

Lesley University

DigitalCommons@Lesley

Expressive Therapies Capstone Theses

Graduate School of Arts and Social Sciences
(GSASS)

Spring 5-21-2022

Examining Resilience in Women Living with HIV/AIDS Through a Photo Narrative Lens

Mary Bell
mbell9@lesley.edu

Follow this and additional works at: https://digitalcommons.lesley.edu/expressive_theses



Part of the [Social and Behavioral Sciences Commons](#)

Recommended Citation

Bell, Mary, "Examining Resilience in Women Living with HIV/AIDS Through a Photo Narrative Lens" (2022). *Expressive Therapies Capstone Theses*. 539.
https://digitalcommons.lesley.edu/expressive_theses/539

This Thesis is brought to you for free and open access by the Graduate School of Arts and Social Sciences (GSASS) at DigitalCommons@Lesley. It has been accepted for inclusion in Expressive Therapies Capstone Theses by an authorized administrator of DigitalCommons@Lesley. For more information, please contact digitalcommons@lesley.edu, cvrattos@lesley.edu.

Examining Resilience in Women Living with HIV/AIDS
Through a Photo Narrative Lens

Capstone Thesis

Lesley University

April 23, 2022

Mary Bell

Art Therapy

Sarah Hamil, Ph.D., LCSW, RPT-S, ATR-BC

Abstract

Women living with HIV/AIDS (WLH) and poverty face numerous challenges to survival. Typically, WLH in the United States have been exposed to more than just a deadly virus; they have often experienced or witnessed drug addiction, poverty, abuse, mental health disorders, homelessness, abandonment, involvement in the sex industry, racism, sexism, prejudice, social injustice, chronic hunger, generational trauma, and violence – community, domestic, cultural, police enforced, etc. The literature reviewed suggests that treating HIV/AIDS requires a holistic approach that pays close attention to the biopsychosocial needs of the individual. In addition to the physical and economic toll the disease takes on the individual, the shame and stigma associated with this disease can lead to isolation, depression, and a state of helplessness. The community project explored the use of photo narrative and art therapy approach in a therapeutic group setting. The project offered WLH a place to safely examine their lives without judgment or fear. The photograph became a tool to contain the difficult experiences, to distance the trauma from the individual, to communicate what may be difficult to express in words, and to highlight and share successes. Through the photo narrative project, each group member created a visual timeline of their life journey/journey with HIV, nurtured community trust and support, and produced a final product that can be used to promote self-esteem, to measure resilience, to educate others, and to reduce stigma surrounding HIV/AIDS. Several recurring themes such as spiritual faith, community support, self-love, and mindful appreciation of life emerged which supported the idea that cultivated resilience in the face of trauma allows WLH to not only survive but thrive.

Keywords: women, HIV, resilience, photo narrative, art therapy, trauma, poverty

This author identifies as a white, straight, middle-class woman from a southern state.

Examining Resilience in Women Living with HIV/AIDS Through a Photo Narrative Lens

Leaving behind nights of terror and fear

I rise

Into a daybreak that's wondrously clear

I rise

Bringing the gifts that my ancestors gave,

I am the dream and the hope of the slave.

I rise

I rise

I rise.

-Maya Angelou, "Still I Rise," And Still I Rise: A Book of Poems

Introduction

While no individual of any single community, gender, race, culture, religion, or economic status, is immune to HIV/AIDS, there are some communities that have been hit harder than others. For many, a diagnosis of HIV/AIDS is not the only challenge they face. It is not uncommon for individuals diagnosed with HIV/AIDS living in poverty to have comorbidities such as depression, anxiety, or PTSD. Many also have severe mental disorders such as bipolar, schizophrenia, or borderline personality disorder. Still others have experienced or witnessed physical or sexual abuse, domestic violence, sex industry involvement, community violence, alcohol and drug abuse, addiction, extreme poverty, homelessness, oppression, racism, exclusion, discrimination, and generational and/or historical trauma. Living with and treating HIV/AIDS requires consideration of the individual in a holistic manner and healing requires attending to the needs of the mind, body, and spirit. To attend to the psychological healing of the

individual, it is essential that the individual play an active role in the process. Part of the process requires mending past trauma, recognizing one's own worth, and choosing to move forward to create a life worth living. Teti et al. (2015) found that the women in their study reported four major transitions of growth associated with their experiences living with HIV "including transformations related to healthfulness, stronger spirituality, self-acceptance, and greater confidence" (p. 12). Receiving a diagnosis such as HIV/AIDS can "threaten people's sense of identity and taken-for-granted assumptions about the temporal framing of their lives" (Ezzy, 2000, p.605) and can bring about these transformations in spiritual beliefs and life priorities. Another part of this process of not only surviving, but thriving, can be accomplished through a narrative approach where the individual uses the arts and storytelling in addition to community support to move forward. Teti et al.'s findings suggest that "positive changes can be encouraged and developed among women – and that women benefit from expressing these transformations" (p.12).

In the article, "I created something new with something that had died: Photo-narratives of positive transformation among women with HIV" Teti, French, Bonney, and Lightfoot (2015) presented their findings in a pilot photo narrative project conducted in three different cities with women living with HIV (WLH). The researchers created a project to explore the strengths and common themes of resilience among women who seem to be not only surviving but thriving while living with HIV. According to the article, women are one of the fastest growing populations with HIV in the United States and "a notable number of WLH [women living with HIV] 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]" (Teti et al., 2015, p.2). Despite this, the researchers discovered that

many of the women in the study were able to tap into resources that helped them thrive even after their diagnoses. The project encouraged women to name these resources, to discuss their experiences with other WLH, and to tell their stories through photo narrative engagement. Finally, the participants shared their visual journeys with others in a photo exhibit. This article inspired many of my ideas for my capstone community project.

My capstone community photo narrative project offered a group of women living with HIV/AIDS an opportunity to take their self-affirmation journeys forward to support increased insight and positive relationships. The project design provided clients with the opportunity to explore, to process, and to share more of their past trauma, to develop a greater sense of pride in themselves, to increase their sense of self-worth, and to build an even greater sense of trust and support within the group. The weekly zoom sessions spent sharing photos and personal stories offered group members a safe space to be vulnerable, explore empathy, offer support, and build relationships with other women with similar experiences. The in-person art-making group sessions offered a place to create collaboratively in a supportive environment. During the creation of the accordion books displaying the life journey photo narratives, the women found creative ways to express themselves on a personal level as well as ways to share their stories with others. The artistic process also provided a way to cope with the stress and challenges of their lives. The use of photography and art in telling each woman's story served as a way for the women and the therapist to discover common themes relating to resilience and strength.

Several professional goals informed and enhanced the creation of the Capstone Thesis Project as well. I was able to gain experience with facilitating art therapy groups and encouraging community growth within the group and beyond. Other objectives of the Capstone Thesis Project included the development of connections in the local arts community and the

strengthening of community networks dedicated to working with the population of individuals diagnosed with HIV/AIDS living in poverty. This project worked on many levels helping the individual explore, process, and find inner strength, building bonds within the community, educating and bringing awareness to HIV/AIDS and poverty, emphasizing the need for financial support for this population, and helping to reduce stigma. Witnessing the resilience of each woman told in their own unique narrative served as inspiration and reflection for the therapist as well.

Literature Review

HIV/AIDS and Art Therapy

When AIDS first began to spread, receiving a diagnosis was a death sentence. Those who were diagnosed suffered greatly, withered away, and died right in front of friends, family, and medical providers who were powerless to offer much help or hope. Today, when health care professionals speak about the disease, they speak about living with HIV/AIDS. The emphasis on the word living cannot be overlooked. In a Stress-Related Growth (SRG) study by Siegel and Scrimshaw (2000) focusing on women living with HIV, “83% reported at least one positive change in their lives that they attributed to their illness experience” (Siegel, Scrimshaw, & Pretter, 2005, p.404). These included a variety of themes relating to living with HIV as opposed to accepting a death sentence due to an AIDS diagnosis. The themes reported included, “health-related behavioral changes, religious/spiritual growth, improvements in social relationship, positive self changes, changes in the meaning and value they placed on life, and positive goal-related changes” (Siegel et al., 2005, p. 404). In the past, medical health providers could only offer limited treatment of symptoms and at the end, hospice care. Mental health providers may have stepped in as well to help a client come to terms with their imminent death. Today,

HIV/AIDS can be treated medically, and patients can live long lives. However, there is no cure for HIV/AIDS and the side effects from medication as well as the stigma associated with this disease can cause many challenges to physical, mental, and social health. It can affect an individual's ability to work, to care for others, and to feel accepted by one's community (Baselga, 2020; Bien, 2005). The stigma associated with the disease still causes many challenges to those diagnosed as they try to go about living their daily lives. As Merz (2007) explained,

an HIV infection affects the entire person in his or her environment. Medical treatment addresses the spreading of the virus in the body and thereby the progression of the illness. Frequently the mental burden involved is neglected. Treatment of an HIV infection should therefore always be interdisciplinary. (p. 446)

Merz (2007) emphasized the benefits of treating mind, soul, and body from a holistic and expansive approach including the use of art therapy interventions. Merz explained, "art therapy is action and resource oriented, this means, patients become active and no longer feel hopelessly exposed to their future lives with a conscious or unconscious focus on HIV" but rather art therapy helps them "to discover inner resources and gather strength" and "to discover new sources of life energy and power" (p. 450).

Merz was by no means the only advocate for using art therapy to treat those living with HIV/AIDS. Tagarro and Catarino (2012) discussed the importance of using art therapy as an essential survival tool for socially excluded people living with HIV and AIDS. They explained, "a creative therapeutic approach develops creative potential that in turn allows for change and the creation of new perspectives" (p.186). Creative expression and telling one's story through a visual or other artistic means can "allow feelings and internal experiences to come in contact

with external reality and enable the responses to be flexible and suitable to the situations” (p.186). Not only can creative expression change the creator’s perspective, but it can change the viewer’s perspective as well. This can be a powerful tool in fighting the stigma associated with HIV/AIDS as well as combatting the isolation and loneliness of those living with the disease.

In their work with the Tree of Life (ToL) curriculum, Vitale, Khawaja and Ryde, discussed the benefits of combining art and narrative therapies to help refugee women living with HIV. In the article, “Exploring the Effectiveness of the Tree of Life in Promoting the Therapeutic Growth of Refugee Women Living with HIV,” Vitale, Kuwaja, and Ryde (2019) described using a qualitative case study methodology to explore the use of the Tree of Life (ToL) project with refugee women living with HIV. The authors presented a thorough introduction to the challenges that refugee women face not only in the countries they are forced to leave but during their journey and once they have arrived in their new countries. These refugee women already face many challenges due to persecution, discrimination, physical, emotional, and sexual abuse, separation from their families and supportive communities, language challenges, housing, health care, and nutrition needs. With the addition of the stigma and health concerns associated with an HIV/AIDS diagnosis, there is an increase in the likelihood of chronic trauma in these women’s future. The ToL process provides a safe space for the processing of this trauma. According to Vitale et al. (2019), the ToL project uses narrative principles such as “respect, externalisation, deconstruction, and storytelling to support individuals to reframe their past traumatic stories by re-writing more empowering and positive self-narratives (Denborough, 2014 as cited in Vitale et al., 2019, p.2). The narrative and artistic approaches encouraged collaboration, a sense of community, and a safe space to process the trauma experienced by these women as they plan for more secure futures.

Similarly, Teti et al. (2015) described the dynamic combination of narrative approach, photovoice, and group dynamics when working with women living with HIV/AIDS and poverty. According to the authors, participants enjoyed sharing their experiences with the group both verbally and visually. The participants also expressed that through the creative process of using visual images and metaphor, they discovered “new ideas or aspects of themselves that they may not have considered if they were communicating verbally only [37]” (Teti et al., 2015, p.14). The use of visual images whether produced through more traditional art making or photography created a safe container, a universal way to convey ideas and emotions, and served as a powerful means of communication. Combining this with the power of storytelling not only works with women living with HIV (WLH) but also is culturally relevant to the WLH with whom Teti et al. were primarily working, black women of lower socio-economic status. Teti et al. explained, “Communicating with stories and pictures may also be a culturally appropriate strategy for WHL. The vast majority of WHL in the U.S. are racial/ethnic minorities [1]” (Teti et al., 2015, p.16). Furthermore, Teti et al. (2016), explained:

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]. (p. 16)

In *My Grandmother’s Hands* (2017), Resmaa Menakem explained how this kind of generational trauma gets embedded in brown bodies and how it affects the way they experience the world and are seen by others. Being able to come to a space where these women can share their experiences through story-telling and visual expression such as art or photography can strength their sense of self-worth and make them feel less alone. Menakem (2017) explained, “Unhealed trauma acts

like a rock thrown into a pond; it causes ripples that move outward” (p. 39). He goes on to explain that over generations, as more bodies are affected by this trauma, whole communities can be affected, as can their ways of acting and reacting. This trauma can spread over generations and across whole communities and can even begin to look like culture. Menakem (2017)

explained that although it may look like culture, it is not. Instead, Menakem (2017) explained,

It’s a traumatic retention that has lost its context over time. Though without context, it has not lost its power. Traumatic retentions can have a profound effect on what we do, think, feel, believe, experience and find meaningful. What we call out as individual personality flaws, dysfunctional family dynamics, or twisted cultural norms are sometimes manifestations of historical trauma. (p. 39)

Women Living with HIV through a Photo Narrative Lens

According to Teti et al (2015), women are one of the fastest growing populations with HIV in the United States. In 2010 the rate of new infections among Black women was 20 times higher than White women, indicating that “racial discrimination may add to WLH’s [women living with HIV] distress [1]” (Teti et al., 2015, p.2). Furthermore, “research has found significant associations between Black women’s experiences of racism and sexism and poor psychosocial functioning [8,9]” (Teti et al., 2015, p.2). Many WLH also “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]” (Teti et al., 2015, p. 2). These are just some of the compelling facts that caught my attention when I read Teti et al.’s article “I created something new with something that had died”: Photo-narratives of positive transformation among women with HIV.” At the beginning of this project, researchers were already aware of the myriad of challenges faced by WLH. Researchers already

knew anecdotally that many WLH not only found the means to survive these challenges but to actually thrive in the face of such challenges. The aim of the research was to determine which features in the lives of these women support such resilience. Teti et al. (2015) were looking for themes or common features found in the narratives of these participants

to understand how women come to thrive and identify positive changes and preventive behaviors [18], aid in the development of health and prevention programs and services for women...allow service providers to acknowledge and respect the power and abilities of their clients [16] ...and change broader harmful stereotypes of WHL as dangerous, sick, or weak [17, 19]. (p. 2)

For the methodology, the researchers recruited the participating WLH from AIDS service organizations and clinics in three U.S. cities. Eligibility included being female, ages 18-65, able to speak and understand English, having HIV/AIDS, and agreeing to take and share photographs. Specific elements were included with each group to standardize project procedures: there were three group photo-sharing and discussion sessions, an individual interview with each participant, and a public photo exhibit. The prompt was the same across the groups as well, a simple invitation to the 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” (Teti et al., 2015, p.5). In the analysis, the researchers discovered recurrent themes both in the challenges faced by WHL such as “stigma, isolation, mental health, personal and community violence, trauma, death of family members, and physical illness” (Teti et al., 2015, p.6) but also themes of resilience and transformation. The four major transformations discovered related to “health, spirituality, acceptance, and confidence” (Teti et al., 2015, p.7).

From Stigma and Isolation to Personal Growth and Acceptance

In the chapter, “Art therapy with HIV-positive/AIDS patients,” Formaiano (2012) discussed the power of using art in therapeutic interventions. He described the theoretical framework chosen for his project, a brief history of the use of art therapy with HIV/AIDS patients worldwide, and the general characteristics of the project. The author emphasized the importance of evidence-based practice in art therapy interventions. Formaiano explained that he chose to use a mixed methodology of art-based and qualitative research to embrace a holistic view. He included questionnaires provided to clients at the end of each project, discourse analysis and client observation, and content analysis of the images individually and as a set over time. He also embraced the use of case studies “due to the fact that they are conducted within the same population and their members share the same pathology, which allows for cumulative evidence based on the efficacy of the art therapy interventions” (Gilroy, 2006, as cited by Formaiano, p. 200). The author described the focus of the study, “to measure both external and internal ‘stigma index’” (p. 201). This topic relates directly to the members of the women’s support group participating in my community engagement project. As evidenced by my interaction with these women, one of the biggest challenges facing those recently diagnosed with HIV/AIDS today continues to be reduced self-esteem and medication adherence. With all the advances in medical research, this diagnosis is no longer a death sentence. However, the stigma, due mostly to miseducation, can cause psychological and physiological harm to these clients. The stigma leads to poor self-esteem, high levels of self-blame and guilt which in turn lead to depression, anxiety, hopelessness, reckless behaviors, and a resistance to medication adherence or the adoption of healthier lifestyles. According to studies at the University of New South Wales (2020), women can counter the loss of self-esteem and control of their lives by “regaining

control of HIV narratives and asserting their right to have pleasurable, fulfilling, and safer sexual lives” (p.81).

Storytelling, Reframing, Creating New Life in the Individual and in the Community

The research project done by Teti et al. (2015) inspired this thesis topic. The goal in designing this project was to streamline two objectives – to gather information and data to help create future programs well-suited for supporting WLH and to provide art and narrative-based experientials and discussions that enable growth of participants in the process. The design of the project offered a multitude of opportunities for growth – growth of the art therapy program, the women’s support group, the individual participants, and the greater community. By including a public showing of the art, there was a possibility to educate the greater community, provoke a more empathetic community response to those living with HIV, and to encourage a newly diagnosed individual to seek help and to maintain a sense of hope. The opportunity to tell one’s story allows for individuals to own their lives – past, present, and future – and to create something beautiful from something painful and challenging. The group offered a chance to grow as an individual but also to grow one’s support network and to find one’s place in the larger community. Finally, this project offers this therapist in training to learn from the clients, to be a witness to their struggles and their strengths, and to be a collaborator in this re-building project.

Method

The inspiration for this community project came from an article outlining a research project completed by Teti et al. (2015) which focused on women living with HIV (WLH) telling their stories of resilience through a photo narrative approach. The population at my internship site contributed to the creation of this community project as well. The intention of this community project was to provide a WLH group a new way to explore, express, and share the

challenges they faced as WLH and to identify and celebrate the strengths they have developed in their transformative journeys to build resilience, self-acceptance, self-love, and a sense of community. Through the inclusion of art and photography, the clients were able to share more of their authentic selves and this vulnerability in turn created a safe and welcoming community of empathy and respect. With the inclusion of a final showcase to share the photo narrative projects with a wider audience came an opportunity to educate, advocate, and promote awareness about HIV/AIDS.

Community description and participants

The non-profit agency chosen is located in the mid-south offers biopsychosocial support to individuals and their families living with HIV/AIDS and poverty. Among the many services that tend holistically to the needs of these individuals, adult group therapy is provided for all who meet the requirements – 18 years or older, diagnosed with HIV/AIDS, resident of the local county, living at or below the poverty level, and certified by the Ryan White Program (a federally funded program that assures health care for individuals living with HIV/AIDS and poverty).

As an intern, I co-facilitate three groups a week including a Women's Support group which has been running for over 10 years. In my time with these women, I have observed many of the characteristics of resilience discussed in the Teti et al. (2015) article. After speaking with my co-facilitator and long-time staff member who created and has continued to cultivate this women's group, I was encouraged to plan a community project with this group. As the only person working at the site trained or educated in art therapy, part of my goal this year has been to incorporate more expressive arts into the site's community. Beginning in September, I joined the women's group and my co-facilitator encouraged me to incorporate art directives into the group

sessions. Back in late September, before the proposal for this project began, the staff member noted that at least one group participant had openly discussed past trauma with the group for the first time ever in response to an art directive included in a session. Paired with the testimonies of challenges, traumatic past events, and ongoing transformation of these strong women as well as the voiced will of these women to continue their growth, I created a project that would benefit both the group members and my own learning experience. By incorporating the creative process, I encouraged the women to find a new way to explore and to tell their own stories. In viewing their stories, as a researcher, I prepared to observe universal themes that explained the reasons for this amazing resilience in the face of hardship. I chose a photo narrative project because I wanted the women to find an artistic medium that would be accessible and non-intimidating where there was a high likelihood of final product success. I chose to use cell phone cameras because all group members had access to this technology already and during the pandemic, this would provide the easiest way to take pictures and share them with the facilitator and group during the sharing and discussing phase (via zoom) of the project. The intention was to provide a readily accessible means of processing, recording, and sharing of their experiences in a creative way with the possibility to reach wider audiences in the future even after the completion of the project.

Pre-Project Preparation – (Sixty-minute zoom session)

As the spring semester group sessions restarted, I led a guided meditation in group focusing on visualizing a place in nature of peace and calm. This set the stage for our return to weekly group sessions and grounded the group as we continued with a general check-in and catch-up time. I followed this sharing with a proposal of my project idea and an invitation to the group to participate. I explained the project, made sure that everyone had access to a phone with

a working camera, and offered a chance to reach out individually if they needed help with the technological aspects. I discussed the purpose of the project and the guidelines of confidentiality. I encouraged participants to ask questions, voice concerns, and/or offered to do that in a one-on-one way outside of group with either me or the staff member/ co-facilitator of the group. I assured the participants that these photos belonged to them and would only be shared within group discussions and in the showcase at the end of the project if they agreed and signed a consent form. I emphasized that these photos would not be included in my thesis paper or published anywhere else. I offered that the photos could be shown anonymously in the final show if they preferred. The group participation in the photo taking and the group attendance varied by week but there were always at least a core group that showed up and participated each week. There were overall ten women involved in the group, seven of whom submitted photographs. Each week, the participants were given an assignment to take photos connected to a certain theme and they were asked to text the photos to me by no later than Thursday evening so I could prepare a slideshow before the group zoom on Friday morning. Mid-week, I would send out an individual text reminder of the assignment to each member of the group. In preparation for the following week's group session, participants were asked to practice taking pictures with their phones and sending them. They were invited to be creative and take photos of anything that appealed to them, considering different perspectives and angles, people, places, and objects. They were asked to text those pictures to the group facilitators before the next group session.

Week One - (Sixty-minute zoom session)

For week one, I began with a warm-up activity in which each participant was asked to choose a color to represent their present state – emotional, physical, mental, etc. Each participant shared a color and explained the significance. Next, the participants were asked to define

resilience and to give an example of resilience either from their own lives or from something in nature. The women were all eager to share examples. Many individuals shared feelings of resonance with what their fellow group members offered. This conversation progressed to the sharing and discussion of the photos that four of the group members had submitted. At the end of the session, the assignment for the following week was explained – Take three to five photos that represent resilience and send them to the facilitators by no later than Thursday evening.

Week Two (Sixty-minute zoom session)

For week two, I began with a warm-up activity. Each group member was asked the following question: If you were an animal, what would you be and why? This gave everyone a chance to play, to think creatively, to use metaphors, and to share a little bit about themselves and their personal defining characteristics. After everyone, including the two facilitators shared, we moved on to sharing and discussing the photos of resilience submitted by the group members. This sharing time became a safe and sacred space where individuals could share part of their story and be honored and validated by the other women in the group. At the end of this discussion, the assignment for the following week was given – Take and send three to five photos showing your strengths and challenges focusing on your life with HIV or just your life journey in general. You may include past challenges and strengths as well as current ones.

Week Three (Sixty-minute zoom session)

For week three, I began the group with a warm-up activity – the group members were asked to give a weather report that represented how they were doing and feeling. This was timely because the previous week, we had an ice storm, and this week, we had sunny beautiful sixty-degree weather. The women enjoyed using the metaphor of weather to describe their moods. Next, we shared the photos of challenges and strengths. We viewed, listened, commented, and

honored the sharing of these photos and all they represented. Finally, I presented the topic for next week's assignment - Take and send three to five images that focus on community and support and represent safety and acceptance. Challenge for the week – try to choose at least a few images that do not include people or faces. Think metaphorically. Think of places and spaces in community and/or nature.

Week Four (Sixty-minute zoom session)

For week four, I began the group session with a warm-up activity designed to engage the group members, allow them to share how their week has been, and to practice acknowledging the good and the bad in our daily lives. Rose, thorn, bud is an activity where each group member reflects on their week and shares one good thing that happened (big or small), one bad thing that happened, and one thing they are looking forward to or are hopeful about. This was a new activity for the group, and they readily engaged in the process with enthusiasm. The facilitators participated as well. After the warm-up, the group shared and discussed the photos of the week. We closed by inviting each member to share a one-word response embodying something they would take from group this week. Finally, I presented the assignment for the following week. Choose your five favorite photos you have taken so far and that you would like to see printed out and included in the final showcase. Also, take a selfie/head shot that shows your personality. Send these to me no later than Thursday evening.

Week Five – (Sixty-minute zoom session)

For week five, my co-facilitator began the group session with a video of Maya Angelou reciting her poem, “Still I Rise.” The facilitator asked that everyone pay close attention and then be ready to give a response sharing how this poem and recitation resonated with them. Each group member shared their response giving examples from their own lives of ways they have

continued to rise. Next, we viewed and discussed the photos of the week. Finally, we shared an exciting announcement that beginning the following week, we would be meeting in person. My co-facilitator shared information on how to access transportation assistance – bus passes, gas cards, and/or arrangements for LYFT services. I explained that there were no new photo-taking directives, but I invited them to keep taking and sharing images. I also explained that we would be doing something creative with printed versions of our photos the following week.

Week 6 – (Sixty-minute in-person session)

This week, we started group with a warm-up activity. We went around the room and shared a word and a movement that expressed how we were feeling to be back in person for group. As each person shared, the others watched and then mirrored/repeated that word and movement. Then, I explained the creative activity of the day. I showed the group members the pre-assembled accordion books we would use to display their photo narratives. Next, I distributed the printed versions of the photos submitted by the group members. For anyone present who had not submitted photos but wanted to participate, they were encouraged to use their phones to take photos during the session or to look through magazines to choose ready-made images instead. Group members were told to look through their images and pick an order to display them to represent their journey. Group members were encouraged to collaborate with others and ask for help as needed. Group members were also invited to give titles to their individual photos or to the group of photos. As group members worked, the facilitators walked around and checked in with each member. I also provided art supplies so individuals could add color, drawings, words, or other creative details to their accordion books to accompany their photos.

Post-Project

For my thesis project, week six was the last group session documented in this thesis. However, the group members continued to work on these photo narrative accordion books for several more weeks during in-person group sessions. These books were displayed at the agency client's day out celebration. After this public sharing of the books and photos, I asked for informal feedback from the group members to discover the group members opinions regarding the project - what they liked and what they thought could be improved.

Information Gathering

My information gathering process included written notes jotted down after each session. Part of my intern duties include writing up formal notes for each group member after each session, so this seemed a natural extension of those observations. Additionally, I often doodled or jotted down key words or phrases during group sessions. During free time usually in the evenings or on the weekend post session, I created my own personal art responses to the experiences witnessed and engaged in during the group sessions.

Results

For the results section, I have shared my observations of the group sessions, including weekly summaries and specific notables that came up in each group. I have also included some of my own response art including my own photo narrative accordion book created in response to all I have learned as a witness to the photo narrative process which has unfolded according to group needs across the span of this project.

Observations

Week One

By Thursday evening I had not received a single photograph so I planned an in-session activity where the participants would find an item in their home that represented them to share

with the group. Then the individual would be encouraged to photograph the item and text it to me. However, in the final five minutes before the group began, several members texted or emailed images to my co-facilitator. While I led a creative warm-up activity, the co-facilitator created a slideshow of the submitted photos. For the warm-up, I asked the participants to choose a color that represented how they were feeling that morning. This was used as a conversation starter to get people talking, as a means of assessing mood and general emotional health and to encourage thinking in metaphors. Interestingly, several people chose the same color but gave very different explanations of what those colors represented. For example, one client chose the color black because she was feeling down but another client chose the color black because she felt elegant. I then asked the group to share their definitions of the word “resilience.” The members all joined in and talked about what resilience looked like for them. This discussion led into the sharing of photos some of which illustrated resilience. For example, one participant shared a photo of a palm tree and shared that like this palm tree, she was able to withstand intense winds and storms, bending but never breaking. She shared that she would entitle this photo “Resilience.” As we showed the photos, each group member or photographer explained their photos and what they represented about them and their life journey. As each person spoke, the others listened attentively and respectfully, silently honoring this person’s narrative. After each person finished speaking, the other participants responded with applause, praise, encouraging comments, observations, and ways that what was shared resonated with them. At the end of this sixty-minute zoom session, I thanked the women for their participation and gave them their assignment for the following week. I asked them to think about how they have experienced resilience and to take and send in three to five pictures that express this resilience.

Week Two

The theme of this week's group was "If I were..." and the goals were to identify metaphors for self through images and imagination. Participants also shared and discussed their photos based on the theme of resilience. We began the group with a check-in/ice breaker – "If you were an animal, what kind of animal would you be and why?" Most participants were very excited to share a response. One client shared that she would be a cat because cats have traits she associated with being strong and independent while also recognizing that cats know how to relax and enjoy each day. This client submitted a photo of her cat sleeping in the sun that week as representing one thing that makes her resilient - her independence. Another group member shared that she was feeling exotic and so she would be a gazelle which could move through the world with grace and beauty. Another individual shared that she would be a camel because she always has reserves in her hump to keep her going. The group members all noted that the same themes kept popping up in our discussions – resilience, strength, community, endurance, self-care, and a sense of joy and grace while moving through the world. As the group members shared and discussed their photos for the week, these themes continued. One group member showed a series of photos and described how the bottle of pills, the stack of books, the exercise equipment, the family, the friends, and the trip to the beach all represented her journey, both the ups and downs, towards reclaiming her life. She shared how proud and thankful she was for all the changes she has made in her life since she became sober. Another group member pointed out that the common theme in each picture was her smile. The whole group agreed and there was a shared sense of community and celebration that could be felt even through the zoom connection. At the end of this sixty-minute zoom session, I thanked the women for their participation and gave them their assignment for the following week. I asked them to take and send three to five photos showing their strengths and challenges focusing on life with HIV or just their life journey

in general. They were encouraged to include past challenges and strengths as well as current ones.

Week Three

As a warm-up activity, I asked the group members to give a weather report to describe their mood that day. Some chose sunny because they were feeling good with the beautiful weather. Others reported variations of cloudy or rainy because there were things in their lives that were stressful or worrisome. After the check-in, we shared the photos of the week and discussed and responded with observations and empathy. We acknowledged the challenges and celebrated the strengths. Some of the shared photos showed great vulnerability; for example, one woman shared a photo of herself with a black eye from a past domestic abuse relationship. She also shared pictures of her beautiful children who were a result of that relationship. She explained that these photos represented two different sides of that relationship – the pain and sadness of the abuse but also the blessing and joy associated with her children. The other group members all chimed in to support this group member and acknowledge their admiration for her courage, her vulnerability, and her strength. This session became a time to honor each woman as they shared their experiences. At the end of this sixty-minute zoom session, I thanked the women for their participation and gave them their assignment for the following week. I asked them to think about community and support and take pictures that represented safety and acceptance. I challenged them to include some photos of places and objects in addition to people.

Week Four

As a warm-up activity, the group members and facilitators engaged in an activity called rose-thorn-bud. Each person shared one good thing from the week, one bad thing from the week, and one thing they were looking forward to. Many of the individuals agreed that they were

looking forward to being able to meet in person for group again. This feeling of a longing for community came up a lot in our discussion of the photos because it was the theme of this group of pictures. One group member shared that she wanted to include pictures that showed her gratitude for this group of women who were supportive and accepting. Another group member shared that she was thankful to have a community where she could let her guard down and be around others who understood the experience of living with HIV. The photos shared included images of churches, buddha statues, crosses, the front door of our agency, family, friends, and sage for cleansing rituals. The women discussed where they find support and community and how little interactions with and kindnesses from others keep them going. At the end of this sixty-minute zoom session, I thanked the women for their participation and gave them their assignment for the following week. I asked them to choose their five favorite photos taken so far that they would like to see printed out and included in the final showcase. As a challenge, I asked them to take a selfie or a head shot that shows their personality.

Week Five

My co-facilitator started the group session with a video of Maya Angelou reciting her famous poem, "Still I Rise." After watching the video, she asked the group members what resonated in that video, in that poem for them. Each group member shared their personal responses. One client shared that this was one of her favorite poems and this was evident as she could be seen smiling and dancing on her zoom screen as the poem was recited. Another woman shared that this poem meant a lot to her as a black woman and explained that in her community women are expected to act as caretakers and to be tough and strong as well even when times are hard, and they are tired. Another woman shared that she could relate to this idea of having to keep rising even through hard times. When this same woman shared photos of herself with her

son at a special event, she admitted that she was amazed at how far she has come. The rest of the group congratulated her and celebrated her resilience and spirit. At the end of this session, we announced that the following week would be held in person, and everyone cheered. I told them we would be doing some creative arranging of our photos in printed form.

Week Six

For the final week, the session was held in person in the group counseling room. Clients gathered around a large conference table to work on assembling their accordion books and to discuss the process. Six group members showed up including several members who had not been able to take pictures over the course of the project. For those individuals, I provided an alternate opportunity so that everyone could participate. When the clients arrived, the table was prepared with the pre-assembled accordion books, a sample book with photos attached created by the therapist, the printed photos taken by the group members, magazines, inspirational quotes, scissors, glue, stickers, washi tape, pens, and markers. The group members were instructed to choose an accordion book and their photos and/or materials of their choice to assemble their individual books to share their stories. While the individuals worked, I watched, anticipated needs, helped provide materials, and facilitated conversation. About half-way through the session, I asked the group members to share what was coming up for them as they worked on their books. I asked clients to share how they felt about their journeys and what they had learned or how they noticed change in their lives. The discussion was rich, deep, and honest. The group members shared their challenges and their successes with the group. Members expressed that they were excited and proud to share their books with others and that they were happy to have the option to keep these books as a visible reminder that they could keep nearby when times were difficult. All the members expressed an interest in sharing their books with the group and in

giving permission to have the books displayed at an upcoming community event for the HIV support site. At the end of the session, each member showed and explained their book. Some members requested to take their books home so they could finish adding final touches but agreed to return them to be displayed at the community event.

Creative Reflections

Throughout the six weeks, I also took photographs and thought about how these photos could represent me and my journey. I chose to focus on nature and my place in it to represent a refuge that I found peaceful and sacred. Spending time in nature and in the art-making process has helped me as I have done my own personal work over the past three years – juggling a full-time job with a full-time graduate school schedule, surviving COVID, and navigating my own mental health journey in preparation to become an art therapist. Figures 1, 2, and 3 portray my own accordion book (Figures 1-3) filled with photos representing my journey as well as two pieces of art I created - one created during the early planning phase of this project (Figure 4) and the other as a reflection at the end of the project (Figure 5).



Figure 1 – Accordion Book in closed position



Figure 2 – Accordion book front panel



Figure 3 – Accordion book back panel

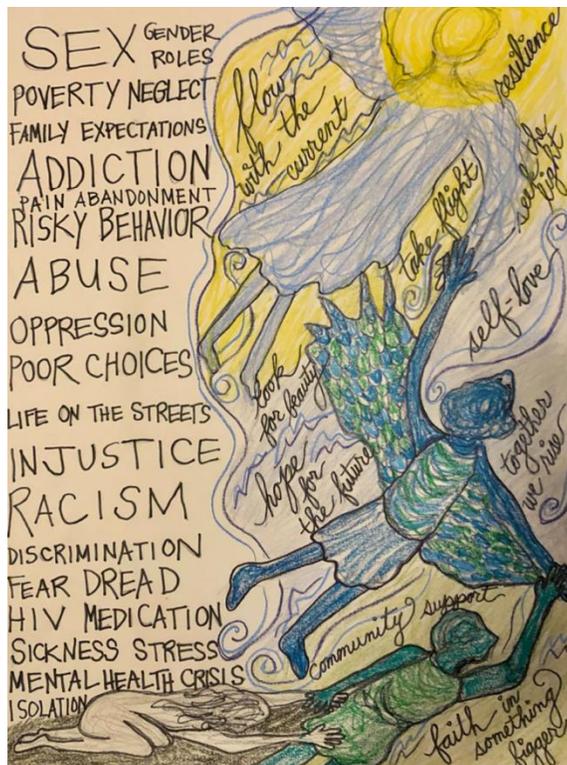


Figure 4 – Pre-Project Art Response – Challenges versus Strengths



Figure 5 – Post-Project Final Response Art – Giving and Receiving

Discussion

According to Teti et al. (2015), “Women are one of the fastest growing populations with HIV in the United States” (p. 2). The rise of infections among Black women is also notable as Teti et al. (2015) point out, “20 times higher than White women, which means that racial discrimination may add to WHL’s distress” (p. 2). Teti et al. (2015) suggested the ramifications of these statistics citing research that indicates, “significant associations between Black women’s experiences of racism and sexism and poor psychosocial functioning” (p. 2). Despite the many challenges mentioned in the research and observed in my clients, WLH (Women Living with HIV) have shown that they are capable of not only surviving but thriving with medical, social, and psychological therapeutic interventions. Social services which can provide housing, food, healthcare, education, and safe living environments as well as linkage to medical care which can provide Antiretroviral Therapy (ART) have been big factors in WLH’s ability to survive this disease. However, the thriving comes with processing the emotional, social, and psychological aspects that are associated with a diagnosis of HIV. Merz (2007) described art therapy as an “action and resource-oriented” (p.450) process that helps WLH to take control of their lives instead of living passively as victims. “Art therapy helps them to discover inner resources and gather strength to accept and endure the disease, but also to discover new sources of life and power” (Merz, 2007, p.450). Photo narrative therapy encourages these women to examine their lives through a different lens and to focus on telling their story through images. By externalizing their experiences, these women can view their struggles as separate from their core being and can objectively see their accomplishments as well. By creating this visual narrative with photography, these women can choose how they want others to see them – as strong, capable, and worthy of respect and love.

In my Capstone project, the women with whom I worked took the project directives seriously. They became involved, proud, and eager to share their experiences with the others in the group – participants and facilitators alike. Despite the challenges of zoom sessions, COVID restrictions, and fluctuating attendance, the group maintained a sense of continuity and momentum throughout the project. The group members were more than willing to share their challenges, their low times, their poor choices, and the traumatic events of their lives but they chose to include their strengths, their support systems, their inspirations, their hopes and dreams, and their joy in their final display of their photos. All the women expressed pride and excitement about their journey through the creation of their photo narrative books as well as that of their life journeys – their spiritual, physical, emotional, social healing – that have brought them to where they are now. Many of the women shared their hopes and dreams for the future by creating realistic but optimistic goals. Many women shared stories where they honored other women in their lives who had inspired and encouraged them. These women all expressed the desire to pass this on to other women in need of help as well. This focus on receiving and giving inspired my final art response (Figure 5). During the project, everyone, including the two facilitators, engaged in this spirit of giving and receiving which encouraged a collaborative safe environment.

For future researchers, I recommend more time for experimenting with photo taking, framing, editing, cropping, etc. I also recommend more time for the group to share and process the final product together before exhibiting to the larger community. However, given all the restrictions due to COVID, weather, transportation, and space and time limitations beyond our control, the project successfully achieved the goals set forth. The group members used art, photography, narrative therapy, and group dynamics to examine their lives, acknowledge their

challenges, highlight their strengths, build community rapport, honor each other's journeys, and produce a final product that could serve as hope, inspiration, education, and a means of reducing stigma. Additionally, the final product in accordion book photo narrative style caught the attention of other members of the agency's community. The executive director, the staff members, the interns, the social workers, the play therapists, the counselors, as well the clients served by the agency were all inspired and intrigued by these creative products. The director and staff members were amazed at what the art allowed these women to express, and the other clients wanted to know which groups they could attend in the future to create such projects. Finally, this project emphasized the capacity for expression, inspiration, collaboration, education, and community-building through the incorporation of expressive arts modalities within therapeutic group dynamics.

References

- Angelou, M. (1978). *And still I rise: A book of poems*. Random House.
- Baselga, S. V. (2020). Interactive documentaries and health: Combating HIV-related stigma and cultural trauma. *Catalan Journal of Communication & Cultural Studies* 12(2) 273-285. DOI: 19.1386/cjcs_00032_1.
- Bien, M.B. (2005). Art therapy as emotional spiritual medicine for native americans living with HIV/AIDS. *Journal of Psychoactive Drugs*, 37(3), 281-292.
- Center for Disease Control and Prevention. (2021, August 9). HIV in the United States and Dependent Areas. <https://www.cdc.gov/hiv/statistics/overview/ataglance.html>
- Ezzy, D. Illness narratives: Time, Hope and HIV. *Social Science & Medicine*, 50 (2000), 605-617.
- Findings from University of New South Wales Reveals New Findings on HIV/AIDS (Radical Pleasure: Feminist Digital Storytelling By, With, and for Women Living With Hiv). *AIDS Weekly*, 28 Dec. 2020, p. 81. Gale Academic OneFile, link.gale.com/apps/doc/A646691570/AONE?u=les_main&sid=ebsco&xid=74c1dfbd. Accessed 20 Oct. 2021.
- Formaiano, L. (2012). Art therapy with HIV-positive/AIDS patients. In C. A. Malchiodi (Ed.), *Art therapy and health care*. (pp. 196-211).
- Menakem, R. (2017). *My grandmother's hands: Racialized trauma and the pathway to mending our hearts and bodies*. Central Recovery Press.
- Merz, R. (2007). Art therapy and AIDS. *Music Therapy Today*, Vol. VIII (3) December. <http://musictherapyworld.net>

- Siegel, K., Schrimshaw, E. W., & Pretter, S. (2005). Stress-related growth among women living with HIV/AIDS: Examination of an explanatory model. *Journal of Behavioral Medicine*, 28 (5), 403-414. DOI: 10.1007/s10865-005-9015-6.
- Tagarro, M. & Catarino, S. (2012). In body and soul: Art therapy with socially excluded people living with HIV and AIDS. In C. A. Malchiodi (Ed.), *Art therapy and health care*. (pp. 184-195).
- Teti, M., French, B., Bonney, L., and Lightfoot, M. (2015). "I created something new with something that had died": Photo-narratives of positive transformation among women with HIV. [Manuscript submitted for publication].
- Vitale, A., Khawaja, N., Ryde, J. (2019). Exploring the effectiveness of the Tree of Life in promoting the therapeutic growth of refugee women living with HIV. *The Arts in Psychotherapy*, 66(2019), 101602, 1-10. DOI: 10.1016/j.aip.2019.101602.

THESIS APPROVAL FORM

Lesley University
Graduate School of Arts & Social Sciences
Expressive Therapies Division
Master of Arts in Clinical Mental Health Counseling: Art Therapy, MA

Student's Name: Mary L. Bell

Type of Project: Thesis

Title: Examining Resilience in Women Living with HIV/AIDS Through a Photo Narrative Lens

Date of Graduation: May 21, 2022

In the judgment of the following signatory, this thesis meets the academic standards that have been established for the above degree.

Thesis Advisor: Sarah Hamil _____ 04/24/2022