

## Commentary

# The Stopping the Spread of Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome through Relationship Engagement Study: An Opportunity for Human Immunodeficiency Virus Prevention in African American Adolescents with HIV-Positive Mothers

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## INTRODUCTION

In 2018 Blacks/African Americans made up 13% of the female population but accounted for 58% of diagnoses of human immunodeficiency virus (HIV) infection among females.<sup>1</sup> Studies show that women have always been underrepresented in HIV/acquired immune deficiency syndrome (AIDS) studies, however, the coronavirus disease-2019 (COVID-19) pandemic has further exacerbated the existing barriers in HIV research.<sup>2</sup> Additionally, with social distancing guidelines in place due to COVID-19, research that requires partnership development with gatekeepers and community-based organizations may not effectively transition to virtual or other remote settings.<sup>2</sup> Black women's underrepresentation in HIV research is in part due to inadequate recruitment strategies.<sup>3</sup> While we use technology to try to compensate for the lack of human connection in research due to the COVID-19 pandemic, it has made recruitment more difficult.

The stopping the spread of HIV/AIDS through relationship engagement (SHARE) Study is designed to address why the prevalence of HIV/AIDS is disproportionately high as experienced by African American women. The SHARE Study is a mixed-methods study incorporating both individual interviews with the HIV-positive mother and the HIV-negative daughter and an online

survey administered by Redcap. Stigma continues to be a large contributor to why African American women resist seeking care.<sup>4,5</sup>

## METHODOLOGY

Addressing stigma and promoting HIV prevention are common aims of many HIV/AIDS research studies; however, the SHARE study is designed to achieve these aims and beyond by exploring domains focused on intergenerational communication, knowledge shared between mother and their Generation Z daughters concerning pre-exposure prophylaxis (PrEP), and exposure to trauma including sexual trauma, physical trauma, and psychological trauma. In addition to participants answering survey questions to assess their experiences, part of the study involves mother-daughter pairs or dyads to answer open-ended questions to help identify themes that have yet to be understood preventing HIV for the next generation.

The experiences of persons living with HIV have changed since the 1980s as at this time to have the illness was a death sentence. Through many scientific advances including PrEP, there are many people who live long lives with HIV. As Generation Z teenagers grow into adulthood in this post-COVID-19 era, studies such as the SHARE study are critical because it helps researchers

to observe their understanding, attitudes, comfort levels, and experiences on decisions to engage or not engage in sex and expressions on sexuality as they transition into adulthood. The SHARE study team has begun the initial stages to de-stigmatize HIV diagnosis by hosting open discussions with community-based organization members *via* Facebook, Twitter, Instagram, and TikTok social media applications as these are applications that have a high Generation Z clientele.

### Barriers

Women and people of color are underrepresented in HIV research, in part due to recruitment strategies that are ineffective for the populations of interest.<sup>3,6</sup> Oftentimes, this is due to social discrimination and incohesive research design that limits convenient participation for the study participant. For example, to reduce the risk of COVID-19, researchers have had to recruit participants online. Unexpected limitations such as distorted availability with researchers and participants, and technological difficulties over the phone and *via* Zoom have been new challenges to face during the COVID-19 pandemic.

Historic injustices such as the Tuskegee syphilis study, have not been forgotten, and many African Americans who would qualify for research studies remain wary of medical institutions.<sup>7</sup> Racism and abuse in the healthcare system prevent African Americans from participating in research studies, as well as fear that research findings are misinterpreted, resulting in exploitation of African Americans, or participation in research that is not beneficial or irrelevant to their own communities.<sup>7,8</sup> Women of all ages cite community stigma as a barrier.<sup>3,6</sup> Loufty et al<sup>3</sup> found that 59% of the women in their study cited the sensitive nature of the topic of HIV-focused research studies as the most important barrier.<sup>3</sup> Furthermore, adolescents may choose not to participate in HIV prevention clinical studies because they may feel as if their participation is an admission of them engaging in risky sexual behavior.<sup>7</sup> This self-preservation bias can prevent researchers from completing successful and representative studies.

Participants who are living with HIV face stigma and shame about their health and such feelings could prevent them from taking advantage of clinical trials and other research studies related to HIV. This is however not just a concern among adolescents, as women of all ages cite community stigma as a barrier.<sup>3,7</sup> Loufty et al<sup>3</sup> found that 59% of the women in their study cited the sensitive nature of the topic of HIV-focused research studies as the most important barrier. Furthermore, adolescents may choose not to participate in HIV prevention clinical studies because they may feel as if their participation is an admission of them engaging in risky sexual behavior.<sup>7</sup> This self-preservation bias can prevent researchers from completing successful and representative studies. Adolescents also reported that the informed consent process was a barrier, as parents of minors must consent while adolescents give “assent” to research studies.<sup>7,9</sup>

### RECOMMENDATIONS

As stated above, the SHARE Study uses the unique lens of moth-

er-daughter relationships to investigate the disproportionate prevalence of HIV/AIDS in African American women. In the pursuit of understanding the HIV/AIDS epidemic among Black women, we have encountered many roadblocks. The scope of the SHARE Study is so unique that there is very little literature available to apply to our study. Specifically, the SHARE Study has faced issues in the recruitment of Black mothers living with HIV and their daughters that meet the parameters of the study. While these parameters are very distinct, which could cause challenges in finding participants, the stigma associated with HIV/AIDS in general and more specifically within the African American population, adds more difficulty in finding willing participants. The SHARE Study hopes to combat these hurdles through a community centered and intersectional approach and encourages other projects with similar aims to do the same. With an intersectional approach to HIV-related research, we aim to increase study participants, reduce HIV-related stigma and overall improve the health and well-being of the underserved population.

### CONCLUSION

In conclusion, the SHARE Study strengthens the literature on barriers to recruitment in HIV-related research in Black women by bringing awareness to the fact that barriers such as stigma and fear of rejection continue to hinder HIV/AIDS research, especially among African American women. The study has encountered many barriers due to the COVID-19 pandemic as well as the inability to recruit more participants. However, the study and the research team aim to work diligently in reducing the existing barriers in HIV research. Multiple lessons have been taught throughout the process. Understanding that there are still many African American mothers who have decided not to disclose their HIV status to their families and that the stigma surrounding HIV/AIDS is still prevalent in society. Based on the history and review of the SHARE study, recommendations have been made to not only make sure that the voice of the HIV community has been heard but also to put thought into action. The community-centered approach is the best mode of action to combat and evaluate the prevalence of HIV/AIDS in African American women. This can be done through media campaigning, integrating family planning with HIV testing, and providing additional services geared to assisting families and their needs. In doing so, the SHARE Study will be able to bring to light the underrepresented community of African American women living with HIV and contribute to addressing the HIV/AIDS epidemic among African American women by assessing the quality of the communication between both mothers and daughters, the impact intergenerational traumas have had on their behaviors and their willingness to be more educated in preventing future HIV infections.

### CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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