



Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.



The art of medicine

A reproductive justice response to HIV/AIDS and COVID-19

Lana is a young Black woman living with HIV in Kingston, Jamaica. A mother of young children, she was concerned about what COVID-19 would mean for her pre-existing diagnosis. During the COVID-19 pandemic she has struggled to find psychosocial support groups, consistent access to antiretrovirals, and employment opportunities to maintain her health and support herself and her family. Pam, a middle-aged HIV-positive woman in Detroit, MI, USA, is a caregiver and local HIV organiser who provides emotional and social support to other newly diagnosed people. She also has chronic diseases and is aware of the treatment-related challenges of taking antiretrovirals together with medicines for her chronic conditions. In my conversations with Jamaican and African American women living with HIV, the diagnosis often took a back seat to more pressing concerns such as financial instability, housing insecurity, access to food and housing, and the desire for social support and psychosocial care. Some of the women I met like Lana and Pam are involved in grassroots networks that provide communal care and resources to support tailored interventions for their unique overlapping needs while mobilising for rights, care, and recognition.

Lana's and Pam's stories speak to the lived experiences of HIV-positive Black women in similar settings as they grapple with the prolonged effects of illness, inequality, and inequities on their wellbeing. I have interviewed a number of women living with HIV in under-resourced communities who face the challenges of social isolation, a weakened social safety net, and reduced economic opportunities while living through two pandemics. Collectively, their experiences highlight the intimate effects of structural inequalities, government inaction, gender inequality, inadequate health-care

access, and social and economic marginalisation. Their experiences also foreground the centrality of a reproductive justice approach in helping curtail the negative impacts of pandemics on Black women and vulnerable communities.

Reproductive justice offers a way of understanding how inequality and power rooted in overlapping oppressions deny access to a range of services, resources, and rights. As a framework and political strategy, reproductive justice moves matters of reproductive health and politics beyond the traditional mainstream emphasis on individual choice and access to abortion, which has been central to many white US feminist agendas of the 1970s and 1980s. Rather, reproductive justice interweaves human rights and social justice frameworks to address the interplay of factors such as race, gender, class, socioeconomic status, sexuality, and disability on the reproductive capacities of marginalised people. These dynamics shape the conditions in which Black women make decisions about how they live, whether or not they give birth or parent, and how they sustain their families and communities. While no single concept captures the complexities and full dimensions of reproductive oppression, the contemporary experiences of some HIV-positive Black women during the COVID-19 pandemic highlight how reproductive justice is helpful for understanding the impacts of global histories of inequality, marginalisation, and structural racism on lived experiences.

Although there has been progress in the past decade with new diagnoses of HIV infection decreasing in women in the USA, women of colour, particularly Black women, have been disproportionately impacted, alongside other marginalised populations. Black women make up an estimated 13% of the female population in the USA, but in 2018 accounted for nearly 60% of diagnoses of HIV infection among females in the country. In 2019, the estimated HIV incidence among Black women was 11 times the rate for white women. In Jamaica, girls and women shoulder a large share of the new HIV infections: women aged 45 years and older accounted for the highest number of new HIV infections in 2017, and HIV prevalence is higher among women aged 15–49 years than among men of this age group.

There is an urgency to address the gendered and racial health inequities that undermine efforts to improve the health outcomes and wellbeing of Black girls and women, especially given the impacts of the COVID-19 pandemic. The harmful impacts of COVID-19 were compounded among some HIV-positive Black women living in the USA and Jamaica who faced material poverty, reproductive injustice, and poor access to health care. In this context, grassroots mobilising and communal care structures have crucial roles in helping to centre the needs of Black women living with

Further reading

- Barrow C, de Bruin M, Carr R. Sexuality, social exclusion and human rights: vulnerability in the Caribbean context of HIV. Kingston, Jamaica: Ian Randle, 2009
- Berger MT. Workable sisterhood: the political journey of stigmatized women with HIV/AIDS. Princeton, NJ: Princeton University Press, 2010
- Centers for Disease Control and Prevention. HIV surveillance report: diagnoses of HIV infection in the United States and dependent areas, 2018 (updated). May, 2020, vol 31. <https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-31/index.html> (accessed Nov 15, 2021)
- Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2015–2019. HIV surveillance supplemental report. May, 2021, 26 (no. 1). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html> (accessed Nov 15, 2021).
- Figueroa JP, Duncan JP, Bailey A, Skyers N. The HIV epidemic in Jamaica: a need to strengthen the National HIV Program. *Rev Panam Salud Publica* 2020; 44: e157



Delmaine Donson/Getty Images

HIV. Community-based HIV/AIDS advocacy organisations, such as EVE for Life in Kingston, Jamaica, and Sister Song in Atlanta, GA, USA, have mobilised groups of women to address the core conditions of disparate vulnerability that unevenly affect Black women living with HIV. Peer-based groups and culturally sensitive services have tailored pandemic responses to meet Black women where they are. For example, EVE for Life, is a non-governmental organisation for women and children living with HIV that provides support for child interventions, HIV care, counselling, and testing, and mentoring, among other activities. This advocacy organisation held virtual peer mentorship support groups that use trauma-informed care services and psychosocial care to help women access health care, understand medication adherence, and process the diagnosis and disease. To address the issues that often burden poor and working-class single mothers, such as the barriers to food and financial resources, EVE for Life also provided cash grants and care packages of foods, hygiene products, baby food, and clothing. These efforts help counter the disparate vulnerabilities that result from economic instability and social and political marginalisation. SisterLove, a leading women's HIV/AIDS and reproductive justice organisation in the USA, works to combat the adverse impacts of HIV and the sexual and reproductive health rights and justice challenges that affect women and their families through education, prevention, support, research, and human rights advocacy nationally and globally. Among its many activities, SisterLove bridges service delivery with community mobilisation and HIV and COVID-19 testing and education while providing the basic resources and training to help meet the daily needs and political interests of Black women. To address the bias faced by Black women in the health system, SisterLove builds awareness of the institutional practices that serve as barriers to quality care and services, and mobilises political participation and civic engagement. It connects community consciousness raising events and digital campaigns around medical and reproductive health literacy education with training of health-care providers to address provider bias and to improve their delivery of consistent and culturally informed care. Such community-based HIV/AIDS advocacy organisations are helping to address the impacts of HIV, COVID-19, gender inequality, and systemic racism by making connections across multiple and simultaneous forms of oppression as they advocate and care for communities that often bear the brunt of illness, inequities, and structural violence. Such community-based advocacy attends to both service provision and community mobilising while proactively building interdependent communal networks of care globally.

The work of such grassroots organisations, alongside the experiences of Lana and Pam, can be instructive for developing and applying a reproductive justice lens to

responses to HIV/AIDS and COVID-19. A reproductive justice approach to HIV/AIDS and COVID-19 recognises that pre-existing inequities heighten vulnerability to infection and death. With COVID-19, in the USA we quickly learned that poor and disenfranchised people of colour were disproportionately affected. Even as these populations shoulder the disproportionate burdens of COVID-19, their over-representation as "essential" workers in public-facing roles on the front line of services has continued. These inequities are typically also embedded within wider contexts of environmental racism and inadequate access to culturally responsive health-care services. Black women's experiences of living, working, and managing ill health and inequities in the context of HIV, COVID-19, and systemic racism underline the need for tailored pandemic responses that focus on the intersecting needs and holistic wellbeing of marginalised communities.

It is necessary to move beyond a biomedical focus on individual risk groups and behaviours and to engage the totality of Black women's lives as we prioritise their holistic needs and interests. Black women living with HIV navigate multiple forces of domination from the judicial, welfare, and social care and health-care systems that subject them to discriminatory practices. Being proactive about their health while also maintaining their caring practices, supporting other peers living with HIV, and pursuing political and reproductive rights becomes challenging when some medical practitioners do not fully account for Black women's holistic and competing needs, desires, and interests.

Responses to HIV/AIDS and COVID-19 can benefit from culturally rooted and community-led approaches that help counter structural racism and control of Black women's bodies and reproductive capacities. As a Black woman who has researched the experiences of some Black women living with HIV in the USA and Jamaica, I have witnessed the powerful impact of their local knowledge and grassroots structures of support and care on sustaining communities amid inadequate resources, political will, and investment. The experiences of women such as Lana and Pam highlight the importance of interdependent networks and communities that meet people where they are while foregrounding the need for meaningful collaborations among medical practitioners, researchers, communities, and activists. Ultimately, HIV-positive Black women's efforts to mobilise for their priorities in the face of inequality, inequities, illness, and racism make a crucial difference to their wellbeing.

Jallicia Jolly

American Studies and Black Studies. Amherst College, Amherst, MA 01002, USA
jjolly@amherst.edu

All names in this essay are pseudonyms.

Fletcher FE, Amutah-Onukagha N, Attys J, Rice WS. How can the experiences of Black women living with HIV inform equitable and respectful reproductive health care delivery? *AMA J Ethics* 2021; **23**: e156-65

Jolly J. On forbidden wombs and transnational reproductive justice. *Meridians* 2016; **15**: 166-88

Jolly J. From "at risk" to interdependent: the erotic life worlds of HIV+ Jamaican women. *Souls* 2019; **21**: 107-31

Jolly J. No one's telling the stories of HIV-positive Black women. In the pandemic, they need more support. *The Lily*, Sept 29, 2021. <https://www.thelily.com/no-ones-telling-the-stories-of-hiv-positive-black-women-in-the-pandemic-they-need-more-support/> (accessed Nov 15, 2021)

Ministry of Health. Jamaica global AIDS monitoring report 2019. https://www.unaids.org/sites/default/files/country/documents/JAM_2019_countryreport.pdf (accessed Nov 15, 2021)

Office of Minority Health, US Department of Health and Human Services. HIV/AIDS and African Americans. 2019. <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=21> (accessed Nov 15, 2021)

Roberts, DE. *Killing the Black body: race, reproduction, and the meaning of liberty*. New York: Vintage Books, 1999

Ross L. Understanding reproductive justice: transforming the pro-choice movement. *Off Our Backs* 2006; **36**: 14-19

Ross L. Reproductive justice as intersectional feminist activism. *Souls* 2017; **19**: 286-314

UNAIDS. Global AIDS update confronting inequalities—lessons for pandemic responses from 40 years of AIDS. July 14, 2021. <https://www.unaids.org/en/resources/documents/2021/2021-global-aids-update> (accessed Nov 15, 2021)

UNAIDS. Country factsheets. Jamaica. 2020. <https://www.unaids.org/en/regionscountries/countries/jamaica> (accessed Nov 15, 2021)

Watkins-Hayes C. *Remaking a life: how women living with HIV/AIDS confront inequality*. Oakland, CA: University of California Press, 2019