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“I created something new with something that had died”: Photo-narratives of positive transformation among women with HIV

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Abstract

A dearth of research describes the strengths of women living with HIV (WLH), yet understanding these strengths can promote women's well-being and healthy behavior. This analysis explores positive life transformations among WLH through photo-stories. WLH ($N=30$) from three U.S. cities participated in a pilot photovoice project to tell their story of HIV. The project included three group meetings, an individual interview, and a public exhibit. Using qualitative strategies of theme and narrative analysis we identified positive transformations in women's photo-stories. Participants were African American (83%) and low income (83%). Women described four major positive transitions in their lives including transformations related to healthfulness, spirituality, self-acceptance, and confidence. Despite challenges, WLH experience positive transformation and growth experiences. Understanding these transformative changes can shed light on women's motivation to make healthy life changes and thus frame strengths-based interventions for WLH. Photovoice itself is a potential strategy to promote WLH's strengths and health.

Keywords

HIV positive women; racial ethnic minorities; photovoice; transformations

INTRODUCTION

With great difficulty, “Alysha” recently learned that she had HIV. Her family “refused to look at her” and she admits she felt suicidal and depressed. Her health is not her only challenge. She grieves the loss of a stillbirth baby and her 8-year old daughter in a tragic house fire. She says her neighborhood is dangerous, violent, and hopeless. When given the chance to discuss and depict her experiences, however, Alysha also defines herself as strong, and identifies ways that she now thrives despite her trials. For instance, she is learning to “accept her HIV diagnosis,” and is committed to becoming healthier, including processing her children's deaths. She is also spearheading community efforts to make her neighborhood

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safer, by leading projects to clean up and rebuild dangerous parts of her environment. Alysha's story is painful and powerful – and although infrequently told, it is not necessarily uncommon. Many women living with HIV (WLH) struggle, but also thrive. This analysis explores WLH's positive transformations and the implications of these transformations for supporting women's health, behavior, and well-being.

Women are one of the fastest growing populations with HIV in the United States [1]. Much has been written about their challenges. Like all people with HIV, women contend daily with a stigmatized, serious, and lifelong illness. Many lack consistent HIV care, and subsequently, access to life saving medications [2]. A notable number of WLH live in poverty and experience limited access to educational and employment opportunities [1], homelessness [3], care-taking responsibilities [4], relationship violence [5], trauma [6], and HIV discrimination [7]. In 2010 the rate of new infections among Black women was 20 times higher than White women, which means that racial discrimination may add to WLH's distress [1]. Research has found significant associations between Black women's experiences of racism and sexism and poor psychosocial functioning [8, 9].

As a result of these vulnerabilities and stressors, The National HIV/AIDS Strategy cites women, and particularly racial/ethnic minority women with HIV, as a high risk population in need of priority attention from both researchers and public health service providers [10]. Understanding how to enhance the well-being of WLH is paramount to improving their health and providing them with skills to protect others and curb the spread of the epidemic [10].

Risks, needs and obstacles are only part of WLH's story, however. Although significant, harmful, and necessary to address, WLH are much more than a collection of challenges. Numerous testimonials [11-14] and a much smaller body of academic research highlights WLH's strengths and accomplishments despite their adversities [15-17]. This research is important because it seeks to understand how women come to thrive and identify positive aspects of their life, which can help clarify WLH's motivation and potential for healthy life changes and preventive behaviors [18], aid in the development of health and prevention programs and services for women that build on their resources [17], allow service providers to acknowledge and respect the power and abilities of their clients [16], and similarly, change broader harmful stereotypes of WLH as dangerous, sick, or weak [17, 19].

While research on women's strengths is minimal relevant to their challenges, research and theoretical frameworks that account for women's positive life transformations are virtually nonexistent. Positive transformations may include women's strengths but also account for additional aspects of women's experiences, such as how women develop strengths or overcome challenges over the course of their HIV. This is particularly relevant as treatment options advance and more women are living longer with HIV. As a result WLH may experience significant changes in their ability to manage their HIV throughout different points in their lives, making it especially important to understand and harness their positive progress.

Much of the research that does exist on WLH's ability to flourish and change their lives is part of a growing body of work on the concept of adversarial, post-traumatic, or stress-related growth (SRG). SRG refers generally to positive changes or transformative responses following a traumatic event [18]. Like resilience, SRG is a positive and strengths-based concept, but SRG focuses distinctly on thriving, not just surviving, a difficult experience [18]. Despite great adversity, diverse groups of people who experience sexual assault, heart attacks, accidents, and natural disasters, report positive life changes or even *benefits* from traumatic challenges [18]. Among a small number of studies with women with HIV, SRG has manifested as a commitment to sobriety or safe sex; greater religiously; stronger relationships; newfound purpose; and an interest in AIDS activism [15, 16, 19]. Health benefits have been reported by WLH who experience SRG, which has been found to be associated with healthy CD4 and viral load counts, [20] as well as lower levels of depression [15]. Therefore, transformative experiences are potentially both powerful and healthy – and thus worthy of further attention and exploration. Although SRG is a helpful place to start, SRG relates women's transformations to trauma only and thus may not sufficiently account for all of women's transformative experiences.

Given the importance of understanding and addressing the well-being of WLH, limited research on WLH's strengths relative to women's challenges, the lack of an existing understanding of women's transformations, and the potential value of identifying positive changes for WLH's health, we explored positive transformations among 30 WLH in three U.S. cities. Expanding upon the SRG paradigm and seeking to add a better understanding of women's positive transformations, we describe the experiences of WLH from their perspective, without framing their experience with HIV as a trauma. We used visual strategies – photovoice and photo-stories (used interchangeably throughout the manuscript), to invite women to share their transformative stories of HIV through pictures, group discussions, and individual reflection sessions. The difficulties and the opportunities associated with HIV can be hard for WLH to identify, express, and share. The telling process requires literacy and communication skills, opportunities for insight, and adequate safety and emotional support. Based on evidence that art encourages safe creativity and insight [21] and the successful use of photovoice to empower participants in public health research [22], we used photo-stories and qualitative strategies of narrative and theme analysis to understand women's positive transformations and their implications.

METHODS

Participants

We recruited 32 WLH for a photovoice project designed to encourage women to share their story of HIV; two participants were lost to follow-up for illness and unknown reasons. The final sample included 30 women, a sufficient sample size to achieve data saturation [23], because photo-based projects include rich details in both text and images [22]. The majority of the participants were poor. Over half (n=18) of the women reported earning less than \$10,000 a year, five women reported earning between \$10,001-20,000 a year, two women reported earning \$20,001-30,000 a year, and five women chose not to report their annual income. Most of the participants identified their race/ethnicity as Black (n=25), three

identified as White, and two as “Other.” On average, the participants were living with HIV for 11 years (6 months to 17 years).

WLH were recruited from AIDS service organizations and clinics in three U.S. cities in the Midwest and Northeast using project flyers and discussions with service providers and potential participants. Sites one and two in cities one and two were chosen because of their existing relationships with the PI's university and their size. Both were large HIV clinics that provided ample recruiting opportunities. After meeting the PI and learning about the project, site three in city three, a community based organization, expressed interest in becoming a recruitment site. All sites served both men and women living with HIV. Sites one and three offered women's support groups and site two offered periodic support and educational retreats for women. A little over half of the participants discussed accessing these supportive services at their respective sites during project discussions. Remaining participants were divided; some reported partial participation in these activities and some participants indicated that the photo-stories project was the first time they were discussing any aspect of their HIV with others. In all sites eligibility included being female, ages 18-65, able to speak and understand English, having HIV/AIDS, and agreeing to take and share photographs. Consent was obtained from all participants prior to their participation in any project activities, which were approved by the primary author's university Institutional Review Board.

Project Procedures and Data Sources

Project procedures were based on photovoice methods – well established public health participatory research methods of using photos to encourage participants to identify and share experiences [24]. The participatory nature of photovoice means that the process is simultaneously research and practice, valuable to both researchers and participants [25]. For example, researchers collect rich participant-driven data from the method and participants benefit as they become empowered to tell and share their stories with others [25].

Photovoice is a very flexible method that has been implemented in various ways depending on individual project goals and research questions [22]. The photovoice project described in this analysis included the following components. To standardize project procedures, we highly structured the traditionally flexible process to include specific elements: three group photo-sharing and discussion sessions, an individual interview with each participant, and a public photo exhibit. We chose these specific elements based on formative research including previous intervention experience with WLH [26, 27] in which women discussed their needs and wants for future interventions. We invited women to tell their story of living with HIV through pictures and discussions or photo-stories, versus the traditional photovoice protocol of asking women to answer a specific research question via the process. Our overall project research aims were to better understand themes that telling one's story through photo-stories generates and how the photovoice process itself affected participants. After reviewing our data we identified more specific themes, such as the one driving this analysis – women's positive transformations.

The primary author co-facilitated project sessions with an assistant. The facilitators delivered the project to women in five separate groups, which ranged from four to eight

participants. Each group of participants attended three, weekly, 2-hour meetings. During the first session, the facilitator explained the purpose of the project and the participants brainstormed different potential ideas for photographs and discussed the ethics of picture taking [28]. Each woman received a camera to keep and learned basic camera functions.

During the second and third meetings, the participants reconvened to review and discuss their photographs. The facilitators led these discussions, using a laptop computer to download digital photos and display them via a projector. Each participant presented two-four photos of her choice to the group and discussed what each photo meant to her. We facilitated these discussions using a semi-structured guide that included the following questions to organize women's stories of HIV: "What does this photo capture about your life or story with HIV?" "What does the picture or issue mean to you?" "What challenges or strengths does the image convey?" After each participant presented and discussed her photos, the group discussed their reactions to the images. Most of the women (83%) attended all of the sessions. In each city, during the final meeting, the group planned a public showing of the photos. Each woman signed a release to present some of her photos at a public HIV community event. The exhibit was optional to protect women's confidentiality, but 70% of the women chose to participate.

Following the exhibit, the primary author conducted one- to two-hour individual-level interviews with each participant to explore her experience in the project and give the women a chance to reflect on their pictures individually. Examples of questions from the interview guide included: "What did you learn about yourself in the process?", "How did you decide what to photograph?", "What story do your pictures tell about your life with HIV?" We offered the follow-up interviews to women in two of the three study sites ($n=20$) and all 20 of the women participated in follow-up interviews. Interviews occurred in only two of the sites because at the project's start, the team assumed that the group sessions would capture adequate information about women's experiences. However, during group sessions at the first site, we discovered that the women wanted more one-on-one opportunities to fully express themselves, which would generate richer data to answer the research questions. In addition to receiving the camera, all of the women were compensated monetarily for their time and received \$15, \$20, and \$25, respectively, for attending each of the three group discussions and \$50 for completing the follow-up interview. We digitally recorded each group and individual intervention session to capture data for analysis.

Data Analysis

Project data were rich and included approximately 300 photographs, 15 group transcripts, and 20 individual interview transcripts. We transcribed all of the group and individual interviews verbatim, and edited them for clarity only. We entered the transcripts into Atlas.ti [29] a qualitative software analysis package to facilitate analysis. To analyze the data we employed a mix of qualitative analysis strategies including theme [23] and narrative [30] analysis – a common strategy used in public health research with vulnerable and complex populations whose data transcripts reveal rich concepts that need to be understood in the context of their overall narratives [31].

First, we analyzed the data for key themes using Charmaz' guidelines for theme analysis strategies [23]. Along with a research assistant, the primary author reviewed the transcripts and photos multiple times to become familiar with the data and key themes. After identifying positive transformations as a key theme in the data overall, we created a codebook describing the most salient transformation themes, and analyzed the data via coding and analytical memos [23]. Coding matched text to themes and progressed in two stages, open or more general coding – which included coding for ten general codes (e.g., HIV-related transformations, family-related transformations), which was followed by selective or more specific coding – which included coding for the final themes listed in this analysis [23]. We wrote analytical notes throughout all phases of coding to highlight key questions about relationships in the data and to refine codes. After coding the data, we generated coding reports that collated the evidence for each theme.

Examples of transformation often occurred within participants' stories. To ensure that we understood the themes with the context of these larger narratives, we also constructed a narrative table for each participant [30]. Each table summarized each participants' overall story conveyed in both the group and individual sessions in a linear fashion (e.g., Was diagnosed in 2005, husband left her as a result of diagnosis, found new housing for self and children, etc.) and included a list of pictures that elaborated on specific aspects of the overall story. Then we drafted and revised the results section using the theme coding reports and the narrative table to ensure proper context of the thematic examples.

Trustworthiness

Our study demonstrates several criteria of trustworthiness: credibility, transferability, and triangulation [32]. Credibility constitutes believable interpretations. Our prolonged engagement with the data involved multiple reads of the transcripts and approximately three months of intensive coding and revisions of codes to ensure that the findings reflected participants' experiences. In data debriefing sessions, both coders discussed coding differences until we reached a sufficient level of agreement and reliability regarding discrepancies. Transferability refers to the extent to which researchers have provided sufficient description to help readers assess whether a study's findings can be transferred beyond the sample [30]. Accordingly, readers may assess the extent to which our findings are transferable to other populations with HIV from the extracts of rich narratives, quotes, and pictures from participants that augment our analyses in the results section. Triangulation occurs when two or three measurement points converge to strengthen internal validity [33]. In this study, triangulation was achieved by multiple sources of data (i.e., multiple data from the same individual), multiple methods (individual interviews, photographs, group interviews), and multiple investigators collecting and analyzing data.

RESULTS

All 30 of the participants discussed major challenges and positive transformative changes in their lives with HIV/AIDS that had significant implications for their well-being. Challenges were significant but varied and included stigma, isolation, mental health, personal and community violence, trauma, death of family members, and physical illness. Below we

describe four major transformations described by the participants despite their challenges in detail – related to health, spirituality, acceptance, and confidence – with quotes and pictures. To protect participants' confidentiality, pseudonyms replace women's real names and photographs chosen for publication are those that represent participant experiences but protect identity (e.g., Self-portraits were excluded).

Transitions to Health and Wellness: “I Can Live with HIV and Not die.”

One of the primary transformations that women described with images and discussions was the transition to feeling and acting healthier. Despite being at different points in their lives with HIV (1 to 22 years), it was common for participants to capture positive progression regarding their health. These stories included broad transitions to feeling healthy or strong overall – and also specific transformations to safer sex, recovery from drug use, adherence to HIV medications, or better mental health. For instance, Adele, who was diagnosed with HIV several years ago, shared two pictures of her church being renovated. She described the pictures – the first of the church in ruins with boards on the windows (Figure 1), and the second of the church in the process of being rebuilt – as metaphors for her own general physical transformation. She explained, “This [old church] reminds me of me. My body got weak and needed re-sewing...The new church is the new me.” She further explained that when she was first diagnosed with HIV the doctors gave her “6 months to live.” She weighed less than 40 pounds and had to be “carried around like a baby.” Eventually she “got up and tried to walk, and said she is now “running.” Images of her illness were hard to forget, but Adele was focusing currently on the ways she was healthy and capable instead of concentrating solely on her illness.

Several participants like Carlotta, Debra, Carla, and Roshona discussed their transition to substance abuse recovery specifically, often describing HIV as “saving their lives” from drug abuse. For example Carlotta said that when she found out she had HIV 11 years ago she was “already killing herself.” She elaborated, “I was 38 years old and I was slowly killing myself doing crack cocaine. When they [doctors] told me I was HIV positive I thought ‘I’m already dead so what’s the difference?’” She went to explain however, that her daughter eventually “woke her up,” and helped her to “have an epiphany” about taking care of herself:

I decided that after all of the years trying to die, I've got a potential death sentence, but do I really want to die? I thought “No.” HIV saved my life...It clicked that if I wanted to live I had to do something different. I packed up and I moved. I left the drugs alone and haven't taken drugs since. I'm nine years clean... I learned that I can live with HIV.

She shared a picture of a long road to share the ongoing and important journey to recovery in her life, titling the photo “The Road to Recovery Never Ends.”

For other women – like Darlene, Marabel, Yasmine, and Maressa – their health transition focused on becoming adherent to life-saving HIV medicines. Darlene, 57 years old and living with HIV for 17 years, admitted that she struggled to take medicine until her friend died, which was her “turning point.” She showed the group two self-portraits of herself with

her plants. In the first picture the plants were wilted and brown. In the second photo the plants were vibrant and healthy. She compared the plants' health to her own:

I wouldn't take medicine for seven years... I wouldn't come to the doctors. I was just giving up. I said, "The meds ain't going to do it." But, one day, my [friend] got sick. It woke me up...It was like [feeding] my plants a miracle drug. When I took that medicine, everything – my color, my pigment, my skin – came back...I thank God that I took the pills because, if I didn't, I'd probably be wilted like the plants, my life going down. But, I came back. I just said, "I'm going to grow...Bring myself back to life."

For other women their most important health transformation was to improved mental health. Carlotta, Sheila, and Camille, among others, described suicidal thoughts when they were first diagnosed with HIV, as well as depression and anxiety. These feelings did not remain or dominate women's lives, however. For example, Sheila said she attempted suicide twice when she was diagnosed with HIV 19 years ago. She displayed pictures of her support systems – her family, her pets, and her medicines, saying:

[Women with HIV] are learning how to live with this disease for a long time. When I first got it, I thought it was a death sentence. I tried to commit suicide. Now, I'm to the point to where I want to live. I've been undetectable for six years. I came a long way.

Participants shared health transformations that involved various aspects of their health behavior and their lives and took place over shorter (several years) and longer (nearly 20 years) spans. Despite the differences in the examples, all of the women described enjoying the opportunity to identify and focus on healthier aspects of their lives which potentially may have helped them realize and further their commitment to health.

Commitment to Spirituality: "My Spirituality Helped Me and Transformed me Around"

Many women remarked that they became stronger in their faith or spirituality as part of their illness experience. Spirituality served as both a source of support and coping and thus supported women's mental health. It was common for women themselves to use the word transformation as part of their conversation about the role of spirituality in their lives. For example, Raquel reported that she was living with HIV for 15 years. She said she has made many "transformations" – including a commitment to having healthier relationships and taking better care of herself with HIV. She shared a picture of a cross in her church because she said that a stronger bond with her church and God has made her who she is today.

It took some trouble to get me to where I'm at. I got to the point where I wasn't paying bills. I'd rather live on the streets. I was ready to sign my kids over. I even took an obituary picture...But God is really important in my life now. I haven't made a complete transformation, but I'm on my way. I'm not where I used to be... I look at my life and what I've been through and where I'm at now. I know without [God] or somebody praying for me, I'd be a whole other person you probably wouldn't even want to know.

Spirituality was a coping mechanism that became stronger for women as they struggled with HIV and other life challenges. Tierra, age 36 and living with HIV for 10 years, described many difficulties in her life including abandonment by her partner and her family, physical abuse, and homelessness. She said she learned to “let it go to God” and felt comfort by putting things – like retribution for her partner who infected her and “over 20 women” in God's hands. Her faith also helped her to think positively. She shared a picture of her daily spiritual readings and said:

I read My Daily Bread every morning. I read health, I read wealth, I read wisdom, and I read spiritual healing. I read what I want to manifest in my life and how I want it to unfold. I get up, I look in the mirror, and I love myself. My spirituality helped me and transformed me around. I'm going to take a negative and turn it into a positive. That's one of my spiritual things, to take and release the fear ...That's why I decided to take a picture of that book [spiritual readings].

Sharnelle, who was living with HIV for six years, also described how she came to depend on her spirituality to help her release negativity with a picture of a burned down restaurant (Figure 2):

Sometimes we feel [like] we are burnt down. But in the end, this will be rebuilt into something. I'm at a place in my life where I want to be resurrected – as you can tell I'm very spiritual. I'm in a place where I want to release a lot of stuff, a lot of anger, a lot of hurt, a lot of pain - my daughter's father, the stupid guys that I've even talked to, the hurt behind those relationships, growing up in a single-parent household. I want to let that go, so I can move forward and become a better-looking [restaurant]. So this I will call “Reconstruction.”

The challenges that women faced were formidable – many times spanning beyond HIV to other painful experiences, like abandonment and abuse. Participants reported becoming stronger in their faith, spirituality, and/or religion – and that these commitments further helped “transform” women positively – as they supported women's mental strength and well-being – aspects that could be essential for women to make and sustain healthy behaviors.

Embracing Self-Acceptance” “HIV Has Freed Me to be Me”

Women commonly described transitioning to accept various aspects of HIV and their lives with HIV. For example, collectively the participants described accepting their diagnosis, believing that they could live with or survive HIV, creating a life and an identity beyond HIV, and understanding how to challenge or manage HIV stigma – others and their own. Moving past denial was a major aspect of this transformation. For instance, Marabel, who had HIV for 17 years, said she initially had an “internal stigma” and could not accept HIV. Because of this she said she “kept [having HIV] inside of me for so many years and then finally, I [decided], I'm going to talk out about it, and when I talked out about it, I felt liberated, I was free.” Sharing a self-portrait, she said she became “comfortable with [HIV] in my own skin.” She said she learned to “accept HIV for what it is” and now describes herself as a different person:

I've chosen not to be ashamed in my life...I'm free to be whoever I want to be. I tell people, "I'm grateful for [HIV]. I truly am." It's like living a whole new life...HIV really made me know who I was overall...I believe that HIV has freed me to be.

Toni also struggled with HIV stigma. Living with HIV for eight years, she described how she wanted to tell more friends and family members about her HIV status, but "wasn't there yet." To explain this visually she shared a photograph of wires, tangled and attempting to connect with each other. She said she was taking baby steps though – and also shared several pictures, including this flower growing out of a rock (Figure 3), to explain that with her art work and her life with HIV, she "created something new with something that had died," and that she was looking forward to "growth" and how "life will find a way" despite HIV and HIV stigma.

For other women, however, self-portraits honored their transition to be more open about HIV or to recognize that they were comfortable sharing their life with HIV with others. For instance Darlene said that through the pictures she showed that she "is strong enough to let everybody know what's going on with me in my life and that I have HIV. I'm not in the closet about it." She said when she showed others her pictures, "I was pulling people to look – 'Look at me. Look at me.'" Yasmine shared a picture of her in the newspaper and said "That picture means the struggle's over and I don't have a problem putting my name to nothing. I came a long way." Sweet also noted her transformation with the phrase, "I came a long way." She said, "I used to hide about my virus. Now I am what I am...I love who I am." She wanted her story of change to inspire others, and said "Life does not end when you get this, you can overcome."

At the same time, other women's transformations, like Maureen, Tammy, Roshona and Tina – who were all living with HIV for more than 14 years – focused on moving beyond HIV and for them, this was progress. Maureen explained that she wanted to continue to take pictures to capture new beginnings in her life – like her school. She said, "I'm not HIV anymore. It's not 'my everything.' It is part of me and it's becoming kind of more in the background of my life." For Roshona, her transformation was becoming just "like everybody else."

I don't think about my HIV when I'm walking down the street or when I'm talking to somebody, "Do they know I got it, or they scared to shake my hand?" I'm just a person like everyone else in the world, trying to survive - who's going to survive. HIV - it don't have me. I got it, but it's working with me.

HIV prompted all of the participants to consider their lives with HIV in new ways. Although acceptance of HIV was different for everyone – some women moved or made steps to move out of HIV-related denial and secrecy, other women learned strategies to confront stigma, and still others expressed a desire to move beyond HIV – reaching their version of acceptance was an important transformation in women's lives, particularly given the barriers that denial, secrecy, and stigma can pose to WLH and their mental, physical, and social health.

Becoming More Confident: “I am Stronger Now and I Don't Give Up”

Through their pictures many women shared that they believed that they were strong, often saying it was the most important thing that they learned about themselves through living with HIV. For instance, reflecting on her pictures of how she became healthier over the course of living with HIV, Adele, who described herself as more recently diagnosed with HIV, said that she learned “I am stronger now and I don't give up, I don't give up no matter what.” Carla, 54, and living with HIV for 12 years, shared a self-portrait of herself as “superwoman.” (Figure 4) She believed the picture revealed her “personal strength” that was important in her journey to become more comfortable with HIV. Tara shared a trilogy of pictures to document her transformation to wanting to live. She shared a photo of a bullet hole (Figure 5). She explained that it marked a key transition in her life with HIV:

This is piece of paper. If you notice the year on it: 2001. That was found in my yard on 9/11. It came from the [location], and that's exactly how it came and I still have it. That was a transition in my life. I finally realized that there were all these innocent people who died in such a tragic way and, here I was, for 11, 12 years, living in this doom and gloom where I could have been living life. It was a really big turning point in my life and I realized that I needed to go on, and I needed to live.

A few women captured their transition to confidence with pictures of awards or accomplishments. For example, Tierra photographed her “little shoe collection” in which she bought or was given a little shoe each time she accomplished something. Among her accomplishments she noted that she moved from rejection, isolation, and homelessness to sending her children to college, keeping them out of foster care, and making sure they had a safe and clean place to live. Adele shared an award she received for attending HIV related classes. She indicated that “I got dementia. The part of my mind that they doctor said was messed up and would never come back to life – that I would never know anything or remember anything – it's all coming back.” This caused her relatives to be very controlling and limit her time out of the house. She said she was now ready to “start speaking up and letting people know how I feel, and take control of my own life.” Similarly, Bobbi shared a photo she labeled her “wall of fame.” She said that as a former drug user, others expected little from her, but that over time she recovered and took part in educational and HIV related classes and groups. Her wall of fame marked these accomplishments and included numerous pictures of certificates pinned to the wall.

It was common for women to experience periods of vulnerability, poor self-esteem, and diminished confidence in their lives with HIV. For many women this period did not prevail however and they were able to regain confidence or identify ways that they were strong amidst struggles, including positive life changes, personal strength, or awards. Such confidence could be continually applied as they face challenges and life changes with HIV and struggle to maintain their health.

DISCUSSION

In this study we sought to uncover and understand women's text and visual examples of their positive life transformations with HIV. Overall, women described four major transitions including transformations related to healthfulness, stronger spirituality, self-acceptance, and greater confidence. All of these experiences exemplified WLH's potential for change, growth, and recovery. Participants' positive transformations do not downplay the seriousness or the number of challenges that women with HIV face. Our findings do, however, highlight that difficult experiences alone do not define WLH or their character and that women with HIV are diverse and complex. Many WLH persist and persevere and create positive life changes in spite of these obstacles. Our findings also suggest that positive changes can be encouraged and developed among women – and that women benefit from expressing these transformations. Further, the motivation behind these changes and the rewards that result from them may shed light on how to motivate women with HIV to enact and sustain healthy behavior changes and how to incorporate these motivations into public health programs for WLH.

Many of the transformations described by our participants have been acknowledged, although only generally, in the stress-related growth (SRG) literature. For example, a small amount of existing research describes the benefits that WLH attribute to HIV related to recovery from substance abuse (health), sense of self (confidence) and spirituality [16, 17, 19]. Our findings, combined with previous research, reiterate that the experiences that women identify as transformative are very important in their lives. Such changes may also be part of WLH's overall transformation to learning to reveal what they want and need as they come to terms with their diagnosis, relationships, and future plans for their care and the care of their families – which can lead to overall improvements in WLH's health and well-being [34].

Our findings extend current research as well. Existing SRG research is trauma-based, and thus has framed HIV as traumatic and elicited benefits that women perceive to have received from various traumatic aspects of their HIV diagnosis. We did not automatically frame HIV as a trauma or ask women to specifically comment on how they benefitted from traumatic aspects of HIV. We posed a more open question to WLH – “Tell us your story of living with HIV” – and as a result, learned about a greater depth and breadth of transformative experiences. We found that there are many positive changes and transformations that women may experience but not necessarily identify as a “benefit” of HIV and that women describe important transformations even if they do not view HIV as traumatic.

For example, the range of health improvements women described was varied and included not only recovery from substance abuse but also included transformations to enacting healthier behaviors in regards to medication adherence, safer sex, and improved mental health. Women also discussed a different vision of and for their physical bodies – like Adele, who made the analogy between her body and the church undergoing renovations. Thus, an additional positive change that women experienced throughout their HIV diagnosis was the ability to experience a new and healthy body despite illness. The ability to recognize that one can change their health behaviors, and the celebration of those new health

behaviors, is extremely relevant among a group of women who are often primarily considered or discussed in relation to their unhealthy or problematic health behaviors, like substance abuse or sex work [1].

Movements towards self-acceptance included many variations of acceptance of living with HIV and along with that, managing the stigma of the virus. As Marabel said, HIV freed her, and many other women similarly described embracing their lives with HIV. But for the others the important transformation was a decision to work on opening up to others, or to move *beyond* HIV to feel and become more like, in Roshona's words, "a person like everybody else." HIV stigma persists among people with HIV and women with HIV report particularly high levels of felt stigma [35]. Given that stigma has been associated with poor health and behavioral health outcomes among people with HIV, such as decreased medication adherence, [36] substance abuse [35] and poor mental health [35], it is very important for women to describe the ways that they can transform the meaning of acceptance and stigma in their lives.

Women were certainly hurt by their challenges, but these difficulties also gave women an opportunity to show their confidence and strengths in a way that was meaningful for their lives and interests. Acknowledging these transformations allowed women to see a different version of themselves, or the complexities of their identities. Through the transformations they became more than a person in grief or as a drug user, which may have helped them leave these states or at least begin to create and tell new stories of their lives.

To our knowledge, no theoretical framework exists to explain the connection between transformative experiences and health changes. Although more research is needed to further develop these components our findings suggest several tentative and potential theoretical explanations of the relationship between transformations and health worthy of further exploration. First, realizing or reflecting on transitions to healthy behavior may help women garner skills that they can use again and again over their life course to reinstate healthy behaviors that may have changed due to life changes and stressors or implement new healthy behavior changes. Simply identifying the transformations may remind women that they are capable of change as well as how they can make healthy changes. Second, focusing on spirituality may give women hope or coping skills that they can use when they face significant barriers to being healthy. Third, recognizing greater self-acceptance may help women manage stigma, which may in turn limit stigma's negative effect on their health behaviors. They may be more inclined to seek help for physical and mental health challenges shamelessly if they realize different ways to think about social stigma. Last, identifying a new sense of confidence may help women realize that they can make changes and that different, healthier behaviors are possible. It may help women reinvent themselves or envision themselves differently or more healthily, which can catalyze health changes.

Our findings also shed light on women's process of identifying transformations through photo-stories. Women reported that they enjoyed talking about their life stories and changing paths with images and group and individual discussions. The use of visual methods in particular gave women a way to access creativity, insight, and concrete examples, which not only produced a rich understanding of their transformations, but may

have even benefitted the women themselves. Thus, many women recognized new ideas or aspects of themselves that they may not have considered if they were communicating verbally only [37]. Visual methods have been lauded historically for their ability to generate creative participant-based research ideas and serve as visual interventions to empower participants [25], but have been underused in HIV research and interventions [21, 22].

DeMarco insightfully points out that researchers and practitioners are often quick to judge women with HIV as unable to express themselves, or to have limited literacy skills which compromise certain forms of expression, such as writing [38]. These important concerns notwithstanding, the structural lack of insight generating opportunities that many WLH have as a result of poverty and discrimination and consequently, missed educational opportunities, may result in poor literacy [39, 40]. Thus, visual methods may be especially important for facilitating expression and insight in accessible and concrete ways among WLH. For example, Adele and Sharnelle both creatively used photographs of buildings as analogies for their chances to be “rebuilt” and “resurrected.” Others like Toni used natural analogies like a flower growing from a rock to express the challenge of “living” when circumstances are barren. Self-portraits helped women to concretely show and accept themselves with HIV because they could visually see changes in their physical and mental health over time. Sometimes self-portraits publically marked a transition to more openness with HIV or gave women a chance to celebrate or problem-solve that openness. Likewise, concrete pictures of awards or accomplishments like Tierra's shoe collection helped women to remember and focus on these specific accomplishments. Although very few studies use visual methods with WLH [22], our findings indicate this is a powerful way to both understand women's transformations and help them to identify and even benefit from discussing them.

Limitations

Our study was subject to several limitations. The aims of this study were to understand the transformation experiences of one group of women – the majority of whom identified as urban, low-income, Black, WLH. Likewise, we did not learn from women who were not able or willing to share their status with other women with HIV, or who may have feared participating in the project. Thus, the findings cannot be generalized to all WLH. This study was exploratory and we collected a limited amount of information about the women and their experiences outside of the project. For example, we did not collect data from every woman about stress reactions, social support, or access and use of mental health services. Certainly, women's experiences with and reactions to particular stressors, such as stigma or violence, and specific supports, such as social support or access to physical and mental services, may affect their ability to benefit from photo-stories. All of our participants reported significant life challenges, but they described varied reactions to stress and levels of support to help them manage these challenges during sessions. For instance some women described fully developed support systems and for others, the project as the first time they disclosed and discussed their HIV or their life challenges. Our analysis was not designed or able to determine the relationship between stressors and supports in the women's environments and the photo-story process. Thus it is unclear whether photo-stories

supplemented existing supports in women's lives and captured women's transformation processes, or if photo-stories initiated women's transformation processes.

The original intent of the project was to better understand themes that photo-stories generated and how the process affected WLH. Thus, group and individual question guides did not ask about transformation specifically. Discussing transformation specifically may have generated additional or different information about the topic. Lastly, we conducted individual interviews with women at two project sites, versus all sites. Conducting interviews with all participants may have generated more details about women's individual experiences.

Implications for Research and Practice

Despite these limitations, our project has important implications for practice and further research with WLH. Regarding practice, our findings indicate that overall, it is important for public health interventions and services for WLH to focus on women's strengths and potential for positive change. Our findings about WLH's strengths can also serve as a reminder to practitioners developing and implementing programs that WLH are not a monolithic group and experience successes as well as challenges [17] – and that women feel prideful about these successes. Often times in popular media and public health images of women with HIV focus on women's challenges. Likewise, public health interventions and HIV interventions in particular typically help people at risk for and living with HIV address what they may be doing wrong – like having unsafe sex or failing to take medications, versus helping them to build what they do right. [41, 42] This is important and understandable because these behavior changes are paramount to the health of women and their partners, and because the challenges women face to living healthily – like poverty, discrimination, violence, and stigma– are so daunting. Women's strengths provide another focus however, and another way to motivate women to be healthy and to consider or make positive changes for their future. All of the women in our study could recognize positive changes and transformations and all of them were rewarded by this process.

The concept of resilience is gaining momentum as an important framework for public health overall [43] and HIV research in particular [41]. Resilience has been associated with reduced sexual risk behaviors [44] and medication adherence [45, 46] – a key component in the health of people with HIV. Several HIV prevention and care scholars have lauded the importance of cultivating resilience among people at risk for and living with HIV [41, 42], particularly for racial/ethnic minority communities [47], but the development of resilience based interventions remains limited [42]. Our findings attest to Herrick's claims that resilience is an “untapped resource” in HIV interventions [41] and that women living with HIV can benefit from public health programs based on these frameworks.

HIV stigma remains a challenge in the lives of women with HIV and some women in our study reported continuing to struggle to be open about their lives with HIV. Thus, stigma and its consequences still need to be addressed by HIV programming and services. But, for many women in our study, strength and progress included moving beyond HIV to acknowledge that they were “not HIV anymore” and that HIV did not need to consume their life even though it was an important health concern. As more and more women access HIV

medicines and live with HIV, interventions and services need to account for how women manage HIV over their lifespan including their changing perspectives on HIV in their lives and their resultant changing service needs. Public health interventions may benefit from focusing more holistically on various parts of women's lives, including their relationships, families, and work and education life, versus simply focusing on the HIV itself. Newly developed and evaluated interventions like the “SMART/EST project” [48] or “Sistah Power” [49] promisingly embrace this trend. Broadening the scope of topics addressed with women in services may help women stay motivated to be healthy for longer, by giving them more things to live and be healthy for.

Furthermore, our research showed that photo-stories are a promising strategy to promote women's strengths and the process may be both a research recording method and an intervention strategy in and of itself. Women responded positively to recounting their stories and strengths and learned from interacting with each other in this way. Communicating with stories and pictures may also be a culturally appropriate strategy for WLH. The vast majority of WLH in the U. S. are racial/ethnic minorities [1]. African Americans have a shared history of physical and sexual trauma and at the same time, are armed with protective strategies to survive racial oppression [50]. Black women in particular might benefit from strengths-based group modalities that incorporate group interactions, story-telling and visual expression [51]. They have historically used group storytelling as an effective means of communication [52], and one study found that Black South African WLH who participated in art therapy showed significantly lower depression levels compared to the control group [53]. Wyatt suggests HIV interventions with African Americans should specifically address cultural context and protective strategies, including interconnectedness, which accordingly, photo-stories promote [50].

Regarding research, then, additional implementations and evaluations of the photo-story process are necessary, with more diverse and larger groups of women. Participants ultimately recognized transitions and correspondent changes in their quality of life, mental health and risk behaviors. This means that understanding women's transformations may be a potentially helpful way to understand WLH's motivation to make healthy behavior changes. Finding approaches to help WLH maintain strategies to engage in healthy behaviors with HIV, such as safe sex, medication adherence, and engagement in HIV care – are priorities of the National HIV Strategy [10]. Meeting these goals can prolong WLH's lives, and also help curb the spread of HIV to others. Behavior change, particularly change that needs to last over the life course, is difficult, complex, and hard to understand, however.

It is necessary, though, to better understand the association between the photo-story process, how it helps women express transformation and change, and how the expression and/or transformation process may be related to health outcomes including both prevention and treatment outcomes [54]. The tentative explanations that we generated about how positive health, spirituality, self-acceptance and confidence transformations are related to women's health need to be tested more extensively to determine the association between photo-stories, transformation, and health behavior. Likewise, the interaction between contextual factors like existing social support and access to mental health services and photo-stories need to be examined more closely.

Similarly, it is important to understand if and how the images – which can be shown and distributed publically, affect other WLH and community members who see the pictures and stories. For instance, Sweet remarked how this aspect of the project was very important to her, that others saw and were inspired by her change. Photovoice projects typically do include the showing of materials to others, but the evaluation of this aspect of the process has been limited [22]. The photographs could affect change in other people with HIV, or serve as ways to reduce stigma and educate the general community by revealing new or deeper aspects of the lives of people with HIV, and encourage empathy for people with HIV.

Maya Angelou noted that “there is no greater agony than bearing an untold story within you.” Our findings support the value in providing women with a space to tell their story, and indicated that these stories are ripe with pain, but also opportunities for transformative change. WLH struggle but also find potential and life amid “something that has died.” HIV is associated with challenge but also opportunities. Understanding and harnessing women's transformations can help us better understand WLH, how they make healthy changes, and what they need to live healthily throughout their lives with HIV.

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Figure 1. Renovation. The participant makes an analogy between an old church under construction and her own health to depict her physical transformation.



Figure 2. Reconstruction. The participant uses a photo of a burned down restaurant to explain how her spirituality allows her to release negativity and rebuild her life and perspective.



Figure 3.
Life will find a way. The participant shows how she is looking forward to life despite HIV stigma with a picture of a flower growing from a rock.



Figure 4. Superwoman. The participant takes a self-portrait of her shadow to show her increasing strength.



Figure 5. I need to live. The participant describes her transformation to wanting to live with a picture of a paper with a bullet hole from 911 that changed the way she thought about having HIV.