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PHOTOVOICE AS A COMMUNITY-BASED PARTICIPATORY RESEARCH METHOD AMONG WOMEN LIVING WITH HIV/AIDS: ETHICAL OPPORTUNITIES AND CHALLENGES

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ABSTRACT: PHOTOVOICE IS A METHOD IN WHICH participants use photography to identify, express, and disseminate their experiences. We conducted photovoice projects with women living with HIV/AIDS ($N=21$) to explore opportunities and challenges associated with the method. Photovoice provided a means to achieve two key principles of ethical public health practice: It gives participants opportunities to define their health priorities, and facilitates participant empowerment. Ethical challenges that were encountered related to exposing, through photographs, one's identity as living with HIV/AIDS, illicit activities, and other people. We discuss lessons learned for future practice to maximize the ethical opportunities and manage the challenges associated with using photovoice as an HIV-related CBPR strategy.

KEY WORDS: photovoice, CBPR, ethics, women living with HIV/AIDS, HIV/AIDS

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THROUGH PHOTOVOICE, UNDERSERVED INDIVIDUALS use photography to capture their personal and community strengths and concerns; engage in critical group dialogue about the photographs; and disseminate their ideas to their communities in photo exhibits (Wang, 1999; Wang & Burris, 1997). Caroline Wang and her colleagues first applied the methodology to study rural Chinese women's reproductive health needs in the early 1990s (Wang & Burris, 1997). Since then, public health researchers and practitioners have applied the method to gain a better understanding of participants' health perspectives, facilitate empowerment, and create a means to translate

research into personal and community advocacy and action (Catalani & Minkler, 2010; Hergenrather et al., 2009).

Photovoice embodies key community-based participatory research (CBPR) principles, such as collaboration between researchers and participants, attention to participants' strengths, and translation of research findings to practice (Israel et al., 1998; Viswanathan et al., 2004). Ideally, the process improves health and well-being through giving participants—who have often been marginalized on the basis of gender, class, race/ethnicity, and other inequities—power and control over the process, and therefore, over solutions (Israel et al., 1998). Thus, photovoice is grounded in the principles of ethical public health practice (Wang & Redwood-Jones, 2001), which highlight the importance of including input from community members in the development of public health policies and programs, and facilitating empowerment of disenfranchised communities (Public Health Leadership Society, 2002).

Adherence to CBPR and public health ethical principles does not happen automatically or without consequences (Green & Mercer, 2001; Israel et al., 1998; Minkler, 2004, 2005; Wallerstein, 1999). Drawing from our experience conducting two different photovoice projects with women living with HIV/AIDS (WLH/A)—the *Sharing Stories* (SS) and *Picturing New Possibilities* (PNP) projects—we identify and discuss the ethical opportunities and challenges associated with using photovoice as an HIV-related CBPR strategy. A growing number of researchers are using photovoice methods with people living with HIV/AIDS (Hergenrather, Rhodes, & Clark, 2006; Marny, McCright, & Roe, 2007; Teti et al., in press). Yet, the social stigma associated with living with HIV/AIDS poses questions about the potential ethical risks of the method. Taking and disseminating images—although central to the power and effectiveness of photovoice—can expose details about participants' lives and identity with HIV/AIDS publicly. The use of images as research data also raises many unique ethical questions worthy of consideration, including the rights of people who take photographs and

who are pictured in them, and how the images are interpreted by the public (Gross, Katz, & Ruby, 1988; Nutbrown, 2011; Schonberg & Bourgois, 2002; Wang & Redwood-Jones, 2001). Examining the balance between the ethical opportunities and challenges raised by using photovoice is critical to maximizing the benefits of photovoice as an HIV-related CBPR strategy.

Methods

IRB Approval and Consent

Sharing Stories and *Picturing New Possibilities* were approved by the primary author's University IRB. After reviewing the project materials with the study PI, each participant signed a project consent, and a release form to share project photographs of their choice in publications and presentations.

Project Descriptions

We implemented SS and PNP to engage WLH/A in discussions about their life experiences, assets, and challenges; and to give WLH/A an opportunity to inform health promotion programs. Women are one of the fastest growing populations with HIV/AIDS (Centers for Disease Control and Prevention, 2011). The epidemic has a disproportionate impact on vulnerable women, including poor and racial/ethnic minority women (*ibid.*). Photovoice presented a way for these women to inform health promotion programs designed to affect their lives.

Both SS and PNP followed the same project format. Each included three group sessions and a photo exhibit. An experienced health educator with a doctoral degree in community health (primary author) co-facilitated the group sessions with a research assistant or a staff member from one of the AIDS Service Organizations (ASO) that served as a primary recruiting center. In session one, we defined the goals and purpose of the project; reviewed the ethics of picture-taking, including general discussions about appropriate and nonappropriate photos and how to obtain permission to photograph others; and trained the participants in camera use. In sessions two and three we facilitated participant discussions about their pictures using a variation of the SHOWeD technique, a well-established technique to guide photovoice discussions (Wang & Redwood-Jones, 2001): What do you **S**ee here? What is **H**appening? How does this relate to **O**ur lives? **W**hy does this problem or strength exist? What can we **D**o about it? The sessions included both individual dialogue and group discussion. During session three we also planned a public photo exhibit and

discussed where to have the exhibit, who to invite, and which pictures to share publicly.

Project Sites

Sharing Stories (SS) took place from November 2009 through May 2010 and included 11 participants from an HIV clinic in a large Northeastern city. *Picturing New Possibilities* (PNP) took place from November 2010 through March 2011 and included 13 participants from an ASO in a mid-size Midwestern city.

Participants

The majority ($n=19$) of the participants in both projects were African American (91%). The mean age of the women was 42 years (range 19–61 years), and on average, they had been living with HIV/AIDS for 10 years (range 1–29 years). Attendance in both projects was high: 91% (21/23) of women recruited attended the first session; 81% (17/21) participants attended all of the intervention sessions; and 62% (13/21) attended the *optional* photo exhibit. The SS exhibit included approximately 20 pictures on display to commemorate AIDS Education Month, at a local HIV/AIDS education event. The PNP exhibit included approximately 30 pictures on display to commemorate National Women and Girls HIV Awareness Day, at an HIV awareness event held at a local community art center.

For the most part, the demographics and experiences of our participants mirrored those of WLH/A who sought services at our recruitment sites, and in the United States overall. Our sample included women facing intersecting sociostructural challenges and inequities, related to their race/ethnicity, gender, socioeconomic, and illness (HIV/AIDS) statuses. These challenges shaped the experiences, narratives, and images that are described in further detail below.

Data Analysis

We took notes during project meetings, collected participant photos, and conducted a group discussion about participants' experiences in the project at the final meeting. We also conducted one-on-one interviews with PNP participants to gain a more in-depth understanding of participant experiences. We digitally recorded all project group sessions and individual interviews. Data for analysis included group transcripts, individual interview transcripts, project notes, and photographs.

The first and second authors reviewed all of the data multiple times to become familiar with the key themes

related to ethical opportunities and challenges. We entered the group and individual interview transcripts into a qualitative software analysis package to organize the textual data, created a codebook describing the key themes, and conducted a content analysis of the data using two strategies derived from Grounded Theory: coding and analytical memos (Charmaz, 2006). In data debriefing sessions, the first and second authors discussed coding, reached a sufficient level of agreement about discrepancies, and made conclusions about key ethical opportunities and challenges.

Choosing photos for the exhibit served as a form of “member-checking,” in which participants reviewed and advised preliminary analyses, and confirmed that these findings represented their experiences appropriately. At the final session we asked participants to choose photos for exhibit display. After performing an initial analysis of the data, we matched photo choices to key themes and quotes in the data. Then we presented a draft exhibit to participants. Participants reviewed the materials and gave input about the exhibit’s overall messages.

Results

Ethical Opportunities

We focus the discussion of ethical opportunities on the way that the projects provided a means to achieve two of the key principles of both CBPR and ethical public health standards (Israel et al., 1998; Public Health Leadership Society, 2002): (1) prioritizing the input of community members (i.e., the participants) in defining their health priorities and public health program needs; and (2) facilitating participant empowerment. We replaced participant names with pseudonyms to protect their confidentiality. Given the nature of the group discussions, in some cases we could not identify the individual speaker, and in these cases we identify the speaker as “participant.”

REDEFINING WOMEN'S PRIORITIES WITH IMAGES: PICTURES OF HEALTH AND TRANSFORMATION

Both photovoice projects (SS and PNP) gave participants a forum to describe their health priorities and health needs by giving them a visual opportunity to define and redefine themselves. Above all, the participants wanted to show others that they were beautiful, strong, and healthy. One of the most common ways that women did this was through sharing self-portraits. For example, Adele said that the very *first* picture she took with her camera was of “me, looking in the mirror to [show] how beautiful I [am].” China shared a self-portrait and said, “This is [me] and I basically love who

I am.” Rubi used the camera to show that she did not “look like she had HIV/AIDS.” While describing her self-portraits, she said, “[I am] the face of HIV today ... a normal person! I call myself the diva, I don’t care what anyone say, I am the diva... Just because you [have] HIV does not mean you are a death sentence.” Roshona made a similar point about her pictures of herself: “I’m a person that looks like they *don’t* have the virus, right...I’m just a person like everyone else in the world trying to survive—who’s *going* to survive.”

In addition to showing current images of their health, the women also used the camera to discover and document healthy transitions from their past to the present. Paula said that the pictures allowed her to *see* how she had changed. Similarly, Sharnelle photographed a restaurant that had burned down, but was in the process of “reconstruction” (Figure 1). She compared the reconstruction process to herself:

Sometimes we feel like with HIV or any other chronic illness that we were burnt down. But in the end, this will be rebuilt into something. I’m at a place in my life where I want to be resurrected... I’m in a place where I want to release a lot of stuff, a lot of anger, a lot of hurt, a lot of pain—my daughter’s father, the stupid guys that I’ve even talked to, the hurt behind relationships, growing up in a single-parent household. I want to let that go, so I can move forward and become a better-looking IHOP. I’ll call this picture “reconstruction.”

The participants were able to express their strengths in their photos. Showing that progress and transformation were possible, the pictures also confirmed that the women were not confined by their past—they could make positive and life-confirming changes.



FIG. 1. Reconstruction.

EMPOWERMENT: ACTION TO SOLVE PROBLEMS

In addition to giving women a space to re-invent and re-present themselves, SS and PNP facilitated participant empowerment by giving women a forum to identify challenges, and a medium through which they could affect personal and community action. For example, Bobbi took a series of photographs of her poor housing. In one image she showed how she dragged a refrigerator to her apartment (Figure 2): “I drug the refrigerator to the house by myself... No one wanted to pick it up ‘cause it was in the trash... [but] I’m looking to see what I can use and make my house better.” It was painful for Bobbi to document her housing, but she wanted to use the pictures to bring about change. She shared her pictures with church members, who helped her to secure a new refrigerator (Figure 3). Bobbi called the new refrigerator a “victory” and a “triumph,” but acknowledged that it did not resolve her larger housing issues. At the community photo exhibit (two months after the project group sessions ended), Bobbi reported that members of her church also helped her move to better housing—proving that she could use the pictures to help better her living environment.

Many women took action to change their communities in addition to their own lives. Alysha expressed significant concerns about dilapidated buildings in her own neighborhood. She took a series of pictures of the buildings and shared them with local leaders (Figure 4):

My main thing was the buildings...Seeing maybe if I could get pictures and talk about it, then I wouldn’t be so mad about it. I was showing the pictures to a [neighborhood leader]... and he asked, “Is it safe for the kids?” I told him, “No, it’s not safe, because we have accidents in these buildings. By



FIG. 3. New refrigerator.

these buildings standing here, just sitting here [falling down], it’s giving pedophiles an easier place to take these kids. We don’t need that.

Then Alysha started encouraging other community members to take action. Her efforts resulted in getting the buildings torn down. She explained the importance of expanding her neighbors’ conversations beyond each other to accomplish this task, “If you open your mouth and talk to them [local leaders and politicians] instead of talking to each other, things will happen—a lot of things will start changing ... Closed mouths don’t get fed.” Once the buildings were torn down, she converted the space into her own community garden (Figure 5). She explained, “I done planted my seeds... I’m going to put another board up there. It’s going to say, Alysha’s Garden—Alysha’s successful garden. I’m going to plant



FIG. 2. Old refrigerator.



FIG. 4. Dangerous buildings.



FIG. 5. Community garden.

a lot of different vegetables and fruits and stuff.” Reflecting on the process she said:

I like looking at this picture [of the buildings] because it lets me know that I can do something and I can actually complete it and feel good about it. When I get depressed about my HIV status, I can look back at pictures like this...they will put a smile on my face because I don't have to sit here and stress about this [HIV]...It gives me a positive thought about things I can do in my life and not be down and out and stressed and depressed about it.

Several other women aimed to affect change in their communities by educating people about HIV/AIDS. For example, Yasmine wanted to educate youth with her photos, and developed an idea for an HIV prevention billboard—a picture of all of her medicines, explaining (Figure 6):

I would have this picture on a billboard versus a condom... Make 'em think...I mean, would you rather be stuck taking a bunch of pills all your life or wrap it up [wear a condom]? Sometimes you can take the simplest thing and people pay more attention.

Ethical Challenges

Taking and sharing pictures also presented ethical challenges. We anticipated that the ethics of images would be an important aspect of the project. In fact, we devoted a portion of the first session of each project to discussing potentially inappropriate pictures for group discussion and public viewing, such as pictures of others who might not want to be photographed, images that could upset



FIG. 6. Medicines for HIV/AIDS education billboard.

viewers, or images that could identify unwanted participants as living with HIV/AIDS. However, we did not anticipate the complexity of the ethical challenges raised by the project processes for participants. We describe in more detail below several of those specific ethical challenges, related to HIV disclosure, illicit activities, and photographs of others.

HIV STATUS DISCLOSURE

Our project enrollment criteria required participants to be open to discussing their lives with other WLH/A. We did not require participants to reveal their identity for the photo exhibit. Attendance at the exhibit was optional, photographs could be authored with pseudonyms or remain unnamed, and women could *choose* pictures for display. If women did choose to identify themselves in their pictures for exhibit, we explained that this could “out” them as a woman living with HIV/AIDS. We discussed photographs that could identify women (e.g., self-portraits, children, detailed pictures of homes or schools, etc.) as well as photographs that could display important aspects of women's life or health, without revealing who they were (e.g., hobbies, medicines, general pictures of environment). Given the scope of options provided by these guidelines, we expected that some women would choose to be open about their HIV status through their photos, while others would remain more private—and that the projects would be tailored to meet the needs of diverse women. We did not anticipate the extent to which women reflected on the role of disclosure in their lives; the stress related to the act of, or consideration of, disclosure; or how difficult it would be to balance the needs of women at different phases of the disclosure continuum in public exhibits.

On one hand, many participants embraced the project, and in particular the public exhibits, as opportunities to express their commitment to being open about their status. China said the project was a chance to show she was not afraid, “I’m not scared of takin’ a picture of me. I’m not scared of how people treat a person with HIV—it is what it is. I have HIV.” Yasmine took a picture of a photograph of herself featured on the front page of a local newspaper. She explained proudly that the picture “means the struggle’s over and I don’t have a problem putting my name to nothing.” Likewise, Maureen explained she had already spoken about HIV/AIDS on television, and this was another chance for her to express herself openly.

On the other hand, other participants struggled with the decision to reveal themselves publicly with their photos. For example, Melodie noted her reluctance: “People aren’t accepting, willing and understanding... I have been through numerous rejections, breakups, just different type of stuff all because of my situation [HIV].” Instead, Melodie photographed her environment to express her experiences. Tina was particularly concerned about losing her job because of her HIV status. Although she reported that she found the project very meaningful—that it helped her to “spread out more,” “get a whole new vision on life,” and get out of her “tunnel [which prohibited her] expansion”—she chose not to share her photos publicly or attend the exhibit. Other women wanted to reveal more about their lives in their photos, but refrained in order to protect their families. For example, Camille described the effects of stigma on her children at school and said that she could not photograph herself because [she had] to “protect [her] children.” Instead, she took a picture of her shadow (Figure 7). Her photo became a powerful symbol of the effects of HIV stigma in women’s lives.

It was difficult to balance the needs of participants who were at different stages of the disclosure continuum in photo exhibits. We planned the exhibits collaboratively with participants. To ensure that the exhibits were comfortable for the greatest number of participants, they took place at small, local HIV/AIDS events. Several participants were dissatisfied with the relatively small nature of the photo shows. For example, Maureen voiced her concerns about the exhibit’s limits:

[The exhibit] was not what I envisioned. I thought it would have been cool if the people who felt comfortable could actually take five, ten minutes and talk about their pictures—how an artist talks about their paintings... [If] there are a couple of [participants] that don’t want their names out there or whatever, [then] they don’t have to do it... Because it just felt like people were looking at it and there was no connection to who it was, you know.



FIG. 7. Shadow of woman with HIV.

Exhibits were cost intensive, and our budget did not allow us to do multiple exhibits to meet different participants’ needs. Thus, to enhance visibility for participants who wanted more time to discuss their photographs, we offered women additional opportunities to talk to the media (radio, television) about their photographs and experiences. Three different women did radio shows and one did a television interview. Maureen also gave a lecture about photovoice where she was able to discuss each of her photographs in greater depth, as she requested. Media activities and appearances took place outside of the scope of the research project. When we learned about these opportunities, we contacted women who were interested, and helped women to participate accordingly.

ILLICIT ACTIVITIES

The participants had mixed feelings about whether or not it was appropriate to photograph pictures of incriminating behavior. Some women were adamant that drug use, for example, was appropriate for photography, especially because it played a role in their life with HIV/AIDS, while other women did not want these kinds of pictures displayed. Through both group discussions and individual decision-making processes, many women generated creative but nonthreatening ways to picture and share drug use and other illegal activities. For example, one woman photographed the place where she overdosed; another photographed her cat—a major source of support in her life during recovery; another photographed a convenience store parking lot where she traded sex for money. Raquel photographed her ashtray to explain the role that drugs played in her current efforts to manage her stress. She described how each cigarette or joint played a specific role in her life (Figure 8):



FIG. 8. Ashtray.

See that long one sitting up there? I was having a good day. See that one that's balled up and scrunched in? That's baby mama. See that one that's empty right there—looks like it's lit and wet a little bit? That's my boyfriend. And that roach over there? That's my [daughter].

These kinds of photos (e.g., the ashtray, the parking lot, the cat) helped women to process these experiences and share them with others, while protecting themselves at the same time.

PHOTOGRAPHING OTHERS

Our project consent process included two steps, to protect participants and the subjects in their photographs. First, participants signed project consents as per the University IRB process. The project consent provided participants with an opportunity to agree to all project activities. The second form of consent was a photo release. The release served two functions. First, by signing the release, participants released specific photographs (of their choice) for use by the project (University) for public exhibit or publication. Second, if participants wanted to photograph others, our IRB process required them to have the people in the photographs sign release forms. We advised participants not to photograph others who did not want to be in the picture.

The release challenged the participants in multiple ways. On one hand, participants struggled with the idea of a release form because they feared it would inhibit their picture-taking ability. Moreover, it was uncomfortable because it was not something that they were used to doing when they took photographs. As a result, participants often brought photographs to the group sessions, insisting that the person in the photo agreed to be pictured, but

failed to sign a release. This often caused disappointment, especially when a participant could not share a photo. For example, Yasmine described how her family was very disappointed that they were not part of the public exhibit:

[My cousins went to the exhibit and said], "We are not up there." I said, "Nobody signed a release form." So, now everybody was like, "That's not fair." I said, "You didn't sign the release form." So now I have a stack of papers at the house with all of these release forms they finally brought back. But, now it's over.

Nonetheless, we explained that this policy, although perhaps not always logical for every participant or situation, was important to protect people in the photos and the participants themselves. Taking a picture of a person without their permission could upset the person in the picture, and put the photographer in danger.

For example, Melodie wanted to photograph the person who infected her with HIV/AIDS, to hold him accountable publicly. The group discussed that it was not only inappropriate for her to photograph him without his permission, but it was also not safe for Melodie. We brainstormed other ways for her to express her frustration over her situation. Instead, she photographed a pile of court letters to represent the time and energy she put into the legal proceedings. She explained the letters and the results of the trial:

Those are all the letters. It took them a year and some months when I was out of work—papers and letters, that I have...He got no chance of probation. Had I not went through with this and said anything, he wouldn't have stopped [infecting others with HIV/AIDS]. I know him personally. He wasn't going to stop.

Detailed conversations about participants photograph plans, and the purpose and importance of the release, helped to assure that women's photographs did not put them or photograph subjects in harm's way.

Discussion

We explored both the ethical opportunities and challenges associated with the use of photovoice among women living with HIV/AIDS. Examples from *Sharing Stories* (SS) and *Picturing New Possibilities* (PNP) indicated that photovoice supported two key ethical principles of public health practice, by providing women with a means to inform public health practice with their experiences, and by facilitating participant empowerment. Our findings support a growing body of research that indicates that CBPR is an effective way to involve

people at risk for and living with HIV/AIDS in the development of HIV/AIDS-related research questions, and the translation of HIV/AIDS research into practice (Corbie-Smith et al., 2011; Griffith et al., 2010; Rhodes, 2006; Rhodes et al., 2010; Rhodes et al., 2007).

Photovoice also offered additional and unique opportunities beyond traditional CBPR projects for WLH/A to participate in research. This was particularly important given that our participants were contending daily with challenges and discrimination related to the intersection of various sociostructural forces, such as HIV/AIDS, gender, socioeconomic, and racial/ethnic status-based inequities. For example, women re-presented and redefined themselves visually with photographs. These images countered stereotypical images of WLH/A as sick, powerless, or unhealthy that are often portrayed in society (Herek, Capitanio, & Widaman, 2002, 2003). Through photovoice, women expressed their health priorities by redefining themselves and what “health” meant to them.

The images also provided a way for WLH/A to disseminate their ideas more widely, and more powerfully, than using words alone. For example, Bobbie illustrated the extent of her housing challenges with graphic pictures of her poor living conditions, and her church congregation helped her to obtain new housing. Alysha provided evidence of dangerous buildings through photos that she shared with community leaders, who helped her resolve that problem. In these examples, participants actually translated the research findings to practice and affected policy changes themselves.

We also identified key ethical challenges to using photovoice with WLH/A. Although many CBPR researchers and practitioners have written about the ethical challenges associated with CBPR in general (Green & Mercer, 2001; Israel et al., 1998; Minkler, 2004, 2005; Wallerstein, 1999), our ethical challenges were somewhat unique to the use of images in the context of HIV/AIDS stigma. Our findings confirm existing research that indicates that HIV/AIDS stigma plays a powerful and damaging role in WLH/A’s lives (Carr & Gramling, 2004; Sandelowski, Lambe, & Barroso, 2004; Wingood et al., 2007). Our experiences also revealed that photovoice may put WLH/A in a position where they need to confront the effect of stigma on themselves and their families, and balance the positive consequences of sharing their lives with others, with the negative consequences of revealing themselves visually and/or publicly.

Our research was subject to several limitations. First, it was limited to the experiences of 21 WLH/A in two cities, and does not represent the views of all WLH/A. Moreover, we recruited women who were willing to talk

openly about living with HIV/AIDS with other women. Women who are not comfortable disclosing their HIV status would likely report different experiences using photovoice. We also did not collect data to understand the reactions or changes among people who viewed the photographs. Lastly, we conducted follow-up interviews with women in one project (*PNP*), but not both. Group and individual level data provide very different forms of information, and it would have been valuable to have both perspectives from both study sites.

Best Practices and Recommendations

Consent Process. A three-step process protects both participants and people in the photos: (1) a project consent that outlines all project procedures; (2) a consent to release specific photos of participants’ choice for public exhibit and publication; and (3) a photo release form to include others in photographs.

Release Forms. Explain the photo release forms to photograph others in detail, and allow participants to practice asking permission and completing the forms, to help them gain comfort with the process. Encouraging people to take many photos and diverse photos (e.g., people, places, objects) can help diminish disappointment if a participant cannot use a picture of a person because they do not have a release. Oral releases may also be an option, depending on IRB requirements and approval processes.

Picture-taking Plan. Discuss photo ethics with participants, including conversations about what kinds of pictures they might take. By giving participants an option to talk about what they plan to photograph, facilitators and participants can problem-solve situations together that could jeopardize participant safety.

Meeting the Needs of Diverse Participants. Photovoice projects can benefit and include participants who are open or private about their identity with HIV/AIDS. Program leaders can help participants identify pictures that meet their needs. We reiterated that revealing one’s identity was not necessary to take and share meaningful pictures or messages.

Adequately Addressing Status Disclosure. Program leaders should plan for difficult discussions about personal issues such as HIV status disclosure, and encourage participants to disclose personal issues publicly only when they feel completely comfortable. Remind participants that each person’s decision about disclosure is respectable and valid—that there were no wrong ways to express oneself safely.

Internet Photo Sharing. Although Internet social networking sites are increasingly common and desirable

ways to share information, program leaders should discuss the additional challenges posed by these communication media.

Collaborative Exhibit Planning. Given the challenges associated with HIV stigma and disclosure, we recommend making the exhibit an optional part of the process. Program leaders can also allow participants to choose pseudonyms to author their work, choose the photos and captions for the exhibit, and review and approve the exhibit. Planning an exhibit collaboratively means that there may be disagreements about the scope and location of the exhibit. We suggest choosing an exhibit plan that feels safe for all participants.

Ongoing Support. Help participants access the necessary support services and referrals that they need to continue to resolve the problems that they identify in the program, once the formal sessions are over.

Educational Implications

The best practices identified above make excellent workshop issues for discussion by any researchers or IRB members concerned with photovoice methods.

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Authors' Biographical Sketches

Michelle Teti has been conducting HIV prevention and sexual health research with women living with HIV/AIDS for eight years. Her expertise is in qualitative methods and participatory action research methods. She was the Principal Investigator of both *Sharing Stories* and *Picturing New Possibilities*. She designed, implemented, and evaluated both projects, and wrote the majority of this article.

Cynthia Murray is a Research Assistant for the *Picturing New Possibilities* project and has analyzed photographic and textual data from both projects, including the data in this article.

LaShaune Johnson is a community-based researcher whose work focuses on addressing health disparities and chronic disease. She has expertise in photovoice methods and helped to write and revise this article.

Diane Binson has been conducting HIV prevention and sexual research for over 20 years. She is a Co-Investigator on the *Picturing New Possibilities* project and has collaborated with Michelle Teti to design, implement, and analyze data from both projects, including the data in this article. She helped to write and revise this article.

References

- CARR, R. L. & GRAMLING, L. F. (2004). Stigma: A health barrier for women with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 15(5), 30–39.
- CATALANI, C. & MINKLER, M. (2010). Photovoice: A review of the literature in health and public health. *Health Education and Behavior*, 37(3), 424–451.
- Centers for Disease Control and Prevention. (2011). *HIV/AIDS among women*, August 10. Retrieved April 24, 2011 from <http://www.cdc.gov/hiv/topics/women/>.
- CHARMAZ, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage Publications.
- CORBIE-SMITH, G., ADIMORA, A. A., YOUMANS, S., MUHAMMAD, M., BLUMENTHAL, C. ET AL. (2011). Project GRACE: A staged approach to development of a community-academic partnership to address HIV in rural African American communities. *Health Promotion Practice*, 12(2), 293–302.
- GREEN, L. W. & MERCER, S. L. (2001). Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? *American Journal of Public Health*, 91(12), 1926–1929.
- GRIFFITH, D. M., PICHON, L. C., CAMPBELL, B., & ALLEN, J. O. (2010). YOUR Blessed Health: A faith-based CBPR approach to addressing HIV/AIDS among African Americans. *AIDS Education and Prevention*, 22(3), 203–217.
- GROSS, L., KATZ, J. S., & RUBY, J. (1988). *Image ethics*. New York: Oxford University Press.
- HEREK, G. M., CAPITANIO, J. P., & WIDAMAN, K. F. (2002). HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991–1999. *American Journal of Public Health*, 92(3), 371–377.

- HEREK, G. M., CAPITANIO, J. P., & WIDAMAN, K. F. (2003). Stigma, social risk, and health policy: Public attitudes toward HIV surveillance policies and the social construction of illness. *Health Psychology, 22*(5), 533–540.
- HERGENRATHER, K. C., RHODES, S. D., & CLARK, G. (2006). Windows to work: Exploring employment-seeking behaviors of persons with HIV/AIDS through photovoice. *AIDS Education and Prevention, 18*(3), 243–258.
- HERGENRATHER, K. C., RHODES, S. D., COWAN, C. A., BARDHOSHI, G., & PULA, S. (2009). Photovoice as community-based participatory research: A qualitative review. *American Journal of Health Behavior, 33*(6), 686–698.
- ISRAEL, B. A., SCHULZ, A. J., PARKER, A., & BECKER, A. B. (1998). Review of community-based participatory research: Assessing partnership approaches to health. *Annual Review of Public Health, 19*, 173–202.
- MAMARY, E., MCCRIGHT, J., & ROE, K. (2007). Our lives: An examination of sexual health issues using photovoice by non-gay identified African American men who have sex with men. *Culture, Health, and Sexuality, 9*(4), 359–370.
- MINKLER, M. (2004). Ethical challenges for the “outside” researcher in community-based participatory research. *Health Education and Behavior, 31*, 684–697.
- MINKLER, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health, 82*(2 Suppl. 2), ii3–ii12.
- NUTBROWN, C. (2011). Naked by the pool? Blurring the image? Ethical issues in the portrayal of young children in arts-based educational research. *Qualitative Inquiry, 17*(1), 3–14.
- Public Health Leadership Society. (2002). *Principles of the ethical practice of public health*. New Orleans: Public Health Leadership Society.
- RHODES, S. D. (2006). Visions and voices: HIV in the 21st century. Indigent persons living with HIV/AIDS in the southern USA use photovoice to communicate meaning. *Journal of Epidemiology and Community Health, 60*(10), 886.
- RHODES, S. D., BISCHOFF, W. E., BURNELL, J. M., WHALLEY, L. E., WALKUP, M. P. ET AL. (2010). HIV and sexually transmitted disease risk among male Hispanic/Latino migrant farmworkers in the Southeast: Findings from a pilot CBPR study. *American Journal of Industrial Medicine, 53*(10), 976–983.
- RHODES, S. D., HERGENRATHER, K. C., DUNCAN, J., RAMSEY, B., YEE, L. J., & WILKIN, A. M. (2007). Using community-based participatory research to develop a chat room-based HIV prevention intervention for gay men. *Progress in Community Health Partnerships: Research, Education, and Action, 1*(2), 175–184.
- SANDELOWSKI, M., LAMBE, C., & BARROSO, J. (2004). Stigma in HIV-positive women. *Journal of Nursing Scholarship, 36*(2), 122–128.
- SCHONBERG, J. & BOURGOIS, P. (2002). The politics of photographic aesthetics: Critically documenting the HIV epidemic among heroin injectors in Russia and the United States. *International Journal of Drug Policy, 13*, 387–392.
- TETI, M., MASSIE, J., CHEAK-ZAMORA, N., & BINSON, D. (2012). Photos to “show the world what we’re going through”: Women use images to talk about living with HIV. *Journal of Applied Arts in Health*, in press.
- VISWANATHAN, M., AMMERMAN, A., ENG, E., GARLEHNER, G., LOHR, K. N., GRIFFITH, D. ET AL. (2004). Community-based participatory research: Assessing the evidence. In *AHRQ evidence report summaries*. Rockville, MD: Agency for Healthcare Research and Quality.
- WALLERSTEIN, N. (1999). Power between evaluator and community: Research relationships with New Mexico’s health communities. *Social Science and Medicine, 49*(1), 39–53.
- WANG, C. (1999). Photovoice: A participatory action research strategy applied to women’s health. *Journal of Women’s Health, 8*(2), 185–192.
- WANG, C. & BURRIS, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education and Behavior, 24*(3), 369–387.
- WANG, C. & REDWOOD-JONES, Y. A. (2001). Photovoice ethics: Perspectives from Flint Photovoice. *Health Education and Behavior, 28*(5), 560–572.
- WINGOOD, G. M., DICLEMENTE, R. J., MIKHAIL, I., MCCREE, D. H., DAVIES, S. L. ET AL. (2007). HIV discrimination and the health of women living with HIV. *Women and Health, 46*(2–3), 99–112.