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Portraits of Well-Being: Photography as a Mental Health Support for Women With HIV

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Abstract

Many women living with HIV/AIDS (WL-HIV/AIDS) experience significant mental distress. Although creative arts strategies are well positioned to help support women by inspiring creativity and meaning-making, few arts programs have been implemented and evaluated with this population. We conducted a photography project with thirty WL-HIV/AIDS from three United States cities. Participants took pictures to capture their life with HIV/AIDS and described their photos and stories in group and individual sessions. Using thematic analysis, we identified that the project supported women's mental health in four ways by facilitating empowerment and helping women to express themselves, address their mental health with new tools like photography, and process past traumas. Photography projects may help WL-HIV/AIDS understand and manage their mental health.

Keywords

Creative arts; HIV/AIDS; mental health and illness; qualitative research; creativity in counseling; mental health; diversity; multi-cultural

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"Couldn't everyone's life become a work of art?"

-- Michael Foucault, 1984

An HIV/AIDS diagnosis can shatter one's identity and sense of purpose (Moskowitz, Wrubel, Hult, Maurer, & Acree, 2013; Norcini Pala & Steca, 2015). Spread by taboo and

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sometimes illegal activities like sex and drug use, the illness requires lifelong management of health behaviors and intimate relationships. HIV/AIDS is no longer always immediately life threatening due to advances in treatments. It is, however, still serious, and can dramatically change a person's perception of their body, health, and future opportunities (Edwards, 1993; Teti, French, Bonney, & Lightfoot, 2015). Likewise, the virus contributes to feelings of isolation and helplessness among people with HIV/AIDS and continues to evoke stigma and fear among the general population (Herek, Capitanio, & Widaman, 2002; Logie & Gadalla, 2009). In short, HIV/AIDS is an ongoing significant personal and public health issue.

As a result, living with HIV includes various stressors. Women in particular face specific gender-based threats to their well-being, such as care-taking challenges (Taylor, Budescu, & McGill, 2011), unmet pregnancy desires (Milan et al., 2005), and trauma and violence (Machtinger, Wilson, Haberer, & Weiss, 2012), in addition to the health, personal identity, and social challenges that all people with HIV/AIDS can experience. It is not surprising, then, that women living with HIV/AIDS (WL-HIV/AIDS) report notable rates of depression (Cook et al., 2004) and anxiety (Ivanova, Hart, Wagner, Aljassem, & Loutfy, 2012), which are in turn, associated with poor quality of life (Zimpel & Fleck, 2013), low adherence to life-saving HIV medications (Tedaldi et al., 2012), and high mortality rates (Cook et al., 2004).

Strategies to support WL-HIV/AIDS's mental health are urgently needed. An important but relatively neglected area of research and practice is the use of creative arts to promote positive mental health among people with HIV/AIDS. Arts-based strategies can help people with HIV/AIDS to manage their illness and symptoms in new and creative ways, rebuild their sense of self, (Aldridge, 1993; Bradley, 2008), and facilitate communication with others (Fraser & Al Sayah, 2011). Although several examples of the use of art in therapy and counseling for people with HIV/AIDS do exist (Feldman, Betts, & Blausey, 2014; Rao et al., 2009; Stuckey & Nobel, 2010), these programs and their evaluations are limited in number. Similarly, the use of photovoice has been suggested as a way to integrate social justice initiatives (via critical thinking and consciousness raising) into counseling, but examples of this in practice are rare (Smith, Bratini, & Appio, 2012). To help address the lack of visual arts HIV/AIDS strategies, we conducted a photography project called *Picturing New Possibilities* to support mental health among WL-HIV/AIDS.

The curriculum for *Picturing New Possibilities* was developed based on the principles of photovoice, a public health strategy in which underserved individuals use photography and narratives to identify, record, and share their personal and community health experiences (Catalani & Minkler, 2010). Our research questions were exploratory: How do WL-HIV/AIDS capture their unmet mental health needs in pictures and stories? In what ways do women's photos and narratives affect and support their mental health? Accordingly, we chose qualitative methods, specifically theme analysis, to understand the key patterns in women's responses that answered these exploratory questions.

Method

Participants

The project sample included 30 women. This sample size is sufficient for qualitative data analysis and saturation (Charmaz, 2006), particularly for photo-based research projects, where data are richly detailed through both text and images (Catalani & Minkler, 2010). The majority of the participants had low or very low incomes; over half ($n = 18$) of the women reported earning less than \$10,000 a year. Most participants identified their race/ethnicity as Black or African American ($n = 25$). On average, the participants were living with HIV/AIDS for 11 years, ranging from a low of six months to a high of 17 years. Previous theme analyses (citations withheld for anonymity during the review) revealed that participants had a complex array of unmet mental health needs such as stress, worry, sadness, fear, and isolation and a deficit of “safe spaces” to express and examine the emotions associated with living with HIV. Thus, understanding how the photovoice process affected these health needs was a research priority and the focus of the current analysis.

Project Procedures

The research team recruited participants from AIDS service organizations and clinics in three United States cities located in the Midwest and Northeast, using flyers and meetings with providers. Eligible participants were HIV positive women, ages 18–65, who were able to understand English and take and share photographs. We obtained consent from all participants prior to their participation in any project activities. Participants chose a pseudonym to replace their real identity in project presentations and manuscripts. These procedures and the research protocol were approved by the primary author’s university Institutional Review Board. The primary author co-facilitated *Picturing New Possibilities* with an assistant. Project procedures are described in detail in (Teti et al., 2015). In brief, women participated in the project in small groups of four to eight. They took pictures to describe their story of living with HIV and shared these photos and narratives in group and individual sessions.

Interview Protocols

We facilitated group discussions with a semi-structured protocol that included questions such as: “Tell us more about this picture” and “What does it say about your life with HIV?” After each participant presented and discussed her photographs, the group discussed their reactions to the images. The individual interview protocol included reflection questions, to better understand the women’s experiences and how the project affected women and their mental health. Some examples of questions from the individual interview protocol are: “What did you learn about yourself in the project?” “What did you learn about living with HIV?”

Coding and Data Analysis

Data drawn from the research were lengthy (approximately 300 photographs and 1000 pages of data) and detailed. Group and individual session transcripts were entered into Atlas ti, a qualitative software analysis package (Scientific Software Development, 2011). We used

strategies of thematic analysis to understand how the project affected women's mental health (Charmaz, 2006). This analysis strategy was appropriate because we were interested in identifying key patterns of mental health experiences among participants. Likewise our primary research questions also sought to identify the major ways (i.e., which could be well captured with themes) that the photovoice process affected mental health. Charmaz's guidelines specifically focus on the importance of finding patterns in participants' stories and organizing them into explanations of phenomena such as, in this case, how the photovoice process may have affected mental health. We generated themes inductively, by focusing on the data provided from women's language and examples. When terms such as "empowerment" and "trauma" appear in quotes, it is because participants used those words, not researchers. To move from preliminary to final themes, we conducted open and focused coding. In the open coding phase, we reviewed the transcripts line by line to identify participants' mental health experiences, organizing these codes into initial themes. Next we reviewed our initial analysis and conducted more focused coding to consolidate, clarify and expand the initial codes and identify final themes. We ensured the trustworthiness of our data through intensive coding, code revisions, member checking to ensure the findings reflected participants' experiences, coder discussions and disagreement resolutions, participant quotes, and detailed information about recruitment, data collection, and analytical strategies (Lincoln & Guba, 1985).

Results

Four themes captured how *Picturing New Possibilities* helped to support women's mental health. The project facilitated participants' empowerment; helped participants express their emotions; gave participants the opportunity to employ new tools (i.e., insights gained from photography, photographs, and discussions) to address mental health distress; and offered a space for women to process past traumas.

Empowerment

By choosing to photograph specific aspects of their lives, participants often took ownership over the stories they presented. If they shared a particular problem with the group, for example, the photo was often the first step in identifying and addressing the challenge. Self-portraits were common ways that participants expressed their control over HIV. Photos allowed them to visually identify elements of control. Discussing pictures of themselves, for instance, Raquel, Yasmine, and Tara countered the traditional medical language of "living with HIV," by saying "HIV has been living with me." Carla expressed these sentiments with a photo of a drawing of herself (Figure 1). On her chin she wrote "empowerment." In other parts of the drawing she listed descriptors of her different roles, such as "sister" or "friend." Carla superimposed the letters "HIV" on these descriptors but noted, "I'm a friend, I'm an aunt, I'm a daughter, I'm a sister, I'm a grandma, and I'm alive. HIV is a component, it does not define me."

Maureen and Alysha had slightly different takes on depicting empowerment and control over HIV. Maureen said that she took pictures of what was important in her life, and through this process she realized that HIV was "becoming more in the background." She said, "I want to

go to school and take a picture. That's the beginning of the rest of my life. I'm not [just] HIV anymore, it's [only] a part of me." Alysha said that taking pictures of different aspects of her life allowed her to envision how she could change and be stronger. One challenge that she photographed in this project was unsafe buildings in her neighborhood. She used her photos to lead an effort to tear those buildings down and replace them with a community garden in her name. She said that each time she took pictures she would think "Maybe next time I take a picture it will be a little better...or maybe I have to change this [issue I photographed] and I can do it." She said the project "made me focus on what I can do instead of running into a brick wall all the time. It let me focus and gave me courage." She said that it reminded her that she could still "do something and I can actually complete it and feel good about it, take control and not remain depressed about HIV."

Express Emotions

Participants' reflections about *Picturing New Possibilities* indicated that the process of taking photos and discussing their lives with the images helped them to realize that they and their feelings "mattered." As Marabel explained, "[In the project] I felt like somebody listened, somebody [thought] I was important ... It gives you a chance to feel validated in your experiences." Similarly, Carlotta and Camile noted that the project was one of the first times they "did something for themselves" and recognized their own emotional needs instead of focusing solely on others' support needs, such as relatives, children, and partners.

Many of the participants said the process, at its most basic level, was a way for them to identify and share their emotions. For instance, Alysha said the project "helped me talk about my feelings," and Carla said the photographs were "a platform" for opening up and sharing. Notably, many women, such as Debra, said they had not previously shared these emotions. Despite living with HIV/AIDS for 14 years, Debra described the project as one of the first times she shared her personal experiences and that she "enjoyed being there."

Another participant, Toni, was struggling with how to let other people know that she was living with HIV/AIDS. Often, her photographs expressed her feelings of "disconnect" from other people and the hurt and frustration this caused. Toni photographed a series of tangled wires (Figure 2) to explain that "she was not there yet" when it came to disclosing her HIV/AIDS status to others, but taking photographs was helping her develop a better plan for this process. For Toni, expressing her feelings through photography was giving her new language to analyze the situation. Describing her photos, Toni said: "[Taking pictures] was less inhibiting than talking because it's taking the picture of the way you feel at that particular time. Photography is another way to talk... [Photography] makes you feel less stressed."

Address Distress

Participants used the camera and their insights from group discussions and individual reflection to directly address distress. Women indicated that the project helped them to focus on concrete, positive aspects of their lives; or use the camera as an engaging activity to distract them from negative feelings and experiences. Several women took photographs of people, items, or activities that helped them relieve stress, so they could remember and pay attention to these things. In this way, by developing a solution for troubling emotions, the

women were addressing their emotional and mental health. For example, Darlene said she looked at the self-portraits she took of herself as “healthy and vibrant” when she was “down and out,” so she did not “dwell on HIV/AIDS.” Other women indicated that they took pictures of things that made them “happy.” For Tina, “happy” photographs were labeled “images of serenity,” such as photographs of her church or the ice-skating rink. For Alysha and Maressa, happy images were photographs of their children. Maressa described capturing memories with her children: “Last year [my son] was incarcerated, and we really missed him. I went through a deep depression. I’m glad I can take pictures of him and just look at him whenever I feel like looking at him.” For some women, photographs helped to put the focus on supportive aspects of their lives, and recognize how they could create new ways of coping with challenges.

Other women used the camera as a tool to distract themselves, keep busy, and stay engaged, which is also a valuable way to manage distress. For instance, Camile described worrying about HIV/AIDS, especially when she rode the bus; she felt like others made assumptions about her HIV status because of where she lived. Camile shared a picture of her shadow to reinforce to others that “HIV does not have a face. It doesn’t have a body. You can’t look at somebody and tell that they have it.” Camile said she would use the camera to take control of her stress and distract herself from the stress of worrying about others: “[Taking pictures] relieves a lot of stress. When I was on the bus, to distract myself, I would take pictures of my surroundings.” She also referred to photography as a helpful “hobby,” which showed her:

How creative I was and that I see life in a different light now, because in the past I was very depressed and suicidal. Now I’m not so much as suicidal or depressed at all. It’s like I’ve got something else to do, a hobby, and it takes away from the depression.

Similarly, Marabel said that taking and sharing photographs “got me out of my depression.” She explained how she used the camera to encourage herself to engage more with her life: “It got me out of the “Go home after I get off of work” [mode]. I had something to look forward to...It gave me the energy to look at having things in my life to do. Throughout the course of the project, many participants described creating a plan to address negative feelings, either by using motivating images or the camera itself.

Process Trauma

Participants captured and discussed elements of various traumas and ways that they worked to overcome traumatic events. The list of participants’ traumas was long and included life threatening car accidents, violent and/or deceitful relationships, rape and HIV infection through rape, child abuse, street violence, home invasion, infant deaths, drug use and drug overdoses, sex work, homelessness, severe illness, HIV stigma and rejection, and suicide attempts.

Several women used their photographs to process grief and loss. Alysha shared pictures of her daughter, who died in a house fire, and said, “The project has taught me how to grieve her death effectively.” Likewise, Ella photographed a picture of her friend, who had encouraged her to go to college but then died in a car accident. Ella said it was “hard to talk about the picture” but it helped her to celebrate how her friend supported her life. In this

way, the project photographs became ways for women to process their traumas in new ways, and became formats to not only despair, but also celebrate the lives of those they had lost.

Many women also used photography to process the violence and abuse they had endured. Tierra described a history of being physically abused by her parents as a child, saying “That’s [how] I became epileptic ... I was abused as a child and beaten continuously in the head.” Not surprisingly, Tierra also said her family rejected her when she was diagnosed with HIV, telling her, “You are just a big disease. You are a germ.” She said, “Nobody was there to be there, help me, support me, or do anything.” She said that the project helped her let go of her “bitterness” by reflecting on painful emotions and past experiences with a “hobby” (i.e., photography). Tierra took a photo of a house that she recently purchased herself, to show that she was in control, and despite past difficulties, “I am going to keep on going and keep on.”

Several women described being diagnosed with HIV/AIDS, sick from HIV/AIDS, or subsequent HIV/AIDS stigma from their partners or families as “traumatic.” Adele said she weighed only 35 pounds when she was diagnosed with HIV, explaining, “They carried me around like a baby.” She took pictures of certificates she earned for completing HIV education programs, which showed she was able to endure and survive severe illness, and that it did not control her life. Tara took a series of pictures to share her journey with HIV/AIDS, which included traumatic but transformative experiences. She first shared a picture of a dark cloud that represented her fear at diagnosis that “she was not going to live.” Tara’s second picture was of a burnt paper that drifted into her backyard on 9/11 (Figure 3). She explained:

We were able to see the towers from my neighborhood, and, when they came down, all the smoke and ash and papers. The whole neighborhood was littered with papers...Six of my friends died that day. It was a really traumatic thing but it was also a turnaround.

She said she “realized that these innocent people died so tragically and, yet here I was, 11 years into my [HIV] diagnosis, living in doom and gloom when I could have been living life. I needed to go on. I needed to live.” Tara’s final photograph was of a beautiful sunflower that helped her to remember that “she survived [HIV] ... Sunflowers don’t live forever but they keep coming back.” Pictures and discussions allowed women to recreate and release past traumas and grow.

Discussion

We explored the effects of a photography project on the mental health of WL-HIV/AIDS. Mental health support for women with HIV is important, because women suffer HIV-related stress (Cook et al., 2004); artistic strategies can potentially address some of these stressors via the benefits of creativity, meaning-making, and new perspectives (Stuckey & Nobel, 2010); existing arts programs supporting mental health among people with HIV are limited; and evaluations of these programs are rare (Feldman et al., 2014). Women in this project described several supportive benefits of taking and discussing photographs. These included

empowerment, and help with expressing emotions, addressing mental health concerns, and processing trauma.

Our findings about empowerment reaffirm other research that photovoice, upon which the curriculum for *Picturing New Possibilities* was based, does promote a sense of individual and collective control (Catalani & Minkler, 2010). The visual aspect of the project was particularly important as a way for women with HIV to identify concrete forms of control in their lives. Taking control over HIV, for example, was made visually evident in self-portraits that *showed* the women and their peers that they were healthy and capable. The way that the women led the project with photographs of their choosing also may have given women control over difficult mental health discussions.

Similar to art therapy, this project may have supported women's mental health by fostering creative and critical thinking opportunities (Feldman et al., 2014). Photography may have also provided women with a non-intimidating and accessible form of artistic expression and analysis, as it is doable without advanced artistic training or skills. Women with lower literacy skills, which are common among people with HIV (Kalichman et al., 2000), may have been able to reflect, think critically, and communicate more effectively with pictures than they would have through words alone.

In addition to taking pictures, sharing the stories behind the pictures was a very supportive process. Research indicates that group story-telling is a particularly relevant form of communication for racial/ethnic minority women who have traditionally used oral histories to communicate their experiences (Banks-Wallace, 2002). As such, Black women, who represent a disproportionate number of women with HIV/AIDS (CDC, 2015) and were the majority in this project, might especially benefit from communal, therapeutic modalities such as photography and photo-sharing (Field & Kruger, 2008).

As women identified their story of HIV through images, they portrayed challenges and also strengths. Much research and practice focuses on the difficult aspects of women with HIV/AIDS' lives (Teti et al., 2015). Indeed, women in this study described intensely painful experiences. At the same time, however, images often reminded the women that they were able to surmount difficulties. The opportunity to reflect on resilience may support mental health, because it recasts women as capable. These findings support a small but growing body of research which suggests that studying and cultivating positive responses to stress may be critical to helping people with serious illnesses, like HIV, maintain psychological and physical well-being (Folkman & Moskowitz, 2000). Resilience is also an essential component of black psychology and counseling strategies for Black women, who may particularly benefit from strength-based models (Williams, 2005). Likewise, popular media often depicts people living with HIV negatively as drug users or sex workers (Krieger, 1992). The opportunity for creative inspiration, through photography, may have been particularly helpful for women to envision different images of themselves and their lives.

Limitations

In addition to major findings, the analysis has some limitations. To participate in the study, women had to be willing to share their experiences with other women. These requirements

might have dissuaded some women from participating, and, these women who feared discussing HIV/AIDS might not have described the same type of mental health support. Likewise, this analysis focused on supportive aspects of the project and indeed, several parts of the process, such as delving into identity or HIV disclosure challenges, was difficult for some women. Participants were asked to describe their lives with photographs and discussions. We did not ask the women to photograph specific mental health issues, or ask them directly about depression, anxiety, or trauma. If we had, women may have talked in greater detail about these experiences. Finally, this study aimed to explore participants' perceptions of photography to support their mental health and wellness. It was not designed as an efficacy study, and we cannot make claims about the utility of photography as an evidence-based process to *treat* mental health.

Implications for Research and Practice

This analysis serves as a crucial starting point to support future photography project development, evaluation, and more widespread dissemination of the process for practice. Future research should examine the effects of photography with larger and more diverse groups of people with HIV. Associations between participating in the process and specific mental health outcomes will be important to assess the full capability of these projects. It is also likely that the photovoice process has similar benefits for other vulnerable populations with different illness experiences. The strengths of photovoice lie in its ability to engage participants in communication, artistic creativity, critical thinking, and group sharing. Thus, it is important to explore and test photovoice with other groups who may have trouble expressing themselves verbally (e.g. people with disabilities) or who are challenged to express themselves as a result of health stigma (e.g., obesity, cancers, sexually transmitted infections, etc.).

Mental health problems like depression and anxiety can be serious and may require multiple strategies, such as behavioral and pharmaceutical treatment. We do not wish to imply that photography can treat or solve these challenges, but that it can perhaps play a role in supporting mental health, decreasing the severity of the problems, and in helping women to access other needed services based on the insights that they gain. Empowerment, expressing emotions, addressing problems, and processing trauma, if done safely, are potentially very valuable for women with HIV/AIDS. Like all programs, this one requires personnel and resources, but it is also adaptable it is to various settings. As such, it may be an effective way to integrate mental health interventions and counseling programs into community agencies and clinics that serve people with HIV/AIDS. Photography is simple but powerful, so paraprofessionals and/or a wide range of agency and clinic staff can be trained to lead the process with strong results (Wang, 1999).

The need for effective, flexible and cost-effective intervention strategies for women with HIV/AIDS will remain because HIV/AIDS continues to be a major health threat among women. As more women live longer with HIV/AIDS, they will need strategies to help them to lead productive and enjoyable lives over their lifespan. Through projects like *Picturing New Possibilities*, women can channel their creativity and insights in order to “talk about

[their] feelings and not [fear] them,” “get out of [their] depression,” and recognize that they are a “survivor.”

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Figure 1.
Empowerment: Carla shows that she can control HIV, which is only one part of her life.

Figure 2.
Not There Yet: Toni shares how she wants to be more open and expressive about HIV.

Figure 3.
Burnt Paper from 9/11: Tara turns a traumatic experience into a chance to grow.