Ethical Challenges and Lessons Learned from Qualitative Research with Low-Income African American Women Living with HIV in the South

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Abstract

African American women living with HIV (WLWH) in the U.S. South encounter heightened marginalization due to the complex intersections of race, gender, poverty, and HIV status. Social vulnerabilities experienced by individuals and communities in daily life have the potential to sharpen ethical tensions in the context of research. Thus, conducting ethical research requires attention to the contextual challenges and concerns of diverse research populations to tailor participant protections to a particular sociocultural context. Using principles from the Belmont Report, the present report draws on data from a qualitative study with 42 African American WLWH in the South by highlighting the first author's accounts of ethical challenges that emerged during data collection. Findings suggest that engaging participants in their natural environments can inform the development of ethical research strategies germane to women's lived experiences. Study findings also contribute to empirical guidance for investigators engaging marginalized populations in scientific research.

African American women in the U.S. South experience disparate HIV-related health outcomes, compared with their counterparts in other areas.[1] Among women in the region, African Americans account for a substantially greater proportion of HIV diagnoses than

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other racial/ethnic groups.[2] Once diagnosed with HIV, African American women are also less likely than White women to achieve viral suppression.[3] Various contextual circumstances underlie the susceptibility of African American women in the U.S. South to these health outcomes.[4,5] For marginalized populations, social and structural inequities are implicated in amplifying the risk for HIV.[2,6–8]

The HIV-related health disadvantages faced by African American women in the U.S. South coincide with geographic and social patterns of other disease burdens. Among other public health disparities, the U.S. South is marked by lower life expectancy than other regions, the highest prevalence of diagnosed diabetes,[9] and the highest heart disease mortality.[10] Several systemic disadvantages heighten adverse health experiences for individuals living in the U.S. South. Historical legacies of stigma are manifested in income inequality,[11] racial residential segregation,[12] and medical, ethical, and other injustices.[13] The legacies of stigma are also associated with constrained choices that proliferate health risks. In particular, slavery in the U.S. South had numerous health consequences, in addition to economic, social, and political consequences, for the people who were enslaved and for their descendents. The health systems landscape is plagued with similar disparities, with lack of insurance, underinsurance, and policies that hamper access to care concentrated in the South.[14–16]

African American women in the U.S. South face the potential for health disadvantages related to their geographic location, minority group membership, and other social statuses.[17] African American women living with HIV (WLWH) in the U.S. South are positioned at the intersection of multiple, coexisting statuses (i.e., HIV status, race, sexual orientation, gender, and other categories), which are structurally embedded within social, economic, and other hierarchies that create, compound, and perpetuate health inequities.[12] Research among WLWH suggests that HIV-related stigmas and their health consequences are exacerbated for groups experiencing coexisting stigmas (e.g., racism, sexism, transphobia, and mental health stigma).[18] The same forms of oppression and marginalization limit women's ability, desire, and motivation to access health care tools—including medical advances such as HIV prophylaxis and antiretroviral therapy—and produce disparate health outcomes.[19]

Ethical challenges: HIV disparities research with marginalized populations.

Ethical engagement of populations unjustly burdened by poor health outcomes[20] in scientific research is a national public health priority for reducing profound disparities in health status at the population level.[21] HIV disparities research aims to understand and reduce racial/ethnic, geographic, and socioeconomic differences in HIV outcomes; as such, many populations of focus in this research include individuals who are disadvantaged by economic, social, and political systems. The intersections of social vulnerabilities such as racism, classism, and geographic location, and HIV status can potentially sharpen ethical tensions in the context of the research process and reinforce existing social power dynamics. In addition to barriers to research participation (such as scheduling difficulties, lack of transportation, and other logistical challenges resulting from scarce resources among economically disadvantaged communities[22]), some contend that a lack of economic resources, health insurance, and health care access heightens vulnerability to unethical research study practices.[23] To no surprise, much of the documented U.S.-based research

study exploitation exists among low-income, racial/ethnic minority populations residing in the South.[24] Thus, conducting ethical research requires attending to the contextual challenges and concerns of diverse research populations in order to tailor participant protections to particular sociocultural contexts.[25,26]

Despite thorough procedural preparation required by the institutional review processes, unforeseen ethical dilemmas may arise when engaging populations in research. This may be especially relevant for qualitative research encounters, given the immersive and constructivist nature of this approach.[27] For example, understanding a phenomenon in qualitative research can be achieved by engaging participants in their natural environments by talking to them, visiting their homes or places of work, and allowing them to tell their stories.[28] However, immersive engagement and interaction with individuals in their everyday environments can present unexpected ethical challenges for investigators. This is especially true for HIV investigators who must be attuned to the safety, confidentiality, and economic needs of study participants in research interactions. Qualitative research with African American WLWH provides an opportunity to understand and document ethical dilemmas in the context of the research process.

The Belmont Report, established in 1974 by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, identifies ethical principles and guidelines to address ethical issues arising from conduct of biomedical and behavioral research with human subjects.[29] The Belmont principles—respect for persons, beneficence, and justice—provide a constructive lens for highlighting ethical dilemmas in the research process and conceptualizing participant stigma, marginalization, and vulnerability within the research context. Utilizing Belmont principles, the present report draws on data from a qualitative study with 42 African American WLWH by highlighting the first author's accounts of ethical challenges that emerged during data collection. The guiding ethical principles provide a useful framework for describing ethical tensions in qualitative research. The aims of this report are: 1) to describe ethical challenges and lessons learned related to conducting qualitative research with African American WLWH, and 2) to make recommendations to improve ethical research practices for engaging African American WLWH in qualitative research.

Methods

The current study draws from a larger, qualitative study focused on pregnancy experiences, motherhood, multi-level HIV stigma, and lived experiences of African American WLWH.[30,31] Semi-structured, in-depth interviews were conducted between 2009 and 2010 with 42 African American WLWH residing in South Carolina. The study employed a qualitative phenomenological research design. The goal of this design is to describe and understand the realities of persons experiencing a shared phenomenon, or to discern a universal essence from participant's experiences collectively.[28] We employed a qualitative approach with African American WLWH to "empower women to share their stories, hear their voices, and minimize the power relationships that often exist between an investigator and research participants."[28[p.40]] Moreover, we sought to gain a deeper understanding of women's physical and social contexts by capturing their experiences and perspectives.

Recruitment took place in clinics, AIDS Service Organizations (ASOs), and community-based settings. Eligibility criteria included self-identification as an African American female and self-reported HIV/AIDS seropositive status, 18 to 49 years of age; ability to speak English, and residence in South Carolina. With respect to the broader study, participants were excluded if they reported being unable to become pregnant because of natural causes, use of an implanted contraceptive device, or prior sterilization procedures. The first author, a self-identified African American female trained in qualitative interviewing techniques, conducted all interviews. Study participants received $25 for completing the demographic questionnaire and participating in the interview. The Institutional Review Board of the University of South Carolina reviewed and approved the protocol. See parent study manuscripts for further study design and procedural details.[30,31]

To guide the current analysis and categorize encountered ethical dilemmas, we used the principles from the Belmont Report—respect for persons, beneficence, and justice.[29,32] Respect for people incorporates two ethical tenets: 1) individuals should be treated as autonomous agents, and 2) individuals with diminished autonomy are entitled to protection to prevent exploitation. According to the Belmont Report, autonomous individuals are individuals who have the capacity to make their own decisions.[29] Beneficence is defined as the investigator's moral obligation to ensure the well-being of the research participant. Beneficence rests on two actions: 1) do no harm, and 2) maximize possible benefits and minimize possible harms.[29] Justice seeks to ensure that the potential risks of research are distributed equally among all members of society with consideration to: 1) equity in research subject selection to avoid overburdening particular groups of people, especially those unlikely to benefit from research; and 2) equitable distribution of benefits resulting from scientific discoveries.[29]

Data analysis.

Participant recordings were transcribed and de-identified. Two coders independently analyzed interview transcripts employing both inductive and deductive strategies with NVivo 11.1.1 software.[33] For the current study, an initial codebook[34] was informed by ethical themes from Belmont principles and field notes and observations resulting from ethical dilemmas germane to the interviews. Key codes included: respect for persons, beneficence, justice, vulnerability, benefits, harms, informed consent, decision-making, stigma, and ethical dilemma. The codebook was refined and finalized through an iterative process. The final codebook was used to analyze data from interviews by identifying emerging themes, ideas, and perceptions from open-ended responses. All coding differences were resolved after consensus was achieved.

Results

Given initial barriers to study recruitment in the parent study, the first author revised the IRB protocol to conduct interviews in a "mutually agreed upon site that provided both the interviewer and participant with privacy, comfort, and convenience." Interviews with 42 participants were conducted in various locations, including: clinics/ASOs (n=19); participants' homes (n=12); university office (n=2); first author's car (n=8); and hospital

room (n=1). In this report, we highlight the most salient ethical dilemmas germane to conducting interviews in different settings utilizing the principles from the Belmont report. The following case studies are based on interview transcripts and field notes and highlight the most salient themes identified during analysis. To protect the identities of study participants, demographic information is not reported, and pseudonyms are used throughout.

Case #1: Interview with Sandy in her hospital room and in the presence of her husband.

Sandy contacted me early one morning about scheduling an interview. I agreed, and asked her to identify an interview location that provided her with privacy, comfort, and convenience. Sandy explained that she was pregnant, nearterm, and admitted into the hospital. She suggested her hospital room as the preferred interview setting. In light of her pending delivery, I suggested delaying the interview. However, Sandy explained that she was admitted into the hospital for monitoring, but felt fine. She added that this was the best time for her to complete the interview because she had nothing else to do. Although I had reservations about interviewing Sandy in the hospital, I agreed to meet her there to assess the situation. When I arrived, Sandy was in good spirits and seemed to be doing well. After explaining the interview process to Sandy, assessing her level of agreement/consent with the interview plan, and observing the potential interview setting, I was reassured and did not believe that the interview setting posed any risks to her. Sandy's husband was also in the room. I expected that he would leave the room before we commenced the interview. When I realized that Sandy's husband intended to stay, I explained to Sandy that the interview contained sensitive questions and that it was best for her husband to leave the room so that she could speak freely. She responded by saying that anything she shared with me, she could share in front of her husband. Sandy also informed me that her husband was aware of her HIV status. Her husband confirmed that he was informed of his wife's status. Despite my concerns related to conducting the interview with Sandy's husband present, I commenced the interview with Sandy under the circumstances that she preferred.

Case #2: Interview with Shelly in my car.

Shelly was my first scheduled home interview. Per conversations with women and clinic staff, I was advised to visit women's homes to mitigate transportation barriers. I looked forward to conducting Shelly's interview in her everyday environment. When I arrived at Shelly's home, she came to the door and immediately stated that I could not enter her home. I didn't fully understand as Shelly initially recommended her home for an interview. Since I was no longer welcomed in Shelly's home, I asked for other interview location suggestions; she immediately recommended my car. I said okay. We walked towards my car, which was parked in front of her house. As soon as Shelly entered my car, she pulled out a cigarette and began smoking. It was close to 100 degrees that day, and I couldn't open the windows because I knew the background noise would interfere with the audio recording. I was slightly irritated by the smoke, but understood that many WLWH smoked as a coping mechanism. I noticed that Shelly was anxious, so I asked her if everything was okay. She revealed to me that she had not disclosed her HIV status to the people that she lived with, but still wanted to participate in the study. Despite unexpected interview circumstances, I commenced the interview with Shelly in my car.

Case #3: Interview with Amber in her home.

One of the first interviews that I conducted in the Low Country region of South Carolina was with Amber. The Low Country is a geographic and cultural region along the coast of South Carolina. I traveled alone to most of my interviews, but I traveled with a classmate to the Low Country interviews since they were further away. My classmate, a native of South Carolina, was familiar with the Low Country region neighborhoods that I was scheduled to visit for my study. He expressed concerns about my safety, particularly related to conducting Amber's interview at her home. I reassured him that I would be fine. However, he elected to ride with me to Amber's home and waited in my car until I finished. When I entered Amber's apartment, I immediately felt a sense of uneasiness upon observing the physical environment. Her apartment was in disarray; the area where I sat during the interview was less than 10 feet away from a large, menacing, barking dog; the dog's training pad was soiled and there was a strong stench. Despite my impression of circumstances, I commenced the interview. About half way through the interview, our conversation was interrupted by aggressive knocking on the door. It was Amber's landlord, who served her an eviction notice. Amber pleaded for one more day to pay rent/meet residence requirements. Her landlord said no. The exchange was unfriendly. Amber returned to the interview, seemingly demoralized and embarrassed. I offered to return another day to complete her interview. Amber insisted that we continue the interview and stated that she needed the $25 compensation. Despite unanticipated turn of events, I continued Amber's interview.

What can the stories of Sandy, Shelly, and Amber teach us about conducting ethical qualitative research?

Respect for persons.—Respect for participant autonomy was thematic across the cases, especially related to respecting women's decisions to select an interview location that provided privacy, comfort, and convenience. As a morally responsible scientist, I believed that my primary role was to prevent harm to study participants who I perceived as vulnerable to stigma and discrimination due to their intersecting statuses of race, gender, poverty, geographic location, and HIV infection. I also believed that I was best equipped to make decisions about participant welfare in light of my scientific and research ethics expertise. In Sandy's case, my ethics training suggested that I should insist her husband leave the hospital room to mitigate invasion of privacy and potential vulnerability in the research process. My qualitative training suggested that a third party present during the interview might in some way influence the interview dynamic and quality of the data. However, as stated by Fisher, "[M]aking judgements solely on the basis of ethical expertise and opinions does not acknowledge individuals as moral agents with the right to judge the ethicality of investigative procedures in which they participate."[35][p.32] As gauged by the participant's body language and gestures, it appeared that Sandy remained open and transparent throughout the interview. Her husband chimed in during the interview from time to time, especially during the pregnancy intentions section, mostly agreeing and supporting particular notions regarding HIV not interfering with their daily lives or family planning decisions. In keeping with a goal of qualitative research, my unplanned interactions with both Sandy and her husband in the hospital setting deepened my understanding of Sandy's lived experiences and reproductive decision-making practices.

Through reflexive practices, it was apparent that my reluctance to conduct Sandy's interview with her husband present was rooted in my own assumptions and biases that HIV stigma would undoubtedly prevent her from speaking freely about her experiences. Such a notion did not include Sandy as an autonomous agent, and perpetuated HIV-associated shame, stereotypes, and stigma imposed by individuals and institutions. By the end of the interview, I realized that my decision to respect Sandy's interview preferences acknowledged her as the expert of her contextual environment, allowing her to make a determination about her own research participation and associated risks and benefits germane to the research setting. Engaging participants in immersive environments taught me that resolving ethical dilemmas requires participant input and in some cases dialogue between the investigator and participant.

Beneficence.—Shelly's was the first of eight interviews conducted in my car due to women's anticipated fear of stigma and discrimination related to their partners, family members, and/or housemates potentially learning of their HIV status. My principal concern with car interviews was the potential for invasion of privacy. Maintaining privacy and confidentiality is especially critical when engaging HIV-positive individuals in research. A loss of privacy and confidentiality can lead to psychological and social harms, including stigma and discrimination, social isolation, unemployment, and homelessness.[36] In light of these considerations, I questioned if my car as an interview location provided Shelly with the necessary privacy, comfort, and convenience. In my ethical decision-making process, I reconciled myself to the evolving circumstances, noting that most interview settings incurred some level of risk for persons living with HIV due to its stigmatizing nature and the lack of available "safe spaces" for HIV-positive populations.[30] While I did not perceive my car as a safe and private interview location, Shelly was best suited to assess research risks and harms, given her experiences navigating through HIV/AIDS stigma and discrimination. Compared with other potentially stigmatizing locations (i.e., Shelly's home, HIV clinics, places that provide housing for HIV-positive persons only), Shelly believed that my car was a safer space that optimized her privacy. I respected Shelly's decision to complete her interview in my car. Through unplanned interactions with Shelly, I learned a great deal about the nuances of HIV-related stigma and disclosure experienced by WLWH, which can ultimately inform tailored research ethics procedures and practices.

Justice.—Justice requires the promotion of equitable research inclusion. Poverty heightens risk for HIV infection and affects the health of those living with HIV.[1,8] Transportation barriers fueled by economic instability can hinder research recruitment and retention.[37] Because justice perspectives call for researchers to mitigate known barriers to participation, I elected to visit women's homes or other places of convenience. However, as a novice researcher, I felt uncomfortable and unsafe in Amber's home; I even considered leaving. In my deliberation, I reflected on my qualitative course that I completed a year before commencing data collection. My instructor, an ethnographic anthropologist, described a graduate anthropology student who conducted an interview in a home that was roach-infested. At some point during the interview process, a roach crawled on the graduate student. To avoid offending the participant in her own home, she continued the interview. That story, in particular, reminded me that less than ideal interview circumstances should not

be the impetus for discontinuing an interview, so I continued. However, when Amber received an eviction notice during the interview, I grew frazzled, and wanted to terminate the interview. Additionally, I had concerns about Amber's psychological state after the eviction notice and was unsure if she would be able to continue the interview. Amber, however, insisted that we continue the interview and stated that she needed the $25 compensation. It is important to note that the majority of study participants (73.8%) reported an annual income under $10,000.

While the relationship between poverty and adverse health is well-established,[38] conducting research with health disparities populations[21] in traditional environments (i.e., university, clinic, and community center settings) prevents researchers from bearing witness to the impoverished conditions, structural violence, and indignities[39] experienced by some populations "targeted" in research. Despite my inclination to leave Amber's home, the research encounter forced me to acknowledge my own biases and perceptions about poverty and insecurity. The encounter also forced me to witness the social, political, and economic systems that create inequity and increase research participant vulnerability. Because of my discomfort with impoverished conditions, I no longer wanted to engage Amber in the research study. However, I continued Amber's interview because justice demanded that I do so.

As an African American female academic researcher interviewing African American WLWH, I suspect that participant/investigator racial and gender concordance offered me initial entrance into the women's lives and facilitated a natural rapport with study participants. Establishing a good rapport with participants is critical to generating rich qualitative data and ensuring a respectful interaction and experience for both the researcher and participant.[40] Building rapport is especially important when engaging African American WLWH who often contend with stigma, discrimination, and judgement in their daily encounters. Despite shared racial and gender identity with participants, my profound discomfort with particular research settings/social situations (i.e., Amber's home, my car, and Shelly's hospital room) reinforced my social and economic outsider status as an academic researcher. Indeed, my status as an outsider opened my eyes to the extant social structures that create and proliferate inequities in health and ultimately contribute to discordance between research investigators and participants.[41]

With respect to my insider status, visible similarities in race and gender identity might have allowed participants to feel more comfortable (than they would have been with a researcher who lacked these similarities) discussing and disclosing sensitive information concerning sexual violence, trauma, depression, isolation, stigma, and discrimination. Dissimilar life experiences and perspectives paradoxically fueled my deep appreciation for the very brave and resilient women in the study who entrusted me with their powerful stories. Drawing on work by Dwyer and Buckle[42] and Obasi,[43] I contend that while my status as both an insider and outsider presented challenges, both perspectives uniquely offer opportunities for meaningful reflection and dialogue, particularly surrounding the importance of decentering sole authority and expertise commonly assumed by research investigators and centering the voices, perspectives, and expertise of research participants engaged in qualitative research.[22]

In short, these experiences highlight important skills critical for qualitative interviewing. For instance, an understanding of the balance between structure and flexibility offered study participants a safe space to explore topics that were most relevant to their lives, even if interview discussions deviated from the established research agenda.[44] Careful probing of topics within a semi-structured interviewing format allowed exploration of concepts that initially seemed tangential, but ultimately led to the emergence of themes that engendered a more dynamic understanding of the lives of African American WLWH in the Southern U.S.

Discussion

This report highlights the tension between scientific goals and ethical duties germane to conducting research responsibly with historically underrepresented populations.[45,46] Although the scientific paradigm requires use of scientific methods, ethical responsibilities require protecting the welfare of participants. Tensions between scientific and ethical duties are not easily resolved through government guidelines or institutional review board procedures and regulations.[35] Kalichman emphasizes the need to guard the interests of all groups involved (the public, the subjects of research, and the researchers themselves) and on these grounds argues for empirical research ethics.[47] The unexpected relational demands that emerge can give rise to moral stress, defined as distress that occurs when investigators confront barriers to conducting research in ways they believe are morally appropriate.[48]

There exists a need for robust empirical evidence to provide guidance for investigators engaging historically underrepresented populations in scientific research. Fisher contends that "there is a growing concern that in the absence of empirical data, participant protection strategies are often based on untested assumptions about participants and communities, institutional biases or anecdotal evidence."[25[p.2]] As highlighted in this report, in the absence of evidence-based ethical decision-making evidence, health researchers may not be equipped to deal with ethical challenges encountered in qualitative research projects.[27] Although this report documents ethical challenges related to conducting qualitative research with WLWH, it also suggests that such research can contribute to developing research ethics policies and procedures by engaging participants in their natural environments.

We draw insight from Corbie-Smith and colleagues' ethical framework and guidelines for engaged research to underscore the importance of allowing individuals and communities to determine what constitutes acceptable research benefits and risks.[37] Because the social, political, cultural, and historical nuances are often not well-understood by researchers and members of institutional review boards due to an absence of empirical data, Corbie-Smith and colleagues recommend the application of innovative models developed by the community to assess community risks/benefits.[37] Future research should elicit feedback from members of the community regarding their attitudes and perceptions of ethically sound and just qualitative research practices and procedures, with consideration of various research settings and contexts.

Engaging in practices that help characterize how biases shape interactions with participants and ethical decisions is central to conducting equitable and just research. The first author's experiences conducting qualitative interviews with WLWH emphasized discomfort related to

particular research settings, which ultimately influenced perceptions of participant welfare and research vulnerability. In the highlighted cases, investigator perspectives concerning safety and vulnerability conflicted with the perspectives of participants, underscoring the need to examine these tensions empirically and to implement approaches that mitigate investigator bias in research encounters. Reflexivity, defined as "attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process,"[49][p.484] is a constructive tool to inform ethical research practices and procedures in qualitative research approaches. Reflexivity contributes to ethical qualitative research procedures by highlighting the ways that various factors shape the data produced and interpretation of such data.[50,51]

Recommended practices include: 1) developing a reflexive journal to document investigator positionality, feelings about research interactions, and decision-making processes; 2) designing research studies with multiple investigators to diversify perspectives, foster dialogue, and increase transparency and accountability in research encounters; and 3) documenting through manuscripts and other publications how one's preconceptions, values, and assumptions shape research interactions[49,51,52] and research ethics decisions. Reflexive practices can also be useful in addressing moral stress experienced by researchers working in environments pervaded by social and structural inequities that affect the lives of research participants.[53] Such inequities are germane to the lives of WLWH, who are often disadvantaged by the intersections of race, gender, and poverty. It is necessary to acknowledge the social, political, and economic systems that proliferate research participant vulnerability, and ethical challenges in the research process.

Conclusion.

This report contributes to empirical guidance for investigators engaging marginalized populations in scientific research by describing ethical challenges and lessons learned in qualitative research with WLWH. Acknowledging the vulnerabilities experienced by individuals and communities who face stigmas is necessary to protect research participants from exploitation and harm. Further, understanding how individuals conceptualize respect for persons, benefits and harms, and justice is necessary to inform the research process and tailor participant protections to a particular sociocultural context. Qualitative research with African American WLWH can inform the development of ethical research strategies germane to women's lived experiences. The collective experiences and narratives of African American WLWH provide a contextual basis to understand and demonstrate respect for women's values and preferences across the research continuum.

Acknowledgments

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