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“Use what God has given me”: Difference and disparity in breast reconstruction

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Abstract

African-American women are significantly less likely to undergo postmastectomy breast reconstruction compared White women in the US. These observed differences have been interpreted as evidence of a healthcare disparity. The current study examines breast reconstruction decision-making among African-American women, locating reconstruction decisions in a context of culture, racial inequality, and biomedicalization. Semi-structured interviews were conducted with 27 African-American women who underwent mastectomy for breast cancer to add patient-centred perspectives to existing conceptualizations of racial/ethnic differences in reconstruction. Participants were socio-demographically diverse, and resided in the New York metropolitan area. Data analysis was informed by grounded theory. Spiritually and culturally-informed body ethics often guided surgery decisions. Participants expressed reservations about breast implants, preferring autologous procedures that use “what God has given.” For some, breast reconstruction restored a sense of normalcy after cancer; others challenged an imperative to reconstruct. Several participants redirected our focus on access to reconstruction toward access to alternatives, noting the low reimbursement for prostheses, or their unavailability in patients' skin tones. We suggest that a framework of “stratified biomedicalization” better addresses the complexities of race, class, and gender that inform preference, access, and recommendations for breast reconstruction, and focuses attention on access to high *and* lower-tech interventions.

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Keywords

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Introduction

Breast cancer is the most commonly diagnosed cancer and second leading cause of cancer death among African-American women (American Cancer Society, 2012a). Healthcare disparities have been documented across the spectrum of breast cancer detection and treatment: African-American women are less likely to be diagnosed with early-stage disease, less likely to receive breast-sparing treatment, less likely to receive adjuvant treatment, and more likely to die compared to White women (Shavers & Brown, 2002). African-American women who undergo mastectomy are also significantly less likely to have breast reconstruction compared with White women in the US (Alderman, McMahon, & Wilkins, 2003; Morrow et al., 2005), an issue garnering increasing research attention and concern.

After mastectomy, options for breast reconstruction include surgery with either saline or silicone implants, autologous tissue reconstruction procedures that use a woman's own tissue transferred from elsewhere on her body (e.g., abdomen, buttock, upper back) to recreate a breast mound, or a combination of the two. Breast reconstruction is widely assumed to provide psychological benefits to women, such as “increasing quality-of-life” and “alleviating the posttraumatic psychological sequelae of breast cancer surgery” (Ceradini & Levine, 2008, p. 73), although empirical support for these claims is limited (Harcourt et al., 2003; Lee, Sunu, & Pignone, 2009). Nonetheless, racial/ethnic differences in breast reconstruction have been described as an additional healthcare disparity (Alderman, Hawley, et al., 2009; Greenberg et al, 2008) prompting legislation and advocacy to promote access and utilization.

The Women’s Health and Cancer Rights Act (WHCRA) is a US federal policy implemented in 1998 to address group differences in breast reconstruction by mandating that a group health plan, insurance company, or health maintenance organization (HMO) that covers mastectomies must also provide reconstructive surgery and other post-mastectomy benefits (e.g., breast prostheses). However, epidemiologic studies reveal that the WHCRA has not increased overall use of reconstruction in the US, or diminished differences by race/ethnicity (Alderman, Wei, & Birkmeyer, 2006). In fact, now a decade since its implementation, African-American women continue to have lower rates of reconstruction (33.5%) when compared with White (40.9%) women (Alderman, Hawley et al., 2009).

Disentangling Difference and Disparity

Eliminating healthcare disparities is a high priority goal among healthcare providers, researchers, advocates, and policymakers. Whereas health status disparities refer to the variation in rates of disease and disability between population groups, healthcare disparities refer to differences in access or availability of facilities and services (Institute of Medicine, 2003). Although conceptually, these boundaries may seem clear, notions of disability, and norms and acceptability for medical intervention are socio-culturally embedded. Thus, not all differences in healthcare utilization are indicative of healthcare disparities, and the distinction between the two is not always clear (Hebert, Sisk, & Howell, 2008). The distinction may be particularly challenging when considering elective procedures that target health-related quality-of-life, such as breast reconstruction. Health-related quality-of-life encompasses physical, psychological, and social domains of health, which are influenced by an individual's experiences, beliefs, expectations, and perceptions. Economic, social, and cultural contexts influence views on what constitutes health, and health-related quality-of-life (Stewart & Nápoles-Springer, 2000).

Inhorn and Whittle (2001) warn that "epidemiology's conceptual models – which are meant to contribute to the prevention of social inequalities in health…may instead reinforce social hierarchies based on gender, race, and class" (p. 553). This critique may well apply to current epidemiological research in breast reconstruction, which upon identifying racial/ethnic differences in utilization assumes, without further investigation, that these differences indicate healthcare disparities. Identifying patterns of breast reconstruction utilization is a necessary step toward identifying the *possible* group-based differences in access to care. However, an *a priori* framing of Black/White differences in reconstruction as a health disparity risks what Guyatt (1993) has described as the hegemony of the (White) middle class outlook in health-related quality-of-life research, in this case by framing White, middle-class women's concerns about, and responses to, mastectomy and breast reconstruction as the norm. Moreover, this *a priori* framework reproduces normative notions of femininity through an assumption that all women would want, and should have, reconstruction after mastectomy, and denies the acceptability of scarred and/or differently proportioned female bodies (Naugler, 2009).

There is an emerging body of survey research that examines sources of racial/ethnic differences in breast reconstruction, with a focus on differences in healthcare provision. Both Morrow et al. (2005) and Alderman et al. (2008) surveyed breast cancer patients recruited from the US Surveillance, Epidemiology and End Results (SEER) registries, but neither found evidence of racial/ethnic differences in whether reconstruction was explained by a surgeon or whether women received plastic surgery referrals. However, Morrow et al. (2005) did find that African-American women were less knowledgeable about reconstruction, and were more likely to report that reconstruction was not recommended and/or was discouraged by their physician. Alderman et al. (2009) found that African-American women were less likely than White women to meet with a plastic surgeon before their mastectomy. In a chart review study by Greenberg et al. (2008), a documented discussion about reconstruction was the strongest predictor of actual receipt of reconstruction. Comparing racial/ethnic groups (analysing White vs. "other" groups), they found no significant differences in documented discussions of reconstruction. However, among patients with whom reconstruction was discussed, (older) age and (non-White) race/ethnicity predicted lower rates of reconstruction. The latter finding may suggest qualitative differences in the nature of discussions about reconstruction among different racial/ethnic groups. It may also suggest differences in patient preferences. In-depth qualitative research can help illuminate and clarify influences on African-American women's breast reconstruction use.

The aim of this interview-based qualitative study is to develop a patient-centred understanding of reconstruction decisions based on the experiences of a diverse sample of African-American women. Whereas current research and policy frameworks *a priori* assume that differences in breast reconstruction are indicative of a healthcare disparity, research is needed that examines African-American women's breast reconstruction decisions from their own perspectives. As with prior studies, we are interested in identifying potential treatment barriers that African-American women may face when trying to access breast reconstruction. However, in contrast to prior studies, we do not assume that reconstruction is the ideal (or lesser) choice, or that rates of reconstruction necessarily ought to be higher (or lower). Rather, we are interested in understanding the individual, cultural, and contextual influences on reconstruction preferences that are less likely captured in existing survey research. Culturally-derived beliefs and values may shape women's reconstruction decisions, as studies suggest that concerns in related domains – including norms related to appearance, sexuality, femininity – are culturally influenced (Becker, 1995; Settles, Pratt-Hyatt, & Buchanan, 2008; Wyatt et al., 1998), as are views of health, illness, and medical care (Whittle, Conigliaro, Good, & Joswiak, 2002). Furthermore, contextual influences such as social class can influence individuals' expectations, and ways of living and thinking about the world (Reid, 1993), and as such, may also affect preferences regarding reconstruction. However, while we widen the lens of prior research to include cultural and contextual influences, we are also cautious of the limits and potential harms of cultural explanations for health differences/disparities that ignore social and historical influences that shape culture, and the provision of healthcare (Mullings & Schulz, 2006).

Mastectomy, Breast Reconstruction, and Psychosocial Adjustment

Since Lorde (1997) first argued that pressure to wear a prostheses (whether external, or implanted) contributes to the secrecy and shame of breast cancer, feminist scholars have critiqued the normalization of breast reconstruction as necessary or essential to a woman's psychological recovery (e.g., Wilkinson & Kitzinger, 1993). Extant studies do not support claims that reconstruction is an "essential element" in breast cancer recovery, as some argue (e.g., Ceradini & Levine, 2008, p. 72). In fact, evidence suggests that women underestimate what their quality-of-life will be without reconstruction, and overestimate its benefits (Waljee, et al., 2011). In a systematic review of patient-reported outcomes after breast surgery, the majority of studies did not find significant differences in assessment of quality-of-life, or more specific measures of body image or sexuality/sexual functioning between women with mastectomy-alone or reconstruction (see Lee et al., 2009), although this research has been limited by the lack of valid and reliable breast surgery outcome measures (Pusic et al., 2007; Potter, Thomson, Greenwood, Hopwood, & Winters, 2009). Nonetheless, higher quality, prospective comparative studies such as Harcourt et al. (2003) (included in Lee et al.'s 2009 review), as well as Parker et al. (2007), reveal similar patterns of adjustment across surgical groups, with adjustment in all groups improving over time. The BREAST-Q, a new, validated patient-reported breast reconstruction outcome measure (Pusic, et al., 2009), will improve future research on quality-of-life, although instruments are still needed that enable comparative research between patients with reconstruction and mastectomy-alone.

The existing research does not negate the benefits of breast reconstruction for women who choose it, nor the potential importance of racial/ethnic differences in utilization. However, consistent null findings regarding differences in quality-of-life underscore the need to understand these differences before advocating for increased use. None of studies in Lee et al.'s (2009) review compared adjustment to mastectomy-alone versus reconstruction specifically among African-American women, and African-American women are poorly represented in existing research on breast reconstruction decision-making overall. This study will add African-American women's perspectives to the existing body of research, and provide a better understanding of the individual and cultural logics, as well as structural barriers, that influence African-American women's use of breast reconstruction. Our focus is on self-identified African-American women in order to follow up on trends identified through prior studies that organize their findings in relation to race/ethnicity. However, while we adopt use of this category, we do so with a cautious awareness of how it can gloss the significant diversity among African-American women. Our analysis attends to the shared social history and material consequences of racialized constructions in the US that impact African-Americans, as well as the diversity among women.

Method

Data analysis was guided by grounded theory methods, which we felt were most synergistic with our goal of better understanding lower rates of reconstruction among African-American women while (as much as possible) avoiding *a priori* ideas about the meaning and consequence of these differences. Grounded theory researchers initially emphasized social processes, whereas psychologists' more recent use of grounded theory shares features with phenomenological research in its emphasis on participants' experience (Willig, 2010). We felt that grounded theory would provide flexibility to examine both the experience of breast reconstruction decisions, while also investigating the processes and contexts of these decisions.

Sampling and recruitment

Women living in the New York City metropolitan area who underwent mastectomy for treatment of breast cancer after the WHCRA were invited to participate. Stratified purposeful sampling was used to ensure recruitment of socioeconomically diverse women with and without reconstruction. Participants were recruited from the following sites: (1) a private, comprehensive cancer centre; (2) a community-based cancer support organization serving African-American cancer survivors; and (3) a community-based patient navigation centre providing prevention, screening, and treatment services for uninsured or under-insured individuals. Eligibility criteria specified that participants self-identified as African-American; were 18 or older; and had undergone breast cancer treatment since implementation of WHCRA. Prospective participants were informed that the goal was to understand how women feel about breast reconstruction, and make surgery decisions.

Study procedures were approved by the cancer and navigation centre's IRB, and the first author's university-based IRB. At the private cancer centre, African-American women undergoing mastectomy who presented at the reconstructive surgery clinic were invited to participate (*n*=14). Some had reconstruction, and others decided against it after consultation. At the patient navigation centre, women who had undergone mastectomy were identified in a weekly treatment team meeting, and were invited to participate at their next appointment (*n*=6). Support group members learned about the study through the group's director, who distributed a recruitment flyer and collected names and contact information of women expressing interest, which was passed along to the research team (*n*=7).

Procedures

In-depth, semi-structured interviews were conducted with each participant in a private space at the clinic, nearby university, or patient's home by one of three female interviewers involved with the study. We strived to include interviewers whose backgrounds were similar to our participants along key dimensions of identity (e.g., gender, race/ethnicity, class) to facilitate comfort and connection. However, given the diversity of background and experiences represented among women in our sample, combined with our own reluctance to assume the importance of any one aspect of an interviewer's identity to this task, the most important selection criteria was the interviewers' sensitivity and skill. Interviews with participants recruited through the patient navigation centre were conducted by a research study assistant who worked at the centre, and who self-identified as Puerto-Rican. In addition, two interviewers, both of whom identified as African-American, conducted interviews with participants recruited from the private cancer centre and the cancer support group. All participants chose to be interviewed in English. All the interviewers had experience working in cancer research, but to our knowledge none had personally experienced a cancer diagnosis. All interviewers had experience, or received training, in qualitative interviewing. Interview questions were developed by the first author, in collaboration with the larger research team, and were informed by an extensive review of published empirical research and personal accounts of women's experiences of mastectomy and reconstruction. Interview topics included: experience of diagnosis and treatment of breast cancer; explanations of decisions to have/not have breast reconstruction; whether they received a plastic surgery referral; with whom they discussed treatment decisions; barriers to treatment/reconstruction; coping and support systems (family, community, religious); body image and sexuality; advice to other women and to physicians. The semi-structured, open-ended interview format gave participants the opportunity to add new domains to interviews to complete their stories and share important information, and our iterative approach allowed us to revise the interview protocol based on participants' feedback and redirection of focus. Participants received $50 compensation.

Data analysis

Interviews were audiotaped, and audio-files were transcribed by a professional transcription service and reviewed for accuracy. *ATLAS.ti* qualitative research software was used to organize data. Data analysis involved iterative processes of data collection, analysis, and conceptual development. A subset of initial transcripts was read by the first author and a team of four graduate students, and analysed using line-by-line coding. As new data were collected, emerging codes were modified through the constant-comparative method, leading to development of an initial codebook, then used to analyse the entire set of transcripts. Each transcript was coded by at least two independent coders. Coding discrepancies were first discussed in coding pairs, which were varied to prevent entrenched roles and hierarchies. The team met regularly to discuss unresolved coding discrepancies, which often presented opportunities to clarify and revise the working codebook. Team meetings were also used to develop a conceptual framework explaining the contexts and contingencies that shaped participants' reconstruction decisions. Although it is impossible to completely excise power differentials within a coding team, the research project was embedded within the context of a feminist research group that strives to be non-hierarchical. The first author endeavoured to provide necessary guidance about the research process without directing the analysis through strategies such as rotating the role of meeting chair.

Evaluative criteria were informed by Lincoln and Guba's (1985) concept of trustworthiness. Prior to coding, the research team discussed pre-existing assumptions. The investigators' different backgrounds – in psychology and plastic/reconstructive surgery – necessitated reflexivity regarding our beliefs, values, and assumptions pertaining to the research question. Strategies such as persistent observation and negative case analysis were used to ensure credibility. Data were collected until saturation.

Sample characteristics

Interviews were conducted with 27 women. Age at mastectomy ranged from 26–78 (mean =52.7 years). Time since mastectomy at the interview ranged from less than 1 month to as long as 8 years (median=10.5 months), with 85% of participants having had reconstruction within the past 3 years. Selected sample demographic characteristics are displayed in Table 1. Approximately 75% of women recruited from the community (support group and navigation centre) decided against reconstruction, whereas nearly two-thirds of women treated at the cancer centre opted for reconstruction. Reconstruction rates corresponded with income. Among participants reporting annual income <US$20,000, 22% had reconstruction, compared with those reporting income between $US20-49,999 and those reporting > $US50,000, where rates of reconstruction were 44% and 75% respectively (*p*= .09). Income and age were entwined, such that women reporting income less than <$US20,000 were older (mean age=58.7) than those in the other two income groups (54.38, and 42.8, respectively). Eighty-five percent of the sample reported religion and/or spirituality as "very important" in their lives, with all others describing religion as "quite" or "somewhat important."

Findings

Reasons for not having breast reconstruction

Although there was no single decision or treatment trajectory among women without reconstruction, our findings illustrate commonly held concerns about breast reconstruction, or aspects of it, that shaped women's deliberations.

Implants and medical (mis)trust—As noted earlier, reconstruction options are either implant surgery (saline or silicone), autologous tissue reconstruction, or a combination of these. Among participants, particularly those recruited from community-based sites, concerns about implants were ubiquitous. Several participants described fears of implant rupture and leakage:

> We went to different classes trying to figure out what to do. The silicone felt very, very good but there's the story about [how] it can open up and leak into the person’s body. (No Reconstruction [NR], Age 66, Cancer Centre)

> He told me if I had a reconstruction, they would give me a tummy-tuck, or I could have implants. Implants was definitely a no-no. I heard a lot of things about them bursting and stuff. I didn’t want any of that. (NR, Age 60, Support Group)

Other participants worried that implants would interfere with detection of cancer recurrence:

> I always figured if cancer should recur, it might be a little bit more difficult to detect if I have implants. That’s what really made up my mind. And I was also afraid that having that inside… could create problems. (NR, Age 57, Support Group)

The American Cancer Society (American Cancer Society, 2012b) indicates that implants rarely, if ever, conceal recurrence. Thus, while this statement might be construed in survey research as ‘misinformation,’ this participant was emphatic that she was well-informed:

> [my doctor] told me it wouldn’t be like I’m thinking…they could find it just as well and easy … he really, really reassured me of that, but in the back of my mind, I just couldn’t— something was telling me not to go through that. (NR, Age 57, Support Group)

Patients may be well-informed, yet still not trust the safety of implants. Despite reassurances, this participant sides with her instincts.

There is now a significant body of research documenting how medical mistrust – a response to the long history of exclusion and medical experimentation on Blacks in the US – impacts healthcare utilization (e.g., Musa, Schulz, Harris, Silverman, & Thomas, 2009). In the case of breast implants, prevailing questions about trust in medicine within the African-American community may intersect with widely publicized controversies regarding the safety of siliconegel-filled breast implants (Angell, 1996). In 2006, the FDA lifted its 14-year moratorium on silicone-filled implants for breast augmentation (silicone implants were already available for breast reconstruction) (Saul, 2006); however, patients may still feel reluctance. Speaking generally about trust in healthcare, one participant explained:

> Being Black… we don’t trust the medical profession. We figure they use us as guinea pigs… look at what happened at Tuskegee. So we don’t go to the doctor. If you have problems, you try to deal with it yourself. …It’s really hard for Black people to trust… it’s something that’s been imprinted in us from the time of slavery. (NR, Age 59, Cancer Centre)

Concerns about implants were captured by the oft-repeated refrain of wanting “nothing foreign” in the body.

> I don’t believe in implants…I don’t want anything foreign in my body that I don’t need foreign. (ATR; Age 26; Support Group).

Implant concerns have been documented in other studies (e.g., Reaby, 1998), and are not unique among African-American women. However, the consistency in how participants expressed concern about “something foreign” is noteworthy, and fits with national surveillance data indicating African-American women receive proportionally more autologous reconstruction than women in other racial/ethnic groups receiving reconstruction (Alderman, et al., 2003).

Body ethics—In addition to being related to concerns about implant safety, concerns about “something foreign” in the body were tied to participants’ values and beliefs about care and treatment of the body that guided what types of procedures they would accept:

> I was going into surgery…to remove a foreign antibody… to consider putting something else foreign in my body was just something I could not accept. (Autologous Tissue Reconstruction [ATR], Age 26, Support Group)

> I wouldn't want to put any foreign thing in my body unless it's ultimately [necessary] for life. (NR, Age 60, Support Group)

Participants’ talk about breast implants, and plastic surgery in general, echoed themes identified in prior research exploring body image among African-American women, such as the ethic of body acceptance (Rubin, Fitts, & Becker, 2003; Parker, et al., 1995). One participant, contemplating the lower rates of reconstruction among African-Americans, explained:

> Black people are just more satisfied with their appearance than White people… we’re more forgiving. (Implant Reconstruction [IR]; Age 39; Cancer Centre).

Or, as another explained:

> White women…they always get implants of some sort. They always want bigger breasts, cause the White male, that’s what they look at…in the Black community the butt is the centre of attraction. That’s what attracts men …they’re not looking at your breasts. But White women… they don’t have butts, so they love breasts. And that’s why, I think, White women love implants. (IR; Age 28; Cancer Centre)

Echoing other qualitative studies of body image and health meanings among African-American women, an ethic of body acceptance, informed by the notion that the body is ‘a beautiful gift from God’, (Abrums, 2000, p. 98; see also Odoms-Young, 2008), informed participants’ reconstruction decisions:

> They spoke about implants, but being African-American, and Pentecostal Holiness…I believe in pureness of the body…everything natural. I had dreads, which is natural, no chemicals, no nothing. … I just got a way of more into the naturalness of the beauty… Whatever God says, that’s what it is, that’s where my heart is at. (NR, Age 54, Navigation Centre)

Whereas for some participants, this translated into a rejection of all reconstruction, including tissue transfer surgeries:

> Why take some part of me, to relieve something that was taken away that God said has to be gone? (NR, Age 52, Support Group)

For others, it was not reconstruction per se, but specifically breast implants, which were problematic.

> Use me. Use my flesh … Give me the natural thing. Use what God has given me, use whatever tissues, take it from the thighs…take it from the back, but use my stuff… I don't want nothing, no more foreign stuff put in me. (NR, Age 58, Support Group)

> He's like, 'we can use your skin'. That made me want to do it. (ATR, Age 26, Support Group)

> I was concerned whether or not, would it be acceptable to God?… would it be… tampering with God's work? I started reading the Koran and the Bible to find out. (NR, Age 50, Navigation Centre)

"I've been through a lot"—Whereas autologous reconstruction was generally viewed as more consistent with participants' body ethics, other aspects of this surgery, including its more extensive recovery and greater time under anaesthesia, were significant drawbacks. Indeed, one commonly cited reason for deciding against reconstruction was a reluctance to undergo further surgery, and concern about pain, recovery, and surgical outcomes.

> I had been through a lot of surgeries for other stuff. I just didn't want any more cutting unless it was absolutely necessary. (NR, Age 60, Support Group)

> When he explained everything to me, that they would be moving muscles and that would make the pain more in my behind, I thought, hmm, pain in the chest, pain in the butt all at the same time? … I've seen others … it looks okay, but nothing to write home about to go through all that pain. (NR, Age 57, Support Group)

> Considering the stomach and the cutting and shrinking and all that, this seems to me like it's a lot of surgery to go through…and not ensuring it's going to work out. (NR, Age 66, Cancer Centre)

As a group, African-Americans face a greater disease burden (Whitfield, Weidner, Clark, & Anderson, 2002). Prior and concurrent illnesses – including HIV/AIDS, diabetes, asthma, and hypertension – were part of the lived experience of many study participants.

> I have been in and out of the hospital… pneumonia…kidney stones… osteoporosis…It's just a lot going on with so many different things. And I am also HIV positive. (NR, Age 44, Cancer Centre).

> I wanted that [autologous reconstruction]… but given my age and I have high blood pressure, he didn't advise me to stay under anaesthesia that long. (IR, Age 64, Cancer Centre)

Avoiding further surgery is a common reason to decide against reconstruction (Reaby, 1998), not one unique to African-American breast cancer survivors. However, this may be a particularly salient theme among women across ethnic groups already burdened by prior illnesses.

Reasons for electing breast reconstruction

That many participants were disinclined to use breast reconstruction for personal, historical, cultural, and medically salient reasons does not mean they were unfazed by bodily changes associated with mastectomy. Participants struggled to adapt to their changed bodies, with some opting for reconstruction to help with this adjustment, and some not.

Feeling normal—The most prominent reason offered by participants electing reconstruction was a desire to look or to feel "normal."

> Just to look normal again…like a normal human being and not some freak animal… when [you're] naked and looking at the mirror, you don't see the same person…It takes a toll. (IR, 37, Navigation Centre)
>
> I felt that I have got back my life, like any other women. I feel equal again, like anybody. (IR/ATR, 54, Cancer Centre)

These participants experienced significant self-consciousness – feeling like a "freak," or less than other women – as a result of their mastectomy. As Kaiser (2008) notes, an irony of the mainstream breast cancer survivorship movement is that women are expected to proudly proclaim their survivorship status, while simultaneously "passing" as unaffected by concealing markers of illness or treatment. "Getting back to normal" held a variety of meanings for participants, including the appearance of a healthy or unaffected body, as well as the reconstruction of an unaffected (i.e., not ill) life (see also Denford, Harcourt, Rubin, & Pusic, 2011).

For Lorde (1997), "the primary challenge at the core of mastectomy was the stark look at my own mortality" (p. 62). Reconstruction may enable distance from reminders of cancer. This may be particularly important for mothers of young children, who must balance awareness of mortality brought on by cancer, with their immediate care-giving needs. One participant with two young children discussed breast reconstruction as a way to restore normalcy for her children. She notes that when her three year-old daughter asked, "*When are they going to put back your breasts?*" she decided, "*My kids, I want them to see me as normal as possible*." (IR, Age 28, Cancer Centre). In contrast, others questioned whether breast reconstruction could restore normalcy:

> I know it's not going to be like a normal breast with no imperfections. If can't be perfect, I ain't worried about it. (NR, Age 60, Support Group)

Moreover, for a select group of participants, being 'one-breasted' or 'breast-less', served as a difficult yet positive reminder of their struggle – an affirmation of life and spirituality after a brush with death. As one participant explained:

> This is how God allowed me to survive…with no breasts. This is who I am, and this is how I am…. I have not worn a prosthetic since the second surgery. I'm just breast-less. (NR, Age 42/47, Support Group).
>
> I walk around, people look at me as if I'm disformed or whatever. But I let them know that I'm alive. It came. I'm a breast cancer survivor, and this reminds me of my struggle. (NR, Age 54, Navigation Centre)

Age—Notably, all six study participants who were under age 40 at the time of their cancer treatment had reconstruction, and younger women were more likely to have reconstruction recommended to them. “Older age” was offered as a reason not to have reconstruction among women spanning a wide age range, from 47 to 70. Breast cancer is an ‘off-time’ health event for young women (Wurm, Tomasik, & Tesch-Römer, 2008), and studies indicate that they tend to have more difficulties with adjustment and distress (Avis, Crawford, & Manuel, 2005). As several younger participants explained:

> I’m still fairly young, so I want something there…I didn’t have a problem losing the breasts, but I just wanted something there. (IR, Age 28, Cancer Centre)

Whereas some women felt their (younger) age necessitated reconstruction, for others it was their physician who made the recommendation:

> In the beginning, I didn’t want reconstruction…[after] chemo and all that stuff…I just want it over…to get back to my life instead of continuously going to these appointments every week.
>
> Interviewer: *What tipped the scales for you?*
>
> *I think my doctors …one sat down, he said, ‘Listen, you are a young lady. Summertime is coming. You may think now that it doesn’t matter, but it is going to matter to you once summer is here and you can’t wear that red tank’… I thought about it and I said yeah, I think he’s right…I didn’t think it mattered, but I’m glad I’m doing it*. (IR, Age 35, Cancer Centre)

This anecdote raises complicated questions: Did this physician help her make a better long-term decision, one that was difficult to consider when she was overwhelmed by cancer treatment? Or was *his* construction of femininity imposed on her, making breast reconstruction ‘matter’? The patient reports feeling glad to have reconstruction; however, we cannot know how she would feel had she decided against it.

Appearance—Other reported reasons for reconstruction included breast symmetry, dissatisfaction with external prostheses, and desire for a wider range of clothing options.

> I always said if I ever got breast cancer I wouldn’t go with any reconstruction…But what made me change my mind was my breast is so large … just to have one, it’s too unbalanced. (IR, Age 64, Cancer Centre)

Several participants expressed dissatisfaction with external prostheses, particularly in relation to clothing and fashion. This frustration prompted one participant, who initially decided against reconstruction, to reconsider:

> I couldn’t wear certain outfits…no matter what they did with the prosthesis. Basically, I was thinking that if I wear anything off my shoulders, I might want some breasts to hold [it] up. (ATR, Age 26, Support Group)

Her dissatisfaction was exacerbated by the fact that she could not find prostheses matching her skin tone.

> At the time I was diagnosed, the prosthesis only came in one colour, which is Caucasian. They didn't come in African-American too much.

Another participant, still considering a delayed reconstruction, explained:

> The bras you buy… to put your prosthesis in, they only come in beige, black, and white …. I've invested too much money in my pinks, my greens, my yellows, my oranges, my reds, my blues, my lilacs…do I want to go through life with just beige, white, and black? (NR, 58, Support Group)

This participant, a self-described "woman of fashion," feared breast cancer would relegate her to a life in neutrals. Although even with reconstruction she may not be able to make use of her extensive bra collection, she speaks to the importance of developing fashion options for women post-mastectomy, with or without reconstruction. As another participant suggests:

> I'm just getting tired of going shopping and having such a difficult time… somebody needs to make clothes for women who have had mastectomy and choose not to wear anything. (NR, Age 42/47, Support Group)

Socioeconomic Status and Insurance coverage—Although none of our participants spoke explicitly about the influence of socioeconomic status (SES) as an influence on their reconstruction preferences or decisions, women in our study with higher income were more likely to have reconstruction. The influence of SES is clearly important, though perhaps through more complicated pathways than simply limiting access. Among patients without reconstruction, neither lack of insurance coverage nor limited access to reconstructive surgeons was identified as a barrier to reconstruction. However, insurance coverage did facilitate access to reconstruction among participants who had or were planning reconstruction.

> I was wondering, who's going to pay for the reconstruction? The doctor said, 'the same insurance that paid to have it removed.' For me, it's Medicaid…Since they'll pay for the reconstruction, I'll have it done. (Plan for future IR, Age 50, Navigation Centre)

> If I didn't have insurance probably I wouldn't have done the reconstructive surgery….because financially I wasn't going to be able to…that surgery is big money. (IR, Age 57, Navigation Centre)

However, returning to the discussions of age and disease burden, the poorest women in our study were also the oldest, and beyond their breast cancer diagnosis, faced a greater disease burden. While insurance coverage is clearly essential to many women's ability to access these procedures, legislation promoting access to breast reconstruction such as the WHCRA may not address the complex pathways through which SES influences utilization patterns, which may include age-based preferences, contraindications due to other health concerns, or beliefs and values regarding medical care associated with being poor which, as Reid (1993) argues, psychologists should consider not merely as a research variable, but a life context that influences varied dimensions of women's daily existence.

In contrast to studies of breast reconstruction utilization post-WHCRA, no studies have investigated the adequacy of WHCRA in relation to women's access to external prostheses, even though breast prostheses should be covered by WHCRA, an issue raised by one participant:

> Interviewer: Did they talk to you or have you investigated whether your insurance would cover surgery if you did-
>
> Participant: Oh, yeah. Which makes me very upset because they'll cover all of that money for the surgery, and when I went to get my prostheses, they would only put out $41, something like that…With the bra, it came to 300--no, $400, something like that. And when I turned it into them, they sent me back $41. But they'll pay thousands of dollars for me to have reconstruction plus to have the other breast done over to make it equal. It doesn't make sense… I'm getting cheated. (NR, Age 57, Support Group)

Describing trends in (bio)medicalization, Clarke, Shim, Mamo, Fosket, and Fishman (2003) note, "innovations accumulate over time such that older, often 'low(er)' technologically based approaches are usually simultaneously available somewhere, while emergent, often 'high(er)' technoscientifically based approaches also tend over time to drive out the old" (p. 166). Inadequate insurance coverage, and the dearth of prostheses in non-White flesh tones, illustrates 'stratified biomedicalization', or what Clarke et al. (2003) describe as the uneven spread of technoscientific interventions, such that "while some protest excessive biomedical intervention into their lives, others lack basic care" (p. 170). Concern about access to breast reconstruction should be accompanied by demands for basic postmastectomy care.

Discussion

Despite a growing literature in medicine and epidemiology examining factors that contribute to African-American women's lower reconstruction rates, to our knowledge this is the first study to examine African-American women's reconstruction decisions qualitatively, through a patient-centred lens. The framework of extant research reflects the technological imperative – namely, that because reconstruction exists, it ought to be used – and concludes that racial/ethnic differences in reconstruction must represent a health disparity. Our findings shed light on African-American women's lower rates of breast reconstruction by highlighting the cascading influences – individual, religio-cultural, medical, and structural – that direct and sometimes delimit women's reconstruction decisions and options. For women in this sample, access per se is not the primary concern. However, interpreting apparent racial/ethnic differences in healthcare preferences is complex (Armstrong, Hughes-Halbert, & Asch, 2006). Situating our findings within both concerns about disparities as well as critiques of normalization, we suggest that a framework of 'stratified biomedicalization' may better capture the complex gendered, classed, and racialized dimensions of breast cancer care that may influence differential use of 'low' and 'high' postmastectomy technologies. Drawing on the work of Ehrenreich and Ehrenreich (1978) and Morgan (1998), Clarke et al. (2003) note the long-standing dual tendencies of (bio)medicalization to both co-opt and exclude. In contrast to a disparities framework, 'stratified biomedicalization' opens possibilities of complex forms of participation and resistances.

Whereas some participants, particularly younger women, sought breast reconstruction as a way to look and feel “normal,” others challenged the imperative to reconstruct, or questioned the disparity in resources available for reconstruction without comparable attention to non-surgical options. Particularly among women recruited from community-based care centres, we heard resounding concerns about the use of breast implants. Concerns about the safety of breast implants are not uncommon (Reaby, 1998), and given the legacy of medical mistreatment in the US, African-American women may be particularly reluctant to accept the FDA, physicians’, or manufacturers’ claims about implant safety. But concerns about implants extended beyond mistrust; rather, they were framed in terms of spiritually-based body ethics. These findings resonate with prior studies emphasizing body acceptance as a core body ethic among religious and/or spiritually identified African-American women (Odoms-Young, 2008; Parker et al., 1995; Rubin, et al., 2003). For some participants, a changed body was a difficult but important reminder of struggle, strength, and faith. For women seeking reconstruction, body ethics influenced their reconstruction type, often as a preference to use “*what God has given*.” For women endorsing a spiritually-based body ethic, “being natural” was as much a part of feminine beauty ideals as having, or not having, reconstructed breasts. These findings may help to explain why African-American women receive proportionally more autologous tissue reconstructions than women in other racial/ethnic groups (Alderman, et al., 2003). On the other hand, only highlighting these trends belies the significant within group diversity among African-American women in terms body acceptance also documented within research (e.g., Sabik, Cole, & Ward, 2010).

For women interested in reconstruction, concerns about implants meant a more limited set of surgery options, which may also contribute to lower reconstruction rates. Some women ruled out autologous reconstruction because of the more extensive surgery and recovery time required, or had medical illnesses that complicated or disqualified them from it, including hypertension, diabetes, HIV, and other health issues that disproportionally affect poor and ethnic minority women. None of the participants in this study reported difficulty accessing reconstruction, although insurance coverage did facilitate receipt of reconstruction for those that desired it. Although it did not emerge directly in our study, it is possible that structural factors influenced women’s receipt of reconstruction.

As the study’s key investigators worked either within a university or an academic medical setting, our analysis was enriched by an invitation to present preliminary findings at the patient navigation centre – our site for recruiting the poorest and most under-served women included is the study. While presenting to a group of patient representatives, patient navigators, research assistants, physicians, and a staff social worker involved in providing patient care at this site, we learned of difficulties coordinating care for women preferring autologous reconstruction at under-resourced hospitals without on-staff plastic surgeons. Although the WHCRA mandates coverage for reconstruction, it “does not prevent a plan or health insurance issuer from negotiating the level and type of payment with doctors” (ACS, 2010). Rates of physician reimbursement by surgical time are lowest for autologous tissue reconstructions (Alderman, Storey, Nair, & Chung, 2009). Thus, it is possible that women who prefer autologous reconstruction – with African-American women over-represented in this group – will reap fewer benefits from the WHCRA than women who prefer implant reconstruction. Even in urban settings where there are more plastic surgeons with specialized expertise in these procedures, access may be stratified based on where women receive care, and the level of reimbursement provided by their particular insurance plan. Physicians in resource-poor hospitals likely face more barriers in scheduling immediate autologous reconstruction (which can require coordination of multiple surgeons), and may discourage these procedures. Further research is needed to examine these potential biases and barriers, and our experience presenting findings to the patient navigation centre highlights how representing the perspectives of clinicians working in under-resourced medical settings, who may be less likely to participate in research and academic publishing, may introduce valuable new knowledge to research on health differences and disparities.

Limitations

Although our study yields important insights into reconstruction decisions among a diverse sample of African-American women, certain limitations should be noted. While our use of grounded theory methods, our reflexive stance, and our use of a semi-structured, open-ended interview protocol were all practices aimed at gleaning meaning from participant narratives deriving from their own experiences rather than from *a priori* theory or assumptions, greater use of participatory methods would have furthered this aim. Participant involvement in study planning, development of the interview protocol, and data analysis would have allowed participants to shape the project to address areas they found most meaningful and add their perspectives to the process of making meaning out of the results.

This research was conducted in one metropolitan area in the United States with a sample of English speaking women and may not reflect attitudes about, or access to, breast reconstruction among women in other contexts. Patients in urban settings may have more healthcare options, including greater access to reconstructive surgeons. A multitude of factors, including differences in healthcare systems, barriers to citizenship status, and accessibility of healthcare for linguistic minorities undoubtedly influence healthcare access and utilization among minority populations in other countries. The specific history of African-Americans in the United States, especially in healthcare and medical research, limit the direct applicability of our findings to other groups among the African diaspora. Nonetheless, quantitative research on attitudes toward cosmetic surgery in the United Kingdom suggests that, compared to White British women, Afro-Caribbean British women may be less accepting of cosmetic surgery (Swami, Campana, & Coles, 2012), and ethnic identity salience, adherence to traditional values, and cultural mistrust may be associated with negative attitudes toward cosmetic surgery among Afro-Caribbean British women (Swami & Hendrikse, 2012). If reconstructive surgical preferences are governed by the same aesthetic concerns as cosmetic surgical preferences, these findings might also apply to attitudes about reconstructive surgery. Qualitative research could help to determine whether the “traditional values” assessed by Swami and Hendrikse (2012) may include cultural beliefs about the care and modification of the body that influence attitudes toward postmastectomy breast reconstruction. Our findings regarding religious and spiritually based body ethics, drawn from a sample of women for whom religion and spirituality were very important, may be less relevant in global contexts or among African-American women for whom religion and spirituality are not as important.

The study's retrospective design, and the relatively wide range of time since mastectomy across interviews, from approximately one month to eight years, is another limitation. Studies indicate that psychological adjustment generally improves over time (Harcourt et al., 2003; Parker et al., 2007). Women treated several years in the past have had more time to adjust to cancer-related changes, or alternatively to seek delayed reconstruction. Women without reconstruction whose mastectomies were more recent were more likely to still be considering breast reconstruction as a future option when compared to women who had lived longer without reconstruction. As views about reconstruction are likely to change over time through adjustment processes, our findings are limited to the meanings women have made about their breast reconstruction up to the time of the interview, and these meanings may be continually revised over time. Moreover, study participants were self-selecting, and the attitudes of participants may be different from women who decided to not participate.

Conclusion

Theorizing about cosmetic surgery, Braun (2009) suggests that although 'choice' is not entirely culturally determined, "clusters of cultural logics lead to particular desires, options and choices, as well as rationales and justifications for actions (and indeed interpretations of, and responses to, them)" (p. 243). Breast reconstruction is an elective surgery, and while it is an important option for those who want it, there is no evidence of diminished adjustment for those who decide against it. We suggest a framework of 'stratified biomedicalization', rather than a presumption of disparity, better addresses the complexities of race, class, and gender that inform preference, access, and recommendations for breast reconstruction, and focuses on attention on access to high *and* lower-tech interventions. Rather than aiming to increase reconstruction rates, a better measure of care is the extent to which women are able to access breast reconstruction *if* they want it, *when* they want it, and *how* they want it. This includes access to autologous reconstruction, as well as ensuring appropriate supply and reimbursement for non-surgical options, such as external prostheses. While ensuring equal access is essential, a social justice approach to breast reconstruction must begin with women's own preferences, rather than imposed assumptions and ideals.

For psychologists who work with women making decisions about breast reconstruction, the task is to open a non-judgmental space for women to articulate their own ideas about the mastectomied body and breast reconstruction, and help women weigh risks and benefits relative to their own values and preferences. Well-intentioned clinicians might feel inclined to particularly encourage reconstruction among ethnic and racial minority women to counter assumed healthcare disparities and promote utilization of cutting-edge technologies among otherwise under-served patient groups; however, knowledge of the current evidence-base regarding quality-of-life outcomes with breast reconstruction and with mastectomy-alone, including the lack of evidence for better outcomes with reconstruction, can help refocus these efforts to a more patient-centred approach. We suggest that clinicians examine their own assumptions about mastectomy and well-being, and build dynamic, individualized understandings of how each woman adopts and applies cultural ideas about the body. A similar self-reflexive action would benefit health psychology researchers, as normative assumptions about race, class, gender, and disability merge with values of biomedicine can readily influence the breast cancer research agenda.

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Table 1

Sample characteristics

	Support Group (n = 7)	**Navigation Center (n = 6)**	**Cancer Center (n = 14)**
Mean age at mastectomy (range)	50.6 (26–50)	57.5 (37–78)	49.9 (28–67)
Reconstruction [a]			
Yes	1	2	9
No	6	4	5
Income median[b]	$30–49,999	$10–19,999	$30–49,999
Health insurance			
None		1	1
Medicare/Medicaid	1	5	3
Private	6		8
Unspecified			2
Relationship Status			
Single	3	3	7
Married/partnered	3	1	6
Widowed	1	1	1
Unknown		1	

[a] Mean for entire sample =52.7.

[b] Median for entire sample =$30–49,999.