Networks That Care

An Ethnographic Research Study of Black Women in New Orleans

ViiV Healthcare
for Women POSITIVE ACTION
tcc group
R&D*

Contents

This research project was conceived and funded by ViiV Healthcare. The study is a key element of *Positive Action for Women*, a pilot initiative for innovative, forward-thinking community collaborations that break down isolation and stigma for women of color living with HIV and link women to networks of care. *Positive Action for Women* is part of ViiV Healthcare's global commitment to research and community programs that close the gaps in data, address social and cultural barriers and drive solutions for women living with HIV.

We would like to thank all the women and their networks who opened their doors and lives to share their stories. We also thank those who provided invaluable consultation and expertise in the research design and making meaning of the key findings, including:

Dázon Dixon Diallo
GA, Founder and President of SisterLove, Inc.
in Atlanta and South Africa

Desiree Evans
LA, Interim Executive Director at Women with a Vision

Lisa Fager Bediako
MD, Founder of Free Mind Communications, Inc.

Marsha Jones
TX, Executive Director of Afiya Center

Lhundyn Palmer
LA, a Founding Member of BreakOUT in New Orleans

Linda Stringfellow
MS, Founder of FABRIC

Masonia Traylor
GA, Founder of and Executive Director of Lady BurgAndy

Gina Brown
LA, Community Organizer, Southern AIDS Coalition

In addition, we thank our Advisory Board members and many colleagues in the field for their input, collaboration, and guidance.

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Introduction

Tosha was in love. She met Jay at work. "We went home and stayed up until like 6 o'clock that morning, just talking. And after that he picked me up and took me to the shower. And we took a shower and had sex. And we fell asleep. And he woke up and told me he had to leave, and that he was HIV+. Like that."

Within the closest networks of support for Southern Black women, sex and health are often taboo subjects, and talking about HIV is especially difficult in this culture of silence. Today, there are 113,784 women living with HIV in the South, more than ever before.[1] While the number of new HIV diagnoses among women of color is declining, 60% of all new HIV diagnoses in the United States are among Black women.[2] Still, complex social dynamics and isolation driven by fear and stigma have limited the promise of medical advances from reducing the impact of the HIV epidemic among those disproportionately affected—including some Black women.

Responding to this current situation, ViiV Healthcare has committed to addressing the disproportionate impact of HIV among women of color as part of our global commitment to support communities most affected by HIV. ViiV Healthcare commissioned this ethnographic research study in New Orleans, Louisiana, to learn from the lives and experiences of Black cis- and transgender women, based on our belief that the perspectives of those most affected by HIV are essential to advancing responsive solutions. Recognizing the long-known potential benefit of supportive social networks, the study explores the networks of care that women create and engage in as a way to understand what works and how HIV care currently fits—and could best fit—into these practices. Lessons learned from this ethnographic research alongside other stakeholder listening activities and landscape analyses inform ViiV Healthcare and our commitment to closing the gaps in care for women.

Gender Identity

For this research gender identity is conceptualized on a spectrum, and we use the term *women* through the report to represent the entire spectrum, including cis- and transgender women.

transgender adj.
Trans is Latin for "on the other side," meaning that a person identifies with a gender that is different from the gender that person was assigned at birth. Some people may not use the label *trans* and instead use a range of terms from queer to feminine-identifying.

cisgender adj.
Cis is Latin for "on the same side," meaning a person who identifies with the gender they were assigned at birth—born female and identify as a female.

"People can't be supportive of something they don't understand," says Tosha.

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1. From data exported from the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Atlas. Centers for Disease Control and Prevention. http://www.cdc.gov/nchhstp/atlas/. Accessed February 8, 2017.
2. Centers for Disease Control and Prevention. HIV Surveillance Report, Diagnoses of HIV Infection in the United States and Dependent Areas, 2015. Vol. 27, table 3b, p. 23. 2016. https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2015-vol-27.pdf. Accessed March 8, 2017.

>60%
of women diagnosed with HIV in 2015 were Black.[2]

139,192
Black women are living with HIV in the U.S. and six territories (2014).[3]

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Black women will acquire HIV in their lifetime, whereas White women face a risk of 1 in 880.[4]

1,974
trans women were newly diagnosed with HIV between 2009 and 2014.[5]

56%
of Black trans women are living with HIV, compared to 17% of White trans women and 16% of Latina trans women.[6]

» The Situation

Women of color are disproportionately affected by HIV, and less than 53% of women are fully benefiting from the standard of care.[7] However, thanks to decades of dedicated resources and the hard work of people living with HIV, advocates, practitioners, policy makers and the industry, recent data indicate progress in reducing HIV diagnoses and racial disparities among women in the United States.[8] While advances have been made, in 2015 alone 4,528 Black women in the U.S. and six territories were diagnosed with HIV, representing more than 60% of the 7,498 of women diagnosed in that year.[2]

As of 2014, 139,192 Black women are living with HIV in the U.S. and six territories,[3] and HIV constitutes the fourth leading cause of death among Black women 35-44 years old[9]. In 2014, 2,361 Black women living with HIV passed away.[10] Despite progress over the past several years, Black women are 18 times more likely to be diagnosed with HIV in their lifetimes than White women—a striking and persistent racial disparity. Estimates are that 1 in 48 Black women will acquire HIV in their lifetime, whereas White women face a risk of 1 in 880.[4] Racial disparities in AIDS diagnoses are also startling—in 2015, 2,806 Black women in the U.S. and six territories were diagnosed with AIDS compared to 765 White women.[11]

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7. Centers for Disease Control and Prevention. HIV Surveillance Supplemental Report–Monitoring Selected National HIV Prevention and Care Objectives, United States and 6 Dependent Areas, 2014. Vol. 21, no. 4, table 5a, p. 31. 2016.
8. McCree DH, Sutton M, Bradley E, Harris N. Changes in the disparity of HIV diagnosis rates among Black women–United States, 2010. *MMWR Mor Mortal Wkly Rep*. 2014; 66(4):104-106. https://www.cdc.gov/mmwr/volumes/66/wr/mm6604a3.htm?s_cid=mm6604a3_e. Accessed March 8, 2017.
9. Centers for Disease Control and Prevention. Leading causes of death in females. 2014. https://www.cdc.gov/women/lcod/2014/black/index.htm. Accessed March 8, 2017.
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It is critical to address the inequities faced by Black women—from prevention to care—in order to close the gap in HIV disparities in the nation.

Transgender women, especially Black trans women, are heavily impacted by HIV in the U.S. Studies suggest that 56% of Black trans women are living with HIV, as are an estimated 17% of White transgender women and 16% of Latina transgender women.[6] Between 2009 and 2014, 1,974 trans women were newly diagnosed with HIV, and unlike cisgender women, new diagnoses are not decreasing.[5] Despite the need and continued calls from advocates, there are still major gaps in data which ultimately impact the resources and services available for transgender people. It is critical to address the inequities faced by Black women—from prevention to care—in order to close the gap in HIV disparities in the nation.[12]

"I got a box that come every month with my pills in it." Tosha leaves the box of pills and other hints around the house, trying to start the conversation about her life with HIV.

In order to understand the racial disparities in new diagnoses, researchers and advocates point to a constellation of factors rooted in a history of oppression such as poverty, housing insecurity, higher rates of incarceration, lower employment opportunities, substance abuse and residential segregation. These factors intersect with personal and communal gender-based violence, sexual abuse, trauma, and HIV stigma in ways that impact new HIV cases and affect women's engagement with care and treatment and ultimately their health.[13] This study is designed based on the concept of intersectionality—the idea that interconnected social categories such as race, gender and class create overlapping systems of discrimination and disadvantage.[14] HIV/AIDS must be seen in the context of a person's complex environment from the physical neighborhood and physical setting a person lives in to the stigma and support embedded in culture and society.

"I told [my ex]," says Tosha, "'I blame you for not being aware, not paying attention. Since you're ready to talk now, let's talk.'"

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12. Beer L, Mattson CL, Short R, Starbinsky J. Gender disparities in viral suppression and antiretroviral therapy use by racial and ethnic group – Medical monitoring project, 2009-2010. 2015. Presented at International Conference on HIV Treatment and Prevention Adherence. http://www.iapac.org/AdherenceConference/presentations/ADH9_OA283.pdf. Accessed March 8, 2017.
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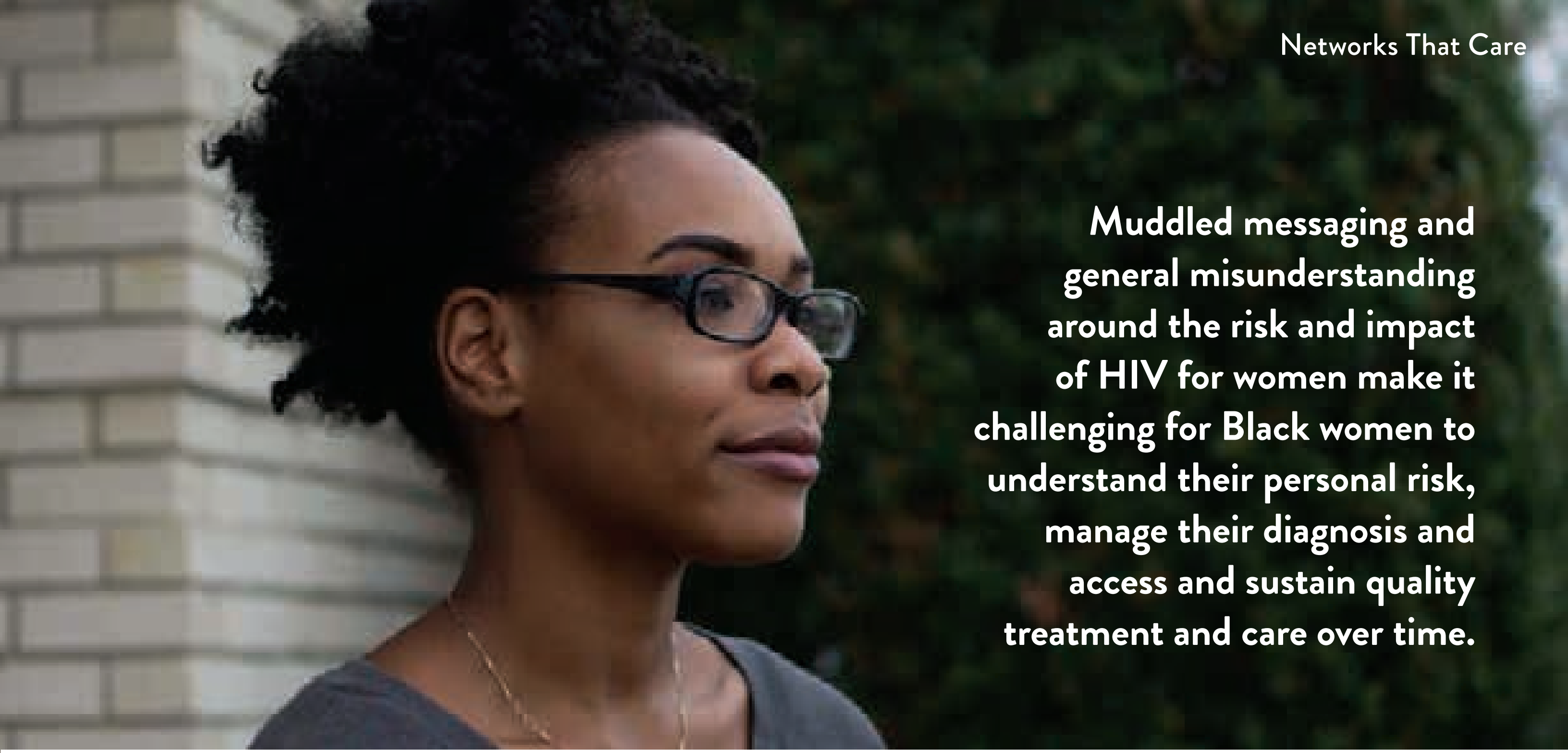
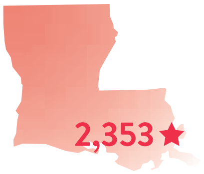


Muddled messaging and general misunderstanding around the risk and impact of HIV for women make it challenging for Black women to understand their personal risk, manage their diagnosis and access and sustain quality treatment and care over time.

While women have been impacted by HIV since the beginning of the epidemic, especially women of color, public discourse has often labeled HIV a “gay men’s disease.” This myth has framed societal and individual understanding of risk and relevance in ways that keep women from engaging in prevention and accessing care and impact research, funding, and policy decisions. Muddled messaging and general misunderstanding around the risk and impact of HIV on women make it challenging for Black women to understand their personal risk, manage their diagnosis and access and sustain quality treatment and care over time. These mischaracterizations represent an additional hurdle for health providers to overcome in their discussions of risk and their attempts to provide clear guidance on prevention strategies such as pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP).

This study explores how these complexities have impacted Black women’s lives and networks in one Southern city—New Orleans. With the third-highest rate of new cases of HIV in the U.S.,[15] New Orleans is home to 2,353 women living with diagnosed HIV.[16] Louisiana is one of the few states in which there were more new HIV diagnoses among Black women in 2014 than in 2010[17] and where Black women were almost 10 times more likely to be HIV+ than White women.[18] New Orleans is a regional hub for transgender women, with 20,900 adults who identify as transgender calling Louisiana home.[19] In addition, New Orleans shares some of the key structural factors characteristic of the Deep South such as high poverty rates, high unemployment and high crime.[20] It is also a city with infrastructure and leadership in the fight against HIV as well as essential community-based organizations led by women living with HIV. By deepening our understanding of the lives of and care networks for women in New Orleans, we hope to gain a window into common experiences of Southern Black women to inform the *Positive Action for Women* initiative.



Louisiana

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15. Centers for Disease Control and Prevention. HIV Surveillance Report, Diagnoses of HIV Infection in the United States and Dependent Areas, 2015. Vol. 27, table 26, p. 106. 2016. https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2015-vol-27.pdf. Accessed March 8, 2017.
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Research Methods

Drawing on established methods from cultural anthropology and other qualitative social sciences, the ethnographic research focused on exploring the networks of care that Black women create and engage with in their communities in order to understand how HIV care can best fit into these networks and practices.

In contrast to statistical surveys or other quantitative methods, ethnographic methods are particularly well suited to exploring women's lives because they allow researchers to gain a valuable depth of understanding (especially on sensitive topics) and a holistic picture.

The study explored how women define health and care, how they provide care for one another and for what reasons and how networks of care are formed in relation to oppressive social structures like racism, poverty and gender norms. Special attention was given to different types of care and the norms and rules that guide care networks.

We aimed to include women with a broad range of experiences across the continuum of care. To reach beyond those with dense social networks connected to the health system, researchers talked with outreach workers and with initial participants in order to grow (or "snowball") the sample of participants. This recruitment approach made it possible to include women who were removed from institutions such as AIDS service organizations—individuals not typically included in research on this topic.

In September 2016, a team of ethnographic researchers from ReD Associates immersed themselves in the lives of women and their networks—capturing the ecosystems of 18 women, along with 20+ family members, friends and case workers. The core participants all self-identified as Black or African American women. Researchers constructed this study with a fluid idea of both gender and sexuality and included a range of participants, not only those who define themselves as cisgender or transgender, but also as feminine-living, feminine-identifying and "other." Twelve of the women were cisgender, and six were transgender. They ranged in age from 21 to 50 years. All of the women had been tested for HIV, with four testing negative and 14 living with HIV, spanning the continuum of care from never in care to having an undetectable HIV viral load.

The data collection methods and analytical approach focused on women's experiences and patterns of thinking. Research was conducted in one location, and findings were analyzed in the context of input from local community and national advisors and previous research studies. This approach allows for understanding networks of care through the eyes of women themselves in order to identify positive levers of care and help prioritize how ViiV Healthcare can support innovative community collaborations that engage and encourage women living with HIV.

networks of care n.

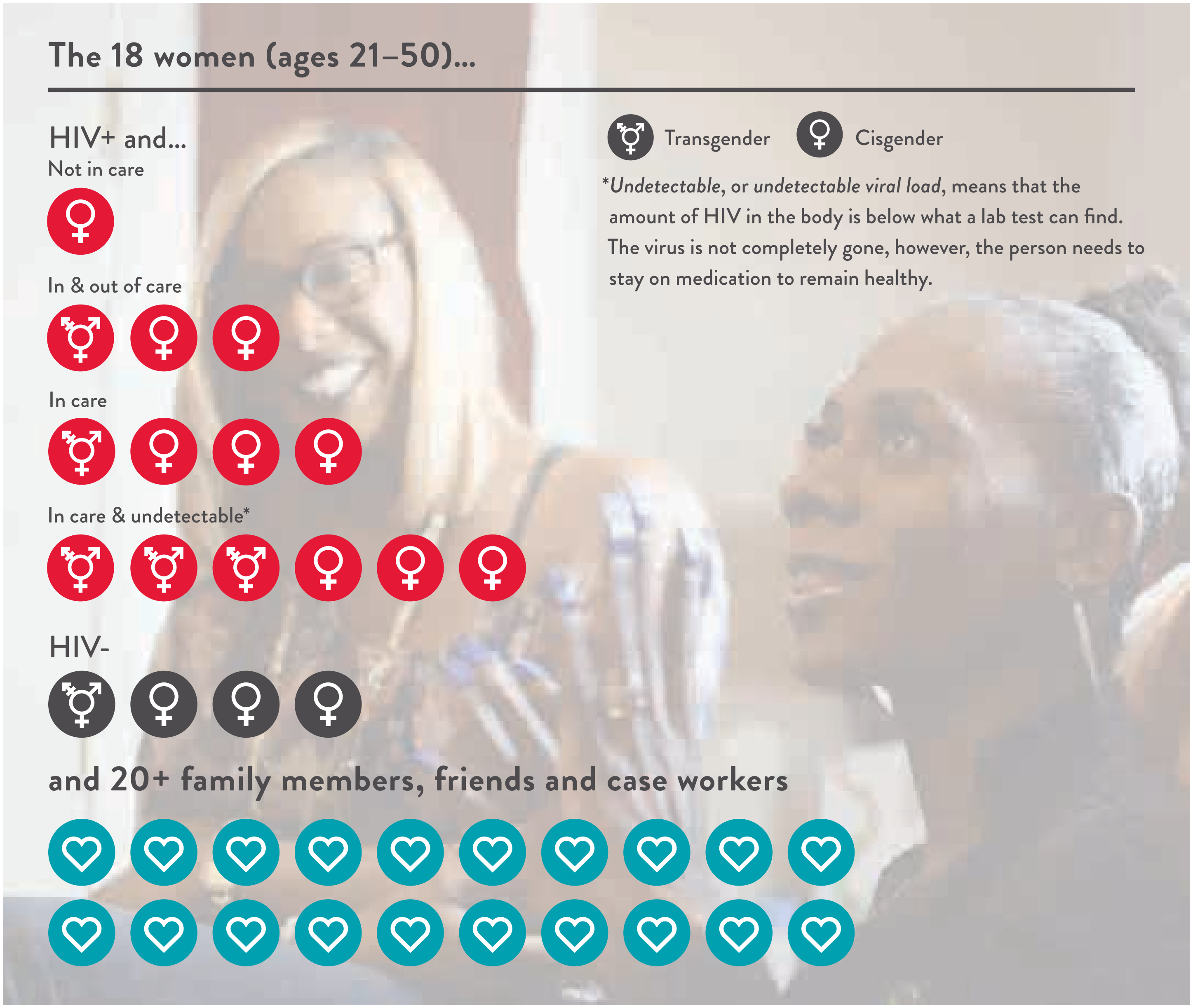
We define a *network of care* to mean the people, things and practices that surround the woman. These networks make up the social web of relationships that are considered culturally meaningful—the most important relationships in a woman's life. Because these relationships are culturally meaningful, they are host to expectations, obligations, challenges and benefits that come with having close ties.

Researchers employed a combination of ethnographic research methods to gather multiple perspectives and experiences. We observed and spoke with women (the core participants), their friends and families, local advocates and service providers. Data were gathered through the following methods:

Participant observation and semi-structured interviews with participants	The cornerstone of ethnographic research is participant observation, a method by which researchers immerse themselves in the lives of those whom they seek to understand—participating in daily activities alongside them, while also asking questions and taking field notes. Researchers conducted in-depth interviews and observations with participants in their homes, favorite local hangouts and local clinics.
Interviews with others in a participant's network	To better understand the core participants' social relationships, brief spontaneous interviews were conducted with friends, families and neighbors who were around during the day of the participant observation.
Network of care kinship chart	In developing a nuanced understanding of the complexities of women's networks, researchers guided participants through a mapping process, building a visual representation of the family (broadly defined) as well as the broader networks of care (people, institutions, etc.).
Social outing observation	To gain knowledge about the contexts of women's lives and their important social relationships, participants invited one person from their kinship chart on a social outing with a researcher.
Semi-structured interviews with community institution representatives	One-on-one interviews with local advocates and healthcare providers (HCPs) were conducted to uncover perceptions about the biggest local challenges and most promising interventions with regard to HIV and AIDS among Black women.
Community institutions observations	Complementing the community institution interviews, researchers conducted observations in those institutional contexts to understand the overall atmosphere, how workers interact with each other and those seeking services and how educational resources are communicated with those seeking services.
Expert interviews and listening sessions	Researchers interviewed 15 additional experts—people who have lived experiences with HIV; community advocates and academic leaders in sexual health, gender and race studies. These one-on-one interviews and discussions situate this current ethnographic research within the rich body of previous research on these topics and put individual perspectives and behaviors in context within larger social, cultural and medical histories. Four local community advocates participated throughout the process, and a group listening session was conducted with national advocates, all to better contextualize and interpret key findings.

This mix of research methods provided the rich data needed to understand women's lives within complex social networks. Subsequently, researchers used an analytic approach informed by grounded theory;[21] rather than begin the analysis with predetermined categories imposed by the researchers, grounded theory provides a framework to develop categories of analysis based on the patterns in the data—on the voices of the women themselves.

At the same time, it is important to acknowledge that all research designs have limitations. In this case, the limitations are that the research was conducted in one city, the sample size was small (18 women) and the time spent with each of the participants was relatively short. To address these limitations, the ethnographic research itself does not claim to be representative of all Black women across the country. This study provides an in-depth look at the structures in which women live, operate and make decisions in one city (albeit a city with features similar to those of many cities in the broader region). Additionally, the research design included the multiple methods described above so as to triangulate findings and to situate them into larger societal and cultural contexts. Finally, the authors note that, although the sample size is small, it is within the established norms for applied research of this type in a specific location and still allows researchers to identify important findings and suggest broader conclusions with new directions about ways to communicate and engage women with care.



The 18 women (ages 21–50)...

HIV+ and...

Not in care

♀

In & out of care

⚧ ♀ ♀

In care

⚧ ♀ ♀ ♀

In care & undetectable*

⚧ ⚧ ⚧ ♀ ♀ ♀

HIV-

⚧ ♀ ♀ ♀

and 20+ family members, friends and case workers

♡ ♡ ♡ ♡ ♡ ♡ ♡ ♡ ♡ ♡

♡ ♡ ♡ ♡ ♡ ♡ ♡ ♡ ♡ ♡

⚧ Transgender ♀ Cisgender

**Undetectable*, or *undetectable viral load*, means that the amount of HIV in the body is below what a lab test can find. The virus is not completely gone, however, the person needs to stay on medication to remain healthy.

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[21] Strauss AL, Corbin J. *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage Publications; 1990.

Findings

Integrating the findings across the mix of methods, researchers found that the biggest challenge for Black women in the study was navigating the social consequences of their diagnosis. In the changing social landscape post-diagnosis, self-care became especially challenging. Findings from the research are organized across three core areas impacting women's experiences:

Cultural norms and understandings around sex and HIV

- » Misinformation about HIV and AIDS is extremely common and impacts women's experiences.
- » Sex and gender norms impact women's health.
- » Scarcity of men, along with potential violence, undermined women's power around prevention.
- » An HIV diagnosis "outed" cisgender women as having potentially broken sexual norms and brought additional judgment on trans women.
- » Transgender women talked more about sex and health, especially with their adopted gay families.

Realities of social navigation and living with HIV

- » HIV diagnosis dramatically impacted the identity of cisgender women but less so for transgender women.
- » For cisgender women, testing positive for HIV felt like "social death." Many chose to hide their status, becoming increasingly isolated and withdrawn.
- » Women blamed themselves.
- » Disclosure has major consequences in women's lives.
- » As a result of potential violence, humiliation and rejection, women developed carefully constructed strategies to disclose their status or chose not to disclose at all.
- » When a woman's disclosure was met with acceptance, the confidante became an important advocate.

Experiences with care

- » Healthcare providers were extremely important for conversations about sexual and reproductive health.
- » Doctor's visits were more than just medication—women framed their engagement and consistency with care as social.
- » Though a quick linkage to care was common in New Orleans, it did not necessarily lead to long-term engagement.
- » Transgender women reported experiences of discrimination in care but were highly engaged once they found a trusted doctor.
- » Both cis and trans women found it easier to stay in care when clinics supported their practical, social and emotional needs.
- » Care keeps women feeling connected, and less frequent clinic visits could be counterproductive.

Cultural norms and understandings around sex and HIV

Misinformation about HIV and AIDS is extremely common and impacts women's experiences.

Testing positive for HIV brought to the surface common misunderstandings about HIV and AIDS primarily based on fear of transmission. Prior to testing positive, these ideas were likely sub-conscious, reflecting societal misperceptions, and did not impact the women's daily lives and relationships. Testing positive changed this. One woman, for example, explained how her family (before they eventually kicked her out of the home) made her bleach the tub after use, eat off different plates, and use a separate washing machine.

Women in this study also explained some of their own common misunderstandings about and fears of HIV when they tested positive:

> “One time I thought just being around a person you could get it.”

> “I thought, ‘I'm gonna die.’ You know on TV everything happens quickly and dramatically. I had this idea that you're dead.”

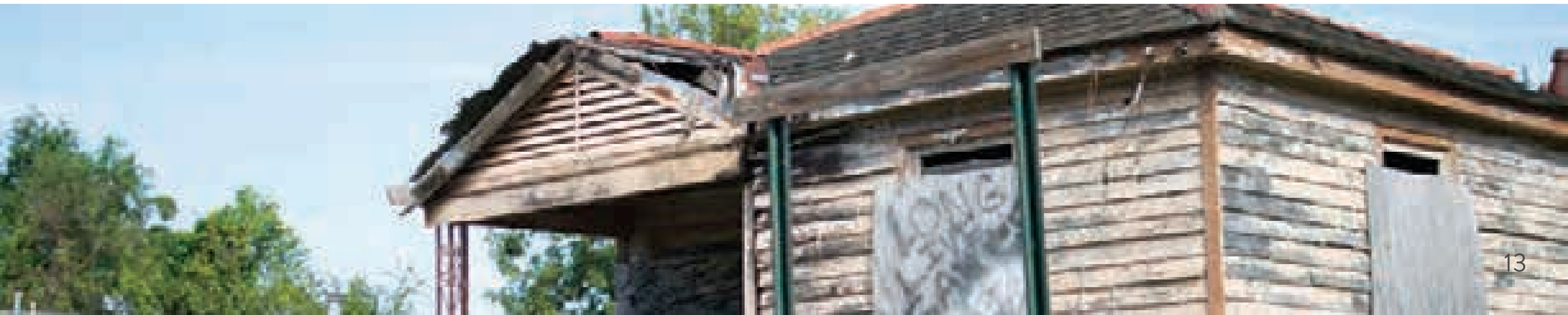
> “[My son now knows] not to mess with my cups, and I make sure I have his stuff for him. He have his own juice box and cups, my nephew has his own cup. And if he do drink out of my cup, I just say a prayer.”

> “I didn't know that HIV and AIDS were different. I thought they were the same thing.”

While many of these misunderstandings were resolved as women learned more about HIV and AIDS, some of them were so powerful that women reported continuing to act on them even when they knew they were not true.

One woman, for example, could not shake the idea that there might be some small chance of passing HIV on to her son through everyday contact.

She said that she didn't kiss him for the first year of his life and that she constantly bleached surfaces in her house. Through this ritual bleaching, she felt she was taking action to cope with the intense anxiety around contagion. And when she was in the company of others, her behavior served a communicative function to ease the misunderstandings she thought that others might have. “Don't worry, I just bleached the seat,” she said to one of the researchers before they used the bathroom.



Sex and gender norms impact women's health.

Sex remains a taboo subject for many Black women in the South. Most women in this study reported that they never talked about sex with their families, that they were not exposed to sex education in school and that religion reinforced silence around sex. Sexual norms dictated that women should be monogamous and should be having sex for reproduction, not pleasure. Most cis and trans women expressed feeling pressure not to appear overly sexualized. All trans women expressed a tension with not appearing overly sexualized and the desire to be seen and validated as feminine and sexually attractive.

> “We talk about everything—except for [sex].”

Most of the women interviewed said that they had their first sexual experiences around 13 or 14 years old. Many also reported sexual abuse, coercive sex and high levels of “exchange sex.” These women do not currently identify as sex workers but explained that sex was often traded explicitly or implicitly in exchange for material goods or other support.

> “I have a foster sister who is in Section 8 housing, but they don't pay water or lights, so she has sex for money. Nobody talks about it because it's like drinking water.”

> “You don't give away your cookies for free.”

Scarcity of men, along with potential violence, undermined women's power around prevention.

Women explained that men in their communities were scarce due to the mass incarceration of Black communities and that a man's presence in their life was precarious. As such, they feared rejection and often wouldn't bring up important conversations about sexual health. Conversations about condoms were especially fraught, as women feared that, if they asked a man to use a condom, they risked angering him by implying that he was unfaithful. Or they worried that asking about condoms implied that they had been unfaithful. Women reported that they not only feared rejection from a man during these discussions but also feared physical violence if they provoked men with discussions about condoms.

> "Condoms imply that something is wrong with someone and that you are cheating."

> "Men will say, 'what are you doing? What's wrong with you?' I never turned it around because I feared being rejected."

An HIV diagnosis "outed" cisgender women as having potentially broken sexual norms and brought additional judgment on trans women.

When women are known to be HIV+, many people assume that the women have broken sexual norms—including those of monogamy and sex for reproduction, often resulting in verbal abuse and harsh judgment. Unlike other regular instances of sex without a condom, instead of getting pregnant these women contract HIV.

Transgender women reported the stigma specifically brought on by HIV differently, since they have already crossed gender norms and were assumed to be breaking with sexual norms. For the trans women in this study, HIV was seen as confirming these negative assumptions.

> "People assume that I was sleeping around but I got it from my partner… in a 13-year relationship. The difference between having HIV when you're trans vs. a heterosexual is that [the doctors] think I am nastier than a heterosexual. They think we already have that nastiness."

Transgender women talked more about sex and health, especially with their adopted gay families.

Transgender women explained that they came to identify as part of an "adopted gay family," separate from their birth family. These supportive networks used the language of family, and became especially important for transgender women who felt excluded or estranged from biological family. Transgender participants explained that these adopted families were often a source of critical information and protection strategies.

> I was new on the scene, and I really didn't know nobody... That's why we have these gay parents who be like, 'Be careful, don't do this.'"

Women reported that these conversations were valuable both for thinking about prevention and for understanding and navigating care, especially if they are HIV+. One woman explained that her adopted gay mom and dad were especially motivating in her efforts to stay undetectable. **"They applaud me for what I do, and that makes me feel good. That's what keeps me going."**

Transgender women also reported more discussion around condoms with sexual partners, a contributing factor in making condoms the norm for the early stages of sexual relationships (**"I *have* to use condoms."**). As relationships became more serious, condoms were used less frequently, both as a signal of trust and also as a way to mark the seriousness of the relationship.

Realities of social navigation and living with HIV

HIV diagnosis dramatically impacted the identity of cisgender women but less so for transgender women.

A positive HIV diagnosis “outed” cisgender women who had broken sex and gender norms. It affected not only how others saw these women, but also how women thought of themselves. Before testing positive, most of the women did not consider themselves the “kind of person” who would get HIV. Women felt and expressed the expectation that they would not get HIV, and a diagnosis broke this norm. They associated HIV with identities more than behaviors and did not think that testing was especially important since they didn’t see themselves as being in groups “at risk.”

> “I always heard the stigma, ‘homosexuals will be first.’ In street terms, it’s a gay disease.”

> “I thought HIV was for people on drugs, prostitutes, and homosexuals.”

As such, when cisgender women tested positive for HIV, it dramatically affected their self-image and made them feel like a different kind of person, one who fell outside their individual, cultural and social norms.

> “I didn’t think that could happen to me… I’m a person I never thought I’d be.”

Transgender women in the study seemed to experience less of this identity shift after testing positive. Many transgender women have already experienced stigma and have already formed identities and communities in reaction to that stigma. (**“When I told my mom I was gay, everything stopped. From then on, everything I did was wrong.”**) The prevalence of HIV among transgender women is significantly higher than among cisgender women, making an HIV diagnosis for a woman living with HIV more normalized. One transgender woman who acts as an adopted gay mother explains: **“I have a lot of gay children who have died from it, or lived with it; people come to me in secrecy… I don’t treat them any different.”**

For cisgender women, testing positive for HIV felt like "social death." Many chose to hide their status, becoming increasingly isolated and withdrawn.

For these Southern Black women, other women in their networks were the strongest source of support, both practical and emotional. The stigma associated with testing positive threatened to jeopardize a woman's entire connection to her community, and many women decided to hide their HIV status, becoming increasingly isolated and withdrawn.

> "I don't want to be talked about... people not liking me, whispering, say nasty things, put something up that's derogatory. I just keep my business to myself."

The challenges of everyday life made it extremely difficult for women to successfully hide their status. Many women lived in tight quarters with family, often extended family, with multiple generations staying together under one roof. One woman, for example, described losing her job as a scaffolder and losing her house, thereby being forced to move in with her daughter, son-in-law and three grandchildren. Because of the challenges associated with hiding HIV status under these circumstances, many women described complex strategies for keeping their status a secret from this close network of family and friends.

> “We on air, [with social media, you] can post what you want, edit. But at home, if we are with people, we feel we always have to be on show. Nobody can be on show 24 hours.”

Strategies to hide one’s HIV+ status

One woman kept her medication hidden in her underwear drawer but was worried that her grandkids would find them. She was also afraid that her family would find out that she was HIV+ if they heard her cry or saw her web browser history. She said:

> “I’d put the towels over my face and cry so they wouldn’t hear me.”

Women reported avoiding clinics that are designated as HIV clinics so that people did not see them going in or coming out. One woman said:

> “That’s why I like going to Dr. ABC because you are not stereotyped. If you go to the [HIV Clinic], it’s as clear as the nose on your face.”

One woman described deliberately gaining weight to avoid looking like she was ill. Despite her doctor’s concerns about her weight gain, she liked the weight because it provided “evidence” that she was healthy.

Women described social media as a “camera,” a way to manage self-presentation. They deliberately posted pictures of weight gain and active lifestyles.

These strategies for hiding HIV status were not only time consuming and taxing but could have real health consequences. **Sometimes women described going to such lengths to avoid people knowing their HIV status that they ended up missing appointments and not taking medication to keep their bodies well.**

For transgender women, multiple social networks provided an avenue to navigate potential rejection. While cis women often had one, integrated social circle, trans women tended to have multiple ones. One woman described having a large gay family—including gay grandparents, parents, and siblings—a pageant family she travels around the country with, a biological family and childhood friends. If one person rejected her for her status, most of her networks would remain intact.

Women blamed themselves.

Women did not blame their partners, the high prevalence of HIV in New Orleans or their circumstances for contracting HIV but instead blamed themselves. **When one woman found out she acquired HIV from her boyfriend, at first she felt so angry she wanted to kill him. But then, she said that she realized: "I can't put my illness on [him]. I'm my own responsibility."**

One woman contracted HIV doing sex work, constrained in her life choices by Hurricane Katrina among other things. She never blamed these circumstances for contracting HIV but rather blamed herself. People who have experienced a traumatic event such as an HIV diagnosis may blame themselves in part because they perceive that they could have avoided the event.[22] In general, women in this study reported low levels of self-esteem, seeing their HIV contraction as a personal failing. This specific tendency to blame themselves compounded other anxieties about their diagnoses so much so that women reported depression, substance abuse, suicide attempts and even self-punishment (such as denying appropriate care and connections to those they love).

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[22] Ellard J. Self-blame following a traumatic event: the role of perceived avoidability. *Personality and Social Psychology Bulletin*. 1996; 25(6):557-567.

Disclosure has major consequences in women’s lives.

When women chose to disclose their HIV status to family, friends and romantic partners, the results could be devastating to women’s lives. Women approached the moment of disclosure to a partner or potential partner with great trepidation. One woman described how, when she told her husband about her diagnosis, he beat her so badly that she was hospitalized; another woman reported being dragged down the street. The threat of violence loomed over women’s disclosure decisions, especially their decisions about whether and how to disclose to male romantic partners. Besides the threat of violence, women knew that disclosure was a “moment of truth”—that a partner would either end the relationship immediately or that the relationship could deepen and change.

> “Once I let him know about that, that’s going to determine whether he’s for me, or he’s not. Now... I don’t know how that’s going to work out. I really don’t. But... I’m just waiting to find out.”

Women reported verbal abuse and humiliation when disclosing to friends and family as well. Several women reported being kicked out of their homes. Others reported being ostracized and humiliated, sometimes forced to use separate plates or to bleach surfaces after use. Women with children reported being especially afraid that violence and humiliation would carry over to their children. That worry—that children would face stigma or violence because of their mother’s status—was responsible for some women keeping their status hidden from those very children or the community at large.

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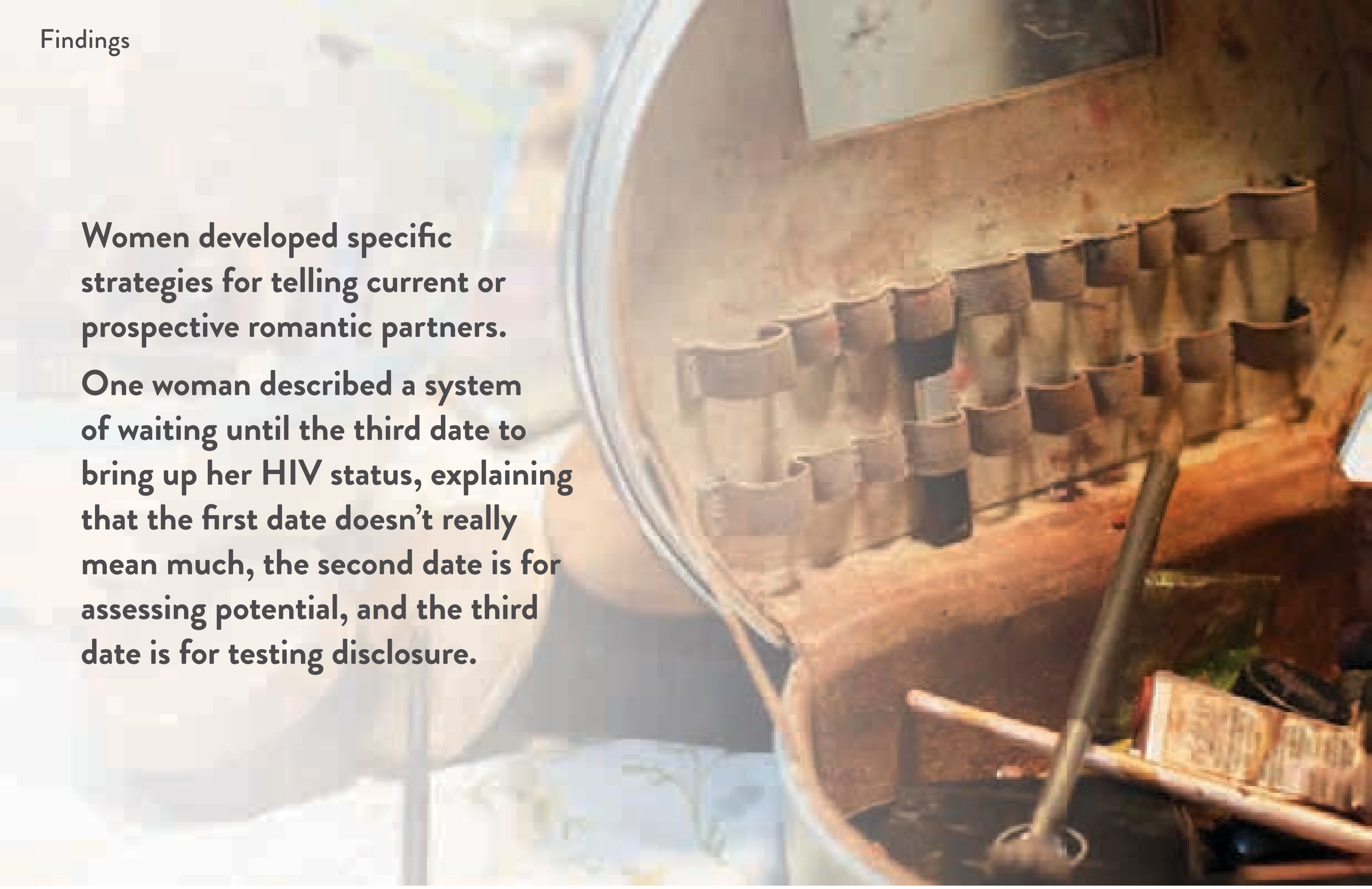

Women developed specific strategies for telling current or prospective romantic partners.

One woman described a system of waiting until the third date to bring up her HIV status, explaining that the first date doesn't really mean much, the second date is for assessing potential, and the third date is for testing disclosure.

As a result of potential violence, humiliation and rejection, women developed carefully constructed strategies to disclose their status or chose not to disclose at all.

One component of the strategy was to carefully choose a safe person, usually female, to disclose to. This person was often someone who either already knew someone with HIV, who had demonstrated openness in some way or who had a high degree of social capital (someone powerful in the social network who could shield them from the negative reactions of others).

Women also employed a strategy of leaving hints around, intending that their family and friends would come to them when they were ready to talk. One woman described leaving her box of medicines out in the open one day. Another described dropping subtle hints like mentioning feeling sick. Women feared rejection or violence from direct disclosure and would therefore test people in their lives with these subtle hints, also giving people the option to process the news on their own before having a direct conversation. One woman explained her indirect disclosure to her boyfriend:

> “He doesn't like to talk about the situation. I haven't told him. When he sees me take my medicine I'll be like, ‘So, you know what this is for, right?’ and he says, ‘I don't want to talk about all that.’ So I think he knows. But he don't say nothing about it.”

When a woman's disclosure was met with acceptance, the confidante became an important advocate.

These key allies provided vital emotional, practical and social support for women in terms of health, personal lives and self-esteem. They provided support with important day-to-day practicalities such as transportation, housing, medication reminders, cooking, child care and medical appointments.

When women felt too overwhelmed, their allies helped with gathering information about HIV and about care. Socially, these champions supported women with disclosure, informing family and extended networks in the role of a liaison who protected the women themselves from the initial violence or humiliation of disclosure.

Some women who worked in community-based organizations or in HIV care also acted as champions to help women through diagnosis and treatment, but these more professional advocates were often under-resourced and limited in what they could do. Nonprofessional, supportive connections are critical for women.

Experiences with care

✚ Healthcare providers were extremely important for conversations about sexual and reproductive health.

Considering the cultural taboo around sex, visits with HCPs were one of the only places women felt they could have conversations about sexual health. However, many women sought out care only after they became sexually active and, further, only engaged with HCPs when they were pregnant or had an infection which was not necessarily HIV. Women generally considered it better not to worry about sexual and reproductive health issues until they were impossible to ignore. In addition, many women expressed their personal feelings of mistrust about doctors and their motives, racial discrimination, pharmaceutical companies and the medical system in general.

> “I didn’t know any Black scientists. Medicine is represented by people who don’t look like me. Why would I trust it?”

> “The doctors don’t care. They make deals with pharmaceutical companies to give patients all sorts of drugs. They use you as a guinea pig.”

Despite this mistrust, once women began visits with HCPs, those conversations were highly valued. Women then expected HCPs to take the lead and to provide accurate and comprehensive sexual healthcare. Women relied upon their HCPs to determine which STIs they should get tested for and believed that it was their doctor’s responsibility to test them.

✚ Doctor’s visits were more than just medication—women framed their engagement and consistency with care as social.

When discussing their consistency in medical and self-care, women did not explain it in terms of their own physical health but rather in terms of their relationships, especially the relationships with their children and families. Both cis and trans women described the support of other people who helped them adhere to care plans, and they described how the other people in their lives were the driving force behind why they adhere.

> “I got a 15-year-old counting on me. I can’t give up. I can’t let my baby see me go now. No. My child would be traumatized for life.”

> “These four people [my mother, sister, uncle, and friend], when they found out, they never turned their back. They actually came with me to the doctor, to the clinic. That’s the only thing that kept me going. Without them four, I might be dead right now.”

Though a quick linkage to care was common in New Orleans, it did not necessarily lead to long-term engagement.

After their diagnoses, most of the HIV+ respondents were linked to medical care within two months. Nonetheless, for most of these women the journeys have been erratic, with irregular care and adherence. Barriers described include:

Disconnected from Standard of Care	One woman was told she didn't need treatment until her viral load and $CD4^{+}$ counts changed. When she finally sought care, she had an AIDS diagnosis. Another woman was told she didn't need medication right away but to come back every two months. She didn't return.
Denial	One woman ignored her diagnosis for eight years because she didn't want to admit how serious it was. She thought, **"I'm gonna be alright."**
Depression	One woman was afraid to take HIV medications because "they remind me that I'm dying."
Stereotypes about mental health	One woman explained the stigma she confronts because of her mental health struggles: **"I went to the hospital like eight times to try to get tested. They said no, you have to go to [HIV Clinic]. They told me if I came back again, they'd send me to a mental institution."**
Bureaucracy	A woman who experienced severe depression struggled to find the motivation to find care, and, when she finally sought care, she said she was given "the runaround" and told that she had to pay for her medication.
Drug use	After her diagnosis, one woman fell back into using drugs and did not enter care.

Transgender women reported experiences of discrimination in care but were highly engaged once they found a trusted doctor.

All trans respondents reported histories of mistreatment in clinical settings. One participant commented: **"The way that I was treated was because I was transgender. They were trying to rush me to go home before my time... I'm a full transgender woman, I have breasts. They put me in a room with a guy."**

> "There's just a lot of personal judgment and stigmatization toward trans."

Despite the consistent reports of discrimination, transgender women in general tended to have more familiarity and comfort with doctors and medications—many had regularly engaged in hormone therapy or undergone gender-affirming surgeries.

Additionally, once these women found a trusted doctor or clinic, they all reported high engagement, including actually enjoying the interactions.

> "When I go to the doctor, I kind of look at it as a reward."

Transgender participants also expressed the importance of gender transitioning and other basic needs such as housing over the anticipated risk of HIV.

> "I live for myself, and my truth... I'm coming into my final stages of transition. I'm reaching my peak."

One woman explained that she used to have to buy hormones on the street market but was now happy that she was able to get them from her HIV doctor. Another woman explained that her doctor had built trust with her by empathizing with transgender experiences:

> "We have a close connection. We get each other. I think she might be trans. I don't know. Maybe she just really understands."

Another woman echoed that sentiment:

> "She's a hell of a doctor. I wouldn't go to anybody else. It's not a doctor-patient thing; we have more of a relationship as people, it's friendly."

Both cis and trans women found it easier to stay in care when clinics supported their practical, social and emotional needs.

In the best-case scenario, care included treating women holistically—meeting all their physical, social, emotional and practical needs. One clinic offered a range of logistical services around housing and transportation which made clinic visits possible.

For women who felt isolated in their homes, clinics provided a social outing when there were few places women could go and feel comfortable. One woman explained that she hated being inactive and having nothing to do, but without a job or the freedom to move about her neighborhood safely, her visits to a local care center were one of the only opportunities she had to get out of her house. Another woman explained how important it was that the clinic staff treat her like a "normal" person, with respect and dignity. Women preferred general health clinics over HIV-specific locations, appreciating places that can provide one-stop-shop services where she could benefit from privacy and discretion.

> "At [local general clinic], they don't treat you like you're contagious. I love going there… I really like that sometimes the doctors eat their lunch in there."

> "Anybody could go to a [local general clinic], not just me. They would never know the difference if you are a patient or not, and I kind of like that. I'm not saying I'm so secretive, but I am."

Care keeps women feeling connected, and less frequent clinic visits could be counterproductive.

When fewer clinic visits were indicated due to good treatment maintenance and health indicators, several of the women who were engaged in care were left spending more time alone, which was difficult because of the social and supportive role that the clinic visits had been fulfilling.

One woman explained how she was very upset that, when she tested undetectable for a third time, she would be re-assigned to a non-medical case worker. She began to tear up describing how she wouldn't get to go to the clinic so often. Another stated that she didn't think she could stay adherent without the routine and support of the clinic.

> "[The doctor] is the one person you talk to. You build that trust. It's someone who knows you. The trust you give into that person is the person you depend on, that's the person you talk to. You don't have anyone else to talk to. You go from one month to three months to six months. Or a year. A person is going to break down. I told my doctor that I was going to see him every three months. I still don't talk to my family about it. I try not to because the stigma is still there."

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Conclusions and Implications

This research illuminates how understanding women's complex social worlds and their ability to navigate delicate social relationships can inform HIV prevention, treatment and care.

Women may face violence and rejection if they attempt to engage in prevention and care practices. Many blame themselves if they are diagnosed with HIV and are faced with misunderstanding and humiliation from their social connections. Contracting HIV is perceived as (and often results in) "social death"—isolation from friends and family, humiliation, depression and an expectation that romantic lives are over. Transgender women face additional challenges, especially in their wider societal interactions and benefit from social networks that are more familiar with and supportive of living with HIV. Understanding these complex mental patterns, social networks and cultural norms is critical to ensuring that women with HIV are valued, supported and successful with their care.

The insights about norms and taboos, disclosure, living with HIV and engagement with care can inform responsive, women-centered solutions in the healthcare field.

Barriers That Impact Care

- Isolation and societal silence around HIV are major barriers to getting the support and care women deserve.
- Misinformation dramatically impacts prevention, treatment and care.
- Social isolation impacts care.

Positive Levers for Change

- Mental health and positive self-image are critical, and women need supportive people in their own communities.
- Taboos around talking about sex make the role and routine of OB-GYN visits critical.
- "Adopted gay families" are assets for transgender women.

» Barriers That Impact Care

Isolation and societal silence around HIV are major barriers to getting the support and care women deserve.

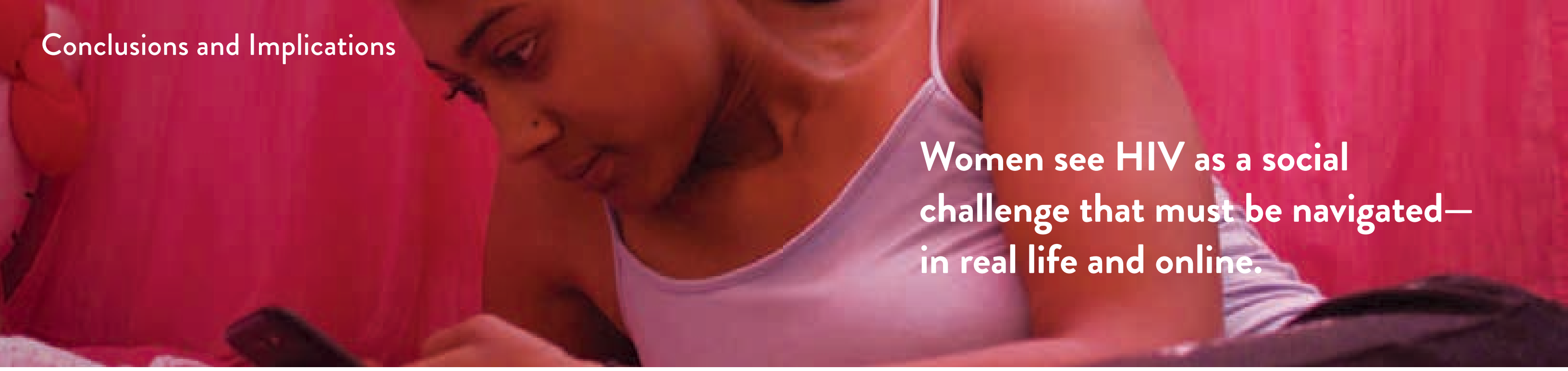
The cisgender women in this study live in a culture where talking openly about HIV and sexual health is taboo across virtually all situations. While transgender women reported less of a taboo in talking about sex, other parts of their environment contributed to social isolation, including transphobia, poverty and substance abuse. For all women, isolation from networks of support exacerbated the challenges of living with HIV and hampered women's efforts at self-care. Strategies that support women in rebuilding social connections that have been impacted by HIV are crucial to improving women's access to and consistent use of prevention, treatment and care services.

Misinformation dramatically impacts prevention, treatment and care.

People tend to think about HIV risk more in terms of identity, and many cisgender Black women do not perceive themselves or other women to be at risk or affected by HIV. At the same time, transgender women often hear the message that an HIV diagnosis is inevitable. Specific strategies for engaging cis and trans women must consider the muddled misinformation about risk, treatment as prevention and women's experiences in order to make treatment and care relevant for women.

Social isolation impacts care.

Women may find themselves socially isolated in a way they haven't previously imagined—ostracized, humiliated and even forced out of their homes. Aside from the important mental health component of this isolation, HCPs should consider that women may not have the social support necessary to get into care and remain engaged. Their transportation or child care may be compromised. They may lack the social support that was allowing them to work and may require practical support to fill these gaps. In addition, the field should take into consideration the social vacuum that HIV creates in these women's lives. Providers may consider how altering the frequency of appointments could impact women's social and emotional health. This also includes ways to supplement clinic visits through partnering with social and support groups for women.



Women see HIV as a social challenge that must be navigated—in real life and online.

» Positive Levers For Change

Mental health and positive self-image are critical, and women need supportive people in their own communities.

Though the health field may understand HIV risk in terms of demographics and structural factors, many women blame themselves for contracting HIV. This self-blame is reinforced by the misinformation, stigma and trauma that they may face in their lives. In addition, although HCPs pragmatically view HIV largely through a medical lens and therefore not as a "death sentence," it is important to understand that many women see testing positive for HIV as a "social death." Women see HIV as a social challenge that must be navigated—in real life and online. The convergence of perceived "social death" and compromised physical health can increase women's vulnerability to substance abuse, social isolation and depression. For these women, professional and community-based mental healthcare is critical and must come before or parallel to physical healthcare.

Taboos around talking about sex make the role and routine of OB-GYN visits critical.

Cisgender Black women in the South report that sex and health are not openly talked about. Much of the information women receive about sex appears to be circumstantial. This study revealed that there were no standard resources about sex and sexual risks that women referred to, but rather they had a mix of media sources and partners, close friends and peers who shared their own personal experiences. One of the only times when sex is directly and explicitly talked about is the OB-GYN visit or other medical interactions related to sexual or reproductive health. These rare opportunities could be leveraged for more education and discussion about risk that is relevant to their lives and would be even more effective if they were initiated early and occurred regularly, before women become pregnant or acquire HIV and/or other STIs.

"Adopted gay families" are assets for transgender women.

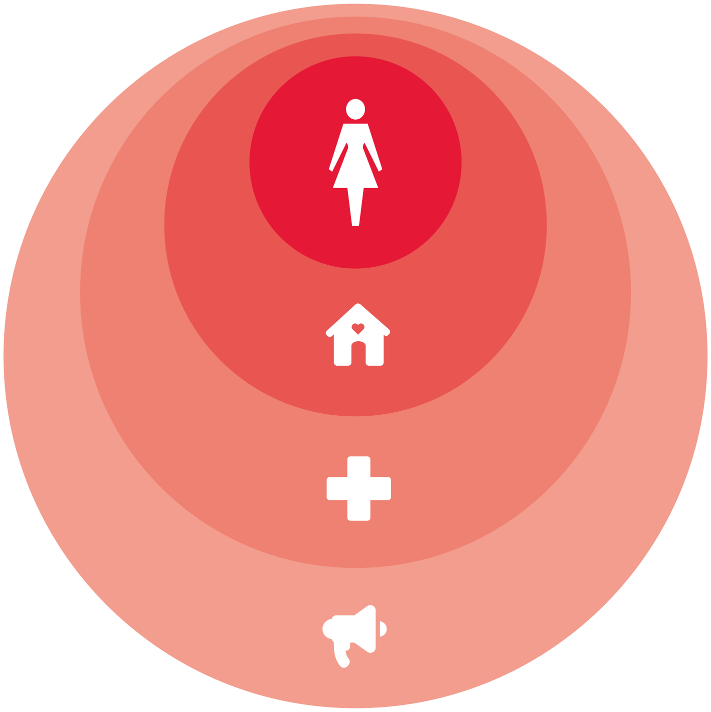
Black transgender women report getting advice and strategies from trusted adopted families. These families can be supported in their efforts to share valuable information about prevention and care. This research showed that messages about PrEP and treatment as prevention (TasP) are especially important for transgender women because of the high rates of diagnosis and prevalence within sexual networks. Helping gay families access, translate and share more life-saving HIV/AIDS-related information builds on the strength of these essential networks.

Going Forward

The ethnographic research presented here is one part of ViiV Healthcare's listening strategy to find new solutions that make a difference in the lives of women living with and affected by HIV.

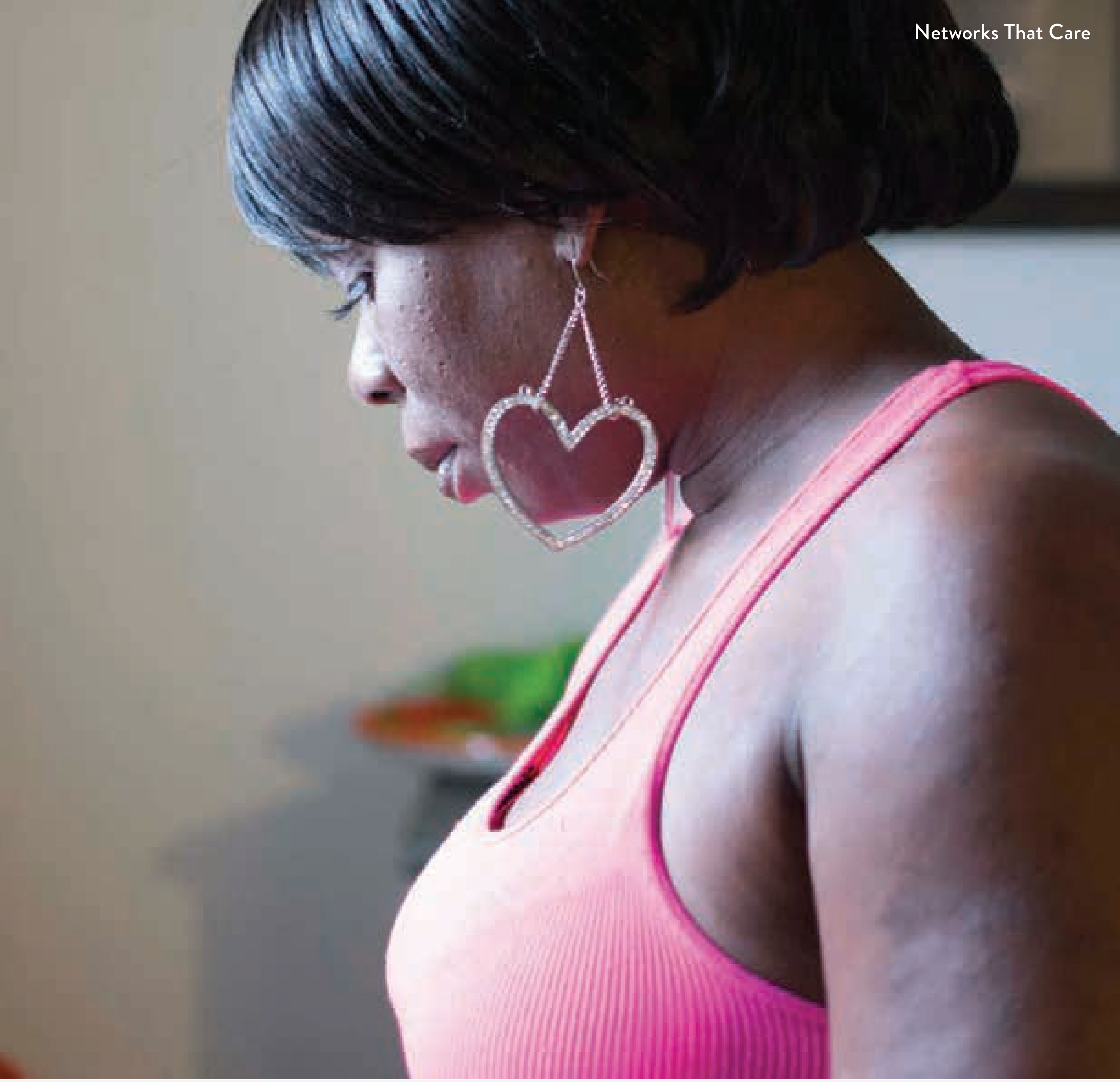
The research and epidemiologic insights from women living with and affected by HIV, community advocates and academic leaders in sexual health, gender and race studies helped us to prioritize and focus our efforts to advance our commitment.

These listening strategies made clear that women of color living with HIV are heavily impacted by isolation at three levels:



- Isolation from their friends, family and peers as a result of fear and stigma
- Isolation and disconnection among local organizations limiting their ability to meet women's needs
- Isolation from the larger cultural conversation around HIV and women's wellness including in clinical research, media, culture and communications

In response to these findings, *Positive Action for Women* (*PAFW*) supports innovative, forward-thinking projects and community collaborations that break down isolation and stigma for women of color living with HIV and link women to networks of care. *PAFW* is one part of our company's global commitment to closing the gaps in research and care for women.



ViiV Healthcare

ViiV Healthcare was established to take an innovative approach to the challenge of HIV—and we do. It's who we are.

An innovative approach means we go beyond developing new medicines. We seek insights to better understand the unmet needs of people living with HIV. We connect individuals and communities to help drive solutions focused on providing the same standard of care for all people living with HIV. We develop and support community programs that focus on HIV prevention, care, and treatment. The voice of the HIV community informs everything we do.

As the only company solely focused on HIV, we think differently, act differently, and connect differently to improve the lives and outcomes for all people affected by HIV.

POSITIVE ACTION

From the beginning, ViiV Healthcare's Positive Action programs have worked to reduce stigma and improve access to care for communities around the world.

As the first global pharmaceutical company program to support communities affected by HIV/AIDS, Positive Action has supported more than 300 programs across the globe since 1992.

To learn more, visit viivhealthcare.com/us and follow us @ViiVUS

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ViiV Healthcare

for Women
POSITIVE
ACTION