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# “My Determination Is To Live”: Narratives of African-American Women Who Have Lived with HIV for 10 or More Years

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## “My Determination Is To Live”: Narratives of African-American Women Who Have Lived with HIV for 10 or More Years

### Abstract

Exploring the experiences of African-American women who have lived with HIV for many years can inform public health practice on how to better serve high-risk populations along the care continuum. To understand the experiences of African-American women who are HIV positive, the researchers used a narrative approach to guide repeat interviews. Under a theoretical framework of Womanism, we interviewed six African-American women ages 48-66 ( $M=57$ ) who have lived with HIV for 10 years or longer and conducted analyses of narrative to identify key themes. The primary themes were: recollecting early hardships, HIV infection, and diagnosis; embracing social support; surviving and thriving; meaning making and HIV. The findings highlight the need for programs specific to long-term survivors, including resilience training, education programs on dating and disclosure, and opportunities to engage in meaningful work or volunteer initiatives.

### Keywords

HIV/AIDS, African American Women, Womanism, Narrative Inquiry, Analysis of Narrative

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## **“My determination is to live”: Narratives of African-American Women Who Have Lived with HIV for 10 or More Years**

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Communities of color are disproportionately affected by health disparities, and public health efforts have been instrumental to reduce the burden of disease. As an example: HIV/AIDS incidence rates in African-American women decreased from 2005-2014, but this population still accounts for 64% of all new HIV infections in women. As incidence rates decrease, public health practitioners must attend to a growing population of long-term HIV survivors. Ensuring Persons Living With HIV/AIDS (PLWHA) progress along a continuum of care is vital to prolonging lives and preventing new infections. The HIV care continuum includes timely HIV testing and diagnosis, linkage to care, engagement in care, anti-retroviral therapy, and viral suppression (HIV Care Connect, 2015). With adequate linkages to care and appropriate treatment, many PLWHA achieve viral suppression. In addition to reducing transmission, persons with suppressed viral loads experience fewer opportunistic infections, have better health overall, and are less likely to become resistant to HIV medications (NAM, 2015). The Centers for Disease Control & Prevention (CDC, 2014) reported life expectancy can increase 40 years for persons in care, but only 40% of PLWHA are successfully linked to care. Therefore, even with evidence of the importance of anti-retroviral therapy (ART), there are barriers to PLWHA along the HIV care continuum.

Research to improve health outcomes for PLWHA has been ongoing for three decades. Lather and Smithies (1997) conducted one of the first qualitative studies to understand the

experiences of HIV positive women. The authors explored the day-to-day lives of participants ( $N=26$ ) by visiting support groups. The findings offered a look at what participants experienced, expressed, and witnessed during the early stages of the HIV/AIDS epidemic. To date, no other published research has provided as intimate a look from a target population's perspective of what it is like to live with HIV/AIDS. In addition to the little attention on the lived experiences of PLWHA, gaps in the literature persist in how public health practitioners can improve the quality for life of this population and how programs can be tailored to long-term survivors (High et al., 2012; High et al., 2008; Slavin et al., 2011). Randomized controlled trials, in-depth interviews, and surveys have explored sources of support, religion/spirituality, and medication-related beliefs of PLWHA (Dalmida, Holstad, Dilorio, & Laderman, 2012; Dalmida & Thurman, 2014; Kalichman, Eaton, & Cherry, 2010; Kremer, Ironson, & Kaplan, 2009). Smith, McCarragher, and Brown (2015) analyzed data from focus groups to assess HIV-related strengths and resilience. The authors' research is the only published study found addressing how African-American women have lived with the disease over an extended period and no studies we are aware of have used a narrative approach to explore the lives of this population. The researchers in this study sought to fill a knowledge gap related to the experience of this population by using a narrative approach to focus on the lives African-American women who have been HIV positive for an extended period. Specifically, we wanted to understand how African-American women who have been HIV positive for 10 or more years gave voice to their experiences. By understanding the lived experiences of long-term survivors, public health interventions can be designed to improve health outcomes and quality of life for this population and reduce health disparities. These narratives may also reduce stigma of PLWHA by providing rich subjective insight to their lives of real people to complement objective population statistics.

### **Self-of-the-Researcher**

African-Americans (rates for men and women combined) comprise the largest number of HIV positive people in the U.S. (CDC, 2016). Although gay and bisexual men of all races are at greatest risk of transmission, women are more susceptible to contracting the virus from men than men are to contracting the virus from women. African-American, heterosexual women are the 4<sup>th</sup> fastest growing population of HIV positive women in the U.S. (CDC, 2015). Therefore, we view HIV/AIDS as a challenge and cause for concern for the entire African-American community. Two of the research team members—Drs. Cherry and Keita—are African-American women, so the HIV epidemic remains in the forefront of our minds. When we think of those most impacted by the virus we often see the faces of women who are mothers, wives, and daughters. Because we see such urgency in addressing the epidemic, our research was guided by a desire to learn more about the experiences of African-Americans who are living with HIV.

Based on Dr. Cherry's experiences within the public health arena and what she considers to be the invisible faces of those impacted by public health disparities, the research team chose a qualitative approach for data generation and analysis. This approach allowed us to emphasize the importance of involving the researched in the research and make space for their stories to be told in their own words. Dr. deMarrais conducted extensive qualitative research and Dr. Davis facilitated a number of mixed methods studies, as well as provided guidance on instrument development. Dr. Keita has worked domestically and abroad with underserved communities and now focuses her efforts on ensuring access to quality hospice care. Dr. Lee worked within the field of healthcare administration for over three decades and offered valuable insight on translating the findings to public health practice. Together, our research team was comprised of public health practitioners, educators, members of underserved

communities with an array of research experiences. We were not only invested in the project itself, but the implications it may have for future narrative, public health, health policy, and gerontology-related research. We were also committed to honoring the stories of the women who participated in this project and have taken great care in the retelling of their narratives.

### Research Design

The authors used narrative inquiry to focus on how participant experiences link to form a narrative. This methodology can be described as “an account of an event/action or series of events/actions, chronologically connected” (Czarniawska, 2004, p. 17). Under the broad umbrella of qualitative research and as described by Josselson (Wertz, Charmaz, McMullen, Josselson, Anderson, & McSpadden, 2011), narrative research focuses on lives as stories with multiple parts. According to Polkinghorne (1988), stories are fragmented parts needing to be pieced together to gain insight of a whole picture. For Kramp (2004), narrative is both a “process and a product” (p. 110) and Clandinin and Connelly (2000) stated, “... narrative is the best way of representing and understanding experience” (p. 18). Therefore, lives can be understood as stories presented or constructed in ways to make meaning of events experienced.

Narrative inquiry is more than a framework to create or collect stories, it shapes how stories are organized and how human experience is understood. Narrative inquiry extends beyond data collection to include data analysis and presentation. This methodology guided interviews with African-American women ( $N=6$ ) from Georgia and South Carolina who have been HIV positive for 10 or more years to explore how participants narrated their experiences as PLWHA. Eligible participants for this study were African-American women ages 21-65 years who were HIV positive and willing to talk about their lived experiences. Participants were recruited by word of mouth. The first author contacted three potential participants she worked with at a local HIV/AIDS non-profit in 2007 to provide an overview of the study and inform them of a time commitment of 3-5 hours, along with a \$25 gift card incentive for each completed interview (total compensation of \$75). All three women agreed to participate. The author asked these women to refer someone else who was eligible and might be interested in participating. Two additional participants were recruited in this manner. A public health practitioner who served on a community HIV/AIDS Board of Directors and knew of the study referred the final participant. Following recruitment, the women completed a pre-screen questionnaire to confirm eligibility and schedule a first interview. All interviews, except one, took place in participant homes and all were recorded with a digital recorder. Consent was obtained using a form approved by the University of Georgia Institutional Review Board. We used a repeated structure of interviews to build rapport, achieve data saturation and triangulation, and establish validity, consistent with the use of this qualitative method as described by other researchers (Knox & Burkard, 2009; Roulston, 2010; Seidman, 2006). Interviews were conducted 3 days apart and an interview guide directed conversations. All the women completed three interviews. The first author transcribed each interview before meeting with a participant for the next interview as a means to follow-up on details. The initial interview ranged in length from 32-108 minutes and follow-up interviews lasted an average of 21 minutes. Participant ages ranged 48-66 years old ( $M=57$ ) and the women had been HIV positive an average of 21 years. Three women had a history of substance abuse and reported contracting HIV through unprotected sex.

Along with transcription, the first author conducted, audio recorded, and analyzed all interviews. Qualitative data analysis software was used for multiple rounds of inductive and deductive coding. Data analysis was influenced by primary (interviews), as well as secondary (literature review) sources. The first author met regularly with the second and third authors to

review findings, discuss data analysis, and achieve researcher triangulation. Analysis of participant narratives guided a comparison of themes within and between participant narratives.

Polkinghorne (1995) defined analysis of narrative as “a temporal gestalt in which the meaning of each part is given through its reciprocal relationships with the plotted whole and other parts” (p. 18). Individual segments of participant narratives, codes, categories, and themes have independent meaning, but when reorganized and re-presented in chronological, storied form present the sum of participants’ experiences. While Polkinghorne provided general guidance on the analysis of narrative process, Labov and Waletzky (1967) presented a 6-part model for structuring the presentation of participant narratives: (a) an abstract of a narrative; (b) the background on the event; (c) the complication, detail of the problem(s), or crisis in the narrative; (d) the evaluation or value to the narrative; (e) the result or resolution; and (f) the completion of the narrative. Five constructs from Labov and Waletzky’s model (abstract excluded) and Womanism, guided the organization of participant narratives into major themes and subthemes.

Ever since scholar and activist Patricia Hill Collins (1996) expanded the theoretical perspective of Womanism, it has become increasingly familiar across disciplines (Musgrave, Allen, & Allen, 2002; Townes, 2006). Collins distinguished Womanism from Black feminist theory and situated it in both racial and sexual oppression. She argued Womanism “offers vocabulary for addressing gender issues within African-American communities without challenging the racially segregated terrain that characterizes American social institutions” (1996, p. 11). Womanism placed participant stories or narratives from this research in categories to be presented and understood based on their merit. The aim of this study was not to compare African-American women’s stories of living with HIV to other women or men living with the disease. Neither was the goal to reframe participant narratives to address systematic constraints to care or other health-related challenges. Rather, we wanted to provide a platform for African-American women to present their stories in their words without the need to distinguish how these stories parallel or differ from other the experiences of other populations. Additionally, while public health relies on statistical data to make informed decisions related to practice and policy, these data are often without the faces or voices of the communities we seek to serve. We know African-American women are disproportionately impacted by the HIV/AIDS epidemic, but what is known about their lives? The richness of narrative inquiry offers a perspective beyond pie charts, bar graphs and statistical tables. Therefore, this research enabled a re-telling of stories of African-American, HIV-positive women based on life experiences, including successes, challenges, and day-to-day negotiations as a way to inform public health practice, while honoring the voices of participants.

## Findings

This study explored how African-American women who have been HIV positive for 10 or more years narrated their experiences as PLWHA. The women shared experiences of growing up with family, early hardships, turning points in their lives leading to and following their HIV diagnosis, and ways they made meaning of their diagnosis. There were many parallels in the women’s stories, including the mode of HIV infection, substance abuse, challenges with dating and disclosure, and what they perceived as necessary to create a new life. The women talked at length about navigating difficult experiences such as abandonment, teenage pregnancy, and loss of loved ones. For half the participants, difficult experiences were a gateway to substance abuse. The women’s experiences of how they first responded to their diagnosis and substance abuse treatment varied, but all participants reached a point where they decided to take an active role in living a healthy life, despite their diagnosis. The women

committed themselves to be involved in community activities and share their stories to educate others. In the following section the participants are introduced.

### **Participants** (pseudonyms have been assigned)

**Amy**, a 59-year-old, divorced mother of one and grandmother of one, was HIV positive for 23 years. She was diagnosed after an intimate partner advised her to be tested. After struggling with substance abuse before and after her diagnosis, Amy completed a drug treatment program and several HIV educational training initiatives to create a new life for herself. She spent her time with family and volunteering in her community.

**Felicia**, a 48-year-old, single mother of four and grandmother of seven, was HIV positive for 15 years. She was diagnosed after her intimate partner became gravely ill. After Felicia's diagnosis, she learned her partner was HIV positive before they started dating but was in denial. Felicia's response to her diagnosis was to immediately join a support group, gain additional knowledge on HIV/AIDS, and talk to other women about risk factors for infection. She worked full time training HIV/AIDS peer counselors, doing advocacy work, and traveling to share her story.

**Josalin**, a 61-year-old, divorced mother of one and grandmother of two, was HIV positive for 27 years. Although Josalin was diagnosed 27 years ago, she believed she was infected 29 years ago by an intimate partner she later found out was an intravenous (IV) drug user. Josalin was one of the first women diagnosed with HIV in her small, rural town. Following her diagnosis, she leapt into HIV/AIDS advocacy work to combat stigma and educate others about HIV/AIDS. Josalin considered herself retired from HIV-related work and referred to herself as an expert crafter. She spent her days hosting crafting circles, knitting, crocheting, scrapbooking, and making trinkets.

**Madeline**, a 66-year-old, separated mother of two, grandmother of six, great-grandmother of 17, was HIV positive for 22 years. She was diagnosed during a time in her life when she was an active drug user and a prostitute. It took Madeline a few years to seek treatment for HIV and substance abuse, but once she did, she built a new life. She spent time volunteering at her church and social service agencies. Following surgery in 2016, she slowed a bit, but looked forward to getting involved in community activities again.

**Rochelle**, a 53-year-old, divorced mother of one, was HIV positive for 18 years. She was diagnosed while pregnant with her second child. Rochelle tracked her infection to a former partner, who never admitted he was living with HIV. It took Rochelle nearly 12 years to fully accept her diagnosis, disclose her status, and get involved in HIV-related education and advocacy work. She co-founded three organizations, including one with her son where they did HIV/AIDS education, advocacy, and public speaking events together. Rochelle's time was filled with work and volunteering in her community.

**Shelly**, a 52-year-old, single woman who had been with her long-term partner for 15 years, was HIV positive for 18 years. She was diagnosed during a hospital visit after becoming gravely ill. Shelly was abusing substances prior to her diagnosis and believed her intimate partner did not know he was positive. Following her diagnosis, she simultaneously began substance abuse treatment and her HIV medication regimen to get better. She spent her time volunteering with her church and community organizations. Her social support network was a large part of her life and included an older sister plus a host of friends.

Across participant stories, we found a trajectory of key themes: recollections of early hardships, HIV infection and diagnosis, embracing social support, surviving and thriving, and meaning making and HIV (see Figure 1). The researchers organized the major themes according to Labov's and Waletzky's (1967) analysis of narrative framework.

While the first four aspects of the model are parallel to the major themes from the participant narratives and move in a linear fashion, the last two segments are joined by a two-sided arrow indicating a reciprocal relationship between evaluation (surviving and thriving) and coda (meaning making and HIV). As participants aged and had additional life experiences, they redefined what surviving and thriving meant, sometimes creating new meaning from their diagnosis.

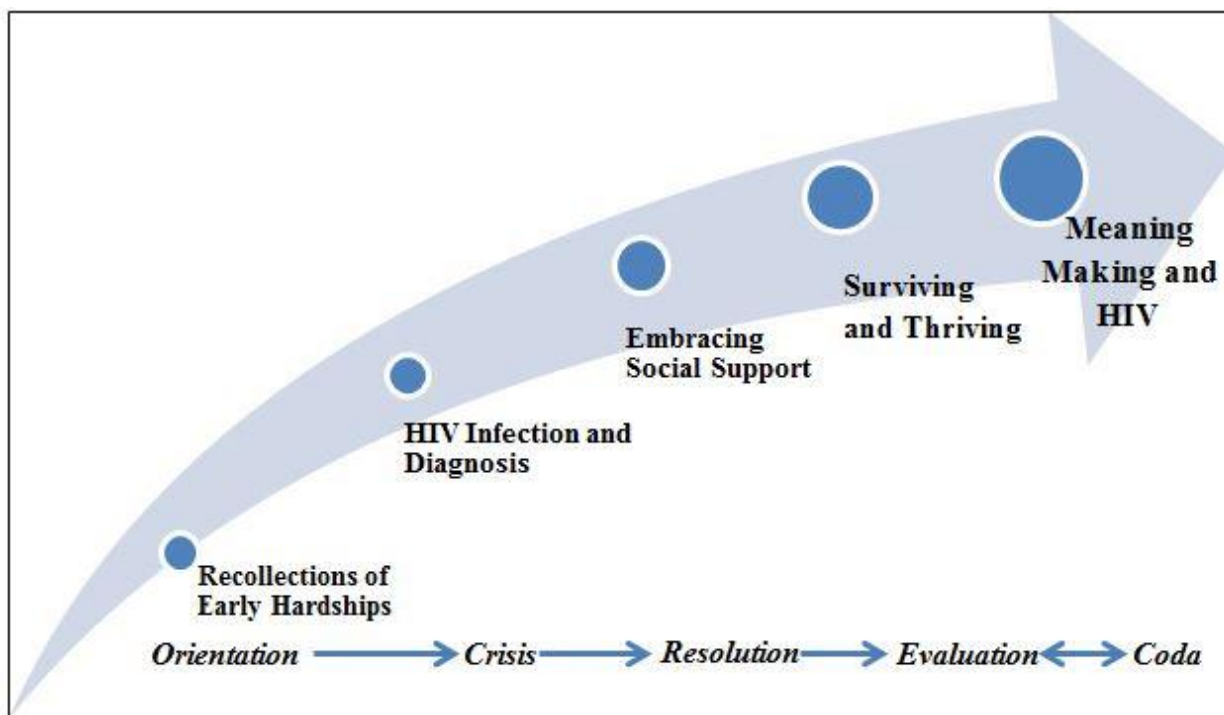


Figure 1. Major Themes Framed in Labov and Waletzky's (1967) Analysis Method

## Orientation

The women were asked to talk about their lives prior to diagnosis. They shared fond memories of growing up with siblings, attending church with parents and grandparents, and working odd jobs to make money. However, the women also shared detailed experiences of hardships from their teenage years until their HIV diagnosis. Two participants described these hardships as breaking points. Madeline shared:

My mother and father were very dysfunctional. She was young, she was like 15 and he was I don't know, 16 or 17. She became pregnant and didn't want my aunt and uncle—who also raised her—to know. So she left home, had the baby, left me in the hospital, and went away. But she did have the dignity to tell them I've had a baby and it's in Beckwith Hospital. They decided, well we're going to get the baby and we're going to keep the baby. I didn't see my mother anymore until I was in the 11th grade and she finally showed up one day.

Felicia recalled growing up in one of the toughest neighborhoods in Georgia, "I was born and raised in The Edge, a very low-income neighborhood, the neighborhood where there are the



highest rates of HIV. Growing up in that neighborhood was tough, but I survived it.” Felicia talked about having been molested and enduring verbal and physical abuse. Two of the other participants faced the challenge of teenage motherhood. Amy’s pregnancy came as a surprise to her, as did the birth of her daughter:

I got pregnant at 14. I was eating up everything Sabrina, and I wasn't paying it any attention—boobs getting big and everything. So that Monday night after I ate, I got a big pain. I said momma this hurt[s] too bad. And then she said well maybe just go use the bathroom. When I went to use the bathroom, my water broke. I didn't know. I said okay, I'm pissing. I guess I was so scared I didn't cry. And she said well, okay just bend down and let me see what's going on. When I went to bend over that's when she saw the head. She said it's the baby. She told me just to fall on my knees and once I fell on my knees Amanda was out. I didn't feel nothing. So I had Amanda at home. I had to get 22 stitches with her I guess because [of] the way that she came out. I didn't want to be bothered with her. I didn't want her. And then I tried to breastfeed her—I tried one time, she pulled too hard. Hell no, no I don't want to do that. I had to do what I had to do. And [then] I went back to school.

Over time Amy and Amanda developed a mother-daughter bond that strengthened over the years.

As the women grew older, three faced a series of traumatic events. Amy came to breaking point when in just 5 years, she had two strokes, and her mother died. She shared:

I had both my strokes in Mississippi. So I had a sun stroke—I was drinking that gin and it was so hot and I had my first minor stroke. It didn't affect me as much. But in my second stroke I went into coma. That's when my mother was in the hospital and I was up there to see her. She wanted some water because she was thirsty and when I went to working with one arm, trying to fill the cup up and to put the straw in [it]. She was gone so she died in my arms and then I just went out. I didn't wake up until 6 months later. I could hear you, I could see you, but I just couldn't talk to you or whatever. When I did wake up out of that I was all discombobulated—legs, arms, hands all messed up—face, mouth turned, everything so I had 2 years of rehabilitation because I had to learn how to talk again, had to learn how to write again, spell again all that. And it was a painful 2 years, because I refused to be in a wheelchair. I have a cane now. It has gotten better since I had surgery on my feet. I used to fall a lot, but after the rehabilitation I started moving around doing a lot.

Following rehabilitation, Amy was married and had her second child, Amir, but the marriage dissolved quickly, and she was met with yet another tragedy. She received a call one day while at work:

I went to the phone. I said who is this, I am working? And he said ma'am this is Sergeant whatever, I think you need to come over to your husband's house. It's been an accident and I said okay, is it Amir? What's the matter, what is going on? And he said I think [it's better] for me not to tell you over the phone—you just need to come. What happened was he and this lady he was dating were arguing and Amir came to talk to him about something and he slapped him. Amir fell and it was a glass table, but it was square so he fell at the edge and cut

his head in the back. [My ex-husband] didn't look at it or nothing to see [if] Amir was okay and he told him to go to bed. They found Amir dead the next morning.

This was a breaking point for Amy. After two strokes, her mother's death, and the loss of her son, she was isolated, confused, and without direction. This was the point where her drug addiction began and spiraled into a history of reckless behavior, including becoming infected with HIV. Josalin's traumatic event happened shortly after she was married. She explained, "I got married—it only lasted 10 months—so I think that was about in '81 or something like that. I really can't remember the date, I try to forget. My husband went to jail for rape. Yes, so that's what happened to my marriage." Josalin did not tell many people why her marriage ended but spoke of the relationship as a major source of shame and embarrassment after her ex-husband's conviction. She relocated to Virginia as a way to get away from the event and move forward.

Madeline thought everything happened all at once, having faced the death of her mother and her son in 1 year and a marriage that ended. When asked how many children she had, she replied:

Two—the other one I lost in 1989; he was a bad boy. He got hung in the city jail in Macon and how—we still don't know. And he had two kids—he had one girl pregnant and one baby already, so here I am with the grandkids. That was kind of hard, but I managed. That's when I really stepped out in the world, after he passed away. I didn't know what to do; I just lost it. That's when me and my husband started having little issues and we finally broke up. Mother passed away in January and [my son] passed in June or July. That's when I decided I'm going to try something different, not knowing that was destruction so I stepped out into the drug world.

Madeline believed she could not handle the unfortunate events in her life, particularly because they happened so close together. For Madeline and Amy, drug addiction was a coping mechanism. Although Shelly did not recall any traumatic events from earlier in her life, she, like with Amy and Madeline, discussed bouts of drug addiction. After Shelly's period of substance abuse and her HIV diagnosis, she began to make a positive turn. For Amy and Madeline, it took time to resolve to seek assistance and move forward. Josalin's relocation after her husband's conviction diverted her attention and she refocused on life in Virginia.

### **Crisis: HIV Infection and Diagnosis**

None of the women thought they were at risk for HIV and all initially perceived the diagnosis as a death sentence. Amy and Madeline allowed diagnosis to be fuel for continued drug use under the notion of having as much fun as they could before they died. With the exception of Madeline, all the women were in committed relationships. Amy shared her experience:

So on his dying bed he told me to check myself to see—to make sure that I was okay and come to find out I wasn't. I was just terrified I guess. I didn't know what to feel or how to feel. I didn't know to be scared or not to be scared, because I really didn't know how bad it was. I didn't have anybody. Amanda was gone, so I just took the drugs and alcohol even more. All I could hear was that it's a death sentence. Okay I'm going to die, so I'm going to go out kicking.

Felicia was with her partner for a number of years and never suspected he was living with HIV:

When I found out my status I was in a relationship and I didn't ask this man his status. We were together about 4 years before I found out that he was positive and the only reason I found that out was because he got sick. In my heart and in my spirit I knew that wasn't just a common cold. I felt like I was going to die ...who is going to take care of my kids? I was a single parent.

Felicia's response was to find ways to care for her children and ensure they would be cared for after her death.

Josalin was in a long-term relationship and engaged to be married when she discovered her partner was an IV drug user. She was diagnosed with HIV 2 years later. She shared,

I was diagnosed in '89, but I take my infection back to '87 because I was living here with my boyfriend and I didn't know he was an IV drug user. When I found out that he was an IV drug user I left him.

Amy, Felicia, and Josalin never suspected their sexual encounters with men they considered intimate partners would lead to HIV infection.

Like Amy, Madeline was heavily involved in the drug world, but also engaged in prostitution. Looking for a way to make money for drugs, she was enticed by a financial incentive to be tested for HIV:

So I took the test and they told us we had to come back to this little house on Aiken Street and get our results the next week—they gave you \$20 then and \$25 later. When I went to get my test, I didn't know they were going to talk to me, I thought they were going to give me the money and I [could] go. They called my name and I went back to get my test. The man said Ms. Hill you need to step to the side. I said okay and of course, I had that attitude—why do I have to step to the side? I want my money.

He finally got back around to me and he said I have good news and I have bad news so which one you want to hear first? I said always good news. He said well I do have your \$25. He said the bad news is you're HIV positive.

Madeline's diagnosis did not encourage her to leave the streets and she continued to do drugs and engage in prostitution before she sought help. Rochelle had completed college, was engaged to get married, and expecting her second child when she was diagnosed with HIV:

When I found out I was HIV positive I actually took [my son] to get tested because I knew the person who I felt had infected me was—I broke up with him at one point and we got back together. It was between 5 and 10 years because by the time they really tested me I was very, very sick. I was 35 and we went to do pregnancy stuff. [The doctor] said everything came back normal except your HIV test, it came back positive. I just heard I was about to die—like you're getting ready to die, that's all I heard.

Shelly moved to Delaware and was living what she described as a fun life when she suddenly became ill:

All of a sudden I had a bad cold and I couldn't eat anything. I just kept throwing up and stuff and so I called my sister and said I feel sick. She came and picked me up and took me to Tanner West. They admitted me to the hospital and ran tests. They told me I had AIDS. I stayed in the hospital, the PCP and AIDS caused me not to walk.

Learning about her HIV diagnosis was enough to prompt Shelly to seek help for her addiction and infection. Her new life began shortly thereafter.

The women talked openly about their experiences with substance abuse, HIV infection, and diagnosis. While three women were substance abuse users at the time of infection, all of them except Madeline, were in what they believed were committed relationships. None of the men involved in those relationships disclosed their HIV status and it was unknown how many of the men knew they were HIV positive. Felicia and Rochelle believed their partners were in denial, but Amy and Shelly thought their partners were unaware of their infection. Josalin and Madeline were unsure if their partners were aware of their HIV status. Despite how the women were infected and where their partners were along the spectrum of disclosure, the women all expressed reaching a point where they had to move past concerns about their HIV infection and create new lives. Gaining social support seemed to have been a significant part of the recreating.

### **Resolution: Embracing Social Support**

Social and family support, from many sources, were readily available to the women. Following diagnosis, family and friends helped the women move on with their lives in healthy and meaningful ways. Felicia and Josalin recalled having significant support from their children and grandchildren. Although Felicia had two sisters who died from AIDS-related complications, her family offered support to her after they were educated about treatment options. She shared, "Yeah, I have a great family support. I educated them first about the virus because they were afraid of it from what they saw with my sisters. My kids give me support. They've been featured in a video with me before."

Josalin's family embraced her diagnosis. Her family owned a restaurant and Josalin shared how her mother approached her diagnosis, as well as how her grandchildren joined her on the advocacy trail:

I come from a family of activists. I was like ma, I don't want people to not come to your restaurant because I came home, and people are afraid of me and my mother was like, "No, that's not how we do things." She said, that's why McDonald's is across the street so we're going to educate these people. So in the to-go orders my mom started putting condoms and information. I had to accept it and become an activist because my family was not going to let it rest. [My daughter] became a little activist and her kids used to go with me to my speaking engagements. They turned the Barney song into an HIV song: "I love you, you love me, let's get together and destroy HIV with a latex condom or having no sex; don't you know you could be next." It was never ever an issue with anyone in my family.

Josalin's entire family stepped in and offered support. Although she discussed her daughter having initial concerns about stigma and what other people would say, this appeared to be short-lived. Shelly's sister was her largest supporter, "She has always been my biggest

supporter. And that's like my best friend, other than God. All my family [are] real supportive—my sister especially because she is my rock.”

Madeline credited family and friends with helping her cope with her diagnosis and continue to enjoy life. Even as she shared parts of her story while crying, she appeared to have worked through diminishing the shame related to her choices and found ways to share her story as a part of ongoing emotional healing. Rochelle’s father set the tone for how she viewed her diagnosis, as well as treatment options post diagnosis. She spoke fondly of him in the following words:

My father worked at Fort Jones 42 years before he passed, and he was more familiar [with] HIV/AIDS than anybody in the family. He said now you're going to have to choose whether you're going to live or die because we all got to die. You have medicine that you can take to save your life so that's what you're going to have to do. That sticks out with me, because me and my father were always close.

Rochelle recalled her father’s words vividly and with authority. To her, hearing her father reinforce her choice to live made a significant difference in how she approached her diagnosis.

While Josalin, Madeline, and Shelly talked about new friendships and how these friendships were instrumental in their lives, Amy and Rochelle moved cautiously to make new allies, focusing on family, volunteering, or working. All the women shared the importance of family, early activism, and changed health behaviors as integral to how they moved from surviving to thriving.

### **Evaluation: Surviving and Thriving**

The women were focused on thriving with HIV. Felicia stated, “I've always survived, and I tell people if I survived The Edge [neighborhood], I can survive anything. And now I'm getting more in tune with myself and getting more in tune with God.” Felicia believed she was a survivor and was proud of the work she did. She reached a point where she focused on her spiritual health. Madeline acknowledged her struggle, but was determined to keep moving forward:

I must say I have really, really struggled, but I was determined when I came out that street, there wasn't going to be any going back. Even though I contracted HIV while I was out there, I had to deal with it. But I don't have many problems with it. I'm doing good and I'm still progressing—I'm looking forward to new eras every day. I know there is a lot more for me to learn and a lot more for me to do to keep myself healthy because new stuff comes out every so often.

The women’s stories of survival, resilience, and perseverance appeared to provide ongoing strength. They recalled experiences as encouragement to face what came their way. For them, they had made it through some of the worst trials anyone can face. One major way all the women shifted the focus away from hardships and trials was through community service. Educational training opportunities and advocacy work became important parts of the women’s lives by allowing them to help others.

## Advocacy, Work, Education, and Training

Learning about HIV/AIDS was personally beneficial for the women and seemed to add meaning to their diagnosis. The women traveled all over the United States and some of them traveled internationally, sharing their stories, and educating others. This work was a major source of pride for them. Amy was eager to showcase her certificates and plaques awarded through the years:

I could start back with Survivor Care Inc. I started there with peer counseling. I went to Washington and did the TOT [Training of Trainers] with the women, children, and friends. My biggest one was Washington because that was like 7 months. We would go and stay a week in Washington and then we would have to come back home and do three workshops here in the community. I really enjoyed it. I got my little certificates—I never leave those down or put them in the closet. I'm proud of those.

Amy discussed opportunities to travel, learn, earn money, and share her story as empowering and a significant part of her recovery. Josalin spoke of similar experiences:

I was with Amazing Friends for a while and I started doing a lot of traveling and going to South Africa, working with the doctors there. I just put myself into it. A lot of stories have been happening where I've educated folks, touched people's lives, and they have come back and especially the ones that were pushing me away and showing me stigma and discrimination.

Josalin had been all over the world participating in advocacy events, speaking on international platforms, and interviewed for features in books and magazines. She was proud of her accomplishments and this pride was a significant factor in why she considered herself retired from HIV work.

Felicia's goal was to remove some of the misconceptions about who is at risk for contracting HIV. Her desire to be involved in HIV-related work served as fuel for disclosing her status to her children. She saw a connection between her HIV-related work and her faith:

I wanted to show women a professional face to HIV and I knew the only way I was going to do that was to put my face out there. So I got asked by a church to do a video down at HIV Network Project. I felt like I could get more satisfaction, and this is something I feel like God needed me to do—to help him to save his children. I started traveling and I started volunteering in the community, then I got blessed with working two jobs in the community and I've been fine. A lot of people out here need that support and I just feel like I'm one of his earthly angels that helps someone get along the way—you know deal with it, live a healthier life. And I tell people it's not that I want to do this; God has me doing this because he knows I can be out there to help his children.

Felicia and Rochelle discussed the importance in women taking a closer look at what *high risk* means and why it is important all African-American women know about HIV. Rochelle participated in a variety of work, including visiting Capitol Hill to lobby on behalf of PLWHA and creating multiple organizations to meet the needs of women who are HIV positive. This was her experience:

I co-created a women's empowerment academy with one of my friends. We have the group called Live for Change—it's a women's health advocacy network. And then I created a women's empowerment academy. I'm working; I'm doing my life, if you don't like it whatever. I just speak out in every way I can. We wrote a grant to Faith Leaders for pastors to talk to people who are HIV positive.

Rochelle's son became a part of her advocacy work as well, "I had him volunteering and he was very supportive. We actually have a group; we're Big Excellence—that's what we call ourselves. He's 6'4" so we go out and speak as mother and son." Having her son on the advocacy and education trail inspired and strengthened Rochelle during her journey.

Madeline had to step away from her volunteer commitments due to surgery but looked forward to being involved again. She worked with the Elizabeth Taylor AIDS Foundation and still had memorabilia sent to her by the organization's co-founders. She talked about her experiences:

My goal right now is to teach others what not to do. Before I got sick I was going to places out of town. I've been to California and New York just doing speeches and telling them that HIV is easily caught because you don't know who has it. On that corner I promise you, everybody that hung over there is HIV positive because we were going behind each other [with] the same people. All my friends that were over there then—they're either passed away or they're sick. And so now I help feed the homeless every fourth Thursday. I did a lot of work with Absolute Love. I did a lot of work with Red Ribbons and a lot of work with the Second Chances House. I even did an interview with Liz Taylor's grandson.

Like Madeline, Shelly's work in the community provided a sense of purpose and pride:

I graduated from Recreating a Life Alliance in Washington DC [and] I went to Baltimore, Fort Lauderdale, and Washington, DC. When I came back to Atlanta I was doing workshops. I have a closet full of certificates from everywhere. I accomplished a lot of goals at the New Beginnings House. I graduated through a lot of stuff: Achieve Weekend and all of that.

Madeline and Shelly volunteered with social service agencies and did a great deal of work with their churches. They regularly fed homeless persons and former addicts and participated in a HIV/AIDS fundraising walks. Community service seemed to be a central part of their lives.

The women discussed opportunities to volunteer, travel, share their stories, and earn certifications as important parts of living with HIV. These added purpose to their lives and allowed them to help newly-diagnosed men and women in some of the ways they were helped by others. Although Josalin was retired from HIV-related work, she continued to welcome people into her home for crafting activities. The other women remained busy with public speaking, advocacy initiatives, and working with social service agencies. However, their stories were not without continued ups and downs: dating and disclosure was a major discussion topic.

### **Thoughts on Dating and Disclosure**

Except for Shelly, the women were single, so they navigated the dating world and considered ways disclosure presented a challenge to dating. Amy decided to steer clear of dating:

I'm comfortable. I'm not in a relationship—don't want one. Ain't looking for one. That's a headache I don't need ... I want to come home, lock my door and be in peace. I don't want nobody knocking at my door or [asking] what time you coming home or where you at on the bus so I'm okay where I'm at.

Amy viewed dating as an unnecessary headache, while Felicia welcomed dating as a healthy part of her life. She dated men who were HIV positive or HIV negative and talked about some of her experiences:

I had this conversation with this one guy that I found out was married and I told him I choose not to date him. He said Oh you keep running your mouth and I'll put your business on Facebook. I said dude, you must not be able to read. I said Google me honey! I was like You are 6 years late—back then—I said you should have Googled me. But sometimes in intimate relationships if you meet someone [and] they don't have any knowledge of the virus it's going to be a challenge. I've had some rejections, but I have more acceptances. It's only one rejection that really stands out to me because I was really beginning to like this guy and I had not disclosed my status. He was everything a woman could ask for, but that rejection! Never heard from him since. Now I choose to date first and get to know them because some of them may not even need to know my status.

Although she faced rejection following her disclosure, Felicia continued to date. Josalin carefully moved into dating and considered not dating as an option:

It's been so long I don't know what to do. Are there some books out now to tell me what to do? So when it comes to dating, I'm okay. I have my lonely moments and wish I had somebody. Having somebody to do something like going out to dinner and then with this big ole house—you notice I've been tearing up the carpet in my house and I've been doing this by myself. And Sabrina, I just broke down and started crying. Sometimes I get overwhelmed with trying to take care of the house by myself. My landlord helps me, but I was like this is why I need somebody.

Josalin saw disclosure as a major obstacle to dating and found ways to creatively decipher what prospective partners thought about HIV, same-sex relationships, and other taboo topics. Rochelle chose to focus on her work life, “I'm just so busy, but I'm like whatever. I think I'd like to be in a relationship, but I'm not willing to go through any drama. I'm watching these chicks like boo, I ain't doing that. They ain't coming up in here.” The women approached ideas about dating differently, but all saw it as something to consider carefully. Concerns about disclosure, stigma, and unwanted drama gave them reason to remain single. Regardless of marital status, all the women in the study created meaning from their HIV diagnosis they were comfortable articulating.

### **Coda: Meaning Making and HIV**

The women expressed many sentiments related to their HIV status, including a belief they had been blessed by God. This blessing was not in the form of their infection, but in their positive experiences since diagnosis. They had moved past any sense of being a victim or villain, to expressions of purpose and empowerment. Amy stated, “I would say having HIV



gives me a sense of direction ... to help someone else.” When asked what being HIV positive meant to her, Felicia responded:

Surviving, living, [and] understanding! It has brought me joy, it really has. It has made me the woman that I am today. It changed my life ... I didn't become a woman until the age of 32 and that was after 4 kids, the car, [and] the place. So I tell people it made me grow up. Some people can't accept it the way I say it, but it made me a better person. I look at life totally different.

Similar to Felicia, Josalin shared:

For me this diagnosis has been a blessing. I've been all over the world, I've met fantastic people, done fantastic things—things that I would have never done before, places that I've never gone before, and touched and saved the lives that I have saved.

For Madeline, being diagnosed with HIV and ultimately entering substance abuse treatment was what saved her life:

When I went through recovery they were talking about how you could just pass away, how things could just happen. I said it's not going to happen—my determination is to live. So when I caught HIV I feel like God blessed me, he blessed me in a way that I could come out of the streets and that I could be able to help somebody else—tell somebody else about this disease and spread the news that this is no play thing—it's real. In a way it's a blessing because it stopped me from doing what I was doing and brought me back to reality. Had I not gotten HIV I would have still been—probably in the streets. I sit here and think about how God has really blessed me with this, because I know people that just passed away with it.

Madeline embraced her diagnosis and saw it as an asset to her life. Rochelle was gratified by the work she did and the lives affected by her work,

Today though, living and thriving with HIV is what it means to me. A bigger purpose—there's got to be. And I've seen some remnants of it with the work that I've done and lives that have been changed so I believe it's what at this point I'm called to do in my life.

The women engaged in making meaning of their diagnosis. For them, HIV added purpose to their lives, gave them a second chance, and allowed them to help others. The women did not discuss their diagnosis in the context of despair or hopelessness. Instead, they framed living with HIV as a positive experience and sought ways to create meaningful opportunities for themselves and others.

## **Discussion**

This study explored how African-American women, HIV positive for 10 or more years narrated their lived experiences. Womanism guided data collection by allowing the authors to focus exclusively on gathering the stories and experiences of African-American women in their words. Labov and Waletzky's model provided a framework to organize and analyze participant narratives. This approach was faithful to the participants' stories and created structure in the

presentation of narratives. The participants described a major life events organized under the following themes: early hardships; HIV infection and diagnosis; identifying sources of social support; surviving and thriving; and meaning making and HIV. They recreated lives for themselves and worked past an initial belief that an HIV diagnosis was a death sentence. Dating and disclosure remained persistent concerns for five of six participants.

HIV/AIDS prevention programs for African Americans continue to be developed and piloted (Jemmott, Jemmott III, & O'Leary, 2007; Wingood et al., 2013). These initiatives demonstrate the efficacy of culturally relevant initiatives and the importance of collaborating with key civic organizations, such as churches, to combat HIV. However, El-Bassel, Caldeira, Ruglass, and Gilbert (2009) reported research has not adequately addressed the needs of African-American women in HIV prevention. The participants' narratives in our study shed light on childhood trauma, dealing with death, and overcoming substance abuse. These findings emphasize how early hardships in life may affect health behavior during teenage years and into adulthood. Public health programming must focus on ecological approaches to the HIV/AIDS epidemic (Newman, Williams, Massaquoi, Brown, & Logie 2008; Sterk, Theall, & Elifson, 2003), and because the stories here highlight the complexity of living with HIV, and the importance of creating a meaningful life after diagnosis, new programs must foster resilience in PLWHA.

Through social support, primarily family members, all the women in this study were living vibrant lives or *thriving*, as they often referred to it. Social support, particularly from family, was significant to help the women in our study accept their diagnosis, choose to live a healthy life, and find ways to thrive. Our findings are similar to Owens' research (2003) that found although family members can be sources of stress, they are essential providers of ongoing support for African-American women living with HIV. This support allowed the women to create other meaningful relationships and embrace opportunities for service. Ongoing research may explore skill-building related to how immediate and extended family members can provide social support for PLWHA.

After diagnosis, all women in this study engaged in HIV-related educational training opportunities and traveled widely to share their stories. Most volunteered with churches and social service or civic organizations. These opportunities provided a sense of accomplishment and pride for participants and are consistent with previous findings on the importance of outreach initiatives in the lives of PLWHA (Rajabiun et al., 2007). The findings from our study reinforce the need to create meaningful work and volunteer opportunities for PLWHA to accept their diagnosis, contribute to the wellbeing of others, and create vibrant livelihoods for themselves (McReynolds, 2001). Additionally, what is unique about study in relation to the research cited in this section is our focus on African-American women who have lived with HIV for 10 or more years. Efforts that target long-term survivors may be advantageous.

Dating and disclosure were important concerns for participants. Even after living with HIV for over 10 years, some women opted to keep their social circles extremely small, avoiding platonic friendships or dating. New relationships meant challenges related to disclosure. The women were afraid to disclose and sometimes avoided dating due to fears related to disclosure or rejection. Some of our findings are supported by previous research (Black & Miles, 2002; Buseh & Stevens, 2007) and highlight the need for ongoing efforts to help PLWHA learn the importance of disclosure, make choices about how and when to disclose, and find supportive networks for disclosure. However, it may be that the challenges of the women in our study and other women differ from disclosure-related challenges for men. While studies have explored intimacy, dating, disclosure, sexuality, and stigma in older PLWHA (Emlet, 2007; Nevedal & Sankar, 2015; Taylor et al., 2016), focused research could address specific strategies to assist women with disclosure and intimacy.

The women had trials and challenges but worked hard to recreate their lives. Consistent with an older study (Dunbar, Mueller, Medina, & Wolf, 1998), the participants progressed through the major stages of accepting their diagnosis and creating new lives: reckoning with death, affirming life, creating meaning, affirming self, and redefining relationships. All the women viewed diagnosis as a turning point; they moved beyond thoughts of HIV as a death sentence and created opportunities to care for themselves and have long, healthy lives.

Participants' descriptions of religion and spirituality mirrored other findings that HIV diagnosis prompts opportunities to create meaning (Dalmida et al., 2012), drives a need for a more intimate, spiritual relationship with God (Ironson, Stuetzle, & Fletcher, 2006), and that diagnosis adds purpose to life (Mattis, 2002). Future research could examine how long-term survivors perceive their well-being and continue to make meaning of their HIV diagnosis.

Although all participants completed three in-depth interviews, there were limitations to our study. The first author conducted all interviews. While the second and third authors reviewed all coding schemes, the first author was the primary coder. The first author recruited participants primarily based on relationships built over time. While familiarity with the first author may have helped women agree to participate in the study and share their stories more openly, these relationships could have biased what information was shared well. Additionally, the authors did not make an effort to conduct purposeful sampling to further diversify the participant pool. Therefore, sample size and participant homogeneity limit generalizability.

While a variety of research designs have been used to improve public health programming, narrative work is also important. The authors believe to improve quality of life and strengthen linkages in care, researchers must also incorporate the perspectives and experiences of PLWHA. To our knowledge, this study was the first narrative study to explore the lives of African-American women who have lived with HIV for 10 or more years. The stories of the women who were interviewed echo some of the available public health research but add the richness of subjective experiences and voices to objective statistical data. That our findings are consistent with the available evidence serves to underscore how qualitative methodologies can be used to research public health concerns. Additionally, the findings here support public health programming for long-term survivors, including ways to foster resilience, create opportunities for meaningful work, and build skills related to dating and disclosure. Future research can include larger sample sizes, possibly throughout the southeastern region where HIV/AIDS incidence rates are the highest and may incorporate other forms of data collection such as demographic surveys and focus groups. Although this study focused on the lives of African-American women, other research could incorporate the narratives of diverse groups of PLWHA, including other women of color, men, and gender non-conforming populations.

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### Author Note

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Cheryl Keita: I am the VP of Organizational Development at Remita Health. I earned a Master's of Public Health degree from Tulane University and Doctorate of Naturopathic Medicine from the Southwest College of Naturopathic Medicine & Health Sciences. My public health experience includes serving in leadership roles domestically and abroad.

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