

MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

How Can the Experiences of Black Women Living With HIV Inform Equitable and Respectful Reproductive Health Care Delivery?

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Abstract

Black women living with HIV (BWLWH) contend with injuries of injustice, which manifest in restricted reproductive autonomy and decision-making power in social and medical settings. Mitigating threats to reproductive autonomy calls for innovations that consider patients' needs and offer insights on how historically situated marginalization influences today's institutional, political, and economic systems and shapes reproductive decision making. In addition to cross-disciplinary expertise and collaboration, integrating structural competency into reproductive health care requires demonstrating respect for the autonomy, lived experiences, and preferences of BWLWH.

Introduction

Health experiences are shaped by the broader social conditions, forces, and systems in which they are situated (eg, social position, norms, and policies).^{1,2} Reproduction is an issue that is uniquely and inordinately subject to social oversight.^{3,4} More specifically, a variety of cultural and historical factors, such as religious and moral belief systems and political ideologies, can manifest in health care systems' policies and patient treatment for reproductive health.^{5,6} Thus, individual reproductive decision-making power is subject to external social influences, including health care practitioner biases.

Restricted **reproductive access** and decision-making power, particularly among marginalized populations, raises ethical concerns.^{7,8} The work of Kimberlé Crenshaw on intersectionality outlines how aspects of one's social identity, such as gender, race, and health status (eg, HIV-positive), can overlap to create compounded injustice in the forms of disadvantage and discrimination.⁹ Consequently, Black women living with HIV (BWLWH) contend with injuries of injustice,¹⁰ which manifest in restricted reproductive autonomy in social and medical settings. Reproduction is particularly medicalized for WLWH, as evidenced by earlier recommendations that advised all WLWH to avoid and terminate pregnancies to prevent transmission of HIV to their fetus or newborn.¹¹ This medicalization of reproduction is magnified for BWLWH, who account for the largest share of HIV diagnoses among women¹² and are at increased risk of adverse health

outcomes (ie, lower antiretroviral treatment adherence and higher morbidity and mortality)^{13,14,15} due to **disparities in health care access**, social inequities (eg, violence, competing life demands),¹⁰ intersecting stigmas (eg, gender, race, class, and health status),^{16,17,18} and dissatisfaction with their treatment by health care clinicians.¹⁹

Contemporary models of care promote informed, autonomous reproductive decision making for WLWH, given the relatively low risk of maternal-to-child (perinatal) transmission (1%-2%) in the United States, which has been made possible by effective public health interventions (eg, universal HIV testing, preconception counseling, family planning) and medical interventions (eg, antiretroviral therapy, preexposure prophylaxis).²⁰ In contrast to earlier work suggesting that HIV posed a challenge for reproduction, recent studies have revealed that HIV-positive status does not diminish women's desire to bear children but rather is one of many factors considered in reproductive preferences.^{21,22} Despite variation in the reproductive preferences of WLWH, studies within the last decade have documented lived experiences of reproductive coercion (or exertion of "power and control over contraceptive and/or pregnancy choices and outcomes"²³) in medical settings, whereby WLWH were given directive advice to abstain from reproductive interests, to have abortions, and to pursue tubal ligations and other forms of female sterilization.^{7,24,25,26,27}

While HIV-related and other forms of stigma are experienced by WLWH in multiple settings, a growing body of literature suggests that stigma and discrimination (both covert and overt) against WLWH in health care settings may be especially detrimental to women's overall health and well-being.¹⁶ A 2018 systematic review of qualitative and quantitative studies conducted in the United States that were published from 2010 to 2017 documents the continued experience of HIV stigma in health care settings, despite decades of development of HIV treatment and efforts to combat and expose the harmful effects of HIV-related stigma.²⁸ A 2020 study of predominantly BWLWH in 6 US cities describes their experiences with lack of compassion, judgment, dehumanization, and disrespect in health care delivery settings,¹⁹ which can contribute to psychological distress, delayed care seeking, and avoidance of care.²⁸ The suboptimal delivery of care to WLWH represents a recurrent ethical dilemma that must be thoughtfully addressed, particularly in the context of reproductive decision-making practices, in order to offer care that is respectful, empathetic, and more effective.

Reproductive Autonomy

Respect for autonomy is a moral principle that has particular salience for patients' preferences and decisions within the context of research, medicine, and health care.²⁹ Autonomy, derived from the Greek *autos* (self) and *nomos* (rule) is generally understood to refer to the "capacity to be one's own person, to live one's life according to reasons and motives that are taken as one's own and not the product of manipulative or distorting external forces."²⁹ Both liberty (independence from controlling influences) and agency (capacity for intentional action) are essential conditions of autonomy. Reproductive autonomy is the "power to decide when, if at all, to have children."³⁰

Threats to autonomy include paternalism, which manifest in systems (eg, political, economic, health care) that restrict people's choices. Examples of paternalism in health care settings experienced and reported by WLWH have taken the form of minimal support for and advice regarding pregnancy,^{31,32} overestimation of HIV transmission risks to infants,²⁵ and lack of patient centeredness,¹⁹ all of which can be interpreted as systematic disrespect for the reproductive choices and moral agency of WLWH. Despite

minimal risk of maternal-to-child transmission of HIV, recent work by Hill and colleagues highlights that WLWH are more likely than women without HIV to undergo tubal ligations to eliminate vertical HIV transmission risks.³³ These findings are consistent with previous work underscoring that perceived negative judgment and stigmatization by health care practitioners and others influence the decisions of WLWH to opt for irreversible contraceptive methods, such as tubal ligations.^{25,34,35}

The lack of training opportunities for clinicians at the intersection of reproductive health and HIV-related care represents a systemic barrier to delivering comprehensive care to BWLWH. Studies of continuing medical education indicate limited HIV-prevention knowledge among family planning practitioners^{36,37} and limited recent exposure to HIV-related training opportunities among primary care clinicians,³⁸ which may potentially contribute to gaps in ethical, evidence-based practice.³⁹

From a social justice perspective, health care professionals' lack of respect for the reproductive autonomy of BWLWH bears a historic resemblance to the social and medical policies that devalued and restricted a woman's right to reproduce and mother as part of a larger institutional attempt to "dehumanize or control Black women's reproductive lives."⁸ More specifically, laws in the United States from the 1850s to the 1970s legally sanctioned the **nonconsensual sterilization** of marginalized groups, including women of low income and with disabilities, women of color, and women with mental illness.⁴⁰ The term *Mississippi appendectomy* was coined to refer to the practice of involuntary hysterectomy at teaching hospitals as training for medical students, often in the US South, without women's knowledge or medical indication and at times with the misguided understanding that their appendix was being removed.^{8,41} These laws took advantage of preexisting stereotypes that women in these circumstances were insane, "feeble-minded," criminal, or incapable of bearing and raising children without state support. Many believed that mental illness, disability, and other characteristics ascribed to these women were genetically transmitted to offspring. Harriet Washington argues that "in a refinement of earlier scientific racism, eugenics was appropriated to label black women as sexually indiscriminate and as bad mothers who were constrained by biology to give birth to defective children."⁴¹ As described by scholars, the oversight and interventions (ie, social, medical, political) specific to Black women's reproductive lives has been historically—and is currently—supported by the notion that Black women are inherently susceptible to "pass on" or "transmit" negative traits or conditions to their offspring,^{3,4} including HIV.

The field of bioethics, however, has paid too little attention to the reproductive rights of BWLWH, a medically and socially underserved population. Here, we focus on Dorothy Roberts' assertion that "reproductive freedom is a matter of social justice, not individual choice."⁸ Thus, mitigating threats to reproductive choice for BWLWH is a social justice imperative that calls for a critical examination of women's lived experiences in the context of overlapping marginalities and intersectional stigmatization.¹⁷ The experiences of diminished reproductive autonomy and heightened vulnerability to reproductive coercion among BWLWH further highlight the need for critical ethical discourse on reproductive injustices. The primary tenets of reproductive justice include "(1) the right not to have a child; (2) the right to have a child; and (3) the right to parent children in safe and healthy environments."⁴² Notably, reproductive justice demands sexual autonomy and gender freedom for every human being. Realizing reproductive justice praxis in clinical settings calls for partnering with reproductive justice organizations and activists who offer the theoretical, practical, and on-the-ground expertise to (1) guide

strategies that create reflective spaces for challenging injustices in reproduction experienced by women who are traditionally marginalized and undervalued in society and (2) integrate reproductive justice perspectives into medical education to equip clinicians with the knowledge and skills to deliver reproductive education and counseling that is attentive to the social and economic needs and realities of their patients (eg, poverty, access to care and insurance, domestic violence, low-resource neighborhoods, stigma, and substance use).⁴³

Relatedly, Scott and colleagues contend that transforming reproductive health care begins with “acknowledgment and protection of the dignity, sanctity, and humanity of Blackness in health services research and provision.”⁴⁴ Toward this end, reliance on stakeholders with the local and contextual knowledge and insights to foster relevant solutions is critically important to effectively support sustainable living and thriving among Black mothers and their families.⁴⁴ The formulation of reproductive ethical questions and analyses must be examined within the context of gender, class, and racial inequality to inform a complex understanding of the role of intersecting identities in decision making on the part of clinicians and patients.⁴⁵ Bioethics as a field has long neglected underlying socioeconomic disparities and the legacies of inequities that in fact give rise to ethical dilemmas and vulnerabilities in both research and clinical settings.⁴⁶ Similarly, we argue that reproductive ethics scholarship and discourse lacks an emphasis on reproductive choice and a focus on the preferences of persons who are traditionally marginalized. Reproductive justice frameworks not only provide an enhanced conceptualization of ethical dilemmas experienced by women and birthing people, but also reveal academic and medical institutional blind spots and biases that continue to perpetuate social inequities^{44,45} and that ultimately contribute to dilemmas in reproductive decision making. Optimal respect for the reproductive desires of BWLWH requires consideration of their decisions within the context of overlapping and intersecting systems of oppression in order to adequately support reproductive decision making.^{8,10,45}

Understanding the Lived Experiences of BWLWH

In general, BWLWH face a myriad of structural inequities relevant to their families’ reproductive well-being, including—but not limited to—lack of access to childcare, health information, transportation, and stable and safe housing, as well as barriers associated with substance use and related recovery.^{10,47} As such, ethical research engagement with BWLWH and other marginalized groups requires creating empowering and reflective spaces and structures that allow individuals and groups to share their stories, reframe existing narratives, and minimize the power dynamics that traditionally exist between researchers and participants.⁴⁸ Similarly, to bolster trust, rapport, respect, and transparency between clinicians and patients, developing innovative health care models and frameworks that give consideration to the complex medical and social needs of medically underserved populations is an ethical imperative. Structural competency is one such framework applied in health care professional training that emphasizes engagement with the sociocontextual realities of patients and communities.⁴⁹ Downey and Gómez argue that “structural competency training with a reproductive health focus might improve clinician sensitivity to social determinants of health, encourage generative self-reflection, and open opportunities for solidarity with patients.”⁵⁰ The integration of structural competency and other fundamental lenses (eg, intersectionality, reproductive justice, critical race theory) into research and practice might offer new insights into how marginalized identities (eg, intersections of race, gender, class, and HIV status),^{10,17} historical realities (eg, devaluation of Black bodies, experimentation on

Black female slaves),^{8,41} and systemic forces (eg, institutional, political, and economic) shape reproductive preferences and decision making.^{32,44,45,50}

Conducting patient-centered research guided by the aforementioned frameworks—including research that examines the lived experiences of marginalized women in various social and health care settings⁴⁸—is fundamental to informing ethically responsive reproductive health care practices and procedures and to improving health-related outcomes.⁴⁹ This process calls for cross-disciplinary collaboration and expertise as well as the engagement of patients and other stakeholders to promote equity in research conceptualization, implementation, and interpretation and in translation of findings.^{43,49}

In addition to understanding inequities formed by intersecting structural forces, researchers must appreciate the resiliencies, values, and protective factors that people develop as a result of their coexisting social statuses. For instance, women managing chronic health conditions such as HIV report that motherhood contributes to a sense of self-acceptance, autonomy, and a feeling of purpose or mission in life.²⁵ While contending with major social stressors such as HIV-related stigma and discrimination and financial hardship,¹³ many women employ resilience-based strategies and engage in health-promoting behaviors.^{51,52} In fact, evidence suggests that many WLWH demonstrate resistance to stigma and discrimination in various ways,^{17,24} including by building supportive communities and developing trusting relationships with HIV clinicians.²⁴ Health care professionals represent key stakeholders in supporting women in achieving their reproductive goals by providing holistic, relevant, and evidence-based care that is tailored to the specific preferences, needs, and life course of their patients. Examples of preferred and desired care expressed by WLWH in a recent qualitative study include care that is knowledge based, patient centered, efficient, equitable, safe, and timely.¹⁹

Centering Patient Preferences

A growing body of literature highlights the importance of centering patient preferences in decision making to improve health outcomes. Centering patient preferences acknowledges that evidence-based recommendations must be carefully balanced with community voices and expressed needs and with cultural nuances to maximize the health and well-being of patients and to minimize undue harms.^{49,53} Respect for patient preferences and agency may be best served by and represented in **participatory research** approaches, which ultimately aim to shape research design and implementation through an iterative, dynamic process that centers the needs,⁵³ realities, and experiences of communities.⁴⁸

In the context of reproductive decision making among Black WLWH, the need to prioritize patient preferences is even more pronounced. Black woman-led organizations such as SisterLove,⁵⁴ the Black AIDS Institute,⁵⁵ the Black Mamas Matter Alliance,⁵⁶ and the Black Women's Health Imperative⁵⁷ are confronting, shifting, and dismantling engendered and racialized oppression of Black women, their families, and their communities by centering Black women as essential change agents and as producers of and contributors to clinical and research guidance in the area of Black women's health. These organizations center Black women's experiences through the following mechanisms: (1) creating and providing leadership opportunities for Black women within the organization; (2) acknowledging Black women as collaborators and partners in health care decisions; (3) centering the lived experiences of Black women in their

programming, policies, and community-engaged research; and (4) ensuring that Black women and communities are at the forefront of their reproductive justice programmatic foci. Thus, these organizations are leaders in the reproductive justice movement and continue to ensure that patient preferences are acknowledged and prioritized.

The COVID-19 pandemic is rapidly changing health care delivery practices, including those related to reproductive health and maternity care.⁵⁸ The recent implementation of birthing policies in many New York City hospitals, for instance, restricts doulas or spouses from being present during labor or birth due to COVID-19 transmission risks.⁵⁸ These practices not only minimize patient autonomy but also potentially jeopardize the health and well-being of pregnant and birthing people,⁵⁸ with WLWH and women with other chronic conditions being especially vulnerable. Indeed, variation in state-supported reproductive health policies bolsters health inequities.^{59,60} Notably, restricted eligibility for Medicaid and the Aids Drug Assistance Program among persons living with HIV affects their access to HIV treatment, care, and prevention—especially in southern states⁶¹—and incidentally restricts both their access to reproductive services (ie, contraception, abortion) and their autonomy. The time is ripe to promote integrating rights-based approaches and reproductive justice frameworks into medical practices and training to reconcile historical and current injustices in health care. This overdue paradigm shift calls for organizational, systemic, and policy changes that require cross-disciplinary expertise and collaboration among health care professionals, medical and social scientists, and reproductive justice leaders. Furthermore, demonstrating optimal respect for the autonomy, lived experiences, and preferences of BWLWH is critical to mitigating unwarranted social, emotional, mental, and bodily harm as threats to informed and autonomous reproductive decision making.

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Citation

AMA J Ethics. 2021;23(2):E156-165.

DOI

10.1001/amajethics.2021.156.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

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ISSN 2376-6980