

# “Now I Know I Love Me”: The Trajectory to Self-Acceptance Among HIV Positive Adults in a Southeastern U.S. Community Center

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## Abstract

Individuals with HIV are now living healthier, longer lives due to the advancement of effective drug therapy. Understanding the dynamic narratives of the aging population of adults with HIV is critical in amplifying the voice of those who are often marginalized and to inform those social and medical providers with whom they most frequently engage. This article describes the narratives of 18 adults between the ages of 38 and 60 years diagnosed with HIV who frequent a community-based center in the southeastern United States. Recorded semi-structured interviews focused on how participants' lives had changed since diagnosis with HIV. Transcribed interviews analyzed for emergent themes. Analysis of participant narratives revealed a cohesive trajectory from self-condemnation toward self-acceptance including acquisition of HIV and judgment of past behaviors, aftermath of the diagnosis, cultivating hope, and self-acceptance. Findings offer a window into the experiences of multiply marginalized adults living with HIV in the southern United States. Examining illness narratives in the context of their unique experience within an exclusively HIV-positive support center may offer valuable information for medical and social service providers as they develop strategies to support the aging population of adults living with HIV.

## Keywords

HIV/AIDS, illness narrative, chronic illness

## Background

Adults living with HIV are now living longer due to significant medical advances in antiretroviral treatment (ART), though the psychosocial challenges of HIV persist. Adults with HIV have higher rates of depression than their uninfected counterparts owing to stigma, social isolation, financial hardships, and poor mental/physical health (Emlet, 2006a; Heckman, Kochman, & Sikkema, 2002; Phillips, Mock, Bopp, Dudgeon, & Hand, 2006; Schrimshaw & Siegel, 2003). In addition, adults who have lived with HIV for many years face concerns related to access to health care services, health insurance, and financial support (Joyce, Goldman, Leibowitz, & Alpert, 2005). Health care providers have also elucidated unique challenges that adults living with HIV face in the post-ART era, including greater need for resources to support long-term ART adherence, which poses a risk of medication resistance, and planning for eventual palliative and end-of-life care (Graham, Shahani, Grimes, Hartman, & Giordano, 2015; Karasz, Dyche, & Selwyn, 2003).

Approximately 1.1 million people in the United States are currently living with HIV (Centers for Disease Control and

Prevention [CDC], 2016a). The southeastern United States continues to experience disproportionate rates of HIV infections, comprising 54% of new HIV infections in the United States (CDC, 2016b). This high prevalence of HIV/AIDS in the southern United States is paired with generally poorer access to health care due to higher populations living in poor, suburban/rural areas and a distrust of the medical system among commonly affected groups (Sutton, Anthony, Vila, McLellan-Lemal, & Weidle, 2010). There are also high levels of HIV-related stigma in this region, leading to delayed diagnosis and care, and contributing to high rates of morbidity and mortality among historically disadvantaged and vulnerable groups in the south (Krawczyk, Funkhouser, Kilby, & Vermund, 2006; McCoy et al., 2009; Nguyen & Whetten, 2003; Reif et al., 2014; Rhodes et al., 2010).

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Many living with HIV in the southeast are “doubly stigmatized” as members of minority racial/ethnic groups, men who have sex with men (MSM), or drug users (Haile, Padilla, & Parker, 2011). The southeast United States is characterized by higher religiosity and often more stigmatization of LGBTQ (lesbian, gay, bisexual, transgender, and queer) groups than other regions (Lichtenstein, 2005; Pryor, Gaddist, & Johnson-Arnold, 2015). Although there are now more effective medical treatments for HIV and an overall reduction in new diagnoses, the effects of HIV continue to be substantial and difficult to manage, especially for those who are part of multiple stigmatized groups. Some have suggested that HIV is becoming a “forgotten” illness due to the reduction in diagnoses, yet prevalence rates in certain areas are comparable with those in some regions of sub-Saharan Africa (El-Sadr, Mayer, & Hodder, 2010). The startling reality of just how significant the problem of HIV remains in the United States speaks to the need to better understand the unique needs and experiences of adults who are living with a long-term HIV diagnosis (Brennan-Ing et al., 2017; Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011). In particular, nuanced information about how adults with HIV manage and make sense of their illness is still vital to social service and public health efforts.

Previous research indicates that patient narratives hold great promise in leading to better understanding of how individuals cope with a long-term diagnosis of HIV: To cope with illness, affected individuals may construct narratives to understand and survive their quotidian, yet often isolating struggles (Malkki, 2011; G. Williams, 1984). Illness narratives, in particular, are dynamic, reflecting ever-changing contexts of individual lives (Kleinman, 1988). Narratives have been described as a way for people to cope with “biographical disruption,” allowing for a reconceptualization of a chaotic, unanticipated life event (Bury, 1982, 2001; S. Williams, 2000). The narratives of adults living with HIV can illustrate how suffering is understood in the face of multifaceted adversity, including stigma, high mortality rates, comorbidities, complex medical management, psychological distress, and poverty (e.g., Bloom, 2001; Mosack, Abbott, Singer, Weeks, & Rohena, 2005; Reyland, Higgins-D'Alessandro, & McMahon, 2002). Thus, although others have explored narratives of people living with HIV earlier in the epidemic, we provide a current, in-depth look into the way HIV is understood as a chronic illness by those affected. We describe the narratives of adults recruited from an interfaith community center in a small, rural town in the southeastern region of the United States, with an eye toward filling a gap in the literature on living with HIV in this region as the HIV epidemic enters its fourth decade.

## Method

Elon University's Institutional Review Board approved this community-based study, which was conducted at a local HIV

**Table 1.** Participant Demographic Features.

Demographic variable (N = 18)	n (%)
Age	
M	48.9 (range = 38-60 years)
Males	16 (88.9)
Ethnicity	
Black/African American	14 (77.7)
White	2 (11.1)
Hispanic	2 (11.1)
History of substance use	12 (66.7)
Education	
Some HS	5 (27.7)
HS graduate/GED	5 (27.7)
Attended college	8 (44.4)
Employed	4 (22.2)

Note. HS = high school; GED = general educational development.

community center in a small southeastern city in the United States. The center, referred to as “The Sanctuary” for the purposes of this article, was funded through a local AIDS service organization and received direct, as well as indirect, support from local religious organizations whose volunteers made meals and lead other group-oriented activities. Primary data collection strategies included participant observation and interviews, activities that were facilitated by the interviewer's experience as a volunteer and community member. The interviewer developed rapport with the community center clients as a full participant in daily activities, such as communal meals and art projects, and was an accepted member of the community; practices noted by Fraser (2004) as important when conducting narrative research.

A total of 18 adults living with HIV participated in the study. The average age of participants was 48.9 years (range = 38-60 years) and the mean number of years since diagnosis was 13.9. Most participants were men ( $n = 16$ ). Demographic features of the sample (see Table 1) were representative of those served at the agency. The average year of diagnosis was 1996 (range = 1986-2005). Half of the participants reported “a great deal or quite a bit of difficulty paying bills” and four were employed at the time of the interview.

Participants were recruited into the study by a trained interviewer. Research participants were eligible for the study if they had no documented cognitive impairments, spoke English, provided informed consent, and had been to The Sanctuary at least once before the interview. All who were approached about an interview accepted, many having participated in the agency's activities for years. The total population at the community center fluctuates. However, approximately, 20 to 22 people regularly attend agency events.

Each participant completed a single semi-structured interview, consistent with narrative analysis approaches, using a protocol adapted from Pierret (2007). Data collection for

narrative analysis entails open-ended interviews with limited interviewer guidance, though the interviewer participates as an active listener, inviting more detail when appropriate (Bruner, 1990; Smith, 2000). Consistent with this approach, the interview began with open-ended questions to encourage participants to describe their journeys of living with HIV; for example, “how has your life changed since finding out you were HIV positive?” and “why do you think you got HIV?” The purpose of the interviews was to elicit information about individuals’ process of making sense of their HIV diagnosis. Participants were also asked to describe experiences of rejection and acceptance to further explore how these experiences might influence illness narratives. Each interview lasted approximately 45 min to 1 hr, and was recorded and transcribed verbatim upon written consent. Participants were given a US\$5 gift card in appreciation of their contributions.

## Analysis

Transcripts were entered into Atlas.ti 6.0 (Muhr, 2012). Data were coded by the interviewer and the research team who were not directly involved in primary data collection. A functional approach to narrative analysis was undertaken, wherein attention was paid to how the storyteller made sense of a “chaotic event,” in this case, their HIV diagnosis (Bruner, 1990). Each coder read all transcripts. Then, a line-by-line open-coding strategy was used to identify emergent themes of sense-making and problem-solving related to HIV diagnosis. Special attention was paid to how the participant communicated the role of HIV in their lives. To ensure that the analysis was carried out systematically, an iterative process was adopted, which is based on a constant comparison method (Miles & Huberman, 1984; Tesch, 1990). Successive interviews were then coded in comparison with the previous interviews, and adjustments were made in the coding rubric throughout the analytic process, so previously coded data were reexamined as additional themes emerged (Hewitt-Taylor, 2001). Members of the research team met regularly to discuss coding decisions and reach consensus on key narrative themes. Analysis of the complete set of 18 interviews continued until thematic saturation was reached (Miles & Huberman, 1984). Finally, the research team worked to develop a framework within which to interpret connections between the themes and their significance.

Following analyses, author (C.D.F.) held a member-checking event. The director of the agency was asked to review the themes and share them with available former participants. The director was the most appropriate person to share project themes with clients due to his long-standing and trusted relationship with the community center. This form of respondent validation allowed for participants to offer feedback on the identified themes and recommend changes or clarification (Mays & Pope, 2000). Their feedback was integrated into the interpretation of findings to reduce errors in the data interpretation (Bloor, 1997).

## Results

Analysis of participant narratives revealed a cohesive thematic trajectory from self-condemnation toward self-acceptance. The four emergent phases in the narrative timelines are seen below.

- Acquisition of HIV: Judgment of past behaviors

In reflecting upon their acquisition of HIV, participants were judgmental of their behaviors that led to their diagnosis, labeling them as immoral or irresponsible.

- The aftermath of diagnosis

After diagnosis, most individuals described an increase in self-destructive behaviors or an exacerbation of existing mental health issues.

- Cultivating hope

First encounters with acceptance and engagement in communities where individuals could be their “true selves” offered glimpses of hope and led to a decrease in previously unhealthy coping mechanisms and/or self-judgment.

- Self-acceptance

Individuals described coming to peace with themselves and their past behaviors, often attributing this directly to the changes in their life that occurred after HIV diagnosis.

### *Acquisition of HIV: Judgment of Past Behaviors*

The modes of HIV acquisition among participants included heterosexual sexual intercourse, intravenous (IV) drug use, and male-to-male sexual contact. Although participants acknowledged the factual, biological nature of HIV etiology, they implied that for themselves, their own behaviors were the actual cause of HIV acquisition—and these behaviors were described with marked self-judgment.

Tom,<sup>1</sup> a long-term survivor of HIV, was judgmental of his engagement in sexual activity with other men:

I think it’s because I had sex with a dude and that’s not actually my character . . . Sometimes I can’t control myself when I want to have sex with another man, so I think of it like a curse, or a stain, or something.

Ronnie, who acquired HIV through IV drug use, attributed his HIV infection to irresponsibility: “In my case . . . it’s bad decision-making. You shouldn’t be out there using needles behind there and going like that everywhere or using drugs period.” Ronnie continued by explaining that he also views his infection as divine retribution for sinful behavior:

There's only one word that comes to my mind [about why I got HIV]. And that's sin. Sin. HIV is a sin disease. It comes from doing the wrong things, causing this illness to come upon you. Using drugs is illegal and if you put it in your body to harm yourself, it's also a sin.

Ronnie's perspective was similar to Bernard's, a gay man, who simply stated, "It's a punishment." According to Ronnie, before his HIV diagnosis, "I was just out there running wild. I guess I was trying to kill myself." Preexisting low levels of self-worth was often cited as a reason for "bad behavior," especially among those who contracted HIV through drug use. Frank, a man who also contracted HIV through having sex with another man, described his diagnosis as a punishment. He was in prison at the time, and his test results came as no surprise:

I thought I was being punished for the stuff that I thought I got away with . . . I wasn't going out there trying to catch it, but I will probably get it sooner or later because of the lifestyle I was living. And I got it. I found out in prison. I don't think I would have known or ever figured out if my partner hadn't died in prison.

Rose, a woman living with HIV since the late 1980s, acquired HIV from IV drug use. Rose described the horrors of the early days of AIDS, when people died very quickly after only knowing their status for a few days. Rose used drugs to escape her life struggles—being "high" made her forget her worries, and she felt euphoric. She had a fatalistic perspective on her own future, so when she first realized that groups of people she used drugs with were contracting the disease, she did not change her behaviors:

[AIDS] was killing people real fast. And I know that I shot dope with these people many times, many years before I knew and found out about [my HIV status] . . . I thought since they were all dying this one week that I was going to die too because we all hung together and shared needles together.

Will, who also acquired HIV through IV drug use, had been living with HIV for 22 years. He attributed his HIV infection to irresponsibility; specifically, the attitude that he was impervious to the disease: "[It came from] not knowing or not thinking it could happen to me." Cameron attributed HIV infection to irresponsibility and engagement in the "wrong" behavior:

If I started out doing the right things, I do not think I would have ever gotten it. Because like I said I was unprotected when I was having sex. I never used no condoms.

Lisa explained that she was uninformed about HIV, even after her partner disclosed his HIV status:

I was ignorant when my partner told me he had HIV, I should have looked into it. It was just like saying I got a cold. So I think it's stupidity and it's ignorance.

## *The Aftermath of Diagnosis*

Discovering one's HIV-positive status was the catalyst for self-destructive and/or an increase in already unhealthy coping behaviors. The stress of living with HIV and the threat of dying from HIV led directly to immersion in what participants would later in their narratives call a period of guilt and hopelessness. Increased or emergent drug use, promiscuity, suicide attempts, nonadherence to antiretroviral therapy, and other psychosocial sequelae were described.

Tom, who identified as heterosexual but contracted HIV through sexual activity with another man, talked about the events directly following his diagnosis. He engaged in a variety of self-destructive behaviors, from isolation to drug use to promiscuity:

I had sex with this dude and my lip broke out, and I went, I checked it out. Then I went into a depression, and I was like oh, man . . . I was not sexually active, I didn't want to be touched, or nothing. I was already funny acting. Then I met this dude one morning, and I was like . . . I had sex with him, and that's when I got into drugs.

Tom's drug use continued and he refused treatment while he was depressed, waiting until his viral load was very high and he experienced the ill effects of HIV. At that time, his drug use also increased—he attributed this to thinking the HIV medications were not working: "It made me want to do more and more, but then I became addicted to it, and I was hanging in the streets and stuff." Only when his HIV symptoms started "slowing him down," did he reduce his drug use and seek outside support for HIV, his frequent engagement in sex with men (that he perceived as uncontrollable) and his drug use. Alan, who also contracted HIV through unprotected sex, attributed his infection due to his sexual addiction. He echoed others who describe the aftermath of his diagnosis as, at first, contributing to worsening of addictions: "[It] got me to the point to reach complete bottom . . . When I first got the news, I had to sink even lower."

HIV diagnoses often came at a time when one's psychological state was already poor. When Rose, who contracted HIV through IV drug use, found out her diagnosis, she attempted suicide by overdosing on drugs:

I went to get tested and found out I had it and I felt like I wanted to die. Because I knew it was going to kill me. And I did it my way, I OD'd, I shot drugs, shot drugs until I passed out because I wanted to kill me . . . I didn't want HIV to kill me. I wanted to kill me. I didn't deal with it very good then.

Rose's narrative about the aftermath of her HIV diagnosis includes only a description of her suicide attempt. She does not explain whether, after surviving her suicide attempt, her drug use continued or if she experienced prolonged psychological effects. She does not describe how she coped during the years between her suicide attempt and her first



experiences with acceptance. However, the suicide attempt clearly reflects her previously self-destructive lifestyle and her response to the trauma of her HIV diagnosis. Frank, who contracted and was diagnosed with HIV in prison, welcomed HIV as a death sentence—which reflects the psychological state he was in at the time. He viewed HIV as punishment and his already low self-worth was only exacerbated by the diagnosis, saying, “I used to hate myself because I was doing drugs. And then I got the HIV. I said a long time ago, this just ain’t worth it, I’d rather be dead, and told my doctor I’m going to die anyways.”

Bill found out his HIV status when he was on the brink of death, and he describes his feelings of guilt as his mother watched him become sicker, guilt that has not left him:

When I found out, I was in the hospital in a coma and so putting your family through so much, you never forget it. I have to look at that in her eyes every single day and I can’t understand what she’s going through. That’s one of the hardest things in the world that I have to deal with.

Bill’s recovery was also difficult psychologically, because he was told that he was alive by the grace of God—an identity he saw as difficult to live up to:

When I got better, everyone says God has special plans for you. Do you know how much pressure that is for someone to say? And you’re sitting there going, I have no clue what he really wants me to do but everyone’s saying that God has something special and you should be doing this.

### *Cultivating Hope*

Participants’ stories about the aftermath of their HIV diagnosis took a turn when asked about experiences with acceptance. Some instances of acceptance were small, in the form of disclosure to only one person, or seeking medical treatment for their HIV infection. No matter the magnitude of the first glimpse of acceptance, it activated a series of positive changes in outlook or behaviors in the person’s life. The first experience of acceptance marked a glimmer of hope in what first seemed, as Ronnie explained, “the end of the world.”

For some, learning more about the disease was helpful in changing expectations that HIV was a death sentence. Tom said, “I started finding out more, and coming up to The Sanctuary, and getting more information about it, and hanging around people, and getting outside myself.” Understanding that HIV was not going to immediately end his life made Tom more adherent to his medications and further reduced his drug use. He sought out contact with other people, whether or not they were aware of his status—and this helped pull him out of what was a deep depression and the peak of his addiction to drugs. Alan sought out as much information about HIV as possible after his diagnosis. The information was vital in providing hope and eventually his ability to return to his “normal” life and routine:

At first I just poured every, every minute I could about learning about other people’s stories, about the medications, about every . . . I mean I even learned about medications I wasn’t even taking. Learning what I could do to stay healthy, about vitamin supplements, exercise . . . Every opportunity I could to stay as positive as I could. But now . . . that’s all great and fine but I still have to work . . . and exist as a human in society.

Ronnie also encountered his first glimpse of hope when he started getting more information about his disease. This led him to seek out religion, which reduced his worries about illness:

As time went on and you find out more about the medicines and the doctor care and stuff like that, you can live and being that I got into church and became a born again Christian. I don’t worry about it as much as some folks probably would be cause of that.

In Ronnie’s rediscovery of Christianity, his HIV status moved to the back of his mind, and he felt relieved that it was no longer consuming all of his thoughts. Religiosity sparked his recognition of the fact that his illness was not going to go away, which allowed him to reclaim his identity and to reduce the potential psychological consequences of being aware of HIV stigma:

I can live with it. Matter of fact, I don’t even claim it for myself. I’m just talking about myself. I’m aware that I have it when we are in groups and stuff and we talk about it. Yeah, I am HIV positive. But as I live my everyday life, I live it as if I’m normal. I’m clean. I don’t feel it’s a thing that I keep on my mind and worry about constantly . . . It’s mentally and physically bearing on the body and the mind. If you was to get deep into it, it takes a toll on you if you let it.

Faith commonly played a role in positively coping with HIV. Cameron had few ill-health outcomes despite his HIV status, which he attributes to God:

I pray to him about giving me strength because if it wasn’t for Him, I wouldn’t survive. I wouldn’t make it. And God is a lot of my medicine and I guess that’s why I never had to take medicine because I use him as my medicine. He is stronger than any medicine out there and I am a true believer in that but it doesn’t have to do anything with faith. I just know that he is looking out for us.

Bill found hope in his recovery from extremely ill health and his mother’s support, which motivated him to continue to take his medications. Despite his anxiety over his “miracle recovery,” and nondisclosure to most people in his life, eventual acceptance in surrounding himself by others with HIV was crucial to his perseverance after diagnosis and lack of outside support:

I moved from California to [the southeastern United States], a total culture shock. I have a few cousins that I know that don’t

know about [my HIV]. It's me and my mom. For two and a half years, I never came to The Sanctuary and one Halloween, this is two and a half years of me being at home not knowing anybody . . . I didn't know anybody. I came up here. Got scared. Came back in February and went bowling and with a couple of people I clicked on, and Mark has always been "Come, come have lunch." We'll go bowling. This place is one of the best places I have ever experienced acceptance in.

For Will, time and health were central to remaining hopeful. He did experience significant negative health problems from HIV. He described dealing with new medications and adjusting to unpleasant side effects throughout the two decades he has lived with HIV, but spoke of them as part of his life that has given him the ability to provide others with hope. Will strategically disclosed his HIV status only to people who he thought would be accepting of him, and explained that he only spends time with people who are "okay with it." He cited The Sanctuary as playing a role in the maintenance of his positive outlook, saying, "I think it's healthy to be around people with the same situation and you can talk about it and not worry about it going out and coming back."

Strategic disclosure was cited by many as the key to managing the day-to-day stress of HIV. Disclosure to the wrong person could lead to rejection, especially because of the HIV-related stigma. For most, the secrecy took a toll. John explained, "It's just how I feel inside—I hold back all my emotions on it and if I am not careful later on that can hurt me too but I've got to where I can hold back some." Surrounded by people at The Sanctuary who were also HIV positive alleviated the burden of the secret and encouraged hopefulness for John:

Around here I can be comfortable with somebody and talk with anyone, to other guys in my lifestyle that I deal with and the lifestyle of being HIV positive. I'm able to talk to the other people that have it and they can help me along, give me good judgments of what to do and how to proceed with my life. So that I can keep myself positive.

Cameron's main concern upon diagnosis was rejection by close friends and family. Complete nondisclosure offers protection from rejection, but the community center served as a place to safely, passively disclose to relieve the burden of secrecy:

None of my family members know anything about me. I really am scared that they would turn against me and I have a strong family and we don't break apart because of something like that, we always pull together, but I would feel like they like I would feel like I couldn't eat off their dishes or drink out their dishes. And that was the only thing that would ever hurt me is if I was to tell my family . . . So to keep from going through that, I just don't tell my family and the only people that really know are the people that come to The Sanctuary and we all together.

Frank was still in prison as he dealt with the first few years of HIV infection, and described marginalization by other prisoners that took a toll, saying, "It was hell." He was not able to talk about his status with anyone, and tried his best to conceal his medicine—but it was difficult to keep his HIV infection private because he became ill with pneumonia twice. Finally, a nurse asked whether he wanted to go to a group to talk to people about his disease, which he was excited about. He became more conscious of his health: "I was concentrating on making it out without dying and I made it out." Finding The Sanctuary gave him a place to go after leaving prison where there was no longer judgment:

I keep coming back here . . . for help. They don't know me from the man on the moon but they stuck by me. When I told my story for the first time, I didn't see no eyes flinch, I didn't see nobody's nose go up, and they still acted the same way [as] the first day they met me.

The aftermath of Bernard's HIV diagnosis was different, in that the diagnosis itself offered hope. He viewed HIV as a punishment for his "bad behavior," but he was relieved when he found out he had HIV. Just like many other adults living with HIV, preexisting behaviors or marginalization contributed to his HIV infection, and his drug use had been at the forefront of his identity. He said, "I was happy. I wanted it. Because I wanted to belong to something other than drugs." His HIV infection ultimately led to encounters with acceptance that he had not had before, because the shared experience allowed him to connect with others: "I never really had any family in my life. It gave me a family." Lisa left her partner after falling into a coma and being very ill for almost a year, after she found out she had HIV. Finding the community center offered support when she did not have it elsewhere: "I have been without a partner since '06. So that's been five years by myself. It takes the loneliness away. I come to The Sanctuary and laugh and joke and cry with everybody." Like many others, she referred to the community center as a home away from home.

### *Self-Acceptance*

Finally, after accumulating positive experiences in accepting environments, reducing harmful behavior, and interacting with others living with HIV, participants described reaching a place of self-acceptance. This was apparent in many ways—places of self-acceptance were not always marked by a radical shift in self-concept; rather, some individuals described an improved ability to cope with the reality of the implications of dealing with HIV for the rest of their lives. For some, caring for their health marked self-acceptance. For others, an explicit proclamation of self-love was shared with the interviewer.

For example, Alan's sexual addiction was mediated by his search for support groups after his diagnosis and "low point."

The support groups made him realize that he had been using sex as a coping mechanism to deal with the childhood sexual abuse he had suffered. Achieving sobriety with the help of his sex addiction recovery group and The Sanctuary was an important step in reaching self-acceptance: “[I’ve been] sober, sexually sober, 8 months now. I owe it to the HIV.” He spoke with pride about his newfound ability to share his story about childhood sexual abuse, because it helped others: “You sit in a group. You talk with James, and me sharing my story, gets him to talk about his abuse and how long has he been coming to group? And it’s finally getting to be talked about.”

After interacting and surrounding himself with others living with the dual stigma of being gay and HIV positive, Bill came to a place of self-acceptance. Although he still feared rejection from his father, he let go of the notion that he necessarily had to be understood by everyone to accept himself and to be his authentic self:

You were born this way. I truly believe that. You can pretend all day long. You can get married, raised kids and everything and deep down inside never be truly happy because you know in your heart this is not the life you really wanted to choose for yourself. Don’t get me wrong. Being gay, I’ve accepted that. HIV, I’ve accepted that. Yes, I would like to live a long, prosperous life. The way medicine is going, there’s a good chance I will but I’ve accepted it and I don’t know . . . For someone else to try to accept it is irrelevant.

Tom also resented his dual stigmatized identity as a gay HIV-positive man, but through contact with others with HIV, he shifted his perspective on homosexuality. He said, “I started to love and get along with a lot of the gay people here and accept the fact, the way I have been.” Roy, another gay man, described his struggles, made more difficult by his HIV status. He found acceptance in being around others in his situation and letting go of his fight against his sexuality: “My god, I have squabbed my eyes out. I have done everything in this world to try to prove the point I’m not gay, but I had to be born gay. I fought it all my life but finally had to come to the extent to live within myself that I’m gay.”

Rose struggled for years with drug addiction. Her HIV diagnosis was traumatic and led to a suicide attempt, rejection from family, depression, and chronic low self-esteem. After cultivating positive experiences by reducing her drug use and finding The Sanctuary, she came to a place of self-acceptance. She did not imply that everything is “better,” but that she was finally at peace with herself:

I started realizing . . . I gotta stop hurting me . . . I realized, “You really didn’t love yourself,” but now I do. ‘Cause I used to say, “I love me, I love me.” I sure didn’t. So now I know I love me, because I don’t do those things to myself. Haven’t dotted all my I’s and crossed all my T’s, I ain’t never gonna be perfect . . . but the most important and baddest things I was doing are no longer here. I’m not that person anymore.

Once Ronnie accepted his HIV status and sought support for his drug and alcohol abuse, he turned over his life to God. He realized that he did not want to act in self-destructive ways anymore, and he started looking at life differently:

You realize that life is more important than just wasting it away on alcohol, drugs, and running up and down the street . . . As much as I hate the disease itself, it’s terrible, I probably would not be where I am today without it. So it probably made a man out of me. It probably opened my eyes to be who I am.

Frank, who like many others found friendship and social support at the community center, simply stated, “I finally found real true unconditional love.”

## Discussion

The narratives described in this article offer a window into the experience of living with HIV as an adult in the southern United States. Poor mental health, social isolation, long-term struggles with substance abuse or addiction, and a lifetime of dealing with social stigma were among the most common issues cited by participants in the present study. Living in the rural south appeared to exacerbate the challenges these individuals face as well as their ability to access resources needed to cope with these challenges. The narratives of resilience shared by participants in the present study reflect a journey from despair to self-acceptance along a trajectory that is similar to what other scholars have documented previously (Emlet, 2006b; Emlet, Tozay, & Raveis, 2011; Nichols et al., 2002; Skaggs & Barron, 2006).

This type of narrative, characterized by a temporally contextualized trajectory, is similar to “polyphonic” and “restitution” illness narratives, which comprise a transformation of self-understanding, spiritual focus, hope, and a new or renewed value system (Frank, 1995; Marcel, 1962). Polyphonic stories, originally identified as a feature of some literary work, emerge from constant internal and external discourse about one’s sense of self (Bakhtin & Emerson, 1993). Restitution stories, as well, do not necessarily comprise distinct events that lead to a conclusion; rather, they are characterized by positive evaluation of events and socially influenced restructuring of self-concept that contribute to a loosely temporal, inspirational construction of what is storied (Frank, 1995). Consistent with Gregg’s (1995) analysis of semi-structured interviews, the individuals in this study used peers as points of comparison that contributed to reframing the way they understood their disease. As community members in our study were exposed to others with substance abuse problems, or those who were engaged in same-sex sexual activity, they shifted their appraisal of certain behaviors (first deemed sinful) to become more self- and other-accepting. The way our participants constructed their HIV illness narratives, organizing them temporally with an endpoint of transformation, has also been documented by others (Ezzy, 2000).



Our participants' narratives largely served as a way to reconcile their diagnosis, which was situated within a period of self-destructive or so-called "sinful" behaviors. The narratives demonstrated that HIV diagnosis itself was perceived as a catalyst for self-improvement and personal change, which ultimately led to a better self-concept, primarily resulting from encounters with accepting peers. Their stories provide insight into the lived experience of HIV beyond health consequences and demonstrate that the overall structure of illness narratives is similar among individuals despite mode of HIV acquisition, which varied across our sample. Valera and Kratz's (2014) illness narrative research with previously incarcerated chronically ill men found similar patterns of reconciliation among men living with HIV. HIV-negative men were more likely to share chaotic illness narratives that described their chronic illness as intolerable and overwhelming. Conversely, all of HIV-positive participants used quest narratives to describe their lives where HIV played a pivotal role in accessing needed resources and served as a reason to change past negative behaviors.

The emergent themes surrounding stigma are not surprising given that many participants belonged to multiply marginalized groups including racial and ethnic minorities, MSM, and substance users. Poor gay and bisexual Black men living with HIV reported that long-standing social stigmas related to racial and social hierarchies continued to adversely influence their daily lives and overall health and mental health despite progress made in the medical treatment of HIV (Haile et al., 2011). The theme of HIV infection as divine retribution for past sinful behaviors is well documented and religious beliefs have been associated with prejudicial attitudes toward those living with HIV (e.g., Madru, 2003; Martin, Young, & Smith, 2003). Muturi and An (2010) found that African American women living with HIV who had high levels of religiosity were more likely to hold the view that HIV was a curse from God. Furthermore, views of God as punishing or judgmental were associated with faster disease progression among a diverse sample of HIV-positive adults (Ironson et al., 2011). Still, Nunn et al. (2013) found that African American places of worship can raise awareness, encourage testing, and promote the destigmatizing of HIV. Taken together, these findings suggest that interfaith community-based organizations that promote the acceptance and support of individuals with HIV can play a key role in reducing community-level HIV-related stigma and promoting the well-being of those living with HIV.

That concerns related to disclosure were common among participants is unsurprising as disclosure is a consistently documented challenge among those living with HIV (e.g., Mayfield Arnold, Rice, Flannery, & Rotheram-Borus, 2008; Scott, 2009). Research focused on disclosure among African American men in the rural south confirms the current study's findings that disclosure to others is limited and may be influenced by initial reactions to sharing their HIV status (Gaskins

et al., 2012). Men living with HIV still experience high levels of shame and stigma, even in social contexts where homosexuality is readily accepted such as San Francisco (Skinta, Brandrett, Schenk, Wells, & Dilley, 2014).

As evidenced by the nondisclosure outside of the community center described by many participants, open discussion about living with HIV may be confined to settings with peer presence. Particularly in the southern United States, stigma around HIV persists and clearly influences the lives of those affected (Krawczyk et al., 2006; McCoy et al., 2009; Rhodes et al., 2010). Having safe spaces in which to share their stories over time in ways that may lead to greater self-acceptance and resilience is clearly an important need of people living with HIV in this part of the United States. The process of reflecting on experiences of HIV over the life course may provide an opportunity for participants to identify moments of transformation where they began to view their illness as a catalyst for positive change in their lives (e.g., Baumgartner, 2002; W. A. Robinson, Petty, Patton, & Kang, 2008).

Social support provides a wellspring of benefits for individuals living with chronic illness to better manage pain and suffering (Repper & Carter, 2011). Although individuals with illnesses that are not accompanied by stigma may also struggle with finding others who can relate to their experiences, those with HIV face compounded challenges due to the nature of HIV stigma and variable geographic prevalence rates. Those with HIV who do find peers benefit from their companions' ability to empathize with HIV-related experiences and the absence of stigma (Molero, Fuster, Jetten, & Moriano, 2011). However, many adults living with HIV are not engaged in consistent medical care or struggle financially, as was the case in this sample, which can hinder one's ability to access peer and mental health support systems (Brennan-Ing et al., 2017).

Finally, previous research underscores the physical and emotional benefits of self-acceptance among adults living with HIV. For example, Horter et al. (2017) found that participants who accepted their HIV status were more likely to engage in care and play an active role in self-management. In research with adults older than the age of 50 years, Emlet et al. (2011) identified self-acceptance as a key theme related to resilience in aging. Teti, French, Bonney, and Lightfoot's (2015) photo-narrative research with women revealed that, despite the challenges of living with HIV, women archived positive transitions in their lives including transformation and self-acceptance. Taken together, the research on HIV and self-acceptance indicates that living with HIV is associated with significant challenges and that it also offers the opportunity for growth, transformation, and insight.

## Implications

We suggest that an applied narrative approach to support for health services in this population may help to elucidate the



unique backgrounds and experiences with HIV, which provide indications of individuals' most pressing challenges, needs, and concerns. Narratives also function as signposts for identifying individual forms of resilience and personal sources of motivation and social support that enable people to cope with challenges over time.

Using stories and open-ended questioning to learn more about a person's background and needs is not new. Many types of health care providers rely on patients' willingness to share stories as a way to build rapport and individualize their care (Gale, Mitchell, Garand, & Wensler, 2003; Launer, 2002). A narrative approach to health care enables the provider to glean crucial information about the context in which an individual must manage their illness and fine-tune medical management to suit a patient's unique needs. Such patient-centered care is increasingly being taught and encouraged in medical education settings (J. H. Robinson, Callister, Berry, & Dearing, 2008). Social service providers, who often work in HIV care settings, are uniquely skilled to integrate narrative-based approaches into their HIV care practices and to encourage the initiation of such discussions by other medical providers. Accordingly, interdisciplinary teams continue to be an important aspect of care for people living with HIV.

A narrative approach offers the potential to explore individuals' experiences and needs within the context of their broader life history (Gale et al., 2003). As such, this approach moves beyond standard lines of questioning as a means of collecting discrete pieces of information for case management, which often require people to articulate what their needs are, their readiness to take on new tasks or seek out new support services, and to verbalize where their strengths and weaknesses in coping with HIV might lie. A narrative approach to health care enables the provider to glean crucial information about the context in which an individual must manage their illness and fine-tune medical management to suit a patient's unique needs. Such patient-centered care is increasingly being taught and encouraged in medical education settings (J. H. Robinson et al., 2008).

For some with HIV, access to medical care is inconsistent or infrequent. Such patients would be well served by being connected to support settings that do not require health insurance or financial commitments. Medical and social service clinicians are often gatekeepers to psychosocial support, whether from mental health clinicians or local community groups. There is considerable research that suggests social support in general can improve health outcomes (e.g., Cohen & Wills, 1985; Phillips et al., 2006), so it should not be underestimated by health services providers who also may be able to refer otherwise isolated individuals to similar support systems as the one described in this study. In clinical or other care settings, eliciting perspectives on illness from patients living with HIV offers insight into which types of outside support might enhance their quality of life, especially

among individuals who have limited resources. Providers may benefit from identifying common threads in HIV illness experience across groups regardless of mode of acquisition, while also keeping in mind that individual experiences are most important in providing the most appropriate, effective care for each of their patients.

## Limitations

The findings of this study must be considered in light of several limitations. The small sample size limits generalizability to the larger population of people living with HIV/AIDS. The number of years most participants had been living with HIV likely provided increased time for reflection and enhanced their ability to identify the shifts in their perspective over time (Malkki, 2011). Although the interviewer spent a year with the community center, which facilitated rapport in interviews, social desirability effects are always a risk in qualitative methods. The narratives were elicited in a one-time semi-structured interview. Continuous engagement with individuals and collection of their stories for an extended amount of time would be valuable to confirm the validity of these findings at different points in their illness experience. More research is needed to understand whether narrative shifts occur in times of better or worsening health. Finally, the individuals interviewed were recruited from a community center that was intended to provide support and therapeutic services. Today many people with HIV now live normal active lives and do not require the support of third parties. Furthermore, others living with HIV may seek and achieve acceptance in other places, which are clinically important to identify for settings where similar programs are not available. Community-based organizations that serve individuals living with HIV can also help to reduce HIV-related stigma at the community level while concurrently improving the quality of life of those they serve.

## Conclusion

Notwithstanding the limitations of this study, findings highlight the power of inviting self-reflection through narrative elicitation—participants' illness narrative trajectories indicated that they perceived an improvement in their psychological state since the time of their diagnosis. For adults with HIV who are living longer, healthier lives, the salience of their illness may not be static from day-to-day. Our findings confirm that HIV still poses considerable psychosocial challenges to those living with the disease. A chronic, stigmatized illness such as HIV is bound to frequently present new challenges to the sufferer, both medically and otherwise. However, the narratives of the individuals in this study offer hopeful accounts of how, with the support of an accepting community, HIV can be managed and made meaningful in individuals' lives.

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## Note

1. The agency and all participants' names have been changed to protect their identities.

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