example, women with private insurance may have a wider range of options, and low-income women may have constraints such as transportation costs or time off work that may inhibit their ability to choose a provider based on other considerations (Kullgren et al., 2012; Zadoroznyj, 2001). Many women using maternity services demonstrate a “consumerist” rather than passive orientation in their selection of a maternity care provider (Zadoroznyj, 2001), in seeking information from sources such as childbirth education classes and the internet (Romano, 2007), and creating a written “birth plan” to be given to the provider or hospital staff (Latham, 2006; Mei et al., 2016). Armstrong (2000) argues that the current medical model of the perinatal period assumes that a pregnant woman acquiring knowledge will result in being able to control the experience of pregnancy and birth, and ultimately lead to better outcomes. In order to have the desired birth experience, women are charged with learning about their options for birth by reading extensively about pregnancy and birth and attending childbirth education classes, and then exerting agency to realize their desires (Armstrong, 2000).

1.2. Medical procedures in maternity care

Increasing use of medical interventions such as cesarean delivery in the past few decades with no concomitant improvements in maternal and neonatal morbidity and mortality has generated concerns that overuse of medical procedures may be a serious healthcare quality problem in this context (Committee on Obstetric Practice, 2017; MacDorman et al., 2008; Molina et al., 2015; Queenan, 2011; Ye et al., 2016). There is broad consensus among experts that the current cesarean rate of 32% in the U.S. is too high, leading to negative health outcomes for women and infants (American College of Obstetricians and Gynecologists, 2014). Among industrialized countries, cesarean rates vary substantially; for example, the Netherlands and Scandinavian countries have cesarean rates of 14–16%, while Germany, Switzerland, and Australia have cesarean rates of 30–32% (Ye et al., 2014). Episiotomy, where a surgical cut is made to enlarge the vaginal opening during childbirth, was used routinely through the early 2000s (Frankman et al., 2009). After a review of the published evidence in 2005 showed that episiotomy did not result in better outcomes for many of the common indications for its use (Hartmann et al., 2005), the American College of Obstetricians and Gynecologists (ACOG) revised its guidelines to discourage routine use (American College of Obstetricians and Gynecologists, 2006). While rates of episiotomy decreased following the guideline change, use of episiotomy remains variable among hospitals (Friedman et al., 2015).

While some women may be comfortable with higher levels of obstetric intervention (Green and Baston, 2007), and in a small subset of cases even prefer to deliver by cesarean (Ecker, 2013), a majority of women seek and plan for a vaginal birth (American College of Obstetricians and Gynecologists, 2013; McCourt et al., 2007), and some women wish to avoid interventions during birth (Mei et al., 2016; Toledo et al., 2012). Beyond obstetric procedures for the birthing parent, parents may opt out of or delay procedures that are routine in many hospitals for the newborn baby. Some of these procedures include antibiotic eye ointment, immediate cord clamping, vitamin K injection, Hepatitis B vaccine, and formula supplementation (Marcwicz et al., 2017; Myers et al., 2015). Few data are available on how many women actually try to opt out of various procedures during the childbirth hospitalization. However, a 2016 study analyzing women’s birth plan requests in a large medical center in Los Angeles found that some common requests included no intravenous analgesia, no epidural, breastfeeding only (i.e. no formula supplementation), delayed cord clamping, intermittent (rather than continuous) fetal monitoring, and no episiotomy. The infant procedures mentioned above were referenced in over 10% of the birth plans examined (Mei et al., 2016).

Theoretically, women are encouraged to be informed and engaged, and to exhibit consumerist behavior (Gee and Corry, 2012). However, in the context of childbirth, women who do so may end up having specific requests to opt out of procedures that are routine at a particular hospital. It is unclear how clinicians, including nurses, physicians, midwives, and other hospital staff, actually react to these types of behavior, and what the impact may be on patient-provider interaction. Furthermore, it is plausible that clinicians may react differently depending on the woman’s race/ethnicity.

1.3. Racial and ethnic disparities in patient-provider interaction quality

Multiple studies have documented poorer patient-provider interactions among patients of color compared to White patients, including lower-quality patient-provider communication (Bertakis and Azari, 2011; Ghods et al., 2008; Martin et al., 2013; Street et al., 2007; White-Means and Osmani, 2017) and less patient involvement in decision making (Attanasio et al., 2018; Lin and Kressin, 2015; Peek et al., 2010; Ratanawongsa et al., 2010). Additionally, patients of color are more likely than White patients to experience discrimination, or unfair treatment based on a category such as race, in healthcare encounters (Hausmann et al., 2008; Hausmann et al., 2009; Weech-Maldonado et al., 2013). Information on the overall prevalence of perceived discrimination in healthcare settings is not regularly collected; however, a 2017 survey of a nationally representative sample of U.S. adults found that 32% of Black Americans, 20% of Latinos, and 5% of White Americans reported having experienced racial discrimination in the healthcare context (Discrimination in America: Final Summary, 2018). There is also a growing literature that describes the experiences of discrimination among women of color specifically during prenatal and reproductive health encounters (Ertel et al., 2012; Mclemore et al., 2018; Nuru-Jeter et al., 2009). In a recent qualitative study of pregnant women of color, a majority of study participants characterized their prenatal care as largely disrespectful and stressful (Mclemore et al., 2018). The results of the Listening to Mothers III survey, conducted among U.S. women who gave birth in 2011 and 2012, indicated that 13% of respondents experienced discrimination due to race, ethnicity, language, or culture during their hospitalization for childbirth (Declercq et al., 2013). Black and Latina respondents were more likely than White respondents to report this type of discrimination (Attanasio and Kozhimannil, 2015).

One explanation for these disparities is that many White clinicians hold negative implicit racial biases and explicit racial stereotypes (van Ryn et al., 2011). These implicit (unconscious or automatic) racial biases persist independently of and often in contrast to explicit racial
attitudes (Blair et al., 2013; Chapman et al., 2013; Cooper et al., 2012; Sabin et al., 2009; Van Ryn et al., 2006; Van Ryn and Burke, 2000). Indeed, while White healthcare providers may consciously reject negative images and ideas associated with disadvantaged groups, they have also been immersed in cultures and a worldview where these groups are constantly depicted in stereotyped and pejorative ways (Fitzgerald and Hurst, 2017). One stereotype is that Black patients are non-compliant; a study found that implicit race bias and race and compliance stereotyping are associated with markers of poor visit communication and poor ratings of care, particularly among Black patients (Cooper et al., 2012). It is also possible that race- or class-based stereotypes triggered in the clinical encounter could result in different reactions to the same behaviors depending on patient characteristics such as race/ethnicity (Shim, 2010). Shim gives the example that following up a discussion of recommended treatment with questions may be perceived by clinicians as neutral or even positive information-seeking behavior from a White patient, while the same behavior from a minority patient might be perceived as the patient challenging the clinician’s expertise (2010). In an analogous scenario in childbirth, a woman may have researched care options and know what interventions or procedures she would like and which she hopes to avoid, potentially resulting in refusal of medical procedures (Afshar et al., 2017; Mei orprocedures shewouldlikeandwhich shehopestoavoid,potentially womanmayhaveresearchedcareoptionsandknowwhatinterventions clinician’s expertise (2010). In an analogous scenario in childbirth, a woman may have researched care options and know what interventions or procedures she would like and which she hopes to avoid, potentially resulting in refusal of medical procedures (Afshar et al., 2017; Mei et al., 2016). When a White woman displays such behaviors, this could be perceived positively as manifestations of health literacy and patient engagement, which are currently valued in the U.S. healthcare context (Koh, 2015; Potter and McKinlay, 2005). However, a Black woman behaving the same way may be perceived as aggressive or a difficult patient (Ghavami and Peplau, 2013; Morgan and Bennett, 2006; Sacks, 2017). In a recent participatory action study of 100 black women who had given birth in California, participants reported having their attempts at self-advocacy suppressed by the clinicians caring for them (Oparah et al., 2018).

In this study, we sought to investigate women's experiences of declining procedures in maternity care. Specifically, we examined the association between women's reports of declining medical procedures and perceived discrimination. Further, we assessed whether declining procedures was differently associated with perceived discrimination depending on the woman's race/ethnicity.

2. Methods

2.1. Data

Data for this analysis are from the Listening to Mothers III survey, a web-based survey of 2,400 women age 18–45 who gave birth to a singleton baby in a U.S. hospital in 2011–2012 (Declercq et al., 2013). The survey was commissioned by Childbirth Connection and conducted by Harris Interactive, which fielded the survey in October to December 2012 (Declercq et al., 2013). Women were sampled from a diverse array of online panels. Those who were selected received an email invitation to participate in the survey. Women who followed the link to the survey website were screened for eligibility (Declercq et al., 2013, pt. Appendix A). The online panel survey methodology that was used does not yield a response rate. The data were weighted such that the characteristics of the survey sample approximate those of the national childbirth populations.

2.2. Key measures

The key independent variable was whether women reported declining any care during their childbirth hospitalization. This was based on responses to the question, “At any time during the hospital stay for your recent birth, did you refuse to accept any care that a nurse, doctor, or midwife offered to you or your baby?” “Care” includes anything that might be done or given to either of you or that you were asked to do (take a test, treatment, medicine, etc.).” There were 39 women who chose not to respond to this question. In the main analysis, these women were coded as “no.” As a sensitivity analysis, we excluded these women, and results were unchanged.

Dependent variables were several measures of women's perceptions of discrimination during the childbirth hospitalization. Women were asked, “During your recent hospital stay when you had your baby, how often were you treated poorly because of …?” for each of the following reasons: (1) “Your race, ethnicity, cultural background or language”; (2) “Your health insurance situation”; or (3) “A difference of opinion with your caregivers about the right care for yourself or your baby.” Response choices for each question were “never,” “sometimes,” “usually,” or “always.” We created dichotomous variables for each type of perceived discrimination, indicating whether the woman reported ever experiencing it. We also created a variable representing whether the woman had reported any of the 3 types of perceived discrimination.

Race/ethnicity was considered to be a potential moderator in our analysis. This variable was based on women's self-reported race and ethnicity, which was categorized as White, Black, Latina, or other.

We also included several covariates in our analyses, which were variables that might be related to women's chances of declining care and to experiences of discrimination. Sociodemographic characteristics were: education level (high school or less, some college, Bachelor's degree, or graduate education/degree), insurance type (private, Medicaid, uninsured or other), age category (18–24, 25–29, 30–34, 35 or older), nativity (US- or foreign-born), and parity (first birth or second or greater birth). Clinical characteristics were: prenatal provider type (obstetrician, other doctor, midwife, other), pre-pregnancy hypertension, pre-pregnancy or gestational diabetes, pre-pregnancy obesity, and type of birth (spontaneous vaginal, assisted vaginal, cesarean).

2.3. Analytic strategy

The first set of analyses examined potential associations between women's characteristics and likelihood of declining care. We examined the overall sample characteristics by whether or not women reported declining any care, using adjusted Wald tests to assess statistical significance, then estimated a multivariate logistic regression model with declining care as the outcome. The second part of the analysis investigated the relationship between declining care and perception of discrimination. In this step, we estimated multivariate logistic regression models with each type of perceived discrimination as the outcome and declining care as the key predictor of interest. Finally, we examined whether the association between declining care and discrimination was moderated by race/ethnicity by adding interaction terms to the multivariate models. Where interactions were statistically significant, we calculated predicted probabilities to aid interpretation (Karaca-Mandic et al., 2012). All analyses were weighted to approximate the national population of childbearing women.

3. Results

Sample characteristics approximate those of women giving birth in the United States (Table 1). Fifty-five percent of women were White, 15% were Black, 23% were Latina, and 7% reported some other race/ethnicity. About 37% of women had Medicaid coverage for the birth, while about 46% were privately insured. Nearly a third of women in the sample were age 18–24, and 15% were 35 or older. Forty percent were giving birth for the first time. Thirty-one percent of women gave birth by cesarean.

Declining care was not significantly associated with race/ethnicity, education, or insurance type in bivariate analyses (Table 1). Women in the youngest age category (18–24) were most likely to report declining some type of care compared to older women. Women who were first time mothers, had hypertension, or had diabetes, declined care in higher proportions compared to those who had given birth before or did not have these medical conditions. Type of birth was associated with
education had higher odds of declining care compared to women with a high school degree or less (AOR = 1.82, p = 0.015). Older women had lower odds of declining care compared to women age 18–24. First time mothers had higher odds of declining care compared to women who had given birth before (AOR = 1.72, p = 0.001), as did women with hypertension (AOR = 1.94, p = 0.005) or diabetes (AOR = 3.13, p < 0.001). Women who had a cesarean birth also had higher odds of declining care (AOR = 1.50, p = 0.030).

As shown in Table 3, having declined care was associated with higher odds of reporting poor treatment during the childbirth hospitalization, whether due to race/ethnicity (AOR = 5.00, p < 0.001), insurance status (AOR = 4.18, p < 0.001) or having had a difference of opinion with a provider (AOR = 4.36, p < 0.001), or any of the above reasons (AOR = 3.89, p < 0.001).

We found that there were significant interactions between declining care and race/ethnicity. For the outcome of insurance-based discrimination, there was a statistically significant interaction between Latina ethnicity and declining care. The predicted probability of insurance-based discrimination was similar across race/ethnicity among mothers who had not declined any care, and higher among women who had given birth before (AOR = 1.72, p = 0.001), as did women with hypertension (AOR = 1.94, p = 0.005) or diabetes (AOR = 3.13, p < 0.001). Women who had a cesarean birth also had higher odds of declining care (AOR = 1.50, p = 0.030).

In multivariate models, there were no racial/ethnic differences in provider opinion with a provider (AOR = 4.36, p < 0.001), or any of the above reasons (AOR = 3.89, p < 0.001).

Table 3

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<thead>
<tr>
<th>Outcome</th>
<th>Refused any care</th>
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<tr>
<td></td>
<td>AOR</td>
</tr>
<tr>
<td>Treated poorly for any reason</td>
<td>3.89</td>
</tr>
<tr>
<td>Treated poorly due to race, ethnicity, language or culture</td>
<td>5.00</td>
</tr>
<tr>
<td>Treated poorly due to insurance situation</td>
<td>4.18</td>
</tr>
<tr>
<td>Treated poorly due to difference of opinion with provider</td>
<td>4.36</td>
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interaction between Black race and declining care for the outcome of discrimination based on a difference of opinion about care. Among Black women, declining care was associated with a 37 percentage point increase in the predicted probability of reporting discrimination based on a difference of opinion, compared to a 20 percentage point increase among White women (Fig. 2).

4. Discussion

In the current U.S. healthcare context, patients are encouraged to behave as engaged consumers (Weil, 2016), including in birth (Gee and Corry, 2012). During the childbirth hospitalization, one form of engaged patient behavior may be to decline certain procedures. This study sought to examine women's experiences of care based on whether they declined procedures, as well as to assess the role of race/ethnicity in this relationship. Declining procedures during childbirth was equally common among women of all racial/ethnic groups and among women with different types of insurance. However, women with graduate-level education were more likely to report declining procedures compared with women with a high school degree or less. Thus, there is some support for the idea that higher-SES women are more likely to engage in this particular manifestation of consumerist behavior in birth.

Among women of all racial/ethnic groups, those who declined care were substantially more likely to report perceived discrimination during the childbirth hospitalization. This suggests that despite exhortations for patients to take an active role in their care, clinicians may not react well to certain types of engaged behavior, particularly in instances where this conflicts with institutional routines. The relationship between declining care and discrimination raises the idea that women who decline care may be labeled “problem patients,” which is a stigmatizing label, at least for the duration of their hospitalization (Lorber, 1975).
Furthermore, we found that the magnitude of the increase of the chances of experiencing discrimination associated with declining care was greater for Black and Latina women than for White women for certain types of discrimination. These findings contribute important new knowledge regarding the reasons why discrimination may occur for birthing people. Specifically, stigmatizing labels may have a differential impact by race/ethnicity, with Black and Latina women more likely to be penalized for declining care during birth compared to their White counterparts. This is similar to findings in other fields, such as employment, in which the impact of having a criminal record (a different stigmatizing label) differs significantly for Black versus White people (Pager, 2003). Specific stereotypes persist regarding Black women in general and Black women’s motherhood in particular (Collins, 2000; Roberts, 1997; Rosenthal and Lobel, 2016). For example, Black women are stereotyped as being promiscuous and aggressive (Ghavami and Peplau, 2013), and Black mothers are often stereotyped as being young, single, and having children in order to obtain public assistance (i.e. the “welfare queen”) (Roberts, 1997; Rosenthal and Lobel, 2011). These stereotypes may result in clinicians viewing Black women who decline care as non-compliant, aggressive or as the “angry Black woman” (Ghavami and Peplau, 2013; Morgan and Bennett, 2006; Sacks, 2017). The same framing might lead a provider to view a White woman who declines a particular procedure as well-educated and decisive about her birth plan and healthcare needs.

Black women may feel obligated to preemptively dispel such stereotypes by managing their own behavior. A qualitative study found that Black middle class women make specific efforts to gain recognition and respect from their health care providers, such as dressing in a way that signals middle class status and trying to convey that they are engaged patients while being careful not to challenge the clinician (Sacks, 2017). These findings align with results from an older quantitative study in which Black patients were more likely than White patients emphasize the importance of positive self-presentation strategies (including dressing well, being friendly, and displaying intelligence) in healthcare settings in order to receive high-quality medical care (Malat et al., 2006).

Our findings offer important insight into the complex and multifactorial ways in which Black women receive lower quality care (Howell and Zeitlin, 2017), experience implicit and explicit racial bias and are disregarded and report not being heard during their encounters with the health care system while pregnant (McLemore et al., 2018). The alarming inequities in maternal and infant outcomes by race underscore the need for Black women and other women of color to be vocal and perhaps at times decline certain procedures in order to protect their health and wellbeing. However, these results suggest that in doing so, women might be putting themselves at greater risk for being discriminated against during a vulnerable time in their lives, which is not only concerning but unacceptable. Several community grassroots organizations led by Black women have developed trainings and workshops aimed at helping expectant women advocate for themselves in response to a barrage of popular press articles that have drawn attention to Black women’s birth experiences (“Ancient Song Doula Services ‘Reclaiming the Ancient Principles of birthing,’” n.d.). Although these projects have the goal of improving Black women’s birth experiences, our findings caution that increased self-advocacy could result in more negative experiences. It is also necessary to change the clinician- and systems-levels factors that produce negative experiences, and specifically to improve the patient-provider relationship.

There are some limitations to our analysis. We did not have information on what type of procedure or care women declined; therefore, we did not know whether the declined care was something that clinicians would be likely to perceive as serious or something more optional, and we were not able to differentiate between procedures for the woman or for the baby. Both the declining care and discrimination questions referred to the entire time period of the hospitalization, so we cannot be sure that declining care preceded perceived discrimination. It is possible that experiencing discrimination could have led some women to decline procedures. The survey did not ask about the race of the provider, and we are therefore unable to disentangle patient race from patient-provider racial concordance. Additionally, being treated poorly due to a difference of opinion with a healthcare provider does not involve being part of a stigmatized group, and therefore may be somewhat outside typical definitions of “discrimination.” However, medical beliefs (including desire for out-of-hospital birth) have been categorized as a basis for discrimination in previous studies (De Marco et al., 2008; Trivedi and Ayanian, 2006). Finally, although the Listening to Mothers data contain information on a nationally-drawn group of women, the sample is not population-based, and therefore may not be entirely representative of the U.S. childbearing population.

We found an increase in odds of perceived discrimination due to a difference of opinion with a healthcare provider associated with declined care that was significantly larger in magnitude for Black women compared to White women. Our results suggest that in the context of childbirth care, women pay a penalty for exhibiting behavior that may be perceived as non-compliant or uncooperative, and this penalty may be greater for Black women—a group that already expends greater effort to manage their image during healthcare encounters in order to counteract stereotypes and receive equitable care. While it is well-known that people of color experience less favorable patient-provider interactions compared to Whites and are at greater risk for being discriminated against in healthcare encounters, our findings further our understanding of this issue by describing who is most impacted negatively when declining a procedure during childbirth.

Acknowledgements

We would like to thank JMag Karbeah, MPH for her assistance in revising the manuscript. Dr. Hardeman’s role in this research was supported by the National Heart Lung and Blood Institute, National Institutes of Health under award numbers R01HL085631, R01HL085631-S2, R01HL085631-S3. Dr. Hardeman is also supported by the Robert Wood Johnson Foundation Interdisciplinary Research Leaders program.

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