

“STRONG BLACK WOMEN”:

African American Women with Disabilities, Intersecting Identities, and Inequality

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In a mixed-methods study of the barriers and facilitators to homeownership for African American women with physical disabilities, self-concept emerged among the primary themes. This article discusses how participants in the study perceived themselves and negotiated how they were perceived by others as multiply marginalized women. Using what I call a feminist intersectional disability framework, I suggest that participants' relationships to care strongly contributed to their self-concept. The “Strong Black Woman” trope and associated expectations had cultural and material relevance for how they interpreted themselves and were interpreted by others as receivers, managers, and providers of care. The material reality of owning or not owning a home did not reveal significant differences in the self-concepts of homeowners versus nonhomeowners. Rather, it was through conversations about homeownership that this data around self-concept in relationship to care was revealed.

Keywords: *self-concept; feminism; disability; race; gender; intersectionality*

Compared to their white counterparts, African Americans have higher rates of poverty, lower rates of educational attainment, and are more likely to be employed in jobs that put their health and bodies at greatest risk (Schulz and Mullings 2006; Seabury, Terp, and Boden 2017; Smart and

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Smart 1997). All of these factors limit their social and economic opportunities and make it harder to prevent the onset of a disability and/or manage or rehabilitate a disability, if acquired. It is therefore not surprising that African Americans have significantly higher rates of disability and of severe disabilities than the white majority population (Beatty 2003; Drum et al. 2011; Smart and Smart 1997). Although African Americans have one of the highest rates of disability, 29 percent of African Americans versus 20 percent of white Americans, there is a dearth of recent statistical data describing their social and economic characteristics (Courtney-Long et al. 2015). The research that does exist suggests significant race and gender disparities among the disabled population, for example, that African American women with disabilities particularly face multiple barriers to resources and equitable treatment in society (Alston and McCowan 1994; Balcazar et al. 2010; Beatty 2003; Oberoi et al. 2015). Despite this, very little has been written about the multiple inequalities that African American women with disabilities or other disabled women of color experience.

The limited studies that discuss the implications of having to confront multiple and compounding systems of racism, ableism, and sexism in the United States context were written primarily by and for service providers who aim to document the racial and gender disproportionality in the quantity and quality of services that women and minorities with disabilities receive (e.g., Alston and McCowan 1994; Balcazar et al. 2012; Wilson 2004). This literature suggests that race, class, and gender biases contribute significantly to how the needs, capabilities, and desires of clients with disabilities are assessed and interpreted by disability service providers who are also more likely to be white, able-bodied, and male (Balcazar et al. 2010). These studies show persistent gender and racialized disparities in the delivery, quality, and outcomes of disability-related services, resulting in African American women with disabilities benefiting significantly less from disability policy than white disabled males (Balcazar et al. 2010; Oberoi et al. 2015). Still, studies conducted from a service provider perspective are more likely to focus on impairment prevention, cure, and expert advice rather than societal change or the lived experiences of African American women with disabilities (Linton 1998). Little is known about how African American women with disabilities experience these barriers, or how their multiple minority identities impact how they are perceived by themselves and others.

This article addresses these gaps in the literature by presenting findings from a study of the barriers and facilitators to homeownership for African American women with physical disabilities. The data provides insight on how African American women with physical disabilities perceived themselves and negotiated how they were perceived by others. Through examining social and

economic opportunities via homeownership, distinct themes related to self-concept emerged. For the purposes of this study, I draw on Rosalyn Benjamin Darling's (2013) use of the term *self-concept*. For Benjamin Darling, self-concept refers to how people come to define their personal and social characteristics, such as race and disability, and their self-esteem. Self-esteem is defined as judgments about the self that are based on personal and social characteristics and are influenced by interactions between the self and society (Benjamin Darling 2013). The analysis reveals that the social implications of being an African American woman with a disability are in many ways different from white men and women with or without disabilities and African American men and women without disabilities. Attention to the multiple forms of oppression that impact African American women with disabilities in varying contexts is needed to understand not only their barriers and facilitators to homeownership but their full access to society. Hence, this article examines the self-concept of African American women with physical disabilities through the lens of the "Strong Black Woman" schema.

CONTROLLING IMAGES AND AFRICAN AMERICAN WOMEN WITH DISABILITIES

Black feminists have documented the significant role that the controlling image or trope of the Strong Black Woman (also called "Super Woman") has played in the social construction of African American womanhood (Collins 2000; Wallace 1999; Woods-Giscombe 2010). This image grew out of the history of African American women's exploitation as unpaid laborers during slavery, and later as underpaid workers and service providers. Their positionality as laborers both inside and outside the home conflicted with the traditional white American family ideal that suggested that women's roles should be restricted primarily to wife and mother. Because their positionality did not allow them to conform to white standards of womanhood and femininity, African American women were ridiculed and objectified through stereotypical images such as mammies and jezebels. These images dehumanized African American women and constructed them as hypersexual and as simple minded; the images also often connected their worth to their physical and emotional labor (Collins 1990).

The Strong Black Woman ideal acts as a counternarrative that celebrates characteristics in African American women who demonstrate their devotion to African American men and families, and to the African American community. These celebrated traits include being selfless, nurturing, resilient, independent, and exemplifying a physical and emotional

will to endure great difficulties. More specifically, Strong Black Women are glorified in the African American community for their ability to persevere in a racist and sexist society. Research suggests that for African American women, aspiring to conform to the Strong Black Woman image can be simultaneously empowering and detrimental to their health and self-concept (Collins 1990; Wallace 1999; Woods-Giscombe 2010).

In the pivotal text *Women and Disability*, Fine and Asch (1985) argued that women with disabilities particularly experience a type of gender “rolelessness.” This “rolelessness” results from a society that tends to construct women with disabilities “as inadequate for economically productive roles (traditionally considered appropriate for males) and for the nurturant [*sic*], reproductive roles considered appropriate for females” (1985, 6). On account of their gender and disability, women with disabilities are socially constructed as weak, dependent, and unfit as providers, and they are considered unable to fulfill their gender expectations as mothers. Therefore, if the characteristics of a Strong Black Woman include being hardworking, independent, and caregiving, then the presence of a disability is in direct conflict with traditional ideals of African American womanhood. In addition, while there is growing literature that identifies the impact of the Strong Black Woman schema on African American women’s health (Woods-Giscombe 2010), this research does not recognize that the schema itself is embedded in an ableist ideology that values independence over interdependence and caregiving over self-care. Moreover, this literature tends to include a narrow conception of strength and resilience that devalues and pathologizes those that are perceived as weak.

FEMINIST, INTERSECTIONAL, AND DISABILITY STUDIES

The analytic framework of this paper is informed by multiple bodies of literature: disability studies, feminist disability studies, and intersectional scholarship. Dominant perspectives about disability in Western society construct disability as a deficit, impairment, and individual tragedy rather than as a system of oppression or as an identity and variant of human diversity. Deficit models of disability primarily focus on rehabilitation and cure of the body to alleviate negative social, physical, and economic outcomes thought to be caused by impairment. However, the social model of disability, which grew out of the disability rights movements of the 1960s and since, strongly critiques traditional deficit model approaches to disability inquiry. This study draws on the social model perspective first developed out of Great Britain that interprets impairment as the physiological outcome, and disability as the social outcome, which are culturally, historically, and geographically contextual (Shakespeare 2006).

This distinction is parallel to the assigned sex/gender distinction and the phenotype–race distinction made in feminist and critical race theories of power and difference. Disability studies is an interdisciplinary field that examines how this social construct is treated and interpreted in society as a minority identity, a system of inequality, and a lived experience (Linton 1998; Siebers 2008; Garland-Thomson 1997). It posits ability and disability as relational constructs that are products of a system of oppression called ableism. Ableism, as a system of beliefs and social practices, assigns value to humans based on embodied characteristics associated with one's actual or assumed ability (Linton 1998).

Feminist disability studies later emerged, critiquing the male-dominated focus of the disability rights movement and the exclusion of women with disabilities in the feminist movement. Informed by the lived experiences of women with disabilities, feminist disability studies critically analyzes the gendered aspects of disability, the relationality of ableism and misogyny, and their implications for society (Fine and Asch 1985; Garland-Thomson 1997). Feminist disability studies, however, is limited in its ability to inform any analysis about the lives of African American women with disabilities because it is a field dominated by white women, with and without disabilities, from Western nations, who tend to exclude the lived experiences of women of color with disabilities and remain largely disengaged with critical race theory.

Intersectional scholarship provides an entry point where the multiple structures of identity and inequality affecting African American women with disabilities can be better understood. Intersectionality is an analytical framework that is specifically derived from the intellectual and activist contributions of women of color; it analyzes, resists, and critiques multiple systems of oppression in the United States. Intersectional scholarship's primary focus traditionally has been on the examination of the complex relationships of race, class, gender, ethnicity, sexuality, and other dimensions of difference. Founders of this scholarship critiqued the essentialist and isolated approaches to the study of these areas of social difference. They also challenged additive frameworks that suggested the accumulation of disadvantage or the primacy of one identity over another. Instead, intersectionality argues that multiple axes of power and difference shape each other, and that people with multiple subordinate identities experience oppression singularly and simultaneously, depending on the context (Collins 2000; Schulz and Mullings 2006; Thornton Dill and Zambrana 2009).

Still, traditionally intersectional scholarship has not included disability as one of its examined axes of domination. Perhaps the primacy of deficit and medical models of disability in research have created barriers to examining disability as an identity and socially constructed system of power. While intersectional scholarship in the study of disability is

growing, this literature is primarily located in special education, health sciences, and rehabilitation fields (Balcazar et al. 2010; Conner 2008; Schulz and Mullings 2006) and through literary, historical, and theoretical approaches in the humanities (Bell 2011; Boster 2013; Logue and Blanck 2010; Pickens 2017; Schalk 2018). Arguably, special education has the largest body of intersectional scholarship on disability. However, this work is limited by its focus on children and young adults with learning and behavioral disabilities. This study adds to the literature by highlighting lived experiences of adults: African American women with physical disabilities.

FEMINIST INTERSECTIONAL DISABILITY FRAMEWORK

To address these gaps, for this study I draw from the previous frameworks to utilize a *feminist intersectional disability framework*. Intersectional research requires recognition of the distinct aspects of identity and systems of inequality, such as race, class, gender, and ability, and how they mutually constitute one another. In this way, it demands of its practitioners integrative thinking throughout theory development and research production (Conner 2008; Schulz and Mullings 2006). Feminist intersectional disability framework is grounded in the following assumptions: First, race, class, gender, and other markers of difference, and the associated systems of oppression, collectively contribute to how disability is acquired, experienced, and socially constructed. Second, the intersection of race, class, gender, and ability oppression contribute to disabled women of color's differential access to resources, opportunities, and treatment in society. Third, disabled women of color experience marginalization within dominant majority communities (i.e., white, able-bodied, middle-class communities), as well as within their minority communities (i.e., black, disabled, poor communities). Finally, ableism is commonly an unaccounted predictor of structural inequality. Because many social problems examined by researchers exclude disability inquiry and its intersections, the conclusions developed to rectify these problems are often incomplete and inadequate.

Thus, in applying a feminist intersectional disability analysis to the housing experiences of African American women with physical disabilities, this study examines how these women discuss their self-concept as multiple minorities and its meaning for their lives. In addition, their interviews illustrate some of the ways that systems based on race, class, gender, and ability interact to produce deleterious outcomes.

METHODS

The major research question guiding the impetus for this study was, "What are the barriers and facilitators to homeownership for African American women with physical disabilities?" However, this article only focuses on a portion of the study based on a subresearch question: "What is the self-concept of participants in a study on the barriers and facilitators to homeownership for African American women with physical disabilities?" The results shared in this article are based on the participant responses to the follow-up interview portion of the larger mixed methods study, and the quantitative sample description is based on the self-administered questionnaire.

To examine the major research question, the study used a two-phase exploratory mixed-methods design. A detailed self-administered questionnaire was distributed in phase one to capture demographic markers. Phase two included qualitative, in-depth follow-up interviews to capture participants' attitudes towards homeownership and housing experiences. A mixed quantitative and qualitative research approach was chosen to allow for an examination of the research question by collecting and analyzing multiple forms of data to compare and validate results from different perspectives (Creswell and Plano Clark 2007). It also enabled the African American women participants with disabilities ($n=32$) to share perspectives about the barriers and facilitators to homeownership by using different mediums (i.e., questionnaire and interview). This strategy was especially useful for people with disabilities, some of whom may not have been able to express themselves as well verbally as through written text, or vice versa. The qualitative data analysis procedures utilized a grounded theory approach. Grounded theory is a set of systematic research procedures used to develop theory directly out of the analysis of qualitative data (Charmaz 2006; Corbin and Straus 2008).

Data collection began in August 2011 and ended in February 2013. Phase one included the collection and analysis of quantitative data through the distribution of a self-administered questionnaire. This self-administered questionnaire was a 58-item cross-sectional survey; it included data collection from participants about social characteristics (i.e., age, race, education, gender identity, marital and parental status); economic information (i.e., employment, income, debt, housing, transportation, and health-related costs); and health characteristics (i.e., physical disability, functional limitations, and emotional well-being). Participants were recruited for phase one through a purposive sampling technique that included both homeowners and nonhomeowners who were African American women with physical disabilities from Maryland, Washington, DC, Pennsylvania, or Virginia (the mid-Atlantic region). Disability rights organizations, disability-related service providers, local

disability advocacy communities, and personal networks were contacted to help identify participants who met the following selection criteria: African American women, ages 25-55, and living in the mid-Atlantic region. Once identified, potential participants received a cover letter explaining the study, an Institutional Review Board consent form, and the self-administered questionnaire. Forty-two people were recruited to participate using these methods in phase one of the study. Thirty-two questionnaires were returned during this time, resulting in a total phase one response rate of 76 percent.

Phase two in-depth interviews of participants were drawn from a subsample of 30 of the 32 participants who also completed the self-administered questionnaire. The subsample included all eight homeowners and 22 nonhomeowners. Follow-up interview participants were recruited through an item at the end of the self-administered questionnaire asking for a follow-up interview. As a thank you, questionnaire participants were entered into a raffle for a gift card. In addition, each follow-up interview participant received a \$10 gift card.

The semi-structured interview posed a series of 28 open-ended interview questions. The questions focused on participants' past and current housing experiences, attitudes and desires towards homeownership, perceived ability to own a home, knowledge about homeownership, housing goals, and how these relate to their race, class, gender and other identities. The interviews were used to enhance and extend the meaning of the quantitative findings by providing experiential details about individual participants, expressed both in their own words and systematically organized by themes within the data using a grounded theory analysis of transcripts (Charmaz 2006; Corbin and Straus 2008). I conducted thematic coding of the data; the first round was grounded coding, based on themes informed by the literature and guided by the results of a 2008 pilot study of the housing experiences of three African American women nonhomeowners with physical disabilities. Self-concept was among the themes generated during the pilot study. This theme emerged out of analysis of the responses participants shared when asked about their past and present housing history and related experiences. While the theme of self-concept was articulated in multiple ways throughout most of the 30 interviews, this article focuses on the experiences of a small portion of participants to provide detailed examples of how the subtheme of care work and its relationship to the Strong Black Woman schema was expressed throughout the study.

Because participants took part in a study about homeownership, they may have had certain personal characteristics and topics in mind before the survey and interview phase of the study. For instance, this study's focus on homeownership attracted participants with higher educational

TABLE 1: Social Characteristics of Sample

<i>Characteristic</i>	<i>Total (n=32)</i>	<i>Total % of Cases</i>	<i>Homeowners (n=8)</i>	<i>Nonhomeowners (n=24)</i>
Age				
Mean	37.8	—	46	35
Range	25-58	—	37-58	25-55
Physical disability				
Cerebral palsy	12	37.5	2	10
Muscular dystrophy	5	15.6	0	5
Multiple sclerosis	3	9.3	2	1
Spina bifida	2	6.2	1	1
Spinal cord injury	6	18.7	2	4
Other	4	12.5	1	3
Disability onset				
At birth (yes only)	18	56.0	3	15
Birth to 3	21	65.0	4	17
4 to 18	2	6.0	1	1
19 to 30	5	15.0	1	4
31+	4	12.0	2	2
At birth (yes only)	18	56.0	3	15
Employment				
Part-time	6	18.7	1	5
Full-time	13	40.6	5	8
Unemployed	12	37.5	1	11
Other: retired	1	3.1	1	0
Education level				
Less than high school	1	3.1	0	1
High school	3	9.4	0	3
Some college	11	34.4	2	9
College degree	10	31.2	3	7
Graduate degree	7	21.9	3	4
Marital status				
Never married	17	53.1	3	14
Married	9	28.1	1	5
Separated	3	9.4	1	2
Divorced	4	12.5	2	2
Widowed	1	3.1	1	0
Other: single	1	3.1	0	1
Has children	12	37.5	3	9

attainment and employment rates than people with disabilities in the general population (see Table 1). Hence, most participants had characteristics associated with the Strong Black Woman trope. Topics related to

housing—such as independence, economics, care taking, and personal relationships—also may have been prompted in the interviews by the phase one questionnaire, influencing the context in which they discussed issues related to their self-concepts. The majority of participants also had early-onset disabilities (see Table 1). This may have impacted their self-concept, especially as it relates to how they identify with and interpret their disabilities. Pseudonyms were assigned to protect the privacy of the interviewees. Finally, because the author of this study is also an African American woman with an apparent physical disability, participants often expressed an identification with the researcher and a vested interest in the success of the study.

CARE WORK AND AFRICAN AMERICAN WOMEN WITH DISABILITIES

These African American women with disabilities internalized, resisted, and negotiated multiple intersecting structural and attitudinal barriers and expectations related to care work as part of their self-concept. Participants described some of the constraints they encountered in participating in care work as African American women with disabilities, and the ways in which those constraints impacted how they understood themselves and their position in society. I define “care work” as participating in the social, emotional, intellectual, and physical labor associated with identifying, requesting, denying, and managing the people, services, and resources that enable individuals to advance and maintain their health, well-being, and overall way of life. This care work includes participating in labor associated with providing and receiving care not only for self but also for others. The participants’ experiences suggest that the intersectional barriers associated with the care work these women confront require them to exemplify Strong Black Woman characteristics (i.e., resilience, independence, sacrifice, endurance, etc.) because of having to go beyond what is generally required of more privileged others to access equitable resources, opportunities, and treatment. In this way, the Strong Black Woman trope has a material reality that is perpetuated not only through Black cultural expectations, but also through institutional structures that affect one’s access to resources and life chances. While most of the interviews discussed self-concept, the stories highlighted here best exemplify the theme of how self-concept was expressed in relationship to care throughout the study.

The participants juggled multiple responsibilities related to care for self and others. Their relationship to care work was both a contributor to and

outcome of their self-concept. For instance, Monica, a homeowner with arthritis, lymphedema, and a heart condition, described herself as someone who had based her self-concept on her ability to help others and be financially and socially independent throughout her life. Becoming a homeowner was among the achievements in her life in which she took great pride. However, in addition to having childhood-onset arthritis, she also was diagnosed with lymphedema and a heart condition three years prior to this study. During her interview, she suggested that she struggled with coping with her new limitations and accepting help from others at work or at home, both places that had become increasingly less accessible to her. For example, when asked why she resisted asking family or friends for assistance with minor chores and maintenance she had difficulty completing around the house, she responded:

I like helping other people physically, spiritually, and financially. And so, you know, I like being able to pay people to do things for me. You know? I'm not a person that always has to have something done for you for free. I would love to have the money so that anytime anything was broken in my home I could have it fixed.

While Monica took pride in her ability to provide care, she resisted receiving the same type of assistance from others without compensating them. Instead, Monica emphasized throughout her interview that she feared becoming a burden on the ones she loved, and she expressed that feelings of shame and embarrassment often prevented her from requesting help from others. This interpretation of her disability affected her personal relationships and ability to advocate for herself at home and work. For example, she had not requested work accommodations that she believed could help alleviate some of her physical pain and work stress because she feared that her coworkers and employer would then view her as a less productive and less valuable employee. However, in reflecting during the interview upon her patterns of resistance to requesting help, she suggested that this was an attitude that she may need to change. She said, "[I]n talking to you and actually talking to a few friends lately, I do think I need to become more open to let people come in and help me . . . Even though you try to portray yourself as a strong person, sometimes you do have little insecurities that you suppress." Monica's interview suggests that she associated strength with not needing or requesting care while simultaneously being freely available and able to provide care to others. Like Monica, other participants shared moments where they had to discern when they believed it was in their best interests to request, receive, and

refuse care, and how to manage the care and help they did receive.

After receiving personal care assistance from her grandmother most of her life, Mary, a homeowner with a spinal cord injury, became aware in her adulthood that she could be eligible for personal care assistant services funded through the state and her medical insurance and decided to apply. After applying for these services, she waited quite some time to find out if her requests for supports were approved, only to learn that her grandmother had been intercepting her phone calls:

I didn't know my grandma was sabotaging the phone calls. 'Cause I was calling every day; 'cause there wasn't nobody callin' me back. And then I finally got a call, and she was tellin' me how she'd been callin' me, but my grandma been tellin' her, "We ain't need no services, I take care of her very well!"

Mary's grandmother was initially very resistant to Mary accepting personal care assistance from anyone other than herself. Mary argued that her grandmother initially interpreted her attempts to gain independence as a personal attack on the quality of care she provided. She did not trust others to provide Mary the same level of care, believing strongly that her care could only be provided by trusted loved ones. Mary further argued:

[B]elieve it or not, the people that take care of you, especially if they a relative, like, they got a system. That's something they had to do, so they more dependent on us than we are on them! 'Cause she upset if she can't do something for me. And if I go out, she stay up until I get there. And I know that's a mom thing, but, it's like, they get so used to doin' it. And then if you try to get your freedom and independence a little bit, they lookin' like, "Well what's gonna happen to me if you go?" . . . I'm like, "You're supposed to have your own identity." . . . I told her I can't be responsible for that, 'cause everybody in charge for themselves.

Although Mary's grandmother was initially resistant to her receiving outside care, after Mary applied for and received funding, for the first time her grandmother began receiving financial compensation for the personal care she had been providing Mary for most of her life. In addition, Mary was able to hire a close friend to assist her more regularly, relieving her grandmother of the workload.

Indeed, the women interviewed frequently argued that the cost of managing care for self and others was a major barrier to their ability to own a home. Carol, a nonhomeowner with muscular dystrophy, specifically highlighted the intersecting barriers to economic advancement

she believed she confronted as an African American woman with a disability:

I'm not, as a female, as an African American, making as much money as my white male counterpart. Even still, disability-wise, I think—and when it comes to things like care, those are things that—they are extra expenses that I have to pay for. So even something as simple as my shower chair or showerhead or Depends underwear or anything like that, that are extra expenses of a disability, they're still extra expenses . . . and then paying a caregiver out of my pocket; those are all things that are taking my money in other ways. So that makes it less available for things like, you know, paying a mortgage.

Camille, a nonhomeowner with cerebral palsy and low vision, also argued that she had fewer opportunities for economic advancement as an African American woman with a disability. Camille is a retired worker from a government agency whose mission is to advance the full inclusion of people with disabilities through employment, education, and independent living. As such, there were many people who identified as having a disability who worked in Camille's office. Nevertheless, Camille argued that she observed significant race-, gender-, and disability-related differences in the way employee positions were organized and advanced in her department:

The white women that I've known on the job with disabilities have a much easier time accessing housing, employment in general. They have higher incomes. . . . African American women with disabilities on the job—we sometimes felt we were way at the bottom of the totem—of the pole—way at the bottom because you're black, you're female, you have a disability. So, everybody was on top of you. That's the way it pretty much worked; you weren't able to get promoted. The African American women without disabilities were promoted before you, even if you went back to school and got a degree. They were promoted before you. Then, the women that were non-African American—not just Caucasian—any ethnicity that was not African American—were promoted before you. So, it got to be kind of discouraging for a lot of women. They would just leave the job, and go out on disability.

According to Camille, her African American women coworkers with disabilities tended to be in low-level positions with little chance of career advancement. Despite being employed, they still struggled to pay their bills because of the added disability-related costs they experienced. Yet, they were not qualified to benefit from government assistance such as

food stamps or Medicaid because of their employment earnings. With no perceived job advancement opportunities, some choose to leave work and go back on government assistance where they could cover their medical bills and have rent control. Throughout the study, the most frequently stated barrier to homeownership that participants gave was economics. Without economic parity, African American women with disabilities are less able to do the care work they need to maintain their way of life and fully participate in society.

In addition to tending to have to manage the cost and logistics of their care with fewer economic resources, multiple participants had children or other loved ones that they provided care for. These participants frequently discussed the structural and attitudinal barriers they confronted in being acknowledged and respected as not only receivers but also providers of care. These barriers hindered their access to the resources and opportunities that would enable them to receive and provide the best care.

In addition to being a retired government worker, Camille was also a mother of two adult children, including an 18-year-old daughter with mental health disabilities who had just started college, and her oldest, a son who had been incarcerated multiple times in the past for drug dealing and was a recovering drug and alcohol addict. As a consequence of her son's difficulties, Camille also had custody of his 11-year-old daughter, whom she had been raising since she was two years old. At the time of the study, Camille was also in love and busy managing the medical care of her fiancé, who had multiple disabilities and was in the hospital. Despite the multiple ways in which Camille successfully provided care to her loved ones, she argued that her competence and ability to take care of herself and others was constantly questioned by service providers and others in her community. When discussing her experience with assisting with the management of her fiancé's care, she shared:

My fiancé's been in the hospital for a while, so I've just spent a lot of time running back and forth trying to deal with the physicians with him, and that's difficult because they see a wheelchair and they assume ignorance . . . what gets me is the prevailing feeling that people with disabilities are not cognizant, they don't know anything, and "What can you do?" You don't talk to them, you talk over them. In fact, I went once when he was in one nursing home with my granddaughter. They were talking to my granddaughter, and I said, "Why are you talking to her?"

When managing care, services or business of any kind, participants frequently shared that that they confronted a pervasive attitude from others that they did not belong, were not competent, and that their presence

and contributions were consistently unacknowledged and/or treated as inconsequential. When discussing the barriers to getting the social services, care, and supports African American women with disabilities need, Mary exclaimed, "Being disabled, you got to fight harder. 'Cause you're female, I'm thinking matters what color and you're disabled, so you got to go that extra mile for them to even pay attention to you." Jessica, a homeowner with multiple sclerosis similarly discussed having to confront assumptions that she was incompetent in the context of advocating for the modifications she needed in her home and negotiating the terms for closing the purchase of her condo. However, she attributed the attitudinal barriers she faced in this process to her race and gender. She said:

It's always the perception, in my opinion, that as African American female, I'm not knowledgeable. So I play along . . . because it typically works in my favor . . . They think I don't know. I let them think I don't know.

Jessica argued that she was able to use to her advantage the low expectations of the lawyers, realtors, and contractors she interacted with in the building and around the purchasing of her condo. Because they were underprepared for how knowledgeable she was about the home purchasing process, and the American with Disabilities Act (ADA) regulations for builders, she strategically used their ignorance as leverage during price and construction negotiations.

Multiple participants expressed concern that assumptions about their capabilities to care for and/or worthiness to have access to the housing they desired may lead to discrimination against them. Tameeka, who was born with arthrogryposis and lived in an apartment of her own with her son, explained, "Most people, when they see me by myself, they probably think that I couldn't keep up a house and keep it clean, keep it modified to my needs, or to their expectations." African American women with disabilities have to contend with racial, gendered, and ability biases that may deter people from renting or selling a home to them. These intersecting biases include a lack of acknowledgment that African American women with disabilities can and do care for themselves and others and that the care they provide is laborious and valuable. Furthermore, intersecting biases construct African American women with disabilities as unfit, inadequate, deviant, and otherwise undesirable and incapable providers, managers, and receivers of care. These biases also impact the policies and practices of the institutions that serve them and the resources that they are able to access. When Donna, a nonhomeowner with cerebral palsy learned that her daughter's kindergarten class was assigned to a third floor classroom in a

building with no elevator, she experienced significant resistance from school administrators to her request for accommodation. However, because of Donna's persistent advocacy on behalf of herself and her daughter, her daughter's class was eventually moved to the first floor. She explained:

I want to see her teacher; want to see her classroom. So on the first floor . . . that's where they do have accessible things. So I just roll up there and drop her off or pick her up from her class and see how she's doing, see how she interacts with the other kids and that's it.

The interviewees confronted intersecting systemic burdens and social cultural expectations that produced a heavier demand for them to care for themselves and others. They managed these multiple and competing tasks with typically fewer resources and less acknowledgment of their needs and labor compared to their more privileged counterparts. The ability to discern when it is in one's best interests to ask for assistance and care, and to advocate for the right to give and receive care, are skills that participants displayed various degrees of mastery regardless of homeownership status. However, homeowners especially suggested that they had to display a command for these skills in the context of gaining and maintaining an owned home. Having a command for assessing their needs, and the ability to identify the people, resources, and networks that can help meet them, was shown to be a strong facilitator of homeownership.

DO AFRICAN AMERICAN WOMEN WITH DISABILITIES "CARE"?

One of the primary characteristics of the Strong Black Woman schema is being a caregiver. Most participants shared multiple ways in which they managed and negotiated their care, and many shared multiple ways in which they were caregivers. This care work was a primary aspect of their self-concepts. Despite this reality, they described encountering a society that does not acknowledge or accommodate the ways they received, provided, and managed care. This lack of recognition and accommodation created greater social and structural barriers for them. Feminists have successfully brought to light the many ways in which women's labor is not valued as much as men's or even recognized as work (Kemp 1994). Similarly, the intensive labor often involved in people with disabilities receiving and/or managing care, and the ways in which the care received is an interdependent process, tends to go unrecognized. These excerpts

highlight that for African American women with disabilities, this is also a racialized, classed, and gendered experience, with social and material consequences.

Monica's interpretation of her disability and its meaning for her life threatened her self-concept. It led her to question if others would perceive her as a competent, valuable, and desirable employee and individual. This internalization led her to resist assistance and support from others in ways that she described made her daily life more difficult to manage at home, at work and in her community. Given the strong messages of worthiness being connected to labor, it is not surprising that Monica would interpret her disability as making her a less desirable employee and person in society. The high unemployment rate of people with disabilities alone suggests that her fears were not unfounded. Still, her story suggests that she interpreted her disability as a limitation that interfered with her ability to perform in ways consistent with her ideal—someone who is strong, physically and economically independent, hardworking, and helpful to others. These characteristics are associated with the Strong Black Woman ideal. As can be understood from the Strong Black Woman trope, associating strength with not needing or requesting help can be detrimental to one's well-being. For African American women with disabilities, it may be especially damaging because of the social, economic, and health disparities they are more likely to experience. The consequences of the type of internalized ableism, racism, and sexism that Monica described can be loss of work or home, exacerbation of illness and/or impairment, and isolation. Internalized oppression is more than a bad or negative "feeling" about oneself or one's identity, but it has social and material consequences for the people affected by it because it also affects the decisions people make.

Mary's experience with her grandmother highlights the multiple complexities and interdependent nature of the relationship between people with disabilities and their caregivers, especially when a caregiver is a family member. Caregivers can be both an asset and hindrance to people with disabilities asserting their autonomy, and to the type of care they would like to receive. However, Mary resisted internalizing her grandmother's desires and expectations for her care. Instead, Mary argued that her grandmother also depended on her for her identity and sense of purpose in ways that also resemble the Strong Black Woman schema. As previously discussed, Strong Black Women are revered for being caregivers or accomplishing in other ways while enduring great difficulties. While this identity is developed to help cope with scarce and inequitable resources, it also becomes a barrier when resources do become available

and fear and mistrust of systems that have historically failed marginalized people drive present decision making. Persistent and repeated experiences of oppression can lead to identifying with struggle in such a way that once relief becomes available, it is not recognizable or desirable for fear it will change or threaten one's current way of life, however difficult. While Mary's grandmother was likely participating in protective practices that African Americans have unfortunately found necessary in a racist world, she also was participating in ableist practices by not informing Mary of the phone calls and making decisions for Mary without her input or consent. Mary suggested that her grandmother's self-concept as caregiver was threatened when Mary worked to gain more independence. After all, how could she be a Strong Black Woman without someone to rescue and care for? Although Mary's grandmother may not have viewed her as competent enough to decide the type of care she wanted, Mary's persistence to follow through with the application for services despite her grandmother's opposition suggests that she perceived herself as capable of making the best decision for her life.

In addition to experiencing constraints from caregivers to accessing the type of care they need and desire, the women in this study experienced significant financial constraints to funding that care. Carol stressed the ways in which African American women with disabilities confront multiple axis of wage inequality based on race, gender, and disability, while simultaneously experiencing higher economic cost. Similarly, Camille clearly delineated that she observed that others had social and economic advantages over African American women with disabilities in her workplace based on their race, class, gender and ability privilege. Camille's interview also reveals the ways in which the presence of a disability does not absolve African American women with disabilities from being impacted by the same social problems affecting the rest of the African American community, such as the prison industrial complex. In this way, participants consistently demonstrated that, compared to their counterparts, African American women with disabilities tend to have greater need and demand to manage and provide care for self and others, with fewer resources, accommodations, or acknowledgment of their needs and capabilities. These disparities, as Carol and Camille pointed out, reduce access to housing, homeownership, and other resources and create barriers to care work.

Camille, Jessica, Tameeka, and Donna's excerpts demonstrate how institutions and their policies reflect attitudinal biases about African American women with disabilities' capabilities and worthiness for access

to resources and opportunities. Medical, housing, and educational policies are constructed to meet the needs and expectations of dominant groups. They were created in a context that assumes male, white, able-bodied, heterosexual, cisgender competence and marginalizes the existence of others. When this happens, other perspectives and bodies are literally left outside of institutions and unable to enter, such as the case with Donna and her daughter's inaccessible public school. Or they may be left completely ignored and excluded, such as with Camille's experience with medical providers. Or they may be underestimated, such as with Jessica and Tameeka.

Despite these constraints, most participants demonstrated a certain amount of self-efficacy, self-awareness, and confidence, which may not have always reduced but at least helped them manage the inequities they encountered. Because the participants were recruited through a snowball sample of members associated with disability rights and advocacy organizations, they were more likely to have been exposed to disability and civil rights empowerment principles and connected to other disabled communities of color. Their proximity to other African American women with disabilities may have enabled them to identify how multiple and intersectional areas of marginalization impact their life. Having access to this community can help reveal common experiences and social patterns associated with their identities which are harder to identify in isolation. In this way, issues that might otherwise be ascribed solely to the individual can be understood as larger social problems.

However, most people with disabilities do not identify with other people with disabilities as a social political group or minority identity (Linton 1998) and African Americans even less so (Bell 2011). Thus, one of the primary barriers to integrating a positive self-concept is the limited access to other African American women with disabilities in contexts that provide opportunities to learn from shared experiences. It is not enough to be near other African American women with disabilities, as may be the case in a nursing home serving predominately African American women. Purposeful opportunities created for community building, empowerment, affirmation, and exchange are important for marginalized people because these can enable the sharing of resources, coping strategies, and collective resistance to oppressive systems and ideologies.

Unfortunately, however, African American women with disabilities are underrepresented and/or misrepresented in research and in U.S. culture, and this creates barriers for them to identify shared interests and develop community. Lack of representation or community leads to experiencing oppres-

sion in isolation and enables the internalization of oppression, just as Monica's experience suggests. Imani, a homeowner with cerebral palsy, argued, "More white women with disabilities are, uh, they get more attention than we do . . . when they put a face on a disability it's typically not a black face, it's typically a white one." When asked how she thought this exclusion affected African American women with disabilities, she responded,

Adversely, because we don't get as much help. What's that saying? . . . The squeaky . . . wheel gets the oil, gets the grease? If you don't know we exist and you don't know what it is we need, how can you help us?

This study demonstrates the ways African American women with disabilities exhibit and identify with Strong Black Women characteristics of resilience, independence, sacrifice, endurance and more. It shows how characteristics and social expectations associated with the Strong Black Woman schema can be both an asset and hindrance to their empowerment. It demonstrates how even when African American women with disabilities perceive themselves as capable of managing, providing, and receiving care, they constantly confront a society that does not view them the same. This lack of recognition and accommodation creates greater social and structural barriers for them to confront. Hence, the Strong Black Woman ideal and expectation had cultural and material relevance for how participants interpreted themselves, were perceived by others, and accessed resources. In addition, exploring how African American women with disabilities experience the Strong Black Women schema makes evident that it is embedded in an ableist ideology that values independence over interdependence, and caregiving over self-care, and includes a narrow conception of strength and resilience that devalues and pathologizes those who are perceived as weak (i.e., African American women with disabilities). Not only are ableist structures not conducive to people with disabilities, but they tend to exacerbate and/or produce impairment. It is not surprising then that research is increasingly linking the Strong Black Women schema to health disparities for African American women (Woods-Giscombe 2010).

More research is needed to learn about the social construction of disability in the African American community, especially as it relates to gender, care work, and women with disabilities. Through using a feminist intersectional disability framework, this study offers a model for how to explore these intersections. African American women with disabilities' self-concept and relationships to their stigma management strategies, access to resources, and integration in society also need to be further explored. While participants expressed that housing and ability to live

independently affected their self-concepts, the material reality of owning or not owning a home did not reveal significant differences between homeowners and nonhomeowners. Rather, it was through conversations about homeownership that this data around self-concept was revealed. The fields that have the most advanced theoretical and methodological tools to further speak to the positionalities of African American women with disabilities, that is, women's studies, disability studies, African American studies, and other areas in the social sciences and humanities, have failed to significantly recognize the need for inquiry about their lives. As suggested by Balcazar et al. (2010), the dominance of medical, rehabilitation, and other deficit models of disability, the limited acknowledgment of disability as a social, political, and minority identity, and the large absence of minorities with disabilities as researchers and scholars, are likely primary barriers to this subject of inquiry. This article intends to help spark the interests of future studies to come. It is clear that the particular configuration of ableism, white supremacy, and misogyny in society has created barriers to inquiring about certain marginalized bodies. These structures of power render African American women with disabilities as unknowable and unrecognized as a marginalized group worthy of exploration. One must wonder, who else is our scholarship and activism forgetting or ignoring? More importantly, what will we do about it?

REFERENCES

- Alston, Reginald J., and Carla J. McCowan. 1994. African American women with disabilities: Rehabilitation issues and concerns. *Journal of Rehabilitation* 60 (1): 36-40.
- Balcazar, Fabricio, Ashmeet K. Oberoi, Yolanda Suarez-Balcazar, and Francisco Alvarado. 2012. Predictors of outcomes for African Americans in a rehabilitation state agency: Implications for national policy and practice. *Rehabilitation Research, Policy, and Education* 26 (1): 43-54.
- Balcazar, Fabricio, Yolanda Suarez-Balcazar, Tina Taylor-Ritzler, and Christopher B. Keys, eds. 2010. *Race, culture, and disability: Rehabilitation science and practice*. Boston, MA: Jones and Bartlett.
- Beatty, Lula. A. 2003. Substance abuse, disabilities, and Black women: An issue worth exploring. *Women & Therapy* 26 (3): 223-36.
- Bell, Christopher, ed. 2011. *Blackness and disability: Critical examinations and cultural interventions*. East Lansing: Michigan State University Press.
- Benjamin Darling, Rosalyn. 2013. *Disability and identity: Negotiating self in a changing society*. Boulder, CO: Lynne Rienner.

- Boster, Dea H. 2013. *African American slavery and disability: Bodies, property, and power in the antebellum South, 1800-1860*. New York: Routledge.
- Collins, Patricia Hill. 2000. *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*, 2nd ed. New York: Routledge.
- Conner, David. J. 2008. *Urban narratives, portraits in progress: Life at the intersections of learning disabilities, race and social class*. New York: Peter Lang.
- Corbin, Juliet, and Anselm Strauss. 2008. *Basics of qualitative research: Techniques and procedures for developing grounded theory*, 3rd ed. Thousand Oaks, CA: Sage.
- Courtney-Long, Elizabeth A., Dianna D. Carroll, Qing C. Zhang, Alissa C. Stevens, Shannon Griffin Blake, Brian S. Amour, and Vincent A. Campbell. A. 2015. Prevalence of disability and disability type among adults—United States, 2013. *Morbidity and Mortality Weekly Report* 64 (29): 777-83.
- Charmaz, Kathy. 2006. *Introducing qualitative methods: Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.
- Creswell, John W., and Vicki L. Plano Clark. 2007. *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage.
- Drum, Charles, Monica R. McClain, Willi Horner-Johnson, and Genia Taitano. 2011. Health disparities chartbook on disability and racial and ethnic status in the United States. *Institute on Disability, University of New Hampshire*. https://sph.umd.edu/sites/default/files/files/Healthpercent20Disparitiespercent20Chartpercent20Book_080411.pdf.
- Fine, Michelle, and Adrienne Asch. 1985. Disabled women: Sexism without a pedestal. In *Women and disability: The double handicap*, edited by Mary J. Deegan and Nancy A. Brooks. New Brunswick, NJ: Oxford Transaction Books.
- Garland-Thomson, Rosemarie. 1997. *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York: Columbia University Press.
- Kemp, Alice Abel. 1994. *Women's work: Degraded and devalued*. Englewood Cliffs, NJ: Prentice Hall.
- Linton, Simi. 1998. *Claiming disability: Knowledge and identity*. New York: New York University Press.
- Logue, Larry M., and Peter Blanck. 2010. *Race, ethnicity, and disability: Veterans and benefits in post-civil war America*. Cambridge, NY: Cambridge University Press.
- Oberoï, Ashmeet Kaur, Fabricio E. Balcazar, Yolanda Suarez-Balcazar, Fredrik G. Langi, and Valentina Lukyanova. 2015. Employment outcomes among African American/Black and white women with disabilities: Examining the inequalities. *Journal of Women, Gender, & Families of Color* 3 (2): 144-64.

- Pickens, Theri A., ed. 2017. Blue blackness, black blueness: Making sense of blackness and disability. *Blackness and Disability*. Special Issue, *African American Review* 50 (2): 93-103.
- Schalk, Sami. 2018. *Bodyminds reimagined: (Dis)ability, race, and gender in Black women's speculative fiction*. Durham, NC: Duke University Press.
- Schulz, Amy, and Leith Mullings. 2006. *Gender, race, class and health: Intersectional approaches*. San Francisco, CA: Jossey-Bass.
- Seabury, Seth A., Sophie Terp, and Leslie I. Boden. 2017. Racial and ethnic differences in the frequency of workplace injuries and prevalence of work-related disability. *Health Affairs (Millwood)* 36 (2): 266-73.
- Shakespeare, Thomas. 2006. *The social model of disability*. In *The disability studies reader*, 2nd ed., edited by Lennard Davis. New York: Routledge, Taylor & Francis.
- Siebers, Tobin. 2008. *Disability theory*. Ann Arbor: University of Michigan Press.
- Smart, Julie F., and David W. Smart. 1997. The racial/ethnic demography of disability. *Journal of Rehabilitation* 63 (4): 9-15.
- Thornton Dill, Bonnie, and Ruth Enid Zambrana, eds. 2009. *Emerging intersections: Race, class, and gender in theory, policy, and practice*. New Brunswick, NJ: Rutgers University Press.
- Wallace, Michele. 1999. *Black macho and the myth of the superwoman*. New York: Verso.
- Wilson, Keith. 2004. Vocational rehabilitation acceptance in the USA: Controlling for education, type of major disability, severity of disability and socioeconomic status. *Disability and Rehabilitation* 26:145-56.
- Woods-Giscombe, Cheryl L. 2010. Superwoman schema: African American women's views on stress, strength, and health. *Qualitative Health Research* 20 (5): 668-83.

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