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Life Lessons from Women with HIV: Mutuality, Self-Awareness, and Self-Efficacy

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Abstract

Women with HIV in the United States cope with multiple traumas that influence adherence to antiretroviral therapy (ART) and well-being. Narrative themes from three life turning points and a projective story task were compared for two groups of women with HIV (HIV well-managed vs. HIV not well-managed, matched on demographics and narrative word count) to understand predictors of successful outcomes. The well-managed group ($n = 10$) was virally suppressed and reported ≥95% ART adherence; the not well-managed group ($n = 10$) had detectable viral load and reported <95% ART adherence. Women were predominantly African American with low socioeconomic status and averaged 46.51 years. A three-stage coding process (with coders blind to group status in stages 1 and 2) involved (1) line by line thematic analyses that generated 155 subthemes reflecting six content areas (interpersonal relationships; culture and community; sense of self; relationship to past, present, and future experiences; self-care; and motivators for change); (2) absence/presence of the 155 subthemes was compared for the two groups; the frequency of 37 subthemes was found to significantly differ; and (3) the 37 differentiating subthemes were conceptually integrated, revealing that the well-managed group's narratives more frequently reflected (a) mutuality (growth-fostering relationships involving reciprocal care and empathy); (b) self-awareness (recognition of personal strengths and weaknesses and multiple factors contributing to life choices and trajectories); and (c) self-efficacy (active coping, self-advocacy, and utilizing resources). Implications for treatment and interconnections among themes are discussed, emphasizing the factors that enable women to care for themselves and others.

Introduction

With the advent of antiretroviral therapies, HIV has become a chronic rather than a life-threatening disease. As with other chronic illnesses, the critical question becomes how to attain adaptive levels of functioning in various aspects of life, such as work and relationships, despite adverse or traumatic environments and experiences.[1]

Women with HIV not only have to overcome the stresses and limitations imposed by their illness but also face other adverse and disempowering life experiences, including a history of trauma (33–67% have a history of childhood sexual or physical abuse);[2,3] intravenous drug use, which caused ~16% of new cases of HIV among women in 2012;[4] and a lack of economic and educational opportunities, including unstable housing.[5] In addition, women living with HIV are frequently exposed to HIV stigma and prejudice[6] and to racial and gender discrimination,[7] with 64% of the 400,000+ infected women in the United States being African Americans, 18% being white, and 15% being Hispanic/Latina.[4]

This article focuses on understanding the life experiences and coping strategies that promote HIV adherence to antiretroviral therapies (ARTs) and positive health outcomes (specifically, HIV biomarkers used in clinical practice), as conveyed through women's autobiographical memoirs and stories, relying on women's own construction of the meaning of significant life events. ART adherence reduces mortality and morbidity rates and enables people with HIV to have higher health-related quality of life.[8] Yet, despite its critical importance, adherence rates remain low, with 25–35% of patients struggling to maintain an 80% adherence rate.[9,10] In general, women with HIV are less likely than men with HIV

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to use ART.[11,12] The CDC estimated that only 32% of infected women had achieved viral control in 2011.[13]

Factors that impede and promote medication adherence and health in women with HIV

Higher HIV viral load and lower levels of ART adherence and $CD4^+$ cell counts (a measure of immune functioning) have been associated with a variety of psychosocial variables, including depression and post-traumatic stress disorder (PTSD);[1,14] lack of social support;[15,16] childhood sexual abuse;[17] homelessness;[11] unemployment;[18] and African American racial/ethnicity (associated with racial discrimination, medical mistrust, and lack of access to healthcare).[11,17] Other identified factors of low ART adherence are parenting stress and child care burden;[19,20] HIV stigma;[21] alcoholism;[22] perceived onerous medication regimen and side effects; and low self-efficacy, health literacy, and self-confidence.[23,24] The relationship between psychosocial factors and biological processes is most likely synergistic, with each changing and influencing the other, both affected by inflammatory processes associated with viral illness and depression.[25]

More recently, the processes that positively impact HIV biomarkers and health behaviors have also been investigated. Factors associated with positive health include exercise;[26] having social supports and high affiliation motives;[27] being aware of social inequities;[7] finding positive meaning in life experiences;[28] engaging in spiritual practices and beliefs;[29] practicing mindfulness;[30] being open about stigma associated with HIV diagnosis, sexual orientation, or other factors;[21] self-advocacy and good communication with physicians;[31] lack of self-silencing with romantic partners;[20,32] and having positive self-esteem, affect, and self-regard.[33,34] Furthermore, having personal qualities that allow for flexibility and self-efficacy, such as a sense of humor, optimism, and being active and goal oriented have also been found to promote medication adherence and health.[33,35] However, the interconnections among the many factors that have been found to contribute to adherence and health are not well understood.

Narrative analysis and women with HIV

Previous studies using interviews and questionnaires to measure factors predicting adherence and biomarkers have only been partially helpful in informing treatment interventions, perhaps because these methods are constrained by what the researchers, rather than the women themselves, deem important, as well as by social desirability pressures that may shape women's responses. Furthermore, these methods may fail to capture changes over time in life experiences and coping strategies.

In contrast, autobiographical narratives reflect women's own perspectives on the trajectory of their lives, including their coping strategies, core motives, affects, and goals.[36] Autobiographical narratives are based not only on the reality of events that have occurred but are also constructed by the individual. They are thought to be central to understanding how individuals form an identity and make meaning of life events, both reflecting and influencing self-beliefs.[37] Similarly, in projective story-telling tasks, the assumption is that participants project aspects of themselves through the content of the stories they tell, revealing conflicts or values that they might otherwise censor or even about which they are not consciously aware.[38]

Previous qualitative studies of women with HIV using journals, life stories, and structured interviews have enriched our understanding of the factors that predict sexual risk taking,[39] HIV infection,[40] medication adherence,[15] and healthcare behaviors,[16] especially in women with a history of abuse.[39] These studies have highlighted the critical role played by social supports[15] and respectful communication with healthcare providers[16,41] in decreasing risk and improving health behaviors. However, often this work has focused on a specific variable of interest to the researchers, for example, abuse or social support, without reflecting topics women themselves might have selected to focus on as significantly affecting their lives.

The current study sought to move beyond previous research on women with HIV to enrich and expand our understanding of the life factors described in women's narratives that are associated with better medication adherence and health. We coded and analyzed the themes of autobiographical narratives and a projective story task, comparing the following two groups of women: an HIV well-managed group (virally suppressed and reporting ≥95% ART adherence) and an HIV not well-managed group (HIV viral load >80 copies/mL and reporting <95% ART adherence). ART adherence and viral load were selected as differentiating factors because they are both critical indicators of HIV health status.[42]

Methods

Participants

Twenty women with HIV from the Chicago site of the Women's Interagency HIV Study (WIHS) were selected to participate in the current study. The WIHS is an NIH-funded, multisite, longitudinal cohort study of more than 4000 women with or at risk for HIV, recruited in three waves (1994–1995, 2001–2002, and 2011–2012). Details of the WIHS methodology have been described elsewhere.[43,44] Women attend semiannual study visits that include psychosocial, behavioral, and medical histories, physical and pelvic examinations, and collection of serologic and gynecologic specimens. Informed consent was obtained from all enrolled women after the study was approved by the relevant Institutional Review Boards (IRBs). Participants received a financial honorarium, transportation support, and childcare for their time.

One hundred Chicago WIHS HIV+ participants ($n=44$, wave 1, and $n=56$, wave 2) were recruited at a scheduled WIHS visit between 2008 and 2012 to generate narratives that are the focus of the current study. Among this sample, 10 women ($n=3$ from wave 1; $n=7$ from wave 2) were selected to be in group 1 (HIV not well-managed) because they were the only participants who met criteria of reporting <95% adherence to ART, having detectable HIV viral load ≥80 copies/mL and CD4 counts <350. The second group (HIV well-managed) of 10 women ($n=5$ each from waves 1 and 2) who had ≥95% adherence to ART, undetectable HIV viral load (<80 copies/mL), and CD4 counts ≥350 was selected from among the remaining 90 women to match the first group on age, socioeconomic status, educational level, race, narrative word count, ever/never reported history of sexual and physical abuse, and ever/never reported history of crack, cocaine, heroin, and injection drug use.

Demographic characteristics of the women are summarized in Table 1. The two groups did not differ in depressive symptoms at the study visit, as measured by the Center for Epidemiological Studies Depression Scale [CES-D,[45] $t(18) = 0.32$, $p = 0.75$], with both groups having mean scores above the clinical cutoff of 16 ($M = 17.15$, $SD = 13.05$). The two groups also did not differ in the length of time they were living with HIV, averaging 15.1 years [$SD = 2.45$ years; $t(18) = 0.18$, $p = 0.86$]. Finally, equal numbers of women (half in each group) were receiving services at an HIV specialty clinic focused on HIV care with comprehensive services, including drug treatment, mental health services, and support groups versus at community clinics that did not specialize in HIV care.

Measures

Projective story-telling task. Women were first asked to generate a story in response to a detailed drawing of an ethnic minority woman with a neutral facial expression looking in a mirror, which previous research has indicated elicits thoughts and feelings about the self.[46] Participants were instructed to make up a story about the picture in as much detail as possible, including who the character in the story was and what she was feeling and thinking about present, future, and past events.

Autobiographical narrative task. Participants were then asked to provide narratives about three significant life turning points, describing what happened and their perspective regarding the importance of each of the three events in their life stories. Instructions were adapted from the Guided Autobiography Task, which has been used extensively in previous research, including with African American women.[36]

Narratives were audiotaped and were generated in the presence of one of two WIHS female interviewers (one African American and one European American) who were known to participants. Interviewers were trained to allow the women's stories to unfold without interrupting and to ask for clarification or elaboration if the content of what the women narrated was unclear or vague.

Coding process. A combination of inductive and deductive methods, as consistent with thematic analysis,[47] was utilized in three stages of analysis as follows. During the first two stages of analysis, coders were blind as to group membership.

Open/substantive coding. Each line of the autobiographical narratives and projective story was reviewed to identify themes by 10 researchers (7 women and 3 men), 8 of whom were European American, 1 of whom was Asian American, and 1 of whom was African American. The group included two doctoral-level psychologists, an MD who treats women with HIV, four graduate students in psychology, and three undergraduate psychology majors. Coders individually reviewed narratives, took notes on each line, and then participated in a group discussion with other coders. The coders engaged in lengthy discussions regarding the major and minor themes and coping strategies identified by each coder in each narrative, repeating this cycle until thematic saturation was achieved, the point at which novel themes stopped emerging from the data and additional observations provided no new information.[48]

Table 1. Sociodemographic and Clinical Characteristics of the Sample

	Entire sample (n = *20*) n *(%)*	*HIV not well managed* (n = *10*) n *(%)*	*HIV well managed* (n = *10*) n *(%)*
Race			
African American/non-Hispanic	18	9	9
White/non-Hispanic	1	1	0
Other	1	0	1
Education			
Grade 11 or less	12	6	6
Completed high school or above	8	4	4
Income			
$12,000 or less	17	8	9
$12,001 and above	3	2	1
Marital status			
Legally/common law marriage	6	3	3
Widowed	2	1	1
Divorced/annulled	1	0	1
Separated	3	1	2
Never married	7	5	2
Other	1	0	1
Incarceration	11	3	8
Childhood sexual abuse	8	3	5
Any abuse ever	20	10	10
Injecting drug use	10	5	5
Crack, cocaine, heroin use	16	7	9
Age in years, mean (*SD*)	46.51 (6.83)	45.90 (6.14)	47.11 (7.74)
CES-D score, mean (*SD*)	17.17 (13.05)	16.20 (14.81)	18.10 (11.77)

CES-D, Center for Epidemiological Studies Depression Scale.

Projective stories were used as additional information about women's past and present self-awareness and self-concept, with special attention paid to the overlap in themes between projective stories and autobiographical narratives. Of interest is that contrary to the instructions they had been given, 8/20 (40% of the sample) referred to themselves rather than a third person character when generating projective stories, for example, saying, ''She looks like me'' and then narrating a story that was at least partly autobiographical.

By looking at the commonalities among codes, six categories were identified, each of which had multiple subthemes, with 155 subthemes identified in total. The six categories and examples of subthemes within each category are as follows: (1) quality of relationships with others (e.g., mistrust, forgiveness); (2) quality of relationship to culture and community (e.g., homelessness); (3) sense of self (e.g., self-acceptance, self-blame); (4) relationship to past, present, and future experiences (e.g., meaning making; hopelessness); (5) self-care (e.g., HIV medication adherence); and (6) motivators for change (e.g., wanting to live, hitting rock bottom).

Selective coding. Narratives were revisited and each participant was coded for the presence/absence of each of the 155 subthemes within the 6 categories previously identified. For example, within the category ''motivators for change'' were, among others, the subthemes of ''wanting to live'' and ''hitting rock bottom'' and each of these subthemes was coded present/absent. Six of the original coders (two doctoral-level psychologists, one MD, and three psychology graduate students) participated in this stage. Levels of agreement for the six coders tended to be high, as evidenced by the number of coders who agreed relative to the total number of coders, averaged over a random sample of 30 subthemes for five participants. The percentage agreement for these 30 subthemes averaged 90%, meaning that approximately five out of six coders agreed on the presence/absence of each subtheme. When coders differed in their subtheme ratings, they engaged in group discussions to generate a final consensus code.

Theoretical coding. At this stage, coders were unblinded as to participant group status, and the two groups (HIV well-managed/not well-managed) were compared on the frequency with which subthemes were present. Subthemes were considered to differentiate groups when at least four more women in one group had the subtheme present when compared to the second group. Using a χ^2 analysis, a difference of 4 women between groups in a sample of 20 is significant at $p = 0.025$. A difference of 4 was chosen because it was the lowest difference between the two groups that would be significant at $p < 0.05$. Because standard errors are more likely in smaller data sets, an alpha value of $p < 0.05$ is acceptable, and more stringent alpha values, for example, $p < 0.01$, are not recommended.[49] Conceptual commonalities among the subthemes that differentiated the two groups were then identified in group discussions and were repeatedly evaluated with reference to the original narrative texts. This process resulted in the identification of three major differentiating themes: Relationship Mutuality; Self-Awareness; and Agency/Self-Efficacy. Finally, narratives of women in the HIV well-managed group were reread to describe the interconnections and temporal relationships among these three identified themes.

Results

The average word count was 1537 ($SD = 535.17$) for the projective stories and 1666 ($SD = 764.15$) for the three turning point narratives.

Subthemes that distinguished groups

Relationship mutuality. Subthemes in this category reflected the degree to which relationships with others were characterized by reciprocal empathy, caring, growth, and support, and changes in these over time. Specific mutuality subthemes that differentiated the two groups are displayed in Table 2 and are illustrated in quotes below.

HIV well-managed group

Women in the well-managed group more often expressed feeling actively validated by at least one person who recognized their worth.

Olivia: ''One of the staff recognized that I had something good in me …I used to have low self-esteem about myself, you know I felt like I can't do nothing….. And so when she called, then I was like'ok, I am good. …. somebody saw that I could do something'… I said thank you for believing in me when I wasn't believing in myself.''

They more often expressed feeling supported by family, friends, professionals and being able to reach out and accept help from others, including professionals. They also more often recognized the importance of sharing their feelings and experiences with others and expressed gratitude for these relationships.

Robin: ''I kept hearing this lady speak and talk about how she survived her tragedies and where she is today and I said I need someone like that … I'm gonna ask her will she be my sponsor. So I asked her and she said yes. And that's one of the best things that could have happened to me. Because some of the stories she shared was similar to mines.''

The importance of having a mutual dialogue with others, in which each member of the relationship is changed by the other, also emerged more frequently in the HIV well-managed group:

Holly: ''(My son) is sick also, so we have a lot in common, him and I. We share our stories and we share how we are now, how we feel and… he tells me how he feel about being born like that…. I share with him. And I tell him over and over, 'I'm so sorry we're sick,' but he's so strong. You know where I'm weak, I see he's strong, and that gives me something to look forward to.''

They more often portrayed a positive relationship with their mothers that they either remembered from childhood or that developed over time, sometimes requiring forgiveness for mothers' perceived previous mistakes. Relationships with others (including mothers) were more often portrayed as becoming more positive over time.

Valerie: ''I started working and was making a wonderful salary as a Certified Nurse Assistant…so I decided to go out and buy a house and my mother she was so proud of me….And we were able to talk about it, to talk about my childhood.'' (Here she is referring to the fact that her mother did not protect her from abuse). ''So we start taking extra

Table 2. Frequency of Differentiating Subthemes for Mutuality and Self-Awareness

Subthemes	*Themes category*	*Well-managed,* N	*Not well-managed, N*	*Total, N*
Feels supported by family, friends, professionals	Mutuality	9	4	13
Talks about positive relationship with mother	Mutuality	8	4	12
Changes toward more positive relationships	Mutuality	8	3	11
Someone actively validated/supported them	Mutuality	7	2	9
Reaches out for help and support from friends or family	Mutuality	6	2	8
Care for self and others balanced	Mutuality	6	2	8
Someone was cruel to them/made them feel worthless	Mutuality	1	6	7
Others seen as objects, used to meet her own needs	Mutuality	1	5	6
Describes lack of dialogue in family	Mutuality	1	5	6
Positive steps initiated by self and others (balanced)	Mutuality	5	1	6
It is about other people doing stuff for her/using others	Mutuality	1	5	6
Finds joy/purpose in helping family	Mutuality	5	1	6
Able to connect past with present/explains motivation for change	Self-awareness	9	2	11
Does not explain motivation to change	Self-awareness	2	9	11
Clear trajectory of change in self-image	Self-awareness	8	3	11
Does not make meaning of challenging life experiences	Self-awareness	1	9	10
Avoids or denies painful realities	Self-awareness	1	8	9
No clear trajectory of change in self-image	Self-awareness	1	7	8
Knowing strengths and weaknesses/recognizing when needing help	Self-awareness	7	1	8
Ties positive affect to fulfilling stereotypic gender roles for women and ties negative affect to not fulfilling those roles	Self-awareness	1	6	7
Makes meaning of challenging life experiences	Self-awareness	5	1	6
Motivated to change because hits rock bottom	Self-awareness	5	0	5
Describes being able to have own home or space as part of identity and healing	Self-awareness	5	1	6
Sexual/physical assault	Self-awareness	5	1	6
Is or was homeless	Self-awareness	5	0	5

trips downtown and having conversations about the past and so then it came up and she was telling me she was sorry about everything ….. And so we talked about it on a regular basis and I was glad that we were able to get it out and I was able to mend …. It has really shaped my life for the better…''

They were more apt to express finding joy/purpose in helping others, with care for self and others balanced:

Holly: ''I have a family member that's sick and I see after them. …even though I'm a sick person I'm able to help somebody else and that makes me feel real good about myself.''

HIV not well-managed

Compared to women in the well-managed group, women in the HIV not well-managed group were more likely to portray someone as having made them feel worthless or having been actively cruel or abusive to them with no empathy:

Jasmine: In the projective story-telling task, she says: ''Most people think she is too dumb to work. So they don't give her a chance''; and later in her autobiographical narratives: ''I had met a lot of people and they would say … bad words, like that so and so, she's got that disease and well, yeah, she'll die tomorrow and things like that.''

They were more likely to describe a lack of dialogue in their families. Their narratives were more frequently filled with disconnected relationships with few to no descriptions of positive relationships, including with their mothers.

Dawn: ''I was eight. My uncle used to come and molest me all the time and he told me if I told my grandmother, uh, his father would put us out. ….. And I told my mom but she wasn't there to help me. With every time I ran away, she sent me back.''

They also more often described relationships in terms of what others could do for them rather than as a mutual give and take; they did not express empathy for others.

Carla: ''I got married 5 years ago…. I wanted to stay clean and he didn't use drugs. Which it turned out that I end up getting married to him and getting off of drugs but I feel that he done the mission that I wanted to accomplish, so now we are not together.''

Self-awareness. Subthemes (listed in Table 2 and described below) reflected the degree to which women recognized their personal strengths and weaknesses; were able to identify the family, community, and personal factors that contributed to life choices and trajectories; and were able to acknowledge the realities of painful experiences.

HIV well-managed

Women were more likely to recognize their strengths and weaknesses, and how to address those weaknesses, including recognizing when they needed help.

Olivia: ''I … think that I'm like really intimate [with men] and stuff really quick, and then I get hurt really fast. … I gotta

be more careful… for me and my kids. My kids come first … and then a man… because it wasn't how I was doing it … So I want to do better.''

They were more likely to connect how the past affected the present and their current lives. They were also more apt to include references to previous homelessness and assaults and to express being aware that they had hit ''rock bottom,'' motivating them to change.

Robin: (describes a painful history of childhood sexual abuse). ''I didn't like men for a long time, a long time. I hated them…. then I went to the street life… of prostitution, drug addiction… And as I got older I got tired… of the streets, the streets was burning me down, burning me out. So I decided to seek help for my drug addiction.''

They were more apt to describe positive changes in their self-image over time.

Deborah: ''[HIV] is something that I have to live with for the rest of my life that I would have never, ever, ever thought of dreaming about having. … And I feel great today about it, where I'm at today. 'Cause I am not nothing that I used to be years ago. Nothing.''

They were more likely to make positive meaning from painful and challenging life experiences.

Nicole: ''If I can go through the things that I went through as a child, I can pretty much get through anything as an adult. … if I can muster all that, then I could just be a better person without (drugs) and it just makes me stronger.''

HIV not well-managed

Women were less likely to make connections between past and present and/or explain motivation for change. Instead, they were more likely to present a disjointed or list-like account of life events, or incomplete details and understanding about how they transitioned from one life event to another.

Alice: (describes relationships she got into with partners): ''I'm getting stuck into situations that I don't even know how I'm getting into those situations…''

Their self-image was more likely to be unchanged over time.

Kimber (projective story): ''She's not coping well…. She may stay like that. She may get some medication that helps her. I don't think she'll ever heal from it or forget it. She may forgive, but the damage is done…..''

They were more likely to blame themselves or cope through avoidance rather than to make adaptive, positive meaning out of challenging life experiences.

Carla: ''I got married, you know so it sticks out a lot, now too that I'm out of the marriage, I relapsed, I lost my finances, you know, so this sticks out a lot. I feel like I'm being punished… Because, um, you know God says…when you get married you're supposed to be submissive to your husband and I cheated and I did everything not right and I just feel like I'm being punished now.''

They were more likely to tie positive affect to fulfilling stereotypic gender roles for women such as getting married or matching one's appearance to dominant cultural standards for women, and conversely, to tie negative affect to not fulfilling those roles.

Janice: In the projective story-telling task: ''In the future she would get married again …. She'll lose a little weight… She'll get… a complete maker over… Not to change anything but to try new makeup a new hairdo, new line of clothes. And, uh, she'll be real happy then.''

Agency/self-efficacy. Subthemes (listed in Table 3 and described below) reflected the degree to which women were able to access resources, advocate for themselves, and utilize active coping skills that enabled them to overcome difficult life circumstances and maintain health. An important component was the self-perception that they could actively affect the course of their lives.

HIV well-managed

Women in the HIV well-managed group were more likely to see themselves as having the capacity to take active and realistic steps and to overcome previous adversities.

Tanya: ''I had quite a few friends and a couple of my male friends had died from AIDS. And so, the realization is I had to quit, get off of drugs and get my life together… I wanted to succeed and what I realized from all that is, if you really put your mind to something you can get it done. So I wanted to live and it might have been a little late, but I wanted to do it and I did it.''

They were more likely to advocate for themselves in healthy ways.

Table 3. Frequency of Differentiating Subthemes for Self-Efficacy

Subthemes	*Category*	*HIV well-managed,* N	*HIV not well-managed,* N	*Total,* N
Clear trajectory of positive change in lifestyle/health	Self-efficacy	9	3	12
Sees herself as able to make active choices	Self-efficacy	8	3	11
Talks about self-care for health	Self-efficacy	8	2	10
Traumatic/hard situations lead to hopelessness/passivity	Self-efficacy	3	7	10
Actually takes needed steps as opposed to just talking	Self-efficacy	9	1	10
Sets up realistic goals	Self-efficacy	6	2	8
Advocates for self in healthy ways	Self-efficacy	6	1	7
No clear trajectory of change in use of substances or health	Self-efficacy	1	6	7
Substance abuse treatment program (residential or AA) a success	Self-efficacy	5	1	6
Self-image as victim; bad things keep happening	Self-efficacy	0	4	4
Spirituality/fatalism discourages proactivity	Self-efficacy	0	4	4
Just talks about goals as opposed to taking action	Self-efficacy	0	4	4

AA, Alcoholics Anonymous.

Valerie: ''Not that I'm selfish today but today you know I feel like I'm more, um geared towards being fair about everything you know even at my age, in my adulthood I just speak out about being fair and being unfair.''

They were more likely to speak about actively working on self-care to improve and maintain health, and to describe their health as improving over time.

Tanya: ''The future right now…is trying to maintain. Trying to stay well… To me it's like being on drugs, trying to stay well, trying to stay up on medicine, trying not to get depressed, trying, ya know, just hoping you don't catch something, get something that can take you down. .. I dunno if nobody else look at it like that but being that I've been dealing with this HIV for, about 20 years almost, I swear it's a job. But I'm going to work this job regardless…''

They were more likely to describe making successful use of substance abuse treatment programs.

Robin: ''I pay my bills. I pay them all on time, that feels good, I can keep a roof over my children head today, and without the 12-step program I wouldn't be where I am today, drug free, happy, living life on my terms. It feels good.''

HIV not well-managed

Women were more likely to set up goals for the future that were vague with an all-or-nothing mindset.

Cora (projective story): ''She looks disgusted. She looks like she wants to change…Her everything. Her surroundings, her company, her man, and her apparel. She looks like she just wants a big change …She's got to rebuild it all over. Every … step all over. Take a good look in the mirror … and put her mind to it and make a decision and just do it.''

They were more likely to talk about goals without taking active steps to meet them.

Alexis: ''It didn't dawn on me, I was just thinking about getting high. And when it hit me, it's too late, the kids is gone, but I, I had a chance to get them back and start my life over. I did it for a little while, then I stopped.''

They were less likely to report any lasting change in substance abuse or help provided by substance abuse programs. Their narratives were less likely to reflect a positive trajectory toward health.

Alexis: ''I met this guy, he introduced me to some treatment, so I went to treatment but I didn't complete it. I went to treatment a lot of times it made me happy, at least I tried, gave it a try.''

They were more likely to express a form of spirituality that focused on asking God to take action or protect them, rather than acting themselves.

Jasmine: (When she got HIV): ''And I said that I needed God to be really in my life, like shield me from everything and really keep me away from people.''

Participants were more likely to describe life events as occurring in a downward spiral in which bad things kept happening with accompanying feelings of hopelessness.

Candice: (mirror story): ''She was sexually abused as a child, and that had went on for most of her life, and then all of her men were domestic abusers and pimps, and they used her and abused… And it looks like she got one titty. So maybe she's lost a breast. And that's traumatic. You lose a breast, and you don't feel like a woman anymore. And um, life's just got her down. She's looking rough.''

Themes that did not differentiate groups

As displayed in Table 4, women in both groups did not differ in some of the most frequent subthemes (occurring in at least 60% of the sample). For example, there were no differences in the frequency with which they talked about HIV, a history of substance abuse, betrayal by others, being motivated to change because of positive relationships with children and grandchildren, compassion toward others, or spirituality. Noteworthy infrequent subthemes ($N < 10$ women total) that did not differ for the two groups were mentioning forgiveness of those who had hurt them in the past ($n = 9$), an inner sense of loneliness conveyed in the projective stories ($n = 8$), the

Table 4. Most Frequent Themes That Did Not Differentiate Groups

	HIV well-managed, N	*Not well-managed,* N	*Total,* N
Holds others partly responsible for life circumstances	8	10	18
Relates to others through words/dialogue	9	8	17
Talks about her relationship with her mother	9	8	17
Talks about her relationship with her children	10	7	17
Betrayal	8	8	16
Describes seeing herself through others' eyes	6	9	15
HIV mentioned	8	7	15
Hopeful that life can get better	9	6	15
Others described in their own personhood	7	7	14
Motivated to change for the better by kids or grandkids	8	6	14
Shows persistence in reaching goals	8	5	13
Spirituality as way to cope	7	6	13
At times lonely, no one to turn to	6	7	13
Pessimism; low self-esteem; hopeless; depressed	5	8	13
Children described positively	6	6	12
Values making children's lives better	6	6	12
Acknowledges substance abuse has interfered with change	7	5	12
Moral compass; talks about right from wrong, fairness	7	5	12
Blames self for failure/life circumstances	6	6	12
Expresses compassion for others	6	6	12

positive value of education ($n=6$), childhood sexual abuse ($n=5$), and the impact of gender/race ($n=4$), poverty or lack of resources ($n=7$), and incarceration ($n=2$) on their lives.

Interconnections among themes

Examining the trajectories of the ten HIV well-managed women's narratives indicated that for seven of them, the growth of self-awareness and mutuality was synergistic, each augmenting and strengthening the other. Both mutuality and self-awareness promoted agency/self-efficacy, enabling women to take active steps to access resources and promote health. Once active steps toward health were taken, relationships were able to become even more mutual.

Self-awareness and mutuality were described as blossoming from relationships in which women felt validated and supported by at least one other person who might be a family member, friend, community member, or professional. Self-awareness and mutuality were also described as developing after becoming a peer advocate; obtaining employment; and/or participating in social or educational programs, including group homes, shelters, treatment programs for substance abuse, physical or mental health problems, and individual counseling. Through these validating relationships, women learned to value and care for themselves and others.

Affecting and being affected by others within a caring relationship often constituted the earliest stages of self-efficacy, giving women a new opportunity to learn how to take active steps to promote positive health and well-being. In particular, taking active steps to overcome addiction was emphasized as a transformative life change that promoted better health and relationships by four of the five women with an injecting substance abuse history in the HIV well-managed group.

Self-awareness also emerged as a form of wisdom borne not only out of mutuality but also out of life experiences, in which women learned of their HIV diagnosis or recognized that they had hit rock bottom, such as when they were homeless or had had a near-death experience. As Deborah states: ''(Getting) HIV—this is what really woke me up off drugs, woke me up to face the fact that my mama's in my heart.''

There was also some evidence that, as consistent with theories about secure attachment, having a positive relationship with their mothers as well as close family of origin relationships may have provided a foundation that enabled women to have more mutual relationships with others later in life. Mothers and their centrality to family networks may play a particularly important role in African American families.[50]

Of the three women in the HIV well-managed group whose narratives did not show the above pattern, two expressed mutuality themes but showed only minimal self-awareness and self-efficacy, suggesting the primacy of mutuality in promoting their health. The third woman's narratives showed all three themes of mutuality, self-awareness, and self-efficacy, but centered on the transformative role of self-awareness, attained through education when she was placed in a group home in a more resource-rich neighborhood than the one she had grown up in. Self-awareness was emphasized as key to subsequent life changes she made, including becoming drug free, advancing her education as an adult, gaining employment, and eventually rebuilding her relationship with her mother, who had failed to protect her from abuse.

Discussion

The two groups of women in our sample, HIV well-managed and HIV not well-managed, are from similar environments with chillingly similar histories of sexual and physical abuse, depressive symptoms, substance abuse, betrayal, limited resources, lack of educational opportunities, and the social stigma of having HIV. With the exception of one white participant, they were racial minority women who additionally experienced the intersection of racism, discrimination, and sexism. Our qualitative analysis of their autobiographical narratives and projective stories indicates that what enabled one group to do better was the experience of mutuality, especially validation by others, which was intertwined with the development of self-awareness, including finding strength and meaning in having undergone trauma and constructing and maintaining a continuity of positive self-identity that involves connecting past and present experiences. In turn, both mutuality and self-awareness fostered self-efficacy and active steps toward self-care.

Our results set transformative life changes and healing squarely within a relational matrix involving growth-fostering relationships, in which each individual in the relationship is changed by the other.[51] Why might mutuality emerge as a critical factor for ART adherence and better immune functioning? Neuroscientific findings indicate that mutuality occurs at a neurobiological level[52,53]; relationships shape neural pathways, and the give and take of mutuality is required for physical and mental health.

Active and shared participatory relationships promote growth and prosocial behavior, while the absence of mutuality contributes to psychological problems, violent conflict, and human suffering.[51,54] For example, nonmutual relationships, including prioritizing care for others over self-care, as well as silencing the self for fear of relational loss and conflict, have been found to be related to heightened depression and lower quality of life in many international samples of women, including US women with HIV.[32,54]

Attachment theorists' findings that attachment and relational patterns can be repaired or relearned throughout the life span, leading to better mental health outcomes,[53] are reflected in our finding that the HIV well-managed women in our sample more often described relationships that became more positive over time, including repairing relationships with their mothers, in comparison to the women in the HIV not well-managed group.

Our finding that self-awareness is associated with mutuality in relationships as well as with better HIV outcomes is consistent with relational therapies,[55] which stress that the growth of self-awareness occurs within the context of relationships and is health promoting. While there are few empirical studies exploring self-awareness in relation to health, Johansson et al.[56] demonstrated that the development of insight mediated better mental health outcomes for individuals with a variety of depressive, anxiety, and personality disorders; those with the greatest insight benefited the most from treatment.

The association between self-awareness and better HIV health outcomes additionally aligns with research exploring mindfulness, consisting of present moment nonjudgmental awareness, to improve health in individuals with HIV. Practiced over time, mindfulness has been found to decrease depression[57] and to attenuate declines in $CD4^+$ count in individuals with HIV.[58] In a study exploring the mechanisms

driving mindfulness interventions, it was the awareness component that, rather than nonjudgment or other factors, significantly related to greater reported meaning in life.[59]

One noteworthy aspect of self-awareness was that among the HIV not well-managed group, happiness was more often equated with success at fulfilling dominant cultural narratives concerning women's stereotypic roles, such as being married to a more dominant partner or to losing weight and becoming more physically attractive. The HIV well-managed group's lack of adherence to these socially valued narratives of how life ''ought'' to unfold for women is a form of self-awareness and confirms theoretical tenets of narrative therapy[60] that resisting dominant cultural narratives in favor of adopting alternative narratives and values that stem from the reality of one's own unique life experiences may be key to health.

Agency and self-efficacy, our third identified theme, focus on accessing and utilizing resources and active coping skills to effect change, as well as believing that change is possible. This is exemplified by Tanya's statement that ''if you really put your mind to something you can get it done.''

Self-efficacy has been found to buffer the negative effects of core belief disruption following adversity[61] and to mediate relationships between literacy and medication adherence[23] and between a phone intervention and smoking cessation for HIV+ individuals.[62] It also predicts adjustment to illness and treatment,[63] longevity,[64] and positive mental health outcomes.[65] In a recent study in which patients with HIV were interviewed about their reasons for leaving care (associated with higher viral load), the three most frequent reasons included the perception that they felt well and therefore did not need treatment, loss of interest in treatment, and not being ready to deal with an HIV diagnosis/avoidance,[66] all of which suggest limited self-efficacy and self-awareness about adaptive healthcare behaviors.

Agency and self-efficacy, including engaging in new activities subsequent to adversity, have been identified as key components of empowerment models in which women overcome adverse life circumstances.[67] Empowerment has been defined by Cattaneo et al.[68] as a process in which ''a person who lacks power sets a personally meaningful goal oriented toward increasing power, takes action, and makes progress toward that goal, drawing on his or her evolving self-efficacy, knowledge, skills, and community resources and supports, and observes and reflects on the impact of his or her actions.''

Although empowerment models share many of the same themes that were reflected in the narratives of the HIV well-managed women, including the importance of self-awareness, supportive relationships, community resources, and self-efficacy, our analysis highlights the relational matrix in which change and healing occur. For the majority of women in our sample, mutuality and self-awareness are precursors for beginning the empowerment process and set the stage for women to develop a sense of self-efficacy, allowing them to set a personally meaningful goal to increase power, such as becoming drug free or going back to school.

Having and gaining access to important resources, such as housing or substance abuse programs, is also identified as a critical part of empowerment, but both groups of participants in the current study talked about acquiring or participating in community resources at similar rates, such as substance abuse and HIV treatment, housing, mental health services, and education. These results were corroborated in structured interviews that had been conducted during the initial WIHS visit, with no significant differences between groups reported in participation in drug and alcohol treatment programs (70% of the sample) or mental health counseling (38% of the sample).

The autobiographical narratives suggest that women in the HIV well-managed group described making better use of the substance abuse programs, seemingly because they brought a sense of self-efficacy to their participation or may have experienced more support and mutuality in the programs. This may have been due to a higher quality of individual programs,[67] but may also have been due to the women's own relational history and capacities. Thus, although access to resources is indisputedly necessary to address social and economic inequities based on gender, race, and class, the quality of resources may be differentially appropriate and adequate for people based on their past relationships and other aspects of their identity, including sexual orientation, trauma history, and race; individuals can use resources in ways that either enhance or limit their chances of doing well.

One of the ultimate goals of self-efficacy and empowerment is to effect change on a macrolevel, including social institutions and policies and to prevent the future occurrence of traumas and inequities, such as abuse and discrimination.[68] Although women in our sample learned to advocate for themselves, the majority of their narratives did not reflect a vision for effecting macrolevel social changes to decrease gender, racial, or health inequities.

Research has indicated that an awareness of social oppression (critical consciousness) relates to lower HIV viremia[7] and fewer psychological symptoms,[69] and that a strong ethnic identity can lead to internalized feelings of hope and personal strength.[70] Similarly, the narrative of the ''strong black woman'' includes caretaking and self-efficacy and may be protective for health. However, the issue is complex because the narrative of the ''strong black woman'' may also prevent help seeking and expression of vulnerability as adaptive coping strategies.[71] The lack of the centrality of ethnic identity and racial critical consciousness to our participants' identity as reflected in their narratives may represent a vulnerability that can potentially be addressed in treatment programs.

Although we tried at all times to see the circumstances described in the narratives from participants' own perspectives, a limitation of our study may be that our implicit biases affected the interpretive process. The narratives may also represent women's perceptions rather than historically factual incidents, although research demonstrates that perceptions significantly affect biological processes. For example, patients' expectations about the effects of a placebo medication alter dopaminergic brain activity in ways similar to actual medications.[72]

Furthermore, the themes we identified in narratives may be affected by women's abilities to express their perceptions in a structured, clear narrative, which may in turn be impacted by their experience of serious trauma, history of substance abuse, and education. The fact that we matched groups on demographics, word count, and frequencies of substance, physical, and sexual abuse minimizes the possibility that these factors may have confounded our results.

It is possible that contrary to our conclusion that there are synergistic relationships among mutuality, self-awareness, self-efficacy, and health, there may instead be a linear relationship

among them such that having worse health and more physical symptoms might negatively impact self-awareness, the ability to engage in mutual relationships, and/or to take active steps toward maintaining health through medication adherence. However, this possibility is rendered unlikely by the fact that each of the three themes we identified showed positive trajectories over time in the HIV well-managed group, with positive growth in these processes described as driving positive health trajectories. Our small sample size also limits generalizability and allows for only hypothesis and theoretical generation, not confirmation.

It is also worth noting that only 10 of the original 100 HIV+ women who completed the narrative task reported being <95% adherent to ART. These nonadherence rates are considerably lower than national data for women with HIV[13] and are perhaps due to the positive impact of being part of a 20-year longitudinal research study, which in itself provides recognition, validation, and mutuality to participants. In fact, the Chicago WIHS site has a retention rate among the HIV+ cohort consistently over 80% throughout a 20-year period. Women sometimes expressed pride, gratitude, and a sense of meaning that they were contributing to the greater good because of their research participation.

Despite the limitations of the study, our findings indicate a new direction for intervention programs for women with HIV who face a unique set of intersecting life stressors based on gender/race and who have had to overcome traumas that are chronic, such as poverty, racial discrimination, substance abuse, and HIV stigma. Through a validating relationship with at least one other person or participation in a social network characterized by mutual empathy and support, women's self-efficacy, agency, self-awareness, and ultimately health will have a chance to flourish. The capacity for and attainment of mutuality and self-awareness can be facilitated through many routes: a healing friendship; relational psychotherapies; being in a caretaking or lay counseling position; obtaining resources such as education; participating in peer support groups; and systematically practicing mindfulness, especially loving kindness meditations (exercises that enhance unconditional, positive emotional states of kindness and compassion toward self and others).[73]

A few HIV treatment or prevention programs for women such as SISTA[74] and WILLOW[75] include a social support component. However, given that social support is a multidimensional construct that can include many forms of instrumental and emotional support, the extent to which these programs emphasize the mutuality aspects of social support is not clear. Our findings suggest that the feature of social support that may be most critical for health is a mutually validating relationship that continues over time, in which women feel valued, understood, and ''seen'' by others, sometimes enabling them to be accepting of formerly hidden and stigmatized aspects of the self. In turn, they learn to value, understand, and ''see'' others and begin to develop self-awareness and self-efficacy.

Our findings thus provide a new roadmap for the critical features of intervention that predict a trajectory of change, beginning with mutually validating and caring relationships in which each member of the relationship is changed by the other. For women with HIV who are substance abusers, self-efficacy targeted on ending substance abuse also should be highlighted. A qualitative study of women with HIV in which participants were interviewed about life circumstances and motivations indicated that those who were not seeking treatment for their HIV were more likely to be using drugs and engaging in risky sexual behaviors than those who were seeking treatment,[76] highlighting the importance of drug use as a barrier to treatment and healing.

Although the development and maintenance of mutual relationships and self-efficacy targeted on ending substance abuse would take time and effort, these goals could be incorporated into existing treatment models in ways that might require only subtle modifications in treatment emphasis and perspective. For example, given that HIV is now a chronic illness, its time course allows for the development of collaborative and mutual relationships with physicians and other medical staff as well as with peers and family members. Personal contact between patients and their HIV health team, including being treated with respect, has been found to improve retention rates,[77,78] and being known ''as a person'' by providers is related to a higher likelihood of undetectable viral load and HAART adherence.[79]

Medical staff could be trained to emphasize patient strengths and resistance to dominant cultural narratives, especially around gender roles and race. Mutual collaborations and decision-making in healthcare could be emphasized, as well as identifying opportunities for patients to be supported by and to care for others, including participation in treatment programs, volunteer, lay counseling, and caretaking employment positions. Both providing and receiving peer support have demonstrated health benefits for many types of populations, including reducing readmission rates among psychiatric populations[80]; and improving self-efficacy, HIV knowledge, condom use, self-esteem, and coping strategies among adolescents and young adults.[81–83]

A qualitative study of peer counselors' perspectives indicated that the relationships they developed with the HIV+ women they counseled were rewarding and beneficial even when maintained by phone contact, suggesting that sustaining these relationships over time would be feasible. One of them articulately identified the importance of mutuality, as similar to our participants, saying that ''… I'm open to helping other people. Because they help me. When I help other people, they [help me].''[84]

The development of self-efficacy seems key to overcoming the learned helplessness and freezing responses that accompany the powerlessness inherent in trauma.[85] Empowering techniques to promote ''unfreezing'' have been embraced by trauma therapists and could be used with women living with HIV, involving tasks as simple as learning to perform and initiate physical movements in a safe space, and as complex as learning interpersonal skills to promote self-advocacy.[85] Our data indicate that all of these techniques will be more effective when learned in the context of a validating and caring relationship. The development of mutually growth-promoting relationships is key in promoting self-awareness and self-efficacy, and together, all three constructs positively impact the health of women with HIV.

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