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Gathering the Evidence: Photovoice as a Tool for Disability Advocacy

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Abstract

The participatory research method Photovoice capitalizes on the spirit of the old adage "a picture is worth a thousand words." We, a group of 10 individuals with spinal cord injury (SCI) and our project facilitator, used Photovoice as means to advocate for equal access to community resources. Often people with disabilities encounter difficulties in helping the able-bodied population to understand issues that are faced by persons who use wheelchairs to move about in the community. Our photographs provide visual evidence that helps us to identify and address issues of accessibility in our community of Charleston, South Carolina. We are using our photographs to educate the public, as well as those who have the political power to make change in our communities. In this article, we share some of the issues we addressed during our project and our thoughts about using Photovoice as a tool to support disability advocacy efforts.

Keywords

Advocacy, disability, community-based participatory research, Photovoice, spinal cord injuries

Photovoice is a community-based participatory research process that places cameras in the hands of "everyday" people, to record life from their point of view, and potentially act as advocates for change in their communities. The resulting photographs provide evidence of life as experienced by the photographers and a means to share their knowledge and experiences with others.[1] In our Photovoice project, a group of 10 participants with SCI took cameras into the community in and around Charleston, South Carolina, to gather evidence of the environmental factors affecting our participation. Our goal is to use this information to advocate for change.

A primary goal of disability advocacy is to identify actions that can improve community participation of people with disabilities. Photovoice allows for the creation of visual evidence of disabling or enabling situations in the community. Disability is as much a result of environmental barriers as it is of physical impairments. Efforts to address these environmental barriers are most effective when based on valid and reliable evidence.[2] This evidence, as documented in our photographs, supports social action to eliminate barriers and level the playing field so we may participate in the community as fully as our fellow community members who do not use wheelchairs. In this article, we describe how we used Photovoice to advocate for the needs and rights of individuals with physical disability in our community. We begin by providing a brief overview of the development and methods of the project, and then move to sharing thoughts about our experiences in the project and with Photovoice.

METHODS

Project Development

The research partnership, that supported our project, between Susan Newman (the researcher) and the disAbility Resource Center (dRC) grew from a prior relationship that the researcher had established with the dRC staff through volunteer work. The dRC is a Center for Independent Living, which is a community-based, cross-disability, nonresidential, nonprofit agency, controlled by individuals with disabilities.[3] Over the course of our project, the dRC facility served as our "home base." During project development, the researcher conducted a focus group with the staff of the dRC to discuss a potential research partnership and identify issues that could be addressed through a Photovoice project effectively. The general theme of this discussion centered on matters of accessibility, whether related to specific health care services, such as the dentist's office, or the community at large.

Based on group consensus, a decision was made to investigate and evaluate general issues of accessibility in the community environment, with a focus on identifying barriers and facilitators for potential interventions. Susan Newman, in the role of Principle Investigator, received an R36 Grant for Health Services Research Dissertation from the Agency on Healthcare Research and Quality and a New Investigator Grant from the Rehabilitation Nursing Foundation to support the project. The MUSC Institutional Review Board approved the project as exempt human research status; thus, participants were not required to sign an informed consent. However, a printed version of all information related to the project that would be contained within an informed consent was provided to and reviewed with each participant by the researcher.

Project Implementation

Sample. Participant recruitment occurred as a collaborative effort between the researcher and the peer counselor at the dRC, Maria Saxon. Our goal was to create a diverse sample of 10 to 12 individuals who were 18 to 65 years old, had chronic paralysis owing to SCI, and used a wheelchair as their primary means of locomotion in the community. We extended invitations to participate in the project to 14 consumers. Twelve individuals responded and agreed to join the project. Ultimately, 10 of this group actively participated in the project (Table 1).

Photovoice Training. The researcher led two Photovoice training sessions for the participants as recommended by Wang and Burris.[1] The first session included an overview of the Photovoice method and examples of previous Photovoice projects. After the presentation, we engaged in a brainstorming session about potential issues encountered in the community that could be addressed using Photovoice and developed ideas for our "photo assignments." The second session provided training in the actual implementation of Photovoice, including the ethical use of photography, consent, and personal safety. The researcher provided each participant with a digital camera, taught him or her how to operate it, and provided practice time. Participants with tetraplegia were provided with adaptive photographic equipment, such as small tripods, support arms, and cable releases, to facilitate their use of the camera.

Data Collection and Analysis. Participants collected data over 4 months by taking at least 10 pictures for each of the photo assignments agreed upon in the training sessions: (1) "What *keeps you from* participating in the community?" (2) "What *helps you to* participate in the community?" and (3) "Create a photo documentary of 1 day you were out participating in your community life." Because of the unique transportation needs of a population with SCI, we decided to modify the Photovoice method as originally described by Wang and Burris.[1] Instead of initial collective group analysis of photos, we opted to conduct individual interviews between researcher and participant after the completion of each photo assignment to minimize the inconvenience to those participants who were reliant on others for transportation

Table 1. Participant Characteristics

Characteristic	*N* = 10
Gender	
Male	60%
Female	40%
Race	
African American	50%
White	50%
Level of injury	
Tetraplegia	30%
Paraplegia	70%
Age (yrs)	
Average	42.1
Range	20–61
Years since injury	
Average	17
Range	2–36

to group sessions. These interviews generally occurred at the participants' homes or other location of their choosing. During the interview sessions, the researcher downloaded the participant's photographs into a laptop computer and configured them so that they could be viewed on the computer screen. The researcher prompted participants to discuss where each picture was taken, why it was taken, what it meant to them, and what they hoped to see happen as a result of the photograph. All of the participants came together as a group after the completion of all of the assignments and interviews. The purpose of this meeting was to see, share, and discuss our pictures as a group, begin to identify common issues that we shared, and celebrate our work. Three subsequent smaller group meetings have occurred to strategize our steps for action. We anticipate additional group meetings as our action plan unfolds.

Dissemination. We are currently in the process of implementing a variety of strategies for disseminating our photographs and the results of this study to the public and policymakers. We developed a brochure describing our project and our findings, which was distributed by dRC staff at Disability Advocacy Day. We have posted a video containing our photos and stories on YouTube (available from: http://www.youtube.com/watch?v=nI4rrTYKmvE). A public gallery exhibit of our photographs is currently in the planning stage. Publication of our results through shared authorship of manuscripts is another strategy. This article is the result of the work of participants who identified an interest in contributing to manuscript development. The researcher acted as lead author by identifying a journal for potential manuscript submission and collaborating with interested participants about the focus of the manuscript. The researcher acted as editor as well, through receipt of the participants' contributions via e-mail or handwritten copy, organizing their contributions into a fluent manuscript, and returning the manuscript to the co-authors for feedback and revisions. All authors approved the final manuscript. The remainder of this article highlights our experiences with this project and the steps we are taking to bring about change.

DOUG'S STORY

Seems as though lately I'm asked to participate in some sort of research study at least several times a year. I guess it's because of the fact that I've managed to survive SCI for 36 years and use a wheelchair. I've been poked and prodded, measured and documented, questioned, and evaluated by many students and a few professors. I always enjoy the participation because it's a great opportunity to hang out with the younger crowd for a while. But this Photovoice project was different. This time it was me doing the research, taking the pictures, and asking questions.

Have you ever parked your car at Wal-Mart and see somebody you believe is able-bodied park in a spot marked for the disabled? If you're like me you think, "Dang, I wish there was a cop close by!" or, "Too bad I don't have a camera right now!" Well this Photovoice project did just that! It put a camera in my hands and sent me out to take pictures. I was determined not to take very many pictures of handicapped parking. Why? Because to me it's the most obvious and prevalent abuse so I figured there would be a tidal wave of those shots. So I focused (pun intended) on some of the other obstacles, such as accessible restrooms. See, I can drive all over creation looking for a place to park my van, but when my bladder is full, I tend to have more of a sense of urgency! Like many who live with SCI, I don't have control of bladder function. So I have a few minutes to locate proper accommodations, but not many! Bathroom construction and design was high on my photo list. I did finally decide to add some parking lot pictures anyway. Parking was just too big of an issue to ignore and I didn't want to diminish the effect of other participants' pictures by not appearing to agree with them on this important issue.

I have a great employer and had absolutely no problem finding subjects for pictures of accommodations. I enjoy the

Figure 1.

fact that others in our community might see the steps my employer has taken to provide a safe, accessible, and functional workplace (Figure 1).

I struggled a great deal trying to think of pictures I could take that describe the "day in my life" series. I could just see the captions, "This is me shaving," or "This me brushing my teeth." I mean, those are things I do everyday. Well, most days anyway. Instead, I decided to attempt to document the things that make it difficult for me to deal with the everyday because of my injury. I found it difficult to explain with pictures things like the fact that I needed extra time in the morning to get ready for work, or that I needed to add 10 minutes of travel time to load myself into and out of my van, or that if I wanted to share lunch with a group from work how frustrating it was to learn the restaurant wasn't accessible. In the end, I think some of those pictures were my best because of the emotions each one stirred inside of me. Those were the things that seemed to bother me the most.

Our Photovoice project provided me a unique method to express my frustrations in a manner that people might understand. I believe that the most important thing a wheelchair user can do to overcome the barriers we face is to educate the public. Not only those close around you, but also the decision makers and the politicians. I don't want "special" parking. I want "equal" parking. And by equal, I mean a spot where I have a reasonable expectation of having the room I need to deploy my van lift and roll onto it. It takes 7 or 8 feet of space on the passenger side of my van to do that. I don't want a special bathroom. I want an equal bathroom. I want to be able to enter a stall and close myself in for some privacy just like everyone else.

I'm extremely happy that I agreed to participate in this project. I would encourage anyone with SCI or any wheelchair user to say "yes" if you are ever asked to become part of a Photovoice team.

COLLECTIVE THOUGHTS

Photovoice works because it draws attention to the disability community, helps us to highlight problems, and find solutions. The unique part of participating in a Photovoice project involves taking the pictures. Photography allowed us to document and share our first-hand experience with accessibility, or the lack thereof in our community. Some of the barriers we identified included buildings without ramps or elevators and parking facilities without enough handicap-accessible spaces (Figure 2).

Figure 2.

The immediate reactions we received while out taking pictures were one of several positive factors from the project. Often when people would see us taking pictures, they would ask questions, presenting a great opportunity for us to educate others. A second positive factor was the increased awareness of barriers in the community from individuals with and without disabilities. Our friends, families, and others said they became more aware of the accessibility of the places where they worked or shopped and businesses they owned. Our awareness of barriers in the community increased as well. The mere act of carrying the camera for the project made us more observant of barriers, whereas before we would often try to find a way

Figure 3.

around the obstacle and consider it just part of our daily life (Figure 3). A third positive factor was the visual evidence the pictures provided. We were able to show the photos to individuals who argued with us that the environmental barriers were minimal or did not exist. The photos will also allow us to go back, identify the barrier, and work to see that the barrier is removed. We will be able to show before and after photos of places that have made changes.

This Photovoice project paves the way for grassroots disability advocacy because it has supported the development of a coalition of citizens with disabilities who have many common concerns. We encourage other disability advocates to use Photovoice to educate the public and empower people with disabilities. Using Photovoice with people with disabilities may present some unique challenges to implementing the method; thus, we would like to share some of the lessons we learned. Photography is an effective means of documenting issues in the physical environment; however, capturing less tangible issues can be challenging. Encouraging and nurturing creativity becomes an important strategy to mediate the challenge of how to capture nonconcrete issues through photography. Many of the participants in our project found effective ways to illustrate nontangible concepts, such as attitudes, and personal feelings, such as altruism, hope, and personal growth through representational images. The participants' reflections on their representational photos are essential to understanding and sharing their intended meaning of the image.

A key logistical point to consider when using Photovoice with people who use wheelchairs is making sure that they have a way to keep the camera readily available and carry it safely while in the chair to avoid damaging the equipment or missing photo opportunities. Neck straps on the cameras or small pouches or clamps on the wheelchair help to keep the camera more readily available and protected from accidental drops. An assessment of each participant's preference, to find out what options for transporting the camera works best for him or her, is essential. The availability of adaptive photographic equipment for people with functional limitations is essential; however, this equipment is often expensive and, without a funding source, creative modification of available equipment may become necessary. We highly recommend engaging the staff of Centers for Independent Living as an excellent resource for assisting with creative adaptation of equipment.

MOVING TO ACTION

We have completed our data collection and analysis, and have identified priority issues to address. Our first goal is to expand our efforts to educate the public about the issues we uncovered. Our project has received attention from the local media. An article documenting our findings related to the abuse of accessible parking received front-page attention in the local newspaper.[4] Our photographs provided a powerful punch to the message by providing visual evidence of parking violations, such as people without parking placards in the accessible spaces and people parking or leaving shopping carts in the van access lanes, thus making it impossible to enter or exit our vehicles safely, if at all (Figures 4 and 5).

Figure 4.

Figure 5.

Preliminary feedback from the community demonstrates that we have found an effective way to educate people about the issues that affect wheelchair users' access to the community. We received a note from one individual who has a disability, but confessed she did not understand about the access lanes for the vans with lifts, and admitted that she had been guilty of parking there. She stated that she would no longer park there now that she understood the purpose of the access lanes, as a result of reading the newspaper article about our project. Another community member wrote a letter to the editor supporting our efforts and encouraging law enforcement as well as the community at large to take action to support our efforts in this cause, stating that "the public needs to be more considerate."[5]

The local media attention has paved the way to meeting with policy makers. We are using our data to educate our legislators and support the passage of laws that will strengthen accessible parking regulations. In preparation for this, we participated in a training session on legislative advocacy, conducted by a local politician. We have engaged in discussion with the state legislator who introduced an updated accessible parking bill last year and have sought guidance from him regarding how our work with Photovoice can support the passage of these bills. Based on his advice, we have initiated a petition in support of this legislation. Members of our group have been invited to come to the state capital when the bill is reintroduced. We plan to share our photographs with the legislators to provide evidence of the issues we uncovered and the need for new laws to protect accessible parking. We hope that our pictures support the policy makers' decision to pass this bill.

CONCLUSION

We were pleased to have the opportunity to participate in this project, especially knowing that we will potentially be helping other people with disabilities by providing new insight into the complexity of living with SCI in the community and the numerous challenges one encounters in trying to maneuver around the community in a wheelchair. We found that participating in the project provided the incentive and the means to take action and do what needs to be done to make our community more accessible. We are excited that this project is not yet over. This is just the beginning for continued progress in accessibility and equality for people who use wheelchairs in the community.

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