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The Art of Resilience: Photo-stories of Inspiration and Strength among People with HIV/AIDS

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Abstract

Using the visual arts to aid healing is a common therapy for people with critical illness, yet the use of art to improve the lives of people with HIV is under-utilized. Eight male and 20 female participants living with HIV in urban areas of the Midwest, U.S. participated in three group photovoice photo-sharing and discussion sessions, post-project individual interviews and a community photo exhibit. We used a grounded theory approach to analyze interview data, and identified three key themes: (1) health and wellness, (2) fear and stigma, and (3) restoring a threatened identity. Participants identified how taking photos, reflecting on and sharing them in focus groups helped them express themselves while living with and coping with HIV. Offering photography as form of expression is a way to foster strength and consequently, improve the lives of people living with HIV. Our participants benefitted from the process of telling their story with images. They were able to express positive aspects of their lives which could be a healthy form of catharsis in and of itself. Future research should continue to investigate how participants in participatory approaches like photovoice, actually do benefit from the research. Although we focused this analysis on resilience, photovoice is flexible and participants' responses to it are varied. Additional outcomes such as impact on mental and physical health, are worthy of additional exploration.

Keywords

AIDS/HIV; Resilience; Empowerment; Photovoice

Engaging arts in health care can enhance patients' moods, emotions and other psychological states (Staricoff et al. 2003). Using the visual arts to inspire creativity, insight, and healing are common therapies for people with chronic illness (Stuckey and Nobel 2010). For

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example, creative arts therapy of drawing was found to enhance emotional expression, spirituality, and psychological well-being among newly diagnosed breast cancer patients (Puig et al. 2006). Creative arts have also facilitated the communication between patients and health care providers. For example, children and adolescents with chronic medical conditions at Children's Hospital in Boston created videos to teach their health providers about their everyday experience with the disease, health and healthcare (Chalfen and Rich 2004). In this article, we discuss the use of photovoice as a tool for fostering a sense of resilience among people living with HIV.

Photography, a special form of visual arts, has been successfully used in medical anthropology and health research (Pink 2004) and public health field via a participatory research method called photovoice as a way for people to identify, represent, and enhance their community (Wang, Cash, and Powers 2000). Through documenting their community strengths and concerns, and engaging in critical dialogue with community members (Foster-Fishman et al. 2005), project participants have experienced empowerment, the process of facilitating self-directed behavior change (Anderson and Funnell 2010). The aim of patient empowerment is to increase participants' autonomy and control over their lives and communities and facilitate their informed decision making (Anderson and Funnell 2010). In their original studies of the application of photovoice to public health, Wang and Burris stated the importance of the empowerment education process through photo novella (Wang and Burris 1994). Since then several photovoice projects have reported facilitating empowerment among poor and marginalized communities who use the photos and discussions to identify and express their experiences (Carlson, Engebretson, and Chamberlain 2006, Aldridge 2007, Booth and Booth 2003, Teti et al. 2013).

Among various means of empowerment, issues of meaning and expression, particularly in health-related contexts, are highly significant and influential as they 'shape and transform experience, behaviors, and institutions' (Crawford 2006). Processes like photovoice that illuminate issues of meaning and lived experience have the potential to empower and give voice to individuals with threatened identities. Health is associated with identity, and widely thought to be an achievement, with a moral imperative for the pursuit of health and wellness serving as an indicator of an intact personhood (Clarke and Bennett 2013, Crawford 2006). A life-long, life-threatening or stigmatized illness such as HIV/AIDS that requires constant management is enough to threaten one's identity as a social person, especially in cultural situations where achieving and maintaining health is prioritized.

The use of photovoice among people living with HIV (PLH) is growing. It has been used to help health providers to understand the stressors and supports among PLH (Schrader et al. 2011); as a tool to facilitate empowerment for PLH to create knowledge, develop partnerships and take action in the communities (Rhodes et al. 2008); and to better understand and support the experiences of PLH (Teti et al. 2013, Teti, Massie, et al. 2012). Many questions remain about the use of photovoice and its effects on participants, however. One important underexplored area is the impact of photovoice on participant's resilience. Preliminary studies indicate that as part of the photovoice empowerment process participants learn to creatively identify their strengths despite their challenges (Teti et al. 2013). This is particularly important given that the majority of scholarly and media attention focuses on the

noteworthy challenges of living with HIV and because studying resilience can shed light on new ways to understand and cultivate empowerment, strength, and new skills among PLH. Thus, in this study, we developed and explored the impact of a pilot Photovoice project on the health and well-being of PLH and focused specifically on the use of art and photographs to help them express themselves and cultivate a sense of resilience despite challenges.

Methods and Study Design

Recruitment

Project procedures were approved by the authors' university institutional review board. We recruited HIV positive men and women to participate in our research project titled '*Picturing New Possibilities* (PNP),' from AIDS service organizations (ASOs – clinics, case management organizations) in two Midwestern U.S. cities. We placed flyers in ASOs serving WLH/A. We also met providers to describe the project and encourage them to invite participants. Interested participants contacted the research team to complete an eligibility screening questionnaire. Eligibility included men and women who (1) were living with HIV, (2) were over age 18, (3) were able to speak and understand English, (4) had sex with a man in the last year or identified as gay or bisexual (men only), and (5) were willing and able to take, discuss, and exhibit photographs. We recruited 8 men and 32 women; two participants were lost to follow-up for illness and unknown reasons. The final sample included 20 women and 8 men, a sufficient sample size for qualitative data analysis, particularly for Photovoice projects in which data include rich details in text and images (Catalani and Minkler 2010). Most of the women (10/12) identified as Black. All men identified as MSM and most of the men (7/8) reported their race/ethnicity as White. More than half (21/38) of the sample reported earning less than \$10,000/year and the remaining participants said they earned between \$10,001 and \$30,000/year. On average, both men and women were living with HIV for 11 years. Men reported slightly younger average ages (36 years) than women (45 years) but similar age ranges, from late teens to late sixties, were reported by both groups.

Project Procedures

The Principal Investigator (PI, 2nd author) co-facilitated PNP with assistance from a Project Assistant. The facilitators delivered the project in small groups of four to eight participants. Small groups were determined based on gender and place of recruitment. Separating participants by gender was purposeful given that men and women have different experiences and challenges living with HIV. We decided that maximizing the similarities between participants would likely generate the most helpful discussions. Each group included three, weekly, 2-hour meetings. During the first session, the facilitator explained that the purpose of the project was for PLWH to share and address their life experiences, strengths, and challenges through photos. The facilitators demonstrated how to use the camera and the participants practiced taking pictures and performing basic camera functions. Each participant received a camera to keep and monetary incentives (\$15–\$40) for completing project sessions. We believed it was important to provide these incentives to compensate participants for their time and commitment photographing their lives. Allowing them to keep

the camera was intended to help promote their use of photography as an ongoing tool beyond the project's completion.

Together, the participants brainstormed different potential ideas for photographs and discussed the ethics of picture taking (For more in depth discussion see Teti et al., 2012 and Wang and Redwood-Jones, 2001) (Wang and Redwood-Jones 2001, Teti, Murray, et al. 2012). First, together the participants and the facilitator discussed and agreed upon images appropriate for sharing and public presentation. The group decided that although the participants could use the camera however they wanted, they would not present nudity, illegal activities, or images that compromised participants' safety for the project. For instance one participant wanted to photograph the face of the person who infected her with HIV, to punish him. The group discussed that this was not safe for the participant and helped her brainstorm alternative ways to capture her emotions about how she acquired HIV. The group also discussed taking pictures of others and decided that such photos were appropriate only if others wanted their picture taken. Each participant learned how to obtain a written release to take pictures of other people. Lastly, the facilitator reassured each participant that they would have the power to decide which pictures they wanted to present at project exhibits and in publications. The project employed a 3-step consent process which included a study consent, a consent to release photographs, and a verbal consent to display photographs in exhibits. Related to that, participants were free to show pictures of their identity and/or author their photographs, or remain anonymous.

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. The session included individual presentations and group discussions of the photos. First, each participant presented 2–4 photos of her choice to the group and discussed what each photo meant to him/her. We facilitated these discussions using a variation of the SHOWeD technique, a well-established technique to guide photovoice discussions (Wang and Redwood-Jones 2001, Catalani and Minkler 2010). The SHOWeD process includes a series of five questions designed to help Photovoice participants talk about their photos: What do you See here? What is Happening? How does this relate to Our lives? Why does this problem or strength exist? and What can we Do about it? We tailored the questions to focus on HIV by adding or substituting a few additional prompts: What does the photo capture about HIV? What story does the photo tell about your life with HIV? How does the photo capture [a particular challenge or strength] with HIV? After each participant presented and discussed her photos, the group discussed their reactions to the images. Most of the participants (83%) attended all of the sessions. In each city, during the final meeting, the group planned a public showing of the photos. Each participant signed a release and chose to present photos at a public HIV community event. The exhibit was optional, but 70% of the participants chose to participate in the exhibit.

Following the exhibit, the PI conducted 1- to 2-hour individual-level interviews with each participant to explore their experience and discuss how the project affected their mental health. Specifically, the questions were designed to capture participants' reflections about the process. Examples of questions from the interview guide included: 'What did you learn about yourself in the project?', 'How did you decide what to photograph?', 'Describe the

experience of watching other people view your photos.’ In addition to receiving the camera, all of the participants were compensated monetarily for their time and received \$15, \$20, and \$25 respectively for attending the discussion groups and \$50 for completing the follow-up interview. We digitally recorded each group and individual intervention session to capture data. Participant photographs, narrative, or stories and discourse shared in the Photovoice sessions were the units of analysis.

Data Analysis

Guidelines for using strategies of grounded theory (Charmaz 2006) guided our analysis of these narratives, prioritizing the experiences voiced by participants. We analyzed the data to understand how PNP helped PLH to address major mental health issues like depression, anxiety, or post-traumatic stress, and how art and photography helped people express themselves and focus on their strengths. We transcribed all of the group sessions and interviews verbatim, and edited them only for clarity. We entered the transcripts into Atlas.ti, a qualitative software analysis package to facilitate data coding (Muhre and Friese 2004). The first and second authors reviewed the transcripts multiple times to become familiar with the data and key themes. Then we created a codebook describing the most salient ‘resilience’ themes from the participant narratives, and conducted a content analysis of the data using two strategies: coding and analytical memos (Charmaz 2006). Coding matched text to themes and progressed in two stages, open or more general coding, which was followed by selective or more specific coding (Charmaz 2006). We reviewed the transcripts in detail and conducted data debriefing sessions discussing coding differences until we reached a sufficient level of agreement about discrepancies to assure the quality or trustworthiness of our analysis (Lincoln and Guba 1985).

Results

Participants included eight men and 20 women living with HIV in urban areas of the Midwest, U.S. Participants indicated the project gave them a ‘muse’ and ‘unleashed the artist in them’, which helped them think about HIV and their life in new ways. The ‘muse’ worked in two specific ways: identifying challenges and articulating strengths faced in living with HIV. Identifying challenges was a first step of sorts toward discovering and articulating their strengths. The themes identified through photographs represented both challenges as well as strengths, and fell into three broad categories: (1) health and wellness, (2) overcoming fear and stigma, and (3) personal growth and restoration.

Striving for Health & Wellness

The most significant health and wellness issues identified through photographs included coping with memory loss, managing a demanding prescription medication regimen, striving to maintain optimum health, struggling to handle the medical insurance paperwork and pay medical bills. The following quote was shared by a man who submitted a photo of an internet webpage depicting various illustrations of human brain anatomy, had been living with HIV for 26 years at the time of data collection, and struggled with memory loss:

A lot of people don’t realize how the virus and medication affect your brain...your memory skills, thinking ability; emotional ability...This picture represents my

memory loss. It is something I struggle with one a daily basis...I write notes about what I am doing each day, so I don't forget.

For some participants, striving for health and wellness manifest through the daily struggle surrounding medication adherence. Taking the prescription medications consistently and correctly is difficult, especially given the well-documented unpleasant side effects. Several participants submitted photos of their medication, sometimes the pills or tablets themselves, or the pill bottles clustered together. Here is what one participant had to share about her complicated relationship with HIV medication and the accompanying medications to combat the side effects:

The pills make me sick most of the time. In the beginning, I was barely listening to everybody [and was not taking the pills]. Because of the side effects. I mean, I was down to the last regimen...I have a love/hate relationship with my medicine.

Another participant shared his struggle to organize the overwhelming amount of paperwork and required documentation for his health care, even after living with HIV for 12 years. Moving from a larger city to a smaller Midwest town, changing medications or any other complicating factor resulted in additional paperwork, depleting his time and resources:

Managed Chaos

It's a full time job managing all of this [medical paperwork]...I'm thankful to have social security and Medicaid, but you still get all this paperwork, and they leave a lot up to the individual to manage it...it's not very easy, and you need outside help...I've started writing and I keep a list of things – like to keep me focused on things that I might need to do that day or that month.

Our participants used photos to identify and share their personal health-related strengths, in addition to health-related challenges. Participants used the terms 'perseverance' and 'longevity' when discussing their commitment to maintain physical and mental health, such as following through with medication adherence, exercise routines, and meditation. For example, one participant shared a photo of his running shoes to demonstrate that exercise is

his strategy for staying healthy and coping: ‘Running is something I do to keep healthy and I enjoy doing it – especially long distance running. It helps keep my mind together.’

Fear, Stigma & Shock

Fear and stigma related challenges included reports of feeling stigmatized, shocked and anxious over having to answer personal and inappropriate questions regarding health status, fear surrounding the possibility of infecting someone else, disclosing HIV status when meeting potential new intimate partners, and fear of rejection. Participants expressed this visually by representing the anxiety, fear, social exclusion and sensation of dread about their diagnosis. The first photo representing this category, ‘Interrogation’ was submitted by a newly diagnosed man, who discovered his HIV status 2 months before data collection. He credited participation in this project as helping him get back out into the world beyond his apartment and forcing him to contemplate his future. Telling others about his HIV status was a very stressful and fearful experience, however. He explained this with a self-portrait equating disclosure to a police interrogation:

Interrogation

I was aiming for a police interrogation [with this photo] – the bright lights in your face. This is my idea of stigma. A couple of people that I told, they instantly went from being a friend to an interrogator, like “How did you get it? When did you get it? What did you do to get it?” It’s very accusational and blaming. “You did this to yourself – what did you do?” And when you first find out, you have to go through this process with all of the official people [case managers, health officials], but then to have your friends ask the same questions...I don’t need to have those conversations.

Other participants worried about infecting others. For example, a man who had been living with HIV for about 3 years but had not yet found a way to disclose his diagnosis to his friends and family at the time of data collection took the following photo entitled, ‘Freak Out.’ He reported feeling continually ‘on guard’ about potentially infecting another person:

Freak Out

I sliced my finger at work and I was freaking out. I cleaned it up and called my friend immediately. He reassured me, “you are not going to give anyone HIV because you cut your finger. You are fine.” I want to protect other people.

Another participant chose to arrange several toy figurines in a photo, ‘Oddball’ to capture his feelings of stigma and exclusion from his family – who he described as ‘small-minded’ when it came to understanding his HIV. Once he told them about his illness he felt like they abandoned him.

Oddball

That’s me on the left, and my family on the right. You can see they are pulling away in front of me and I’m looking back. I feel a little forsaken by them sometimes. They don’t understand, and I’m not sure they want to. I feel perturbed because I don’t feel like they put forth the effort.

A woman living with HIV for 22 years at the time of data collection submitted 'Day of Diagnosis,' a photo of ominous clouds overtaking a previously sunny sky to represent her fear in her early diagnosis experience:

Day of Diagnosis

It's just this big black cloud coming at me... consuming me as the light and sun just faded away. I felt total doom and gloom... I never really expected to live. So, this just kind of shows where my head was at 22 years ago. I just wanted to die.

Participants expressed a sense of resilience despite stigma, by reflecting on how far they had come and letting go of the need to hide their identities and diagnosis. The photo of a flowering plant emerging from a crack in a section of worn, grey concrete was submitted by a participant as an expression of what she has witnessed as a person living with HIV. She had the following to say about the photograph: 'Life will always find a way. It is a hard life we lead, but it's still life. Somehow, life will find a way.' The fear of rejection inspired this next photo, 'No Dumping.'

No Dumping

I see this sign all of the time and I never really noticed it, but I thought it was interesting because we could put this on any HIV positive person - you cannot dump them. Because you feel like if you tell someone you are going to get dumped or you will not be loved. When you have to have the talk, it's like you want to preface it with "You are not allowed to dump me, just based on this. If you don't like me as a person, or you think I'm annoying, that's one thing – but if this is the one reason why you dump me – that is ridiculous."

Journey toward Restoration

Participants underwent a process of becoming reacquainted with themselves after diagnosis, and each occupied a different place along the continuum from a newly diagnosed life disruption, to an opportunity to reevaluate one's life and advocate for others along the journey toward restoration. Restoring a threatened identity, or working to reestablish an intact social identity was challenging due to fear surrounding HIV status disclosure, writer's block for creative pursuits, searching for a meaningful way to channel one's talents and abilities, recognizing the need and struggle for support, the challenge of travel due to restrictions, and concerns about how to spend time/with whom to spend time. The photo "Another Path" was submitted by a man struggling to tell his family about his HIV status and change of career:

Another Path

My dad was in the military and I grew up in a military environment. That's the community I was raised in, that is what I've always known. I thought I would do that too. Finding this out, it's highly likely I'll be considered unfit for military service. That's the path that I was on, but now I don't know where my life is going to go from here. It's daunting and overwhelming. I need to tell my parents I'm not graduating on time and I won't be in the military anymore. I have to tell them something.

This photo, 'The Legacy' was submitted by a man who was frustrated by writers block after learning his HIV status:

Legacy

These are the words that I write – and my piano. Writing music is something I do for fun, but since finding out [about HIV], I rarely write anything anymore. A lot of my initial thoughts were about how I could leave some kind of legacy. Writing and recording myself are things I want to do, but I want to make sure it's perfect now. It's very hard to try to do because I beat myself up. Is this good enough? If this was the last thing that I wrote, would it be good enough?

A similar sentiment was expressed by another participant when he shared the following:

Lost Muse

I used to paint all of the time. Then I just lost interest and I still haven't gotten back into it. Family and friends ask me to paint them something and I just can't think of what to paint. I worry more about perfection now.

This participant identified through photographs his concerns about how he spends his time since becoming aware of his HIV status. He submitted this photo of a clock collection, "Valuable Time" to represent his process of personal reflection and reevaluation: 'When I was diagnosed with HIV, I thought of time differently. It makes you think differently about 5 or 10 years down the road, where you'll be...I value time more.'

One participant submitted a photo of six stuffed animals arranged according to the colors of the rainbow to represent his feelings about coming to terms with his identity, diagnosis and the opinions of others in his small Midwestern town:

Being gay is a part of who I am...It isn't always easy being gay...We have to hide who we are, if they find out, they go after you...It's getting better though...I don't care what anybody else thinks is important. I don't feel like I have to hide it anymore.

Another participant, a woman who had been working to overcome her fear about disclosing her HIV status, heard her own story 'out loud' for the first time when she shared it with the focus group. She expressed that accepting herself and sharing her story will help others, and learning that feeling like she different from others is not necessarily a bad thing:

Don't Try to Fit In

Well, it's kind of how you feel. We stick -- I feel like sometimes I stick out like a sore thumb. But, I'm tired of it. And, maybe I was just born to be different. It's okay. At least, that's my philosophy on it.

Discussion

For the participants in this study, resilience was expressed through photographs that identified the challenges and strengths associated with striving for health and wellness,

overcoming fear, stigma, and shock, as well as the journey toward personal restoration. Participants identified how taking part in the photovoice project helped them express themselves and identify their strengths while living with and coping with HIV. Their responses served to inform our expectations of arts-based public health interventions. Creativity and insight can help PWH build and express resilience, and see their lives differently. Offering photography as form of expression is a potentially simple way to foster strength and consequently, improve the lives of PLH. Our findings support evidence for the helpfulness of art therapies for people with HIV (Field and Kruger 2008). Photovoice and photography, however, may be more accessible for vulnerable populations with little arts experiences. The only learning required is how to use a camera. Participants can creatively express themselves with a basic but powerful modality. Thus photovoice provides another option for artistic expression and healing.

Striving for health and wellness extended beyond fitness routines, to include medication adherence issues, coping with memory loss, and struggling with medical insurance paperwork and medical bills. The pursuit of health and wellness echoed the ‘health as achievement’ literature (Clarke and Bennett 2013, Crawford 2006). This commitment to achieve and maintain an identity as a healthy person was repeatedly tested, as our participants wrote notes to themselves to battle against memory loss, endured a ‘love/hate’ relationship with lifesaving, but unpleasant medication, and shuffled through mountains of paperwork. In these cases, resilience was found in the process of acknowledging the daily challenges and identifying strengths through photographs.

Photos addressing issues of fear, shock and stigma demonstrated the obstacles these participants have navigated, or were in the process of navigating. They displayed an ample awareness of way in which this diagnosis could potentially change how others viewed them. The moral imperative of health mentioned previously is tied to what Crawford refers to as ‘danger-consciousness’, which carries expectations of vigilant self-monitoring for ‘ambient and omnipresent potential harms’ (Crawford 2006:403). Fear about the social as well as physical dangers of living with HIV were exhibited through the photos ‘Oddball’, ‘Day of Diagnosis’ and ‘No Dumping’, and ‘Freak Out’, which represented the embodiment of ‘danger-consciousness’ in its purest form. Our participants reported that living w/HIV placed a strain on their personal relationships, specifically when their friends and family expected them to answer personal and inappropriate questions regarding the acquisition of the virus, as depicted in the ‘Interrogation’ photo. They remained committed to addressing these challenges however and part of portraying them was an act of resilience and resistance to these obstacles.

Restoring a threatened identity resulted in several examples of education and advocacy among our participants. They faced challenges to their creative pursuits, travel, and relationships, but also resiliently expressed self-acceptance and personal growth through photo sharing and focus group discussions, through a process that is consistent with an empowerment approach focused on autonomy and informed decision-making (Anderson and Funnell 2010). These sessions invited the participants to reflect on their experiences, acknowledge the challenges they have faced, and identify personal strengths. The ‘restoration’ was not achieved by returning to one’s previous condition, but rather through

experiencing the sense of an intact personhood, with a new appreciation for all that has been endured.

Conclusion

HIV/AIDs as a highly stigmatized illness could threaten the identity and social belonging of people affected. Photovoice provided an anonymous and practical conduit for PLH to express themselves in daily-life settings and through their own artistic creations. The use of photographs prompted participants to discuss issues and experiences that might have otherwise gone unexamined. The themes of their stories included striving for health and wellness; fear, shock and stigma; restoring a threatening identity. Our findings have implications for public health, rehabilitation and social service professionals. This project confirmed that photovoice helped the PLH to tell their stories that were hardly known by the general public and health policy makers. Health professionals and health interventions should incorporate photovoice to learn more about the lived experiences, including resilience, of vulnerable populations like people living with HIV. To health professionals HIV may be seen as a single incident, but for people living with the illness, it often constitutes a major thread in their everyday lives.

Photovoice has been defined as a community-based participatory research method, which can simultaneously benefit both researchers and participants (Wang 1999). Benefits to researchers, such as rich data about people's lived health experiences, are clear. Benefits to participants, however, are explored and presented less often (Catalani and Minkler 2010). In our case participants benefitted from the process of telling their story with images. They were able to express positive aspects of their lives which could be a healthy form of catharsis in and of itself. Future research should continue to investigate how participants in participatory approaches like photovoice, actually do benefit from the research. Although we focused this analysis on resilience, photovoice is flexible and participants' responses to it are varied. Additional outcomes such as impact on mental and physical health, are worthy of additional exploration.

Due to the exploratory nature of this research, a relatively small number of participants was acceptable. However, future research can benefit from a larger number of participants and more male participants. Despite the limitation, this study led light on the potential for future photovoice interventions to help vulnerable populations empower themselves and to increase their resilience, which can subsequently increase the quality of their lives.

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