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PRACTICE-BASED REPORT

Voices of African American Health: stories of health and healing

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Few creative methodologies have been used in minority and underserved communities to elucidate the health challenges they face. Photovoice is a qualitative method that enables individuals to share their experiences with a given topic, such as chronic illness, through photography and inspires positive community action. Voices of African American Health was a photovoice project in which 24 African Americans living in the Piedmont Triad region of North Carolina took photographs and journaled about their experiences with chronic disease over a four-week period. Stories and photos that emerged from this program fell into four broad themes: limited health care access and perceived poor quality of care; religion and spirituality; expression and release of emotion; and coping mechanisms. This project used artistic means to enable community members to portray their experiences with chronic disease as a means to increase awareness of minority health. A traveling art exhibit showcases participants' photographs and journal vignettes, allowing them to share their stories with viewers from a diverse audience.

Keywords: African American; photovoice; community health; storytelling; photography

Introduction

While many initiatives have sought to raise awareness about minority health, few have used creative, multidisciplinary methodologies. The current project, Voices of African American Health (VAAH), used photovoice and storytelling to help an African American (AA) community explore and articulate personal stories of illness and healing and to contextualize minority health.

Photovoice is a qualitative methodology in which participants use photography to record their communities' strengths and challenges. Through photovoice, community members explore their own stories from *emic* (internal) perspectives, promoting the identification and examination of factors that outsiders may overlook. Therefore, the approach yields a deeper understanding of health phenomena that can inform interventions to improve health outcomes for minorities (Castleden, Garvin, & Huu-ay-aht First Nation, 2008).

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A basic premise of photovoice is that *images teach* (Wang, 1999). Through photography, people can communicate their experiences in a manner that transcends words. Community members can educate influential advocates in the community, such as policymakers and gatekeepers, on the issues most important to the community. Stakeholders can learn through the pictures what it is like to live in that community, survive a certain condition, and overcome related challenges (Baker & Wang, 2006; Wang, 1999; Wang & Burris, 1994, 1997).

Using photovoice methodology and journaling, an academic medical center partnered with a local community arts organization to implement Voices of African American Health. The program aimed to (1) illustrate the experiences of African Americans living with or caring for someone with chronic disease, and (2) create a forum through which photographs and words can communicate these experiences to increase public awareness of AA health.

Program Description

VAAH was a program conducted in a well-established AA community in the Piedmont Triad region of North Carolina (NC). The Society for Arts in Healthcare (TheSAH) provided funding for the project under its Johnson & Johnson grants. The project targeted AA individuals who have been affected, first-hand or as caregivers, by one or more of the major disparity areas identified in *Healthy People 2010*: cancer, cardiovascular disease, diabetes, HIV/AIDS, immunizations, and infant mortality; plus the minor areas of mental health, hepatitis, syphilis, and tuberculosis (US Department of Health & Human Services, 2000).

Twenty-four AA individuals, aged 29–74, completed the project. All but three were female. Recruiting proved difficult at first for reasons we do not understand; however, we were able to reach our target using assistance from a community advisory committee. We did not assess education and income, as the community partner felt these questions would be inappropriate and decrease participation. The academic partner's Institutional Review Board provided human subjects oversight and protection. Each participant provided informed consent, which included notification and agreement to the project's methodology, public exhibition, and dissemination beyond this exhibition.

Participants remained actively engaged with the project for approximately two months. First, they attended two two-hour training sessions at the community partner's art gallery, during which they learned basic photography and storytelling skills. Internationally known professionals conducted both of these sessions. For one month, participants took photographs and wrote corresponding journal entries. The photo assignment was, "Show us what it is like to live with your illness or to care for someone living with chronic disease." Participants had the opportunity to meet weekly with a local writer to discuss their successes and challenges with communicating their stories. The ground rule set for this project was that it was up to participants' discretion as to what their pictures showed; if they took pictures that showed their face, the potential existed for them to be identified. Thus, maintenance of confidentiality remained in the control of the participants.

At the end of that month, the participants returned to the art gallery and took part in two discussion sessions (for journaling and photography). During these sessions, participants discussed what the photovoice process was like for them, shared their pictures and journal entries with one another, and detailed the process they used to determine which pictures to take and how to tell their stories. Two trained facilitators led these sessions and took process notes.

Finally, participants attended a focus group to provide feedback to the project team regarding their successes and challenges with photovoice.

At the end of the project, we created a formal art exhibit to display the participants' stories of AA health. We chose 40 representative entries from over 1000 photographs and 24 journals, and all participants' voices were represented. This exhibit continues to travel and be displayed in health care and arts settings around the state. We kept a log of exhibit visitors and encouraged them to share their comments about the exhibit.

Evaluation

Process Evaluation

Process evaluation took place via focus groups, during which participants discussed their photovoice experiences, recounted challenges they encountered, and provided recommendations for future projects. Specifically, the groups focused on journaling, photography and the discussion sessions.

Journaling proved challenging for many participants, but it was also cathartic and validating. They felt the process freed them to talk to someone who would not talk back and was therefore a means to express themselves freely. Some participants felt the process was painful, but they expressed that working through the pain helped them begin to heal. One participant stated, "Some days you are writing and the tears are running and you want to say, 'okay, I don't want to do this anymore,' but you can't give up that easy." Someone else noted, "[The process] made me feel more grateful . . . that I'm still here, that God let me stay here, and I'm here for some reason. [It] made me aware of the fact that there are people a whole lot sicker than I am."

When asked about the photography, most participants stated that they enjoyed taking pictures and that this process also was healing for them. They described facing "old wounds" and finding peace; the pictures helped them initiate a journey of exploring emotions about the past and reaching newfound understanding of their experience. For example, a female participant whose daughter had died from HIV/AIDS shared, "Taking pictures of my daughter's things brought a feeling of finality, closure." Another participant related photographs as spoken words that told her story: "Getting it out, it breaks you down a little bit. It hurts to say it out loud but it helps to say it out loud, too." The participants reported that the process enabled them to tell their stories in their way, through their own eyes. As one man stated, "What if the pictures aren't great? What is important is the story."

Participants felt the discussion sessions promoted self-reflection and connectedness with one another. They appreciated freedom from censorship and the opportunity "for people to be people." Participants reported appreciating the opportunity to tell their stories and to listen to others' stories. A participant noted that hearing about others' journeys "made me more compassionate about other people's illness." Another benefit of the discussion sessions was the opportunity to network; participants reported that they were "coming full circle to be able to help each other" and "do something more to help others."

These process measures indicate that the project was successful in promoting cohesion among participants and that this storytelling process adhered to the spirit of photovoice. Participants made connections with and taught one another about their lives through their photographs and journal entries, discovering in the process that they had more in common than they had imagined.

Outcome Evaluation

The main data from the project were photographs and journal entries; transcripts of the discussion sessions supplemented these items. To derive meaning from the data, the study

team conducted qualitative analysis using the grounded theory methods described by Arcury and Quandt (1998). Four primary themes emerged: (1) feelings of limited health care access and perceived low healthcare quality; (2) the significance of religion and spirituality in healing; (3) the role of emotion; and (4) the development of coping mechanisms. Prior to analysis, transcribed journals were de-identified. As identification through photographs was in the hands of the participants, the project team did not alter any photographic data.

Limited healthcare access and poor healthcare quality. Many participants expressed their frustration with the low quality of care they felt they received as users of the healthcare system. Some felt that this was due to their African American heritage, whereas others felt it was simply a reflection of the system as a whole. Some participants noted that it was important that people take charge of their care rather than allowing the system to dictate their treatment. However, they stated that doing so requires some level of medical expertise or experience with the system. A participant with breast cancer noted:

I still did not have a primary care physician, so again I called my GYN physician and asked him to schedule a biopsy for me. He tried to get me to come and let him examine the area, that it was probably a clogged duct. I insisted on a biopsy. But what about those people who don't know about the system, who can't fight?

Some participants did not feel they could trust their providers; one person reported, "Many doctors in this system just try to load patients up with medication they don't need." Other participants stated that they did not receive accurate diagnoses or timely proper medical treatment or felt that the healthcare staff did not treat them with simple kindness and respect. A participant shared:

Since caring for my mom, I've had confrontations with two of her doctors who I later fired. They were not providing her with the best care.... It took not being a "lady" and a "professional" to let these doctors know I would not tolerate the lack of patient care and their failure to grasp my mom's healthcare needs.

There was also distrust of the system itself. As a participant said about her brother, who had had a kidney and pancreas transplant, "Medicaid stopped his coverage for anti-rejection medications after ten years because he lived too long."

Religion and spirituality. Participants described the role of religion and spirituality in their lives (Figure 1). They felt religious beliefs strengthened them and helped them face the emotional and physical challenges inherent to living with chronic illness. Pictures that supported this theme included shots of churches, crosses and devotional household items. One participant wrote, "If you've got God with you, you can walk through anything. You don't have to worry about all those obstacles that get in your way; you can make it."

Spirituality was more than a coping strategy; participants viewed God as a healer who worked in tandem with the medical professionals but ultimately decided how their illness progressed. One participant said, "If God chooses to take me today, there's nothing I can do about it. I've had a good life. It hasn't been an easy life, but it's been a good life." Many participants stated that, if they lived through their illness, they had a greater purpose to fulfill. For example, a cancer survivor wrote about the day she was diagnosed: "I asked God, 'Why me?' A second later I heard a voice say, 'Why not you?' Maybe it is because I can talk to women and men about early detection and taking care of their health."



Figure 1. An Image of a Cross over Ground Zero Brings to Mind the Importance of Spirituality in the Face of Suffering.

Expression and release of emotion. Participants reflected upon emotions they experienced as survivors of illness or caregivers for people living with chronic disease and discussed how these emotions were important in healing. Participants took pictures of themselves releasing their emotions; for instance, one woman suffering from mental illness photographed herself wringing her hands. As one female participant said, reflecting on having cancer “makes you mad a little bit – you have to be mad, but you’re stronger.” Other participants expressed gratitude and happiness to have survived their condition thus far. Some even took pictures of themselves receiving treatment. One cancer survivor, who had been given two years to live by his providers, wrote on his two-year anniversary, “Today I celebrate life” (Figure 2).

Another cancer survivor wrote:

Laugh at cancer. Yes you can. Cure cancer with laughter, no, but a growing body of evidence says that laughter can make a difference in the physical functions that can lead to better health. Laughter is medicine that has been around a long time and promoted by researchers as a way to control the uncontrollable.

Many participants expressed feelings of loss – of freedom, loved ones, life or lifestyle, or even of a body part. For example, a female participant who had had a mastectomy wrote, “I understand how an amputee feels now. I have lost a part of my body, and I have an ugly scar to prove it... It makes you feel less of a woman, physically and emotionally.” A participant who lost a baby close to term wrote, “When my milk came in, I wished I was dead. Breastfeeding meant so much to me. I had the hormones, no baby. I had the milk, no baby. I had the wounds, no baby.” She took a corresponding photo of an empty playground (Figure 3).

Coping mechanisms. Participants discussed the coping strategies they developed while navigating the challenges of living with chronic illnesses. Some relied on the support of



Figure 2. A Man Receives Chemotherapy but Celebrates Life.



Figure 3. An Empty Playground where a Mother's Child might have Played.

family and friends to help get them through difficult periods. For many participants, coping meant helping others by volunteering, speaking publically about their illness and early screening, or providing encouragement to others. Participants took photographs of themselves getting mammographies or otherwise helping other people. A breast cancer survivor wrote:

After being home for a couple of months, I felt a void in my life. I wanted to reach out and touch another sister [who] was suffering. I called Cancer Services. I have been volunteering since then To see a smile on a young or older woman's face during your visit and to give them a hug reassuring them that they are not alone was and is the biggest reward.

For others, coping meant making themselves look and feel better. For example, a female participant who was living with lupus wrote:

Now I do what it takes to make me feel comfortable. If it takes a wig to make me feel good, I do it. If it takes make-up to make me feel whole, I do it. If it takes dressing up to help me to love me, I do it. When I feel like I look good, I feel better about myself. This is a part of my mental healing. The physical healing means taking the medicine as directed by the doctors, eating properly and exercising regularly.

This participant also took pictures of the make-up and accessories she uses to help herself feel better (Figure 4).

Photovoice Exhibit

We evaluated the final exhibit by the number of attendees who came and the feedback they provided. More than 840 people visited the exhibit. Attendees included study participants; policymakers, such as the local mayor, state representatives, county commissioners, and other city officials; community gatekeepers; and community members. Representatives of medical institutions (including two of the area's leading healthcare organizations), hospice



Figure 4. Make-up, Medicine, and Accessories Allow some Individuals to Cope with their Disease.

administrators, and local healthcare providers also attended. Due to the wide array of visitors to the exhibit participants were able to speak directly, through their art, to influential advocates in their community. Community response to the exhibit was supportive, with many persons giving positive feedback via comments in an exhibit journal. For example, one attendee wrote that “the photos and journals are a creative way of displaying health issues occurring in the African American community.”

Challenges Encountered

No significant methodological or ethical concerns arose during the study. Engaging in the photovoice process proved challenging for some participants, as they revisited painful memories and untold stories. We offered referrals for care as needed to support participants in this journey, but no one requested assistance. We implemented the Medical Outcomes Study 36-Item Short Form (MOS SF-36) to measure changes in health-related quality of life, but the term of the project was too short to notice significant differences. We therefore relied solely on qualitative evaluation measures. Future projects would benefit from exit interviews that probed changes participants experienced during the course of the project.

Conclusions and Future Plans

Photovoice is a unique participatory method that can be applied to any community, though it is especially powerful in allowing people whose voices traditionally go unheard to tell their stories (Wang, 1999). VAAH demonstrated that photovoice is an effective vehicle for illuminating concerns related to chronic disease, the US health care system, and caregiving that a NC AA community faces.

Engaging in photovoice gave participants a chance to share their experiences with health and the healthcare system directly with other community members, healthcare professionals, influential advocates, and policymakers. It was beyond the purview of this study to examine the impact the project had on the community over time – i.e. whether there were any policy changes or changes in providers’ behavior as a result. However, the reach of this project with respect to policymaker and provider behavior could be significant, given that attendees in these positions commented very positively on the powerfulness of the program. Both seeing the photos and reading the vignettes was critical to visitors to the exhibit “hearing” the participants’ stories, which would not have been whole without either of them.

Many “lessons learned” evolved from this study. For example, the art gallery administration wanted to select exhibit photographs based on artistic merit, whereas the university partner preferred to allow the participants to choose them for the sake of fostering community ownership of the end product. These contrasting opinions and preferences should be explored up-front, before the project is implemented, and consensus should be obtained. Furthermore, future studies might consider using digital cameras rather than disposable cameras, as VAAH participants found the disposable cameras difficult and frustrating to use. They wished they could see their pictures as they took them to ensure they captured their subject and meaning accurately. Other projects have used digital cameras successfully (e.g. Hergenrath, Rhodes, & Clark, 2006). Alternatively, participants could use their own personal cameras to increase comfort, familiarity, and confidence in taking photographs. Third, the participants found telling their stories to be quite challenging. Having the support of a local writer helped ease their writing experience; the authors therefore recommend that support be offered to participants as

they tell their stories. Referrals to mental health providers may also be necessary during this process and should be arranged as needed, even though the project is not meant to be therapeutic. Finally, participants requested that fellow community members, rather than professionals, be used as trainers so participants can better relate to the facilitators.

This project has many implications for practice. Photovoice, as a participatory methodology, can be used as part of program planning to identify concerns that the community would like to address and to build a coalition for beginning to address them. Using participatory methods, researchers can get a better feel for the communities they serve, thus tailoring their intervention so it speaks to the community's needs rather than imposing an *etic* (outsider's) perspective on the program. Another practical implication is that photovoice uses arts to tell a story and to spark action; community-based organizations, medical care facilities, and arts and health care organizations could use these methods to create exhibits detailing the personal stories of the individuals they serve. Because the photographer speaks directly to the viewer via his or her photographs, photovoice provides a unique opportunity for provocative storytelling.

Our project provided valuable information about the experiences of one underserved, under-researched community. It is innovative in that it utilizes journalism in addition to photography to enable participants to tell their stories more fully. Moreover, we presented the findings of the project via professional, traveling art exhibit rather than a community forum to increase visibility. Our analyses were simple and straightforward, letting the participants speak for themselves rather than imposing an outsider's viewpoint. Our project emphasized individual voices rather than group responses, so we did not examine differences in the experiences of males and females. We did not feel, knowing these participants, that analyzing the data according to gender would be fruitful or appropriate. However, future programs may benefit from including this element. The project team plans to use the VAAH findings as lessons learned for future participatory action programs in AAs and other underserved communities. Specifically, we hope to use photovoice methodology to encourage members of the NC African American, Latino, and American Indian communities to share what health equity means to them.

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