Photovoice With Vulnerable Populations: Addressing Disparities in Health Promotion Among People With Intellectual Disabilities

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*Cardiovascular diseases (CVD) are the leading causes of death among Mexican American adults living in the United States. Using data from a modified Behavioral Risk Factor Surveillance Survey and guided by the Anderson model, this study examined the effect of nativity on CVD screening practices among 423 Mexican American adults in Chicago. Dependent variables included having had a blood pressure and cholesterol screening and a routine checkup in the past 2 years. Multivariate analyses were used to control for sociodemographic factors while accounting for complex sampling design. Compared to those born in Mexico, U.S.-born Mexican Americans had greater odds of obtaining blood pressure (*OR = *5.61) and cholesterol screenings (*OR = *1.60) and having a routine checkup (*OR = *2.69) in the past 2 years. Health professionals wishing to increase screenings for CVD risk factors among Mexican Americans in northern cities should understand the impact of nativity on screening practices.*

Keywords: *Photovoice; people with disabilities; health disparities; community-based programming; Hispanic Americans*

Photovoice has been described as a participatory action research (PAR) method that is based on health-promotion principles (Wang, Cash, & Powers, 2000). This approach has been used by public health researchers working with vulnerable populations who have little power and limited access to health-promotion programs, such as youth and homeless persons (Strack, Magill, & McDonagh, 2004; Wang & Pies, 2004). Photovoice has also been successfully employed among Latinos to explore Latino adolescents' immigration experiences (Streng et al., 2004). Photovoice has also been shown to be an effective participatory research method for obtaining the views of people with psychiatric disabilities, and it has been employed to engage mothers with learning difficulties (Booth & Booth, 2003; Bowers, 1999). However, to our knowledge, there is no published literature on the use of Photovoice with people with intellectual disabilities (PWID), a group that experiences limited autonomy and health disparities: specifically, poorer health outcomes and quality of care compared to the nondisabled population. Although addressing health disparities is a public health priority and many vulnerable groups have been recognized by public health professionals, health disparities among PWID have largely been ignored (Kirschstein & Ruffin, 2001). PWID have historically had few opportunities to actively participate in health-promotion programs and in health research in which their perspective is recorded and included when developing programs or policies (Horwitz, Kerker, Owens, & Zigler, 2000; Rioux, 1997). Using Photovoice methodology in health-promotion planning and research enables PWID, who may otherwise not have a voice, to record and reflect on their health beliefs and priorities (Wang & Burris, 1997; Wang & Pies, 2004).

With a national focus on health disparities, it is important for public health professionals to be inclusive of vulnerable populations whose health issues are traditionally not addressed in the public health arena (Kirschstein & Ruffin, 2001). This article presents a pilot study that employed Photovoice to enable the

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voices of PWID—specifically, Latinos with intellectual disabilities (ID). This article has three goals: (a) to briefly raise awareness of health disparities among PWID to encourage health-promotion professionals to consider working with this population, (b) to describe the strategy of using Photovoice among Latinos with ID to guide the development of culturally appropriate health-promotion programs, and (c) to encourage the use of Photovoice in health promotion when engaging PWID.

BACKGROUND

People With Intellectual Disabilities

The second goal of Healthy People 2010 is to improve the health of all U.S. citizens "by increasing the quality and years of healthy life and eliminating health disparities" (U.S. Department of Health and Human Services, 2000). Yet there is little discussion in public-health literature about health disparities among PWID. The lack of attention among public health professionals is disquieting because there are more than 4 million persons with intellectual disabilities in the United States, and the number continues to grow (Fujiura & Yamaki, 1997). Adults with ID are at higher risk for chronic diseases, and onset of chronic diseases occurs earlier compared to the nondisabled population (Draheim, McCubbin, & Williams, 2002; Draheim, Williams, & McCubbin, 2002; Horwitz et al., 2000). They are more likely to report poor health and be overweight than those without ID (Fujiura, Fitzsimons, & Marks, 1997; Horwitz et al., 2000). PWID also have low levels of physical activity and consume high-fat foods (Draheim, McCubbin, et al., 2002; Draheim, Williams, et al., 2002; Fujiura et al., 1997). It has been reported that health care among people with ID is often mismanaged. Those with chronic conditions are diagnosed at later stages and their conditions are more likely to be improperly managed (Beange, McElduff, & Baker, 1995; Evenhuis, Hendersen, Beange, Lennox, & Chicoine, 2000; Fisher, 2004). Communication and attitudinal barriers between PWID and their health care providers and caregivers, physical barriers in health care settings, and inadequate professional training about disability issues also contribute to inequitable health care among PWID (Marks & Heller, 2003; Ruddick, 2005).

Addressing health disparities among people in this group is difficult because they are often poor and marginalized by society (Beange et al., 1995). Literature reporting the perspective of PWID is limited. Historically, research and health-promotion programs including PWID have been rare because this population was often regarded as incapable of expressing their own health needs and incapable of learning health-promoting skills (Evenhuis et al., 2000). Health practitioners have assumed that PWID do not have the ability to participate in their own health care. Often the health care needs of PWID are determined by their caregivers or practitioners who may not be familiar with the individual or not aware of the unique issues of working with a person with ID (Ouellette-Kuntz et al., 2004). As a result, the focus on their health has been mainly on addressing conditions associated with their disability rather than their general health and well-being (Evenhuis et al., 2000; Horwitz et al., 2000). The misconception about their abilities may contribute to the relatively small number of health-promotion programs that are tailored for this group.

Recently there has been more health-related research conducted among PWID to obtain their perspective about their own lives (Gill & Brown, 2002; Thompson, 2002). However, published literature on health promotion is still relatively uncommon, and much of what exists tends to report results from quantitative surveys that evaluated a small number of existing health-promotion programs (Heller, Hsieh, & Rimmer, 2004; Rimmer, Heller, Wang, & Valerio, 2004).

Actively involving PWID in health-promotion research and planning provides them with opportunities to develop new skills and confidence. It may potentially encourage them to take responsibility for their own health. The involvement of PWID also provides them with an opportunity to shape health-promotion programming so that it will be more relevant and sustainable. Furthermore, including PWID in shaping the research questions gives health researchers a broader perspective on what influences the health and well-being of this group. Photovoice enables this active participation by having PWID take photographs that represent their health perspectives and then reflect on the photographic images during interviews. This is a stark contrast to having PWID answer formulated survey questions with set answers that have been developed by researchers, which is the more typical form of collecting information about their health knowledge and behaviors.

Latinos

The U.S. Secretary of Health and Human Services report "Closing the Gap, a National Blueprint to Improve the Health of Persons With Mental Retardation" states that minorities with ID experience more difficulties concerning access to health care compared to their nonminority counterparts (U.S. Public Health Service, 2002, p. xii). Although there is little known health data on ethnic subgroups among people with ID, there is extensive evidence that nondisabled Latinos living in the United States experience health disparities. Latinos have high prevalence rates for many chronic-disease risk factors and behaviors. Many Latino subgroups experience greater prevalence of risk factors for chronic diseases compared to non-Hispanic Whites (NHW; American Heart Association, 2002). In particular, Mexican Americans are more obese and overweight, have a greater prevalence of diabetes, and are more physically inactive than their NHW counterparts (American Heart Association, 2002). Health beliefs and priorities among Latinos are influenced by cultural norms and values about health (Larkey, Hecht, Miller, & A la Torre, 2001). Researchers recognize the need for social and behavioral studies to be culturally anchored in the norms, beliefs, and experiences of the population that is being studied (Ashing-Giwa, 1999; Marin & Marin, 1991). Understanding the cultural health beliefs of Latinos with ID can facilitate the development of culturally relevant health-promotion programs to address their health disparities (Ashing-Giwa, 1999; Marin & Marin, 1991). Therefore, employing Photovoice among Latinos with ID has the additional benefit of capturing their culturally based beliefs and their perspectives about their daily lives.

STRATEGY

Photovoice is "a process by which people can identify, represent, and enhance their community through a specific photographic technique" in which participants take pictures that are meaningful to them (Wang, 2003). During the subsequent interviews, participants reflect on the meaning of the images and critically discuss the strengths and weaknesses of their social or physical environment represented in the photographs. Finally, they advocate for change by communicating what the pictures revealed to those who influence program development and policy (Wang & Burris, 1997). Photovoice has been used to empower people in countries including India, China, and the United States.

Photovoice methodology is based in Freire's critical consciousness in the respect that members of a community can critically reflect on their photographic images, express their social experiences, and use the consciousness toward taking action (Wang & Burris, 1997). Photovoice is also influenced by feminist theory in that it acknowledges that actions that influence a community should come from community members. It also emphasizes the importance of the subjective experiences of community members (Strack et al., 2004; Wang & Burris, 1997; Wang et al., 2000). Many PWID have less autonomy in their lives than their nondisabled counterparts because caregivers, service providers, and community agency staff oversee most aspects of their daily lives. Photovoice provides an avenue for PWID to communicate their health beliefs and priorities to the people who oversee their health and well-being.

The Pilot Study

The Photovoice component was a part of a larger 1-year pilot study that was conducted in collaboration with a community agency serving PWID in a predominantly urban Latino neighborhood. Agency administration contacted the local university to identify a university collaborator for developing health-promotion opportunities at the agency. They were referred to the first author, who applied for and received a Mary E. Switzer Merit Fellowship from the National Institute on Disability and Rehabilitation Research to conduct a pilot study. The study was designed to understand the health beliefs and perceptions and explore the health priorities of Latinos with ID and important others who influence the daily lives of these PWID. One goal of the pilot study was to provide the data to the community agency and a task force of community, university, and agency partners to be used to guide the development of appropriate and relevant health-promotion programs for Latinos with ID in the community. In addition to Photovoice, the study also conducted focus groups with Latinos with ID, their caregivers, agency staff, and community leaders. The pilot project's results are presented in a separate manuscript.

The Partnership

The mission of the community agency is "to support and challenge urban families to achieve excellence and participate fully in community life" through programs "to enrich and empower people with disabilities, the disenfranchised, and the underserved" (El Valor, 2005). In addition to serving youth, the agency serves 76 adults with ID, the majority of whom are Latino. Working with the agency to employ a PAR tool such as Photovoice was relatively easy because their mission is well aligned with the goals of PAR. The agency administration initiated the partnership, and the agency administration and staff were actively involved throughout the study.

Photovoice Recruitment and Training

Adult Latinos with mild to moderate ID were recruited for the Photovoice component. According to the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*), a person with an intellectual disability has "the presence of a sub-average general intellectual functioning associated with or resulting in impairments in adaptive behavior" (LaBruzza, 1994). The disability must have started before adulthood (age 18) and have an enduring effect on development. The agency determined the level of capability based on the Inventory for Client and Agency Planning (ICAP) assessments, which are completed by counselors at the agency and the parents or guardians (Bruininks, Hill, Weatherman, & Woodcock, 2004). ICAP measures adaptive and maladaptive behavior, diagnoses, support services needed and received, and ability to participate in social/leisure activities. A person with a mild intellectual disability is described as a person who has an IQ between 50 and 70. A person with a moderate disability has an IQ between 35 and 55 (Luckasson & et al., 2002). The agency groups PWID by ability and interests. All participants with mild to moderate disabilities were verbal and were in the same or similar groups at the agency.

Participants in the Photovoice component of the project were recruited from the focus groups so that they were already used to talking about their health in a group setting. Although recruiting participants from the larger focus group component of the pilot study may have resulted in selection bias, this bias was decidedly less important to the goals of the study than the benefit. As a result of their focus group participation, the participants who volunteered were already thinking about their health and what affects their health. Considering the limited intellectual ability of this group, it was thought that this would facilitate the participants to independently think about the influences on their health when they took pictures.

All study participants signed an informed consent form that was carefully adapted for persons with lower comprehension and approved by the university Institutional Review Board. If the participant was known by agency staff to be illiterate, it was read to them with a witness present, and they were asked questions to verify that they understood the content. Four Latinos with ID volunteered to participate. The two men and two women, aged 32, 42, 46, and 68, had a diagnosis of mental retardation, Down Syndrome, or cerebral palsy. Three participants were Mexican American and one was Puerto Rican. All lived in or near the Chicago neighborhood that the community agency served. Three lived with their family and one lived in a group home with other PWID.

Each participant was trained in Photovoice by the principal investigator (the first author). First, participants were educated about how to be responsible when using their camera and the responsibility they held with the use of the camera. This included providing examples of how to obtain permission from people prior to taking their picture. The potential risks of taking photographs in their community were discussed. Next, each participant was trained on the use of throwaway cameras. Agency staff members were consulted on how to ask about health, an abstract concept, in the most concrete way to ensure understanding. Each participant was asked to think about "what helped or hurt their health." They were asked to take pictures of "what they felt made them healthy or sick." To further promote understanding, participants with ID were provided with the examples given by their peers during the focus groups. Finally, the researcher walked around the agency with them when they took their first few pictures to reinforce the purpose of the picture taking.

Agency staff members who were participating in the project were trained on the purpose of the Photovoice aspect of the pilot project. Staff members were also trained on the ethics of taking pictures and asked to ensure that the participants were being responsible when taking pictures at the community agency. A description of the project's purpose and process was distributed to other staff members. Staff members who were actively involved agreed to remind the participants to continue to use the camera and to bring it back to the agency.

Photovoice Process

After the training sessions, the researcher frequented the agency once or twice a week for 3 weeks to see how the participants were doing with the project and to be available to answer questions. The agency staff reported that the participants said that they finished their film within the first 3 weeks. However, staff said that it was difficult to get the participants to return the cameras to the community agency. Although they were frequently reminded, participants had the cameras for about 3 months. Once the cameras were returned, the film was immediately developed to minimize the time between picture taking and the interview to reduce the risk of participants forgetting why they took certain pictures.

Based on the quality of the pictures and a brief discussion with participants in their interview about the use of the camera, it was apparent that three of the participants had no trouble using the camera or flash. Almost all their pictures were identifiable and used during the interview. Unfortunately, one participant seemed to have a hard time using the flash. Some of his pictures were over- or underexposed. He had few pictures that could be reflected on in an interview because the images were indiscernible. He was provided with another camera, but he never returned it. Therefore, he was unable to be interviewed.

Reflection

The Photovoice methodology developed by Caroline Wang includes a group interview for critical discussion and reflection (Wang & Burris, 1997). Instead of a group interview, Photovoice participants with ID were interviewed one-on-one in a private setting at the community agency during their day program. This process was tailored from Wang's methodology because it was deemed more important to obtain depth in the health perspectives of the Photovoice participants with ID. A range of viewpoints had already been identified during the focus groups.

During the individual interviews, Photovoice participants with ID reflected on what the images meant to them when thinking about their health and well-being. They discussed how the images represented their experiences and how those experiences related to their health (Wang & Burris, 1997). Doubles of each role of film were developed. A set of pictures was given to the participant prior to the interview and then the second set was brought to the interview. Although general questions were asked, most of the discussion was free flowing. Each interview was audiotaped so that exact quotes could be used in reports to the community, in articles, and in the pictorial scrapbooks provided to the participants. Participants took pictures indoors and outdoors around their community, at their home, and at the community agency.

Analysis

All Photovoice interviews were recorded and transcribed verbatim into Spanish and then into English and matched with their pictures. Confidentiality was maintained by removing all personal identifying information from the transcripts prior to analysis. Data analysis of the interviews was conducted in conjunction with the focus-group data. Data analysis and results of the Photovoice are discussed in another article.

After completion of the analysis, the participants were brought together in a member-check focus group to discuss the themes identified in their interviews and to verify that the health beliefs and priorities identified were true to the participants. Once the interviews were completed and transcribed, the researcher created a scrapbook of photos and matched quotes from the interviews with pictures for each participant. Similar to findings among other Photovoice researchers, the photographic method seemed to foster a sense of pride and confidence among the participants (Strack et al., 2004). Participants proudly showed their scrapbooks around the agency and discussed their photographs with friends and staff. Staff reported that there was a lot of discussion about the scrapbooks among the PWID at the agency, and many individuals expressed the desire to participate and have scrapbooks as well.

The findings of the Photovoice process and the focus groups were included in a report. A second report was made for people with low literacy. The findings were presented during a town hall meeting attended by community stakeholders (e.g., agency administration and staff, caregivers, PWID, community leaders, university faculty and students). One of the Photovoice participants discussed his experiences and presented his scrapbook during the town hall meeting. Meeting attendees, including adults with ID from the agency, responded to the presentation and participated in a discussion.

The town hall participants used the findings and the responses to them to identify recommendations and action steps for developing health-promotion programming. The recommendations and action steps were summarized in a report and given to the agency administration and university faculty who are working together to develop programs.

RESULTS

Although the results are presented in another paper submitted for publication, there were some unique themes identified with Photovoice. A Photovoice participant took pictures to document his health and his belief that environmental factors affected his health. He had his mother take a picture of him in bed because he wanted to discuss his health conditions and how they affected his life. During his interview, the picture prompted him to discuss his views that the weather and pollution in his community influenced his asthma.

Photovoice helped participants to emphasize the importance of their social activities and of being able to participate in community activities. A participant took several pictures of her best friend at the community agency, including one of her dancing. She said that she enjoyed dancing and believed that it was good for her. She also talked about how spending time with her best friend made her feel good. Another took a picture of the local park and expressed an interested in playing games there. The participant who was in a wheelchair took a picture of his family van that was modified for a wheelchair occupant and had someone take a picture of himself in his wheelchair. He talked about how these accommodations enabled him to go places with his family and participate in activities at the agency.

Lessons Learned

This was a pilot Photovoice study with Latinos with ID. There were four major lessons, as follows:

1. Photovoice is a useful method for engaging people with limited social and communication abilities. It actively engages PWID. Photovoice methodology also provides something concrete: photographs that prompted participants to talk about their perspectives about their health and well-being.
2. The modification of the Photovoice group interviews to individual interviews was effective in providing rich stories and details that were not obtained through the focus-group component of the larger study. Even with the limited communication abilities of PWID, the one-on-one interviews with the photographs were effective for facilitating deeper discussion.
3. Photovoice, in comparison to the focus groups employed in the larger study, identified physical environmental factors that were thought to affect health.
4. It may have been helpful to formally engage the caregivers of the Photovoice participants in the Photovoice component of the study and also ask for their help in returning cameras.

One caregiver was known to have informally aided a Photovoice participant with his pictures. Formally involving caregivers in the Photovoice aspect of the project may have eliminated the problem of camera returns and poorly exposed pictures. However, it is important that engaged caregivers are encouraged to support the autonomy among participants with ID.

DISCUSSION

Although this Photovoice pilot study among Latinos with ID is limited in its generalizability because of the sample size, selection methods, and uniqueness of the population, this study still suggests that this method can be successfully employed to actively involve PWID in shaping decisions that influence their lives. Furthermore, it is useful for including PWID program in planning and research. This is especially important for PWID because they traditionally have been left out of these decisions and treated more as research subjects rather than research partners or collaborators (Ward & Trigler, 2001). Photovoice methodology enables PWID to express their real-life experiences through photographic images that represent their perspective as they interact socially within their home, agency, and neighborhood environment. Based on the experiences of this pilot study, it is apparent that Photovoice enabled a sense of ownership among PWID in the research process while also providing researchers with rich insights into the health perspectives of PWID. It also helped identify culturally based beliefs and activities of interest to Latinos with ID. Engaging PWID in health-promotion research and planning through the use of Photovoice encourages PWID to actively think about their health in the context of their daily life.

Recommendations

Including Photovoice in projects with PWID enables them to actively participate and reflect on what influences their health as well as to record and reflect on their health beliefs and priorities. The use of traditional survey methods to determine health knowledge and beliefs may not accurately reflect the true knowledge and beliefs of PWID because of their intellectual limitations, whereas most people, including those with intellectual impairments who are socially marginalized, can learn to use a throwaway camera (Wang & Burris, 1997). Anecdotally, people who have administered surveys to PWID have suggested that PWID are very agreeable and will answer questions from someone they perceive to be an authority figure in a manner that they think will please that person. Therefore, the use of Photovoice recognizes that these marginalized people have insight into their own health beliefs and priorities that cannot be known or fully understood by public health professionals without employing empowering and creative techniques to obtain their true perspective. An important goal of using Photovoice in health promotion among PWID is to have those who may participate in health-promotion programs guide the development of these efforts to ensure their saliency and sustainability. However, the ultimate goal should be to empower PWID to express their needs and become actively involved in the decisions that influence their lives.

Given these goals, it is important that projects using Photovoice tailor the process to accommodate the varying intellectual capabilities of PWID. It is also useful to record the interviews and disseminate their own words even if their language is not as sophisticated as people without ID. This is essential because PWID are a vulnerable population who are subject to people such as their caregivers, health providers, and staff at the community agency speaking for them.

Implications for Applications

This exploratory study begins to fill a gap in the literature on planning and research strategies for health promotion among PWID. This study adds to a very small number of public health publications that discusses PWID with the purpose of addressing their health disparities. This study provides evidence that Photovoice methodology may be an effective method for engaging vulnerable groups, including people who have low literacy or who may have intellectual disabilities, in health-promotion program planning and research. Photovoice enables representatives of vulnerable populations with limitations in intellectual capabilities or disempowered populations to express their beliefs and priorities in the context of their own lives through photographic imagery. Foster youth disproportionately have intellectual disabilities and are considered another vulnerable population that lacks a voice (Hochstadt, Jaudes, Zimo, & Schachter, 1987; Leslie et al., 2005). They too can benefit from participating in Photovoice for empowerment as well as to help health professionals understand their health needs so that their health disparities can be minimized.

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Erratum

Jurkowski, J. M., and Paul-Ward, A. (2007). Photovoice With Vulnerable Populations: Addressing Disparities in Health Promotion Among People With Intellectual Disabilities. *Health Promotion Practice*, *8*(4), 358-365. (Original DOI: 10.1177/1524839906292181)

In this article, the abstract should have appeared as follows:

Eliminating health disparities is a national priority. People with intellectual disabilities (PWID) are a vulnerable group that experiences health disparities. However, their health disparities have largely been overlooked. Photovoice is an effective method for engaging PWID in health promotion planning and research. This article discusses the importance of including PWID as a priority group, presents a Photovoice project among Latinos with ID, and concludes with recommendations for employing Photovoice with PWID. The Photovoice project was a part of a larger pilot study that aimed to enable the voices of Latinos with ID and guide the development of health promotion programs at a community agency. The findings were presented in reports and at a town hall meeting during which attendees responded and developed actions steps for improving health promotion for PWID. Each Photovoice participant received a scrapbook of their photographs as a keepsake of their experiences participating in the project.

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