



Published in final edited form as:

*Health Promot Pract.* 2013 November ; 14(6): . doi:10.1177/1524839912465749.

## Written and Spoken Narratives about Health and Cancer Decision Making: A Novel Application of Photovoice

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### Abstract

Photovoice is a community-based participatory research method that researchers have used to identify and address individual and community health needs. We developed an abbreviated photovoice project to serve as a supplement to a National Cancer Institute (NCI)-funded pilot study focusing on prostate cancer (PrCA) that was set in a faith-based African-American community in South Carolina. We used photovoice for three reasons: (1) to enhance communication between study participants and researchers; (2) to empower African-American men and women to examine their health decisions through photographs; and (3) to better understand how participants from this community make health-related decisions. The 15 individuals participating in the photovoice project were asked to photograph aspects of their community that informed their health-related decisions. Participants provided written and oral narratives to describe the images in a small sample of photographs. Four primary themes emerged in participants' photographs and narratives: 1) food choices; 2) physical activity practices; 3) community environment and access to care; and 4) influences of spirituality and nature on health. Although written and audio-recorded narratives were similar in content, the audio-recorded responses were more descriptive and emotional. Results suggest that incorporating audio-recorded narratives in community photovoice presentations may have a greater impact than written narratives on health promotion and decision-making and policy-makers due to an increased level of detail and personalization. In conclusion, photovoice strengthened the parent study and empowered participants by making them more aware of factors influencing their health decisions.

### Keywords

community-based participatory research; African American; health decision making; photography; qualitative analysis

### Introduction

Photovoice is a form of community-based participatory research that has grown in popularity in health promotion research and health advocacy since its inception in the late 1990s (Wang & Burris, 1997). Developed by Caroline Wang and Mary Anne Burris as a method to improve understanding of individual and community health needs, photovoice empowers individuals and communities through the use of photography (Wang & Burris, 1997). Researchers using photovoice distribute cameras to a group of community members and ask them to document the reality of their lives (Wang et al., 1998). Participants then share and discuss their photographs with one another and with members of the community. Through this process, participants may engage policymakers in critical discussions about community concerns to help initiate social change (Wang, 2004).

In the current study, we used photovoice methodology for three primary purposes: (1) to enhance communication between study participants and researchers, (2) to empower African-American men and women to examine their health decisions through photographs; and 3) to better understand how participants from this community make health-related decisions. With photovoice, these goals are possible because the method creates a participant-driven dialogue between participants and researchers that allows topics and questions to arise that researchers may otherwise not have anticipated. As a participatory method grounded in theories of critical consciousness and empowerment education (Wang & Burris, 1994), photovoice also increases individuals' control over their health and their community's health by raising their social awareness and engaging them in advocacy and policy formation. More specifically, photovoice provides individuals an opportunity to drive change at the individual level, through consciousness raising, and at the community level, through a community-initiated dialogue about community needs. Through this process, photovoice increases community members' self-confidence, critical awareness, and knowledge of possibilities for social change by asking participants to share their lives and listening to them speak about what they know best. (Martin, Garcia, and Leipert, 2010). By improving communication between participants and researchers and enhancing participants' critical awareness, the researchers leading the current study ultimately sought to learn about the ways in which participants make health-related decisions, particularly those related to prostate cancer screening.

The secondary purpose of conducting this photovoice project was to explore the ways in which incorporating individuals' spoken narratives, in addition to their written narratives, could enhance photovoice methodology. Researchers in the field of digital storytelling and auto-photography have enhanced photography projects with audio-recorded narratives (Noland, 2006; Xu, Park, & Baek, 2011), however, there is limited literature documenting the use of oral narratives in photovoice projects, especially initiatives focused specifically on health. Although researchers using photovoice may audio record participants' responses during a project's interview or focus group stage, audio-recorded narratives are commonly not shared with external audiences as part of installations or community presentations. Because photovoice is often used with vulnerable populations, such as those with low levels of educational attainment, literacy, and English proficiency (Kramer, 2010; Martin, Garcia, & Leipert, 2010), it is particularly important to consider ways to enhance the methodology to the meet the needs of participants.

### Project Description

The current study used photovoice to enhance a National Cancer Institute (NCI)-funded pilot study set in South Carolina titled "Promoting the Role of Cancer Research Within an African-American Faith-Based Community: A Focus on Prostate Cancer." Conducted in partnership with a NCI Community Cancer Centers Program, the pilot study was designed to assess African-American men's and women's knowledge and attitudes regarding prostate cancer (PrCA) prevention and screening and to determine culturally appropriate strategies for promoting PrCA research among African Americans in a faith-based community. African-American women were included in the pilot study, as previous research has demonstrated African-American men's reliance on spouses and female family members for health and cancer information and decision making (Friedman et al., 2009; Friedman et al, 2012a; Friedman et al., 2012b).

As part of the pilot study, the research team conducted 22 focus groups with 81 participants. Fifty-six of the 81 focus groups participants (69.1%) participated in a four-week, four-module pilot education program. Photovoice was used with a subset (N=15) of pilot study male participants (n=7) and their female partners (n=8) to further explore issues related to health and cancer decision making through images and written and spoken narratives.

Decision making is a particularly important concept to consider within the context of PrCA due to the current controversy surrounding prostate specific antigen (PSA) screening (Barry, 2009). The PSA test frequently provides false positive results leading to over-diagnosis and treatment of cancers that are too slow growing to be a health threat (Barry, 2009). As a strategy to address uncertainties related to PrCA screening, the American Cancer Society (ACS) strongly recommends shared decision making between healthcare providers and patients regarding whether or not to be screened for PrCA (Smith, 2011). Because of the importance that is placed on shared and informed decision making for PrCA screening, we wanted to use photovoice to learn more about how participants were making decisions about their general health.

## Methods

### Community Setting

This photovoice project took place in Spartanburg, South Carolina, over the course of four weeks. The City of Spartanburg has a population of 37,013, 49% of which is African American. The percentage of residents living in poverty is 23%, and median household income is \$33,276 (U.S. Census Bureau, 2010). The NCI-funded PrCA education study and accompanying photovoice project were conducted at the Spartanburg County Downtown Public Library.

### Photovoice Methodology

The research team aligned photovoice project meetings with the four education sessions scheduled as part of the larger PrCA screening pilot study. At the first session, researchers selected the first 15 volunteers (7 males and 8 females) to participate in a photovoice project that would involve taking photographs of places or objects in their community that influence how they make decisions about their health. At the second education session, the research team distributed consent forms and digital cameras and instructed participants on the basics of photovoice methodology and ethics. Participants also were informed that their photos would be displayed at the closing reception of the larger PrCA education study. Participants were asked to take up to 15 photographs over a one-week period, returning the cameras at the week-three education session. At that time, participants would choose their six favorite photographs to be printed. Participants received a modest incentive when they returned the cameras to the research team.

The research team printed the photographs and returned them to participants at the week-four education session. Along with the photos, the research team distributed a list of five questions based on the set of questions commonly used to guide photovoice discussions known by the mnemonic “SHOWeD” (Wallerstein, 1987; Wang et al., 2004). The modified questions developed for this study were as follows:

1. What do you see here?
2. What is really happening here?
3. How does this relate to how you make decisions about your health?
4. Why does this situation exist in your community?
5. What can we do about it? (If it is a picture of something positive, you may not want to do anything about it.)

Participants were asked to answer the questions on note cards for each of their top three photos. Participants numbered note cards to correspond to the number recorded on the respective photograph. Once participants answered the questions, they were asked to return

the completed note cards along with corresponding photo to the research team. As participants turned in note cards, a member of the research team led participants to a quiet room and recorded an oral caption for participants' same three photographs. Captions were based on participants' oral response to question number three above: "How does this [image] relate to how you make decisions about your health?" Participants' responses were uploaded, transcribed, and entered into NVivo9 software to assist with coding, text retrieval, and data organization (QSR NVivo9, 2010). Through an open coding process, both written and audio captions were reviewed by three of the authors and conceptualized into as many categories as necessary. Codes were then reshaped into categories that represented larger narrative themes (Strauss & Corbin, 1998). Narratives, along with corresponding photographs, were then categorized using these themes. The lengths of participants' written and oral narratives were also compared.

Written responses and digital recordings were used to develop two presentations for the closing reception of the overall PrCA education study. One presentation featured participants' pictures along with quotes from their written responses to the question that asked how the visual image in the photograph related to how they made decisions about their health. The second presentation was in a multimedia format with audio files of the participants answering that same question playing as corresponding photographs were projected on a large screen.

## Results

Of the original 15 photovoice participants, 14 participants ranging in age from 38 to 64 years completed the study. One female participant was unable to complete the project due to family obligations. Forty-three percent of the individuals participating in photovoice were full-time employees, 1 (7%) was a part-time employee, and 7 (50%) were unemployed. Nine (64%) participants had annual incomes between \$20,000 and \$59,999. Half of the participants were high school graduates or had obtained a GED; 4 (28%) had obtained bachelor or graduate degrees; and 2 (14%) had some college or technical training.

In total, photovoice participants provided narratives for 42 photographs. Their written narratives provided in response to answer number three averaged nine words per photograph, whereas audio-recorded narratives responding to question number three averaged 39 words per photograph. Although the audio-recorded and written narratives were similar in content, audio-recorded narratives were more descriptive and provided more examples from participants' lives.

Qualitative analysis of the photovoice images, written narratives, and audio recordings reflected four major themes: 1) food choices; 2) physical activity practices; 3) access to healthcare; and 4) influences of spirituality and nature on health. Although they were not identified as major themes, several of the participants' photographs and narratives reflected themes that aligned with topics discussed at the education sessions.

### Photovoice themes

**Food Choices**—Of the 14 participants completing the photovoice project, nine took at least one photograph of food. When participants reflected on images of healthful food, they commonly mentioned that healthy eating is one action they take to achieve good health (see Figure 1). For example, one female participant reflecting on a photograph she took of healthier packaged food options wrote, "With cancer common in my family, I hope this change [eating healthier foods] helps prolong my health."

Also connecting diet to cancer prevention, a male participant who took a photograph of fried food in a cafeteria line wrote, “A person who eats a lot of fried food is more inclined to cancer than those who eat green vegetables.” Another male participant talked about healthful eating in the context of PrCA specifically stating that eating healthful foods is not only important to maintaining one’s general health but also to preventing PrCA.

Participants commonly mentioned that making healthful eating decisions was difficult due to the availability of unhealthy options. One male participant who took a photograph of a counter-top grill stated, “With all the choices of unhealthy foods that we have, it’s difficult to find different healthy foods you do like.” Further, participants who took photographs of unhealthy foods frequently stated that their food choices were based on convenience. Reflecting on a photograph of a pizza box, one female participant with children said, “This is a quick, fast choice for eating.”

Another commonly stated subtheme related to images of unhealthy food focused on family eating traditions. One female participant who took a photograph of a salt container wrote, “Most African Americans were brought up using a lot of salt.” Another female participant stated that making the decision to bake or fry chicken is difficult “because of the way we were raised—to fry, fry, fry.” Although some participants recognized social and environmental factors influencing healthful eating decisions, most participants still discussed eating decisions as an individual level choice. One female participant wrote, “Choices. We all have to make choices about our health. Choose the one you think is better for your health.”

**Physical Activity Practices**—Nearly half of participants took at least one photograph that reflected a message about physical activity. The narratives participants provided focused on both community-level facilitators and barriers related to physical activity. Participants mentioned places in their communities where they could exercise including a bike or walking track, dance center, and fitness center (see Figure 2). Participants who reflected on photographs of public areas or community centers for physical activity frequently mentioned social elements related to exercise. For example, one female participant who took a picture of her community’s walking trail stated, “The Pride Trail has the entire community up and moving.”

In general, participants’ photographs reflected positive aspects of their community related to physical activity. Only one photograph presented a community-level barrier to physical activity, and that photograph focused on a mound of dirt placed in the middle of a baseball field. Reflecting on the situation, the male participant wrote, “I like to exercise, and as you can see, we cannot exercise on our softball field no more.”

Some participants framed physical activity practices in discussions around recreation and sport, including photographs of footballs, basketball balls, and baseball fields; however, most participants discussed physical activity as a strategy for getting in or staying in shape. Reflecting on a photograph of his bike, one participant stated, “I love riding a bike, and I bike every day back and forth to work. It also keeps me in shape.” Similarly, a female participant wrote in response to a photograph she took of a fitness center, “I go to exercise at a gym so that I can keep my body mass down and help to prevent some health issues.”

Barriers to regular physical activity were similar to those related to healthful eating including time and convenience. For example, reflecting on a photograph he took of an exercise ball in his home, one participant stated, “With the constraints that we have on our life with kids, school, and work, trying to find time for exercise is one of the most difficult things to do.” Thus, participants’ solutions to overcoming barriers related to physical

activity were to make time for exercise and to incorporate small actions throughout the day to stay active. Just as with healthful eating, participants viewed physical activity as an individual-level decision.

**Community Environment and Access to Care**—Nearly half of the participants took photographs of places or locations in their community that influenced their health decisions. Many of the photographs featured images related to access to healthcare. One female participant who took a photograph of a local cancer center said, “This is where I go in order to have my mammogram done once a year so I can protect myself against breast cancer.” Another female participant who took a photograph of hospital wrote, “There are plenty of medical facilities in my surround area to help educate and take care of us.”

Participants also were aware of places in their community that provide services to uninsured or low-income populations. One male participant who took a photograph of a health clinic said, “St. Luke is a place I can go and get help for my sickness because I don’t have any insurance.” Only one participant took a photograph of a negative image in the community environment (see Figure 3). Instead of seeing the situation as discouraging positive health decision, this image motivated the participant to make better health decisions (see caption).

**Spirituality and Nature**—Participants viewed their spirituality and natural surroundings as factors influencing their health. Images related to spirituality included both structures such as churches and natural landscapes. Photographs focusing on nature included images of wildlife, open fields, and wooded areas. Participants provided positive descriptions of how these images influence decisions about health. For example, a participant reflecting on a wooded landscape wrote:

Everything you see is all natural, and because it’s natural, it looks so beautiful. If you take care of yourself and do the right thing and take the proper precautions about your health, then you will look as beautiful of this picture.

Participants who took photographs of nature often discussed the environment as a “godly creation.” One participant who took a photograph of a natural landscape stated that because nature and people are “godmade,” it is important for people to take care of themselves and their surroundings. Another participant took a photograph of the church he attended (see Figure 4), explaining that he prays for his health at church.

## Discussion

### Themes and Content of Parent Study

The themes that emerged throughout the photographs and narratives were reflective of those that emerged in focus groups from the larger PrCA study. Specifically, participants discussed challenges related to time constraints and family practices that prevented them from making positive health decisions about their diet and lifestyle. The role of church and spirituality in maintaining and achieving good health also was a theme that emerged in the focus group transcripts from the larger study and photovoice images and narratives (Friedman et al., 2012b).

A few participants made direct connections between their experience in the photovoice project and the overall PrCA study. This was evident in narratives that included references to PrCA and other cancers and in responses to a question included in the larger project’s final survey asking participants about their photovoice experience. Speaking of her participation in the photovoice project, one female participant wrote, “It helped reinforce the important information that we have been going over the past few weeks.”



All participants responded positively to a question included in the final project survey that asked photovoice participants about their experience in the project. Several participants stated that the photovoice project made them more aware of how they make decisions about their health. One male participant indicated, "Taking the pictures made me more mindful of healthy alternatives." Similarly, a female participant wrote, "I enjoyed taking pictures of things I needed to start doing to stay healthy." Other participants appreciated that the photovoice project allowed them to express themselves and tell others how the community was making it possible for residents to make decisions that promote health.

Participants shared their photographs and narratives with participants from the larger study as well as with the research team from the university and the local cancer center. The photovoice display and presentation were viewed as a positive way to conclude the study as it provided all participants with an opportunity to reflect on the information presented during the education sessions in the context of their community. Further, the photovoice project enhanced the research process by strengthening the communication between researchers and participants and allowing participants to become community researchers and advocates. Much of what participants shared with researchers as part of the photovoice project would not have surfaced as part of the parent study.

Because the photovoice project was conceived as a complementary component of a larger study, the findings were somewhat limited compared to studies using only photovoice methods. Due to time constraints, the research team modified the traditional photovoice protocol to work within the timeframe of the larger study. Thus, the training session was short; there was only one round of taking photographs; and instead of focus group discussions, participants were asked to provide written responses on notecards and audio-recorded responses. Despite these modifications, the photovoice project enhanced communication between participants and researchers regarding decision making and raised awareness among participants about how they make health-related decisions in their communities. In the future, researchers may consider incorporating a photovoice component into larger studies to provide participants with an opportunity to engage in participant-led research.

Researchers may also consider the strengths and weaknesses of providing participants with a specific photovoice question, or topic, to explore. The phrasing of the question for this photovoice project was somewhat broad, resulting in a more general discussion about health. However, findings demonstrating how and with whom participants made important decisions about their health were critical for determining how to engage African-American men, families, and communities in shared decision making about PrCA screening.

### **Practice Implications**

The research team found that the photovoice project enhanced knowledge about both individual- and community-level factors influencing the ways in which African-American men and women make decisions about their health. Researchers should consider adding abbreviated photovoice projects to larger studies to increase participants' involvement in the research process and further explore particularly important public health issues.

The research team also found that there were clear advantages to asking participants to provide oral narratives about their photographs, as participants' responses to a specific question were more prolific when they were spoken as opposed to written. This may have occurred because participants had limited room to write on note cards, had low literacy levels, or felt more confident in their speaking rather than writing skills. The descriptive data gathered through the audio recordings enriched the study's findings by providing greater clarity regarding participants' health perspectives and decision-making behaviors. This

finding suggests that audio-recorded spoken narratives can enhance traditional photovoice methodology and may even be preferred to the collection of written narratives in some circumstances.

Spoken narratives also enhanced the photovoice presentation at the study's closing reception, as the emotion was evident in participants' voices. Such emotion was not apparent in the written narratives, suggesting that audio narratives may have a greater impact on decision-and policy-makers by bringing participants and participant concerns to life. Future researchers and advocates may consider adding an audio component to photovoice presentations and installations. This would move traditional photovoice methodology toward digital storytelling and documentary film, both of which have traditionally combined audio narrative and still images (PhotoVoice, 2012; Whiteman, 2009).

Ultimately, this photovoice project revealed that participants were knowledgeable of the steps they needed to take in their daily life to attain and maintain good health, but there were common obstacles, such as family practices and time limitations, that prevented them from taking action. To address cancer disparities and make it possible for vulnerable populations to make informed decisions that positively influence their health, researchers must understand more about the social, cultural, and contextual influences on decision making. Researchers' success will continue to be largely dependent on individuals' ability to develop an awareness of the ways in which multiple external factors influence health. Reflective of its theoretical underpinnings in critical consciousness and empowerment education, photovoice can help individuals become aware of the socio-economic and structural factors influencing health and identify solutions to improving the health of their communities. As a result, participants are empowered by gaining control over their health.

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**FIGURE 1.**  
This picture relates to how I make healthy decisions about my health because it is of healthy food and healthy drink, and that's what I do to keep my body healthy.



**FIGURE 2.**  
Many people in my community do not get out to exercise.



**FIGURE 3.**  
People just don't care about the concerns of others. This situation makes me want to keep up with my health.





**FIGURE 4.**  
A place I go to pray for my health. People should attend church to improve their health.