Factors Associated With Use of a High-Volume Cancer Center by Black Women With Ovarian Cancer

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QUESTION ASKED: For a black woman diagnosed with ovarian cancer, what are the patient-, provider-, and systems-related factors affecting her ability to access and use care at a high-volume cancer center?

SUMMARY ANSWER: Black women treated at our high-volume cancer center had overlapping internal attributes and similar journeys that led them to seek and obtain treatment there. They also had shared perceptions about the barriers they and other black women faced, and how those could be overcome.

WHAT WE DID: We conducted semistructured qualitative interviews with black women diagnosed with ovarian cancer; recurring themes were identified in transcribed interviews through the process of independent and collaborative thematic content analysis.

WHAT WE FOUND: Study participants were comfortable navigating the health care system, understood the importance of self-advocacy, and valued the expertise of a specialty center. Barriers to obtaining care at a high-volume center included lack of knowledge about the center, lack of referral, transportation difficulties, and lack of insurance coverage. Race itself was not identified as a barrier.

BIAS, CONFOUNDING FACTORS: We used a small convenience sample that may have been representative of our patients; however, it may not have been representative of all black women everywhere. Our results may lack generalizability but do give a solid foundation on which we can build additional studies. In addition, there may be elements of recall and selection bias on the basis of which patients chose to participate. It is possible that the process of obtaining care seemed easier in hindsight after patients had already successfully accessed the care.

REAL-LIFE IMPLICATIONS: Despite these limitations, the current study filled a critical gap by interviewing black women about their experiences accessing and using care for ovarian cancer. Our findings provide a template and conceptual framework for research at both high- and low-volume centers. We identified a need for collaboration with black communities and outreach to black patients and their social networks and diagnosing providers. Our findings suggest that if patients knew that treatment at a high-volume center was associated with improved survival outcomes and that access to this type of care was available to them, they would use it. Potential barriers to access can be overcome by internal character traits or external support from social networks. Regardless of affiliation, it is important for diagnosing physicians to refer patients with suspected advanced ovarian cancer to high-volume centers regardless of their race or socioeconomic status.

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CARE DELIVERY

original contribution

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abstract

OBJECTIVE Disparities exist between population subgroups in the use of gynecologic oncologists and high-volume hospitals. The objectives of this study were to explore the experiences of black women obtaining ovarian cancer (OC) care at a high-volume center (HVC) and to identify patient-, provider-, and systems-related factors affecting their access to and use of this level of care.

MATERIALS AND METHODS Twenty-one semistructured interviews were conducted as part of an institutional review board–approved protocol with women who self-identified as black or African American, treated for OC at a single HVC from January 2013 to May 2017. Recurring themes were identified in transcribed interviews through the process of independent and collaborative thematic content analysis.

RESULTS Five themes were identified: (1) internal attributes contributing to black women's ability/desire to be treated at an HVC, (2) pathways to high- and low-volume centers, (3) obstacles to obtaining care, (4) potential barriers for black women interested in treatment at an HVC, and (5) suggestions for improving HVC use by black women. Study participants who successfully accessed care were comfortable navigating the health care system, understood the importance of self-advocacy, and valued the expertise of an HVC. Barriers to obtaining care at an HVC included lack of knowledge about the HVC, lack of referral, transportation difficulties, and lack of insurance coverage.

CONCLUSION In this qualitative study, black women treated at an HVC shared attributes and experiences that helped them access care. There is a need to collaborate with black communities and establish interventions to reduce barriers, facilitate access, and disseminate information about the value of receiving care for OC at an HVC.

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INTRODUCTION

Despite growing evidence that ovarian cancer outcomes are improved at tertiary care centers, disparities among population subgroups in using and accessing high-volume providers and high-volume centers (HVCs) persist.[1-3] This holds true regardless of insurance status, comorbidities, cancer stage, or tumor grade. Women treated for ovarian cancer at HVCs are more likely to be white and have higher household incomes and private health insurance.[4] Black women with ovarian cancer are less likely to use HVCs; consequently, they are less likely to receive optimal surgery, adjuvant chemotherapy, and care adherent to National Comprehensive Cancer Network guidelines.[5-8] As a population, black women have lower overall survival rates.[9] However, studies also show that with equal use of expert care, the differences in treatment and survival dissipate.[10-12]

There is a dearth of published literature on the experiences of black patients with ovarian cancer accessing HVCs. Previous research has prioritized identification of disparities using national, statewide, and hospital-based databases, demonstrating that black women have poorer outcomes and less access.[6,7,10,13-22] Hypotheses regarding why such disparities exist have been extrapolated from these retrospective population-based studies.

Currently, there is no validated tool to assess the experiences of patients with cancer attempting to use the health care system. Qualitative research methodology serves to explore beliefs and attitudes, is a useful research approach in understudied areas, and is ideal

ASSOCIATED CONTENT
Data Supplement
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for gathering new information on recurring phenomena. There are more than 50 qualitative studies in ovarian cancer research, but to our knowledge, no prior study comprehensively has investigated the experiences of black women accessing care. Because racial disparities in access exist regardless of insurance status, the patient population at our HVC offers a unique opportunity to explore the experiences of black patients. With respect to racial disparities, patients' experiences in obtaining this level of care and perceived barriers to accessing care are of specific interest. The objectives of this study were to investigate the experiences of black women obtaining ovarian cancer care at a single HVC and to identify patient-, provider-, and systems-related factors affecting their ability to access and use this care.

MATERIALS AND METHODS

We conducted semistructured interviews with patients treated at a National Cancer Institute–designated comprehensive cancer center (Memorial Sloan Kettering Cancer Center). After approval of this study by the Memorial Sloan Kettering Cancer Center Institutional Review Board, research personnel used a prospectively managed database to identify all living women diagnosed with ovarian, fallopian tube, or peritoneal cancer older than 18 years of age, who self-identified as black or African American treated at our institution (starting in 2017, working back in time to 2013). We used the electronic medical record to confirm the demographic and treatment information of eligible women. We excluded women who were cognitively impaired or did not speak English.

A recruitment letter was sent to eligible participants, who were subsequently contacted by phone (in reverse chronologic order). Some were also approached during clinic visits. We purposely oversampled patients with advanced disease. Figure 1 depicts the patient flowchart. Patients who agreed to participate provided verbal consent by telephone or in person before their interview; consent included permission to audio-record the interviews.

After a review of the literature, a semistructured interview guide was developed with a qualitative methods specialist (E.S.) from the Behavioral Research Methods Core Facility and reviewed by coauthors for content, clarity, and relevance. The interview included open-ended questions in five domains, detailed in the Data Supplement.

Individual interviews were conducted by phone or in person. Interviews were recorded and transcribed. One author who has formal training in qualitative research methodology (R.A.C.) conducted all the interviews. Participants were able to interpret questions independently and respond freely. The interviewer used the conversation as an opportunity to explore previously unidentified areas of inquiry if she determined they were relevant to the research objectives. This interview format is the one most commonly used by qualitative researchers.[23]

Transcripts were coded by three trained authors (R.A.C., E.S., M.B.) using grounded theory.[24] The authors reviewed and coded transcripts through independent and collaborative thematic content analysis[24-27] using ATLAS.ti (ATLAS.ti Scientific Software Development, Berlin, Germany), a qualitative data analysis software package.[28] During the first stage of content analysis, each coder independently read five transcripts (20% of total proposed sample), identifying key narrative content, creating codes, assigning relevant codes to content, and developing a codebook. The team met weekly to discuss differences in interpretation and reach consensus. After completion of coding, the team engaged in a secondary analysis in which they synthesized coded narrative content and described recurring themes. As is ideal for most qualitative studies, thematic analysis was performed in parallel with patient accrual. This allowed the investigators to develop a better understanding of the research question as study enrollment continued. By coding interviews as they were completed, data saturation was determined.[23,29]

Recent qualitative studies conducted in a comparable population have reported on data derived from seven to 28 participants.[30-34] The Behavioral Research Methods Core Facility has expertise in this area and estimated that a reasonable goal was 25 participants (although data saturation among a relatively homogenous group often occurs within the first 12 interviews).[35] In this study, data saturation was achieved after 21 patients were interviewed and enrolled.

RESULTS

Participant Cohort

Twenty-one women were interviewed. Median age at diagnosis was 59 years (range, 35 to 79 years). Median time from date of diagnosis to date of interview was 17 months (range, 6 to 322 months). Twenty participants were initially diagnosed with advanced-stage disease; 11 had evidence of disease and were undergoing treatment at the time of their interviews. Most received all their care at this HVC; two patients had surgeries at outside hospitals (OSHs), three initiated chemotherapy at OSHs, and three had been treated at an OSH at the time of initial diagnosis but transferred to our institution when diagnosed with a recurrence.

The neighborhood median income for the cohort was $70,873 (range, $30,779 to $109,258). According to 2014 Census data, seven of 21 participants (33%) lived in zip codes with a median income below the national average. Sixteen (76%) had employer-sponsored insurance, and four (19%) had government safety-net insurance. Table 1 lists demographic information.

Thematic Findings

In the following sections and the Data Supplement, we summarize five main themes and representative quotes from the analysis.

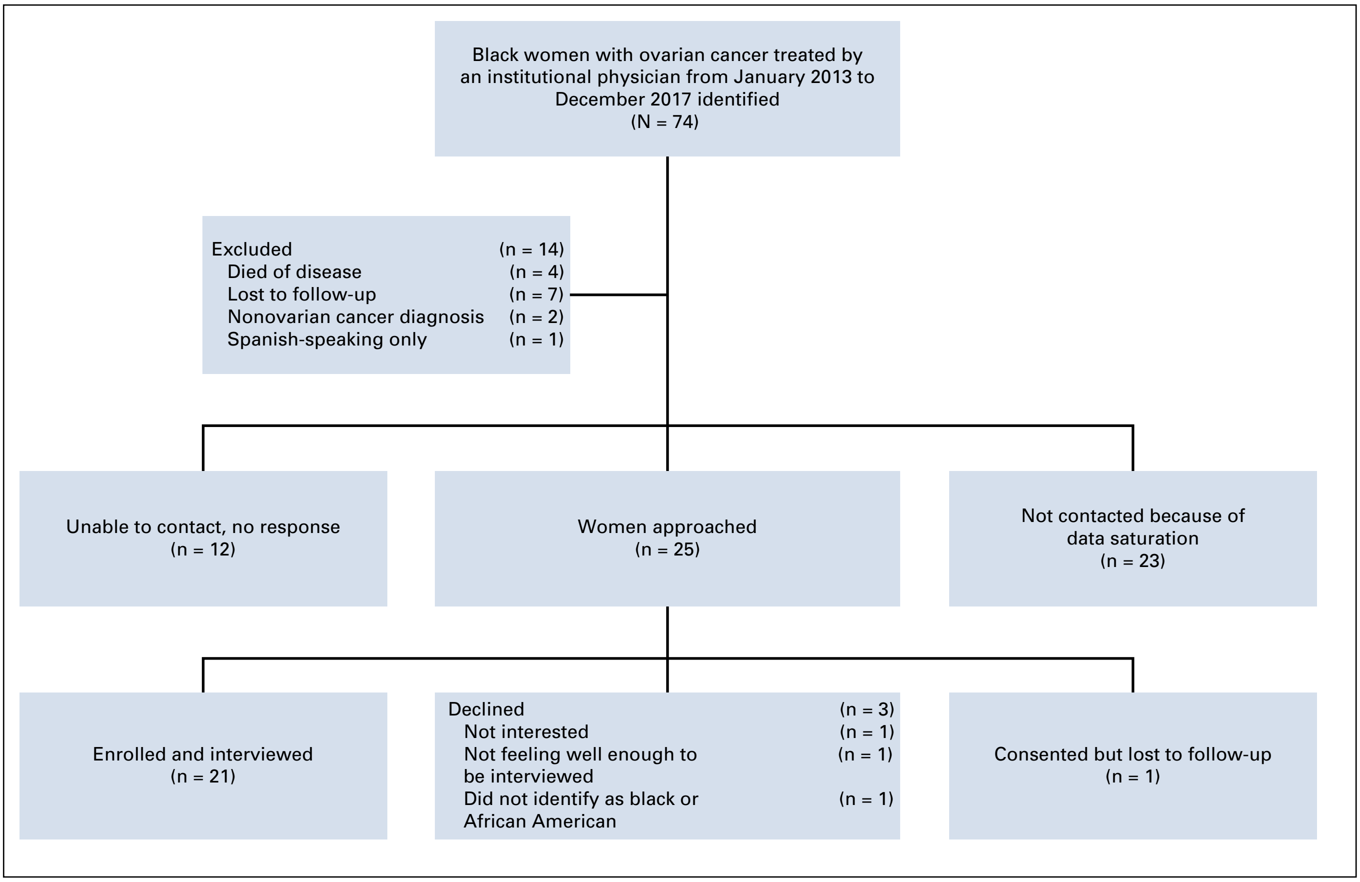

FIG 1. Patient flowchart showing how patients were accrued to the study. An institutional database was used to identify eligible participants. We sent a recruitment letter to the women who had been diagnosed with advanced disease and subsequently contacted them by phone in reverse chronologic order to seek their participation. To expedite accrual, some participants were also approached during medical oncology clinic visits.

Theme 1: Common characteristics. Many interviewees described character traits that made them more likely to seek care at an HVC. The most commonly described traits were health literacy, persistence, self-advocacy, and perceived value in expert/specialty care.

Participants characterized as health literate had a baseline understanding of the health care and/or insurance system and how to navigate it:

> So I sat down at my computer, and I had not accessed my records through my primary doctor because I hadn't been going there that long.…And on the very first page, the very first test result was the CA 125 high.…So when I saw that, I immediately called my oncologist and asked for an appointment.…I also downloaded all the test results that the primary care doctor had done.

Several women discussed having to advocate for themselves. They described scenarios in which they had to be patient and persistent to get an appointment.

> I kept calling them. Can I get this appointment? Well, Ms T, you have to get the paperwork and so I made sure to keep following through and following up until I got my appointment. And made sure I faxed and did the necessary steps that were asked.

Many participants perceived additional value in undergoing treatment at a cancer specialty hospital. They expressed hope that they would have a better outcome by going to an HVC. One woman compared specialty hospitals with specialty restaurants:

> When you want an authentic experience—let's say you like Korean food, right? You're going to go to House of Seoul for Korean food. You're not going to go to Beni's Trattoria Italiano for Korean food. They may have one night that they serve great Korean, but then they go back to selling pizza every day. My philosophy is I want to go to a place that has experts in cancer, that that's all they do, that's all they know, that's what they're trained to do.

Theme 2: Journey to our institution. Participants were asked to share stories of how they came to our institution for treatment. They were most often diagnosed by a general gynecologist (38%), primary care physician (19%), or

TABLE 1. Patient Characteristics

Characteristic (n = 21)	Value
Median age at diagnosis, years (range)	59 (35-79)
Median age at interview, years (range)	60 (42-80)
Median months since initial diagnosis (range)	17 (6.8-322.5)
Median neighborhood income, $ (range)	70,873 (30,779-109,258)
Ethnicity	
Black, non-Hispanic	19
Black, Hispanic	2
Marital status	
Single/never married	8
Married	8
Divorced/separated/widowed	5
Education	
High school	2
College degree	3
Graduate degree	4
Unknown	12
Profession or former profession	
Business/sales	5
Education	6
Administrative	4
Domestic	1
Other	5
Health insurance	
Employer	16
Medicare	2
Medicaid	2
Unknown	1
Stage at diagnosis	
I	0
II	1
III	11
IV	9
Recurrent disease	
Yes	11
No	10
Currently receiving treatment	
Yes	11
No	10
Vital status	
Alive with disease	11
No evidence of disease	10
BRCA status	
BRCA 1/2 mutation positive	2
BRCA 1/2 mutation negative	12
Unknown/untested	7

NOTE. All data are No. unless otherwise indicated.

gynecologic oncologist (14%; Table 2). Diagnosing physicians either referred these women directly to our institution (24%), to another HVC they were affiliated with (19%), to another HVC they were not affiliated with (5%), to a low-volume center (LVC) they were affiliated with (14%), or to an LVC they were not affiliated with (19%). Several patients reported that they had never received a referral from their diagnosing physician (19%). Four general paths to our institution emerged: (1) patients were referred by the physician who diagnosed them or by another external physician (33%); (2) they were referred by a member of their social network, such as a friend, family member, or coworker (29%); (3) they did their own research, usually on the Internet, and determined that our institution was the best place for treatment (19%); and (4) someone, usually a child or sibling, served as a medical surrogate and dictated where their treatment should take place (19%). Participants who lacked the traits and values that emerged in theme 1 often had another person involved in their medical decision making who directed their care.

Theme 3: Obstacles. Many of the interviewees faced potential barriers to initiating care at this HVC, such as unfamiliarity with the facility, lack of referral, limited access (ie, transportation difficulties, financial obstacles, insurance issues, and so on); however, these obstacles were overcome by internal character traits or external support from social networks. Patients referred to LVCs spoke about having to advocate for referral to an HVC or having a member of their social network suggest seeking another opinion. Several women, who may have lacked health literacy, described not knowing that cancer centers existed or feeling that they did not belong to the appropriate sociodemographic for a specialty center:

> I had an idea of [this hospital] but my idea was probably just a private hospital and I couldn't afford it. So I wasn't going to explore it but [my son] went online and then I called and when I called they asked me the type of insurance I had and then I gave it to them and they accepted it.

We hypothesized that some participants may have seen race as a potential barrier to accessing HVC care. However, when asked, 20 of the participants (95%) responded "No," and one said she was uncertain whether race had played a role.

Theme 4: Why don't more black women come to our institution? Participants were asked to share their views on why more black women do not use our institution for ovarian cancer treatment. Reflecting on their own experiences, many concluded that there was a lack of knowledge in the black community about the potential for care at an HVC. They also described the importance of the trusting relationship that exists between patients and diagnosing physicians, and hypothesized that if diagnosing physicians do not refer black patients to our institution, few of their

TABLE 2. HVC Referral Attributes

Referral Attribute (n = 21)	No. (%)
DP	
General gynecologist	8 (38)
Primary care provider	4 (19)
Gynecologic oncologist	3 (14)
Emergency department physician	2 (10)
Gastroenterologist	2 (10)
General surgeon	1 (5)
Other/uncertain	1 (5)
DP referral	
LVC affiliated with DP	3 (14)
LVC not affiliated with DP	4 (19)
HVC affiliated with DP	4 (19)
HVC not affiliated with DP	1 (5)
This HVC	5 (24)
No referral from DP	4 (19)
Treatment location	
All treatment at this HVC	13(62)
Outside surgery, chemotherapy at this HVC	2 (10)
NACT initiated at outside hospital	3 (14)
OSH primary treatment, treatment for recurrence at this HVC	3 (14)
Track to this HVC	
MD referral	7 (33)
Social network referral	6 (29)
Independent research	4 (19)
Surrogate-guided	4 (19)

Abbreviations: DP, diagnosing physician; LVC, low-volume center; HVC, high-volume center; MD, medical doctor; NACT, neoadjuvant chemotherapy; OSH, outside hospital.

patients will seek care here for themselves. Numerous participants brought up the fact that this HVC does not accept certain forms of insurance and the difficulties posed by traveling to our institution for treatment as possible obstacles to initiating care here. There was significant overlap in these subthemes, described in the following quotation and in the Data Supplement:

> I think the difference is simply in the sense of information and access. And believing that you deserve the best. It's those three things—information, then access, which comes from the information. And that the end for you to believe that, you know, you deserve the best care that you can get.…So I feel that they don't come here because of the lack of information.…And also…many of them don't believe that they can, you see since they are poor…they are a minority, you know, because of their prior experiences in the society.

Theme 5: How can we encourage more black women to use our services? Several interviewees had suggestions for improving black women's use of our institution. Lack of knowledge about this HVC was frequently cited as a potential barrier. They suggested addressing this through outreach to patients, their social networks, and diagnosing providers. In addition, participants felt there was a lack of diverse patient-directed marketing. Some had seen commercials highlighting the research conducted at our institution but would have preferred ad campaigns focusing on high-quality patient care:

> Patient 74: Going into the community is the way you get the work done.…Go to the churches on Sundays in various places, start with Harlem. Go to Spanish Harlem, you know, go to the Bronx. Go to Brooklyn, Queens, you know, and even Staten Island you see because one place to find these people is in the church.
> Daughter: Since you started your care here, I noticed that there has been a series of ad campaigns. But those ad campaigns have always been focused on, like...
> Patient 74: Science.
> Daughter: And finding a cure. Right. And maybe the same way that you can focus on having an ad campaign advertising that [this HVC] is doing the research to find a cure, there should also be, like, an ad campaign saying, you can come here.

DISCUSSION

As novel treatments improve survival outcomes, the elimination of health care disparities remains a priority.[36,37] To comprehend the complexities of disparities in provider preference and use, we must understand patients' experiences. This study fills a gap in our understanding of the factors associated with use of an HVC by black women with ovarian cancer. Our results indicate that black women treated at this HVC have overlapping attributes that led them to seek and obtain treatment here. They also have shared perceptions about the potential barriers faced by other black women and how those can be overcome.

A 2014 qualitative study on the perceptions of investigators, research staff, and referring clinicians regarding barriers to and facilitators of minority recruitment for clinical trials at five National Cancer Institute–designated cancer centers reported similar observations. Although the authors did not assess the opinions of minority patients directly, they found that many stakeholders thought developing a rapport with minority communities and external physicians would be a primary facilitator for increasing minority participation in clinical cancer trials.[38] Although our focus was not clinical trial enrollment, those sentiments were echoed by our participants with respect to increasing black patients' use of HVCs. Thirty-three percent of our participants were referred by their diagnosing physicians to hospitals that did not have expertise in ovarian cancer treatment. More than half of the diagnosing physicians who referred patients to LVCs were not affiliated with said LVCs. Of note, these patients either had Medicare insurance or were employed in blue-collar jobs. This highlights the potential age-related and financial obstacles to seeking expert treatment. Developing a rapport with diagnosing physicians and educating all providers on the benefits of ovarian cancer care at HVCs could shunt a large group of eligible black women into HVC systems.

A 2003 survey of a sample of US residents examined how patients choose physicians.[39] The authors found that race and ethnicity were strong determinants, even after controlling for health and insurance status; black patients were less likely than their white counterparts to seek information from social networks and more likely to use formal sources, such as referring physicians. Although a large portion of our cohort did rely on their social networks for recommendations, more were referred by a diagnosing physician. Lack of physician referral emerged as a potential barrier (but a modifiable barrier) for other black women seeking care.

Another key component in accessing an HVC is the phone call. In our cohort, the phone call to initiate care was most often made by participants themselves; however, surrogates and diagnosing physicians may also call and make appointments. Admittedly, all HVCs cannot accommodate all patients. Currently, this is a systems-related barrier, not modifiable at the provider or patient level. Preferably, patients who cannot be seen at one HVC because of insurance issues can be referred to HVCs that accept their insurance. When no other options exist, a patient may be referred to an LVC. However, this should seldom occur in the patient population we serve because this state is home to more than 100 gynecologic oncologists and only two low-access counties in which only 1% of the state's female population lives.[40]

As with most qualitative studies, ours was a small convenience sample. It may be representative of black women at an urban cancer center but not of all black women in other settings. Although our results lack generalizability, they do provide a basis for future studies and interventions. The combination of phone and in-person interviews was particularly helpful, allowing us to sample a diverse group of women at various stages of their journey through treatment. Because we depended on patient reporting, there may have been elements of recall and selection bias. The process of accessing care may have seemed easier to some patients in hindsight.

Despite these limitations, this study fills a critical gap by interviewing black women about their experiences accessing and using care for ovarian cancer. Our findings provide a template and conceptual framework for research at both HVCs and LVCs. Future research should explore the experiences of black women who do not use expert care.

This study identifies a need for collaboration with black communities and educational interventions for the general population. Our findings suggest that if black patients know that treatment at an HVC is associated with improved survival outcomes and that access to this type of care is available to them, they will use it. As a community of providers and researchers, it is our responsibility to provide patients with as much information as possible so that they can make optimal health care decisions. Clinical practice should offer relevant information so that treatment decisions are aligned with the individual patient's needs. Regardless of affiliation, it is important that diagnosing physicians refer patients with suspected advanced ovarian cancer to HVCs.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

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Manuscript writing: All authors

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Accountable for all aspects of the work: All authors

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Factors Associated With Use of a High-Volume Cancer Center by Black Women With Ovarian Cancer

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