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Self-Advocacy Among Black Women During the Perinatal Period: Prevalence and Relationship to Patient Experiences

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ABSTRACT

Introduction: Black women experience many barriers to receiving high-quality maternal healthcare. The ability of Black women to self-advocate may mitigate these threats to their health. Limited research describes Black women's self-advocacy during the perinatal period and how self-advocacy related to other relevant concepts. The aim of this study was to describe the relationship between self-advocacy, patient–provider relationships, and mental health outcomes among Black women in the perinatal period.

Methods: This cross-sectional descriptive pilot study recruited Black women who were either in their 3rd trimester of pregnancy or within a year postpartum to complete surveys describing their self-advocacy (Female Self-Advocacy in Cancer Survivorship Scale adapted for perinatal period) and maternal health outcomes (trust and comfort with maternal healthcare providers—Patient–Provider Relationship Scale; abuse and disrespect during childbirth—Mothers of Respect Index; experiences of discrimination—Experiences of Discrimination scale; depression—Edinburgh Postnatal Depression Scale; and postpartum posttraumatic stress—City Birth Trauma Scale).

Results: $N = 40$ participants were recruited between January and September 2022. Participants reported moderate levels of self-advocacy which were associated with trust and comfort with healthcare providers ($r = 0.57–0.76$, $p < 0.001$). Feeling respected by healthcare providers was positively associated with two self-advocacy subscales ($r = 0.42–0.44$, $p < 0.01$). Depression was inversely related to all self-advocacy subscales ($r = -0.47–0.62$, $p < 0.001$).

Conclusion: Black women's self-advocacy during the perinatal period is associated with trust and comfort with healthcare providers, perceptions of respect from their providers, and perinatal depression. Future research should focus on promoting trusting, respectful relationships between Black women and their maternal health providers.

1 | Introduction

The US has one of the highest rates of maternal mortality for high-income countries in the world, and the rate of Black maternal deaths is nearly three times that of white mothers (40.8 compared to 17 per 100,000 births) [1]. A 2016 study found that Black mothers with a college education were more likely to experience severe complications of childbirth than white women who had not graduated high school [2]. This demonstrates disparities in maternal mortality extend beyond socioeconomic status or education level and is explicitly tied to race.

Poor maternal health outcomes among Black women have been attributed to myriad factors including historical and pervasive structural racism in the field of obstetrics and gynecology [3], governmental policies [4], clinician training and behavior [5] including

implicit and explicit bias in care delivery [6], and patient characteristics such as slower decline in blood pressure and higher rates of hypertension postpartum for Black mothers [6]. Growing research points to the "weathering" of Black women's bodies after enduring the lifelong stress of societal racism that causes more adverse maternal health outcomes [7]. A relatively underexplored way to address structural and interpersonal racism driving poor maternal health in Black women is to understand and harness their abilities to stand up for their health needs and values.

Self-advocacy (or speaking up for oneself) is a key way in which patients exert autonomy over their health and healthcare. The Patient Self-Advocacy conceptual framework [8] describes the process by which cancer survivors encounter challenging situations, orient the challenge to their personal priorities, and engage in self-advocacy behaviors of informed decision-making, effective communication with their healthcare providers, and connected strength to ensure their needs are met. The framework also describes how patient self-advocacy—precipitated by patient-level precursors including social support, education, and background—leads to higher patient quality of life, improved physical and emotional symptoms, and more proactive use of healthcare services. By addressing challenges in ways that align with their priorities, individuals ensure that their values and needs are addressed promptly and efficiently. Importantly, the Patient Self-Advocacy conceptual framework does not specify the type of challenges that elicit self-advocacy, allowing for application to health-specific contexts (e.g., symptom management, treatment decisions), social contexts (e.g., difficulty interacting with healthcare providers or family caregivers), and structural barriers (e.g., discrimination, lack of access, etc.). Despite Black women advocating for their needs, their efforts are frequently dismissed or insufficiently addressed, exposing these women to poor health outcomes. They experience higher rates of depression and posttraumatic stress compared to white and Latina counterparts [9–11] thought to be driven by barriers to accessing care and receiving care sensitive to the interplay of health and sociocultural experienced by different minoritized groups. Black women's responses to these challenges—including their self-advocacy—is not well understood nor is the impact their self-advocacy has on their larger health or care received [12].

The relationship between self-advocacy and Black women's perinatal experiences requires further understanding to mitigate the health risks associated with not being able to speak up [12]. The overall purpose of this study is to describe the relationship between patient self-advocacy and conceptually linked concepts thought to drive why patients self-advocate and the results of such advocacy. Our research question was, "What is the relationship between patient self-advocacy and patient precursors to (trust and comfort with maternal healthcare providers, abuse and disrespect during childbirth, experiences of discrimination) and outcomes of (depression, trauma) self-advocacy?"

2 | Materials and Methods

2.1 | Design

This descriptive cross-sectional pilot study used quantitative research methods to capture the self-advocacy experiences of Black women who were pregnant or recently gave birth. Researchers followed the strengthening the reporting of observational studies in epidemiology (STROBE) guidelines. The study was approved by the institution's Human Research Protection Office (STUDY21090127) including protection of human subjects and plans for mitigating the risks of distress and confidentiality associated with study participation.

2.2 | Setting

Participants were recruited through collaboration with clinical and community partners that serve a large proportion of Black birthing women/people including an academic obstetrics clinic and several community organizations that support Black individuals. Between January and May 2022, we distributed recruitment flyers in clinics and posted recruitment messages through registries. Once individuals contacted the research team expressing interest in participation, study staff called them to verify participant eligibility and, if eligible, schedule data collection.

2.3 | Sample

A convenience sample of participants were recruited. Participants were eligible if they met the following criteria: age ≥ 21 and ≤ 45 years old, self-reported Black racial background, > 6 month pregnant to ≤ 12 month postpartum, and with English literacy. Of note, all participants self-identified as female using "she/her" pronouns and are therefore referred to as "women" throughout the manuscript. A sample size calculation was not performed as the study was intended to prepare for a future intervention study and to inform future power calculations for a self-advocacy pregnancy study.

2.4 | Data Collection

Once identified and screened eligible, the study team introduced the study to potential participants including the purpose, procedures, and risks and benefits along with ways to mitigate risks. After participants verbally agreed to participate, they completed an online consent form and questionnaires online via the Qualtrics data management system (Qualtrics, Provo, UT). Three participants (3/43; 7%) verbally consented to the study, but never completed the consent and questionnaires and with no future contact. After data completion, participants were mailed a prepaid $25 debit card.

2.5 | Measures

We selected validated, robust patient-reported measures that are commonly used among perinatal populations. We purposefully included measures that mapped onto the Patient Self-Advocacy conceptual framework and accounted for potential drivers of self-advocacy in Black women including predictors (perceptions of trust, comfort, and disrespect related to healthcare providers; discrimination) and outcomes of self-advocacy (depression, posttraumatic distress). The self-advocacy measure was the only instrument not previously used within this population and therefore underwent additional psychometric testing described below.

2.5.1 | Patient Self-Advocacy

As no validated measure of perinatal self-advocacy is known to exist, we adapted the Self-advocacy in cancer survivorship (SACS) scale [13] to the perinatal population by working with a panel of maternal health experts and Black birthing persons. This panel convened several meetings to review, critique, and adapt the original measure for use in Black perinatal populations including edits to the item wording and instructions. After the panel confirmed face validity of scale, we conducted formal reliability (Cronbach's α) and validity (factor analysis) testing which demonstrated accuracy and consistency among Black pregnant individuals. This 20-item Likert-type scale assesses individuals' perceptions of their ability to self-advocate, defined as asserting their values and priorities in the face of a challenge. The total scale ($\alpha = 0.902$ within the current sample) includes three subscales: (a) making informed decisions about their perinatal care ($\alpha = 0.798$), (b) effectively communicating with their maternal healthcare providers ($\alpha = 0.829$), and (c) connected strength, or balancing their ability to give and receive support ($\alpha = 0.869$). Item responses range from 1 = "strongly disagree" to 6 = "strongly agree." Higher scores (range: 6–120) indicate higher self-advocacy.

2.5.2 | Trust and Comfort With Maternal Healthcare Providers

The quality of the patient–provider relationship was assessed using the patient–provider relationship scale (PPRS) [14]. This 14-item Likert-type scale asks individuals to indicate the frequency of support, respect, and care they received from their providers from 1 = "never" to 4 = "always" (Cronbach's $\alpha = 0.91$). Higher scores (range: 14–56) reflect higher trust and comfort.

2.5.3 | Abuse and Disrespect During Childbirth

The mothers of respect index (MORi) captures if individuals perceive their maternity provider interactions to be respectful, their impact on patients' comfort, and patients' perceptions of discrimination and racism [15]. The 14 items were rated as "yes" "no," or "not applicable" (Cronbach's $\alpha = 0.94$). Items were coded so that higher scores (range: 0–14) indicated higher perceived respect from maternity providers.

2.5.4 | Experiences of Discrimination

The 19-item experiences of discrimination (EOD) scale asks individuals to self-report the frequency by which they have experienced major discrimination, discrimination in their day-to-day life, their perception of why the discrimination occurred (e.g., their race, gender, religion, etc.), and how they respond to those experiences (Cronbach's $\alpha \geq 0.74$) [16]. The nine major discrimination questions ask participants ("yes" or "no") if they have ever experienced considerable instances of discrimination such as being unfairly fired or not hired, unfairly stopped and searched, unfairly prevented from moving into a neighborhood, and unfairly denied a bank loan. The 10 day-to-day discrimination items ask participants how often (1 = never, 2 = once, 3 = 2–3 times, and 4 = ≥ 4 times) they experience more recurring discrimination such as being treated with less respect than others, receiving poorer service at stores than others, or others acting like the person is dishonest or not smart. Based on their responses to these questions, participants are asked the degree to which their gender, race, age, religion, body type, skin color, education, and disability impacted their experiences of discrimination.

2.5.5 | Perinatal Depression

The 10-item edinburgh postnatal depression scale (EPDS) [17] measured individuals' perinatal depressive symptoms over the prior week. Response options are on a 4-point Likert-type scale (Cronbach's $\alpha = 0.87$). Higher scores (range: 0–30) indicate more depression symptoms with a score ≥ 10 indicating possible depression.

2.5.6 | Postpartum Posttraumatic Stress

If participants indicated they had already given birth, they completed the city birth trauma scale (CBTS) which captures individuals' postpartum posttraumatic stress [18]. The 23-item scale is based on the Diagnostic and Statistical Manual—V criteria and asks the frequency of different thoughts or experiences (e.g., unwanted memories of the birth, feeling negative about the birth, irritability, etc.) from 0 = "not at all," 1 = "once," 2 = "2–4 times," and 3 = "5 or more times" (Cronbach's $\alpha = 0.92$). The scale is comprised of four subscales: intrusions, avoidance, negative mood and conditions, and hyperarousal. Higher scores (total range: 0–69) indicate higher postpartum posttraumatic stress.

2.6 | Analysis

2.6.1 | Quantitative Aim

Data were reviewed to ensure normal distributions, types and patterns of missingness, and any outliers. Since missingness was < 5%, no imputations were made. After assuring that all assumptions for statistical testing were not violated, we calculated measures of central tendency, frequencies and percentages, and other descriptive statistics for each scale. We then calculated Pearson correlations between the self-advocacy scale, proposed precursors to self-advocacy [trust and comfort (PPRS), abuse and disrespect (MORi), discrimination (EOD)], and outcomes of self-advocacy [perinatal depression (EPDS) and perinatal trauma (CBTS)]. Analyses were performed using IBM SPSS Statistics (Version 29) software.

3 | Results

A total of 40 women were enrolled and completed measures (see Table 1 for demographics and health history information), with a mean age of 31.1 (SD = 5.2) years. Most (52.5%) participants were in their 3rd trimester, although 17 (42.5%) were within 1 year postpartum. Almost half of participants (47.5%) were living only with a partner while 37.5% were living alone. Most (60.0%) participants

TABLE 1 | Participant characteristics ($N = 40$).

	N	%
Age (mean, standard deviation)	31.1	5.2
Race		
Black only	35	87.5
Black and white race	4	10.0
Black and aboriginal (self-identified)	1	2.5
Ethnicity		
Hispanic	1	2.5
Non-Hispanic	39	97.5
Living situation		
Living with partner	19	47.5
Single, living alone	15	37.5
Living with family and/or friends	5	12.5
Living with partner and family	1	2.5
Relationship status		
In a relationship, not married	17	42.5
Single, not in a relationship	16	40.0
Married	7	17.5
Gender identity		
Cisgender	40	100.0
Other (e.g., transgender, genderqueer, non-binary, etc.)	0	0
Sexual orientation		
Heterosexual	37	92.5
Bisexual	3	7.5
Highest educational degree		
High school of GED	9	22.5
Some college, associate degree, or diploma program	17	42.5
Bachelor's degree	5	12.5
Master's degree	7	17.5
Professional degree (PhD, JD, MD, etc.)	2	5.0
Household annual income		
< $20,000	12	30.0
$20–40,000	14	35.0
$40–60,000	5	12.5
$60–80,000	2	5.0
> $80,000	4	10.0
Prefer not to answer	3	7.5
Type of health insurance		
Medicaid	22	55.0
Private	11	27.5
Medicaid and private	3	7.5
Other	4	10.0
Perinatal phase		
3rd trimester	23	52.5
0–3 months postnatal	9	20.0
3–6 months postnatal	5	12.5
6–12 months postnatal	3	15.0

were in a relationship or married while 40.0% were single. Most had at least some college or an associate degree (65.0%) and had an annual household income less than $40,000 (65.0%). Participants either had Medicaid insurance alone (55.0%), Medicaid supplemented by private insurance (7.5%), private insurance (27.5%), or another type of health insurance (10.0%).

Participants reported moderately high levels of self-advocacy with a total mean SACS Score of 96.7 (SD = 14.4). Subscale scores (Table 2) were highest for informed decision-making followed by connected strength and then effective communication with maternal healthcare providers. They also reported high levels of trust and comfort with their maternal healthcare providers (M = 49.2, SD = 6.8) and feeling respected during their childbirth experience (M = 11.4, SD = 3.4). Participants' perinatal depression scores were high (M = 16.9, SD = 5) with 37 out of 40 participants reporting a clinically significant score ≥ 10. Postpartum trauma was low (M = 10.5, SD = 6.5).

Participants reported high levels of discrimination (Table 3). The most commonly reported types of major discrimination included unfairly not being hired for a job ($n = 22$; 55%), being unfairly discouraged by a teacher or advisor to continue their education ($n = 16$; 40%), and being unfairly denied a promotion ($n = 15$; 38%). The most frequent day-to-day discriminations reported were having people act as they were better than you ($n = 15$; 38%), people acting as if they think you are not smart ($n = 14$; 35%), and receiving poorer service than other people at restaurants or stores ($n = 11$; 28%). Most women attributed these experiences to their race ($n = 35$; 88%), gender ($n = 29$; 73%), skin color ($n = 25$; 63%), and age ($n = 23$; 58%).

3.1 | Precursors

Total self-advocacy and all subscale scores were strongly positively correlated with participants' trust and comfort with their maternal healthcare providers ($r = 0.57–0.76$, $p < 0.001$) (Table 2). To a lesser extent but still significantly, participants' perceived respect received during childbirth was positively associated with two self-advocacy subscales (informed decision-making and connected strength) as well as the total self-advocacy scale score ($r = 0.42–0.44$, $p < 0.01$). Experiences

TABLE 2 | Descriptive and correlational data between patient-reported outcome measures.

	M	SD	1	2	3	4	5	6	7	8	9
Self-advocacy											
1. Informed decision-making (7–42)	33.50	5.52	1.0								
2. Effective communication (6–36)	29.98	4.96	0.771***	1.0							
3. Connected strength (7–42)	33.18	6.31	0.584***	0.469**	1.0						
4. Total self-advocacy (20–120)	96.65	14.40	0.905***	0.846***	0.824***	1.0					
Predictors											
5. Trust and comfort with maternal healthcare providers (14–56)	49.18	6.81	0.723***	0.672***	0.571***	0.759***	1.0				
6. Abuse and disrespect during childbirth (0–14)	11.38	3.42	0.440**	0.260	0.424**	0.444**	0.430**	1.0			
7. Discrimination: total major (0–9)	2.85	2.29	−0.253	−0.208	−0.096	−0.211	−0.376*	−0.091	1.0		
8. Discrimination: total day to day (10–40)	25.50	8.37	0.109	0.103	−0.088	0.039	0.132	−0.025	−0.569***	1.0	
Outcomes											
9. Perinatal depression (0–30)	16.85	5.00	−0.584***	−0.546***	−0.472**	−0.619***	−0.511***	−0.166	0.311*	−0.166	1.0
10. Postpartum posttraumatic stress (0–69)[a]	10.48	8.47	−0.330	−0.290	−0.308	−0.340	−0.469*	−0.107	0.162	0.180	0.592*

Note: M and SD are used to represent mean and standard deviation, respectively. Trends in significance are noted though the sample size in insufficient to determine statistical significance *indicates $p < 0.05$. **indicates $p < 0.01$. ***indicates $p < 0.001$.

[a]Only participants who had given birth ($n = 17$) completed the postpartum posttraumatic stress scale. The numbers in the parenthesis indicate the range of possible values for each measure.

TABLE 3 | Participants' prior experiences of discrimination and their responses ($N=40$).

	N	%
Major discrimination[a]		
Not hired for job for unfair reasons	22	55.0
Unfairly discouraged by a teacher/advisor from continuing education	16	40.0
Unfairly denied a promotion	15	37.5
Unfairly stopped, searched, questioned, physically threatened, or abused by the police	13	32.5
Unfairly prevented from moving into a neighborhood because landlord or realtor refused to sell or rent a house or apartment	13	32.5
Unfairly fired	12	30.0
Moved into neighborhood where neighbors made life difficult for family	8	20.0
Received service from someone that is worth than what other people get (e.g., plumber, mechanic)	8	20.0
Unfairly denied a bank loan	7	17.5
Day-to-day discriminations[b]		
People acted as if they are better than you	15	37.5
People acted as if they think you are not smart	14	35.0
Received poorer service than other people at restaurants or stores	11	27.5
Been called names or insulted	9	22.5
Followed around in stores	9	22.5
Treated with less respect than other people	9	22.5
Been threatened or harassed	8	20.0
Treated with less courtesy than other people	6	15.0
People acted as if they think you are dishonest	5	12.5
People acted as if they are afraid of you	4	10.0
Attribution of discrimination		
Race	35	87.5
Gender	29	72.5
Skin color	25	62.5
Age	23	57.5
Education or income	20	50.0
Body type	17	42.5
Ancestry of nationality	9	22.5
Sexual orientation	5	12.5
Religion	4	10.0
Physical ability	3	7.5

[a]Major discriminations were asked as "yes" or "no" responses.
[b]Day-to-day discriminations counts are those which the participant self-reported happening "four or more times," which was the maximum option.

of discrimination were not significantly associated with total self-advocacy.

3.2 | Outcomes

Perinatal depression was significantly negatively associated with self-advocacy total and all three self-advocacy subscale scores ($r=-0.47$–0.62, $p<0.001$). Postpartum posttraumatic stress was not significantly associated with self-advocacy.

4 | Discussion

As the first study assessing self-advocacy among Black women in the perinatal period, this study provides key insights into how patient self-advocacy corresponds with patients' relationships with their healthcare providers, experiences of discrimination, and depression. Patient-reported outcome measures demonstrated that women had moderate levels of self-advocacy and that this correlated with higher trust and comfort with medical providers. Black women who felt their healthcare providers understand them and support their health were more likely to report being able to make informed healthcare decisions, communicate openly with their maternal healthcare providers, and seek support when needed.

Findings reflect recent calls for more patient-centered approaches to address the maternal health inequities found across the US [19, 20]. Models of care are needed that elevate patient experiences, incorporate communities' experiences with maternal healthcare, and identify strategies that support the unique perspectives and shared collective experiences of Black women [21, 22]. The National Institute of Health recently called for multi-level, comprehensive approaches to transform maternal health and address structural racism [23]. By understanding the self-advocacy strengths of Black women, particularly informed decision-making and effective communication with healthcare providers, researchers and providers can build on women's strengths to confront threats to Black maternal health. Qualitative and longitudinal data collection could explore where Black women learn to self-advocate and how threats to their health, discrimination, and poor patient–provider relationships affect their self-advocacy behaviors. This could help explain if women's moderately high levels of self-advocacy were out of necessity (e.g., having experienced several challenges within their care) or contentment (e.g., having few barriers and thus not requiring strong advocacy).

Based on these findings, a key area for future research includes supporting the relationship between Black women and their maternal healthcare providers. This reflects findings from Okpa et al. [24] that demonstrated women were more likely to self-advocate when they became familiar with the members of their healthcare team and could openly engage in discussions. Similarly, Flynn et al. found that Black pregnant women were more likely to be considered "lost to follow-up" and that maintaining relationships with healthcare teams required significant self-advocacy from the woman [25]. Recent studies have demonstrated that members of the perinatal healthcare team recognize how racism impacts the delivery of care, and desire training to combat these inequities [26]. This can provide the foundation for providing respectful, informed care that promotes women's self-advocacy. For example, [27] community-based programs developed by and for people of color should be advertised as resources to support Black women. For example, the Birthing Hut, LLC provides doula services and trained Black Birth Advocates to combat maternal health inequities. Healthy Start (a nationally funded program) and Pittsburgh Black Breastfeeding Circle are examples of Black-led organizations that provide maternal health services and policy agendas to ensure Black women receive support within and outside of their maternal healthcare providers. Elevating these organizations is critical to ensuring that Black women have the resources they need in their community to reduce their risk of maternal and infant adverse outcomes and promote systems changes.

Participants reported frequent incidents of discrimination along with depression. These experiences reflect high levels of systematic racism within the area in which the sample was recruited [28]. While discrimination and depression were not associated with self-advocacy, major discrimination was associated with women's trust with their maternal health providers. A potential explanation for the lack of association is that the discrimination scale did not specifically ask participants about discrimination within healthcare settings, which could more acutely capture how discrimination either prompts or hinders patient self-advocacy. National trends demonstrate a disproportionately low number of Black physicians providing maternity care [29] which could also impact the discrimination experienced by this sample. Poor mental health is known to be associated with instances of discrimination, both resulting in barriers to accessing healthcare and receiving quality care [30, 31].

This study has limitations which impact the interpretation of results. Surveys did not ask participants to differentiate between types of healthcare providers, limiting the interpretation to a broader level and not classified by roles of midwives, physicians, nurses, etc. Our sample had considerable levels of formal education and higher ages, which based on the research in cancer populations is known to affect their self-advocacy and comfort with providers. Moreover, as a pilot exploratory study, this study did not have the required sample size necessary to achieve statistical power nor the geographical heterogeneity necessary for external validity, so results must be taken with caution. As the first study using a theoretically based self-advocacy framework in perinatal populations, these data can inform future studies seeking to make clinically meaningful differences in Black individuals' perinatal health.

5 | Conclusion

This was the first study to directly describe how Black women self-advocate in the healthcare setting and how this correlates with predictors (trust and respect with healthcare providers) and outcomes (depression). Black women have several self-advocacy strengths on which they can rely when faced with the inequities and barriers to healthcare. Despite these strengths, Black women continue to experience racism and worse maternal health outcomes, and self-advocacy cannot overcome such failures from providers and systems. Future research should explore additional drivers of self-advocacy to focus interventions on contexts in which patient self-advocacy can mitigate risks and provide upstream support including a broader array of healthcare outcomes so that future interventions can directly support women in ensuring they are equipped to manage the challenges of being Black and pregnant in the US.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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