

Rehabilitation NURSING

Evidence-Based Advocacy: Using Photovoice to Identify Barriers and Facilitators to Community Participation After Spinal Cord Injury

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KEY WORDS

*community participation
disability advocacy
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People with spinal cord injury (SCI) face many environmental barriers to community participation. In this article, a community-based participatory research (CBPR) project that implemented the Photovoice method with 10 individuals with SCI to gather evidence of the environmental factors affecting their participation in the community in and around Charleston, SC, is described. The specific aim of this project was to use Photovoice to create an evidence base of environmental barriers and facilitators to community participation through analysis of data based on the World Health Organization's International Classification of Functioning, Disability and Health taxonomy of environmental factors. Barriers and facilitators were most frequently photographed in the built environment. The participants have started to share their evidence of issues affecting citizens with disabilities with the public and policy makers. The results of this project illustrate that Photovoice is effective in empowering individuals with SCI to address environmental factors affecting their community participation.

Life could be like a caged bird if you let it. How would that bird feel? It can't get out of that cage. Every now and again I get that feeling, like I'm caged in ...and, if you caged a bird up long enough, that bird is going to die, see, just from heart trouble, you know. They need to get out from those four box walls, get out to the beach, get out to the shopping center, and get out and smell the roses, you know... these things here make me feel like I'm out of the cage. So you can kind of see how important it is. —Participant 8

Approximately 255,000 people in the United States have a spinal cord injury (SCI; National SCI Statistical Center [NSCISC], 2008). Research goals outlined by the National Institute of Disability and Rehabilitation Research (NIDRR), as well as Healthy People 2010, encourage the identification, evaluation, and elimination of barriers in the environment that inhibit participation in community activities by people with disabilities (Centers for Disease Control and Prevention, 2000; Department of Education, 2006). Many rehabilitation professionals only encounter individuals with SCI in the clinical setting, limiting their insight into the social context of disability. The shortened, postinjury inpatient rehabilitation stay makes it especially difficult to develop an understanding of the environments to which people return after discharge from acute rehabilitation (Kroll, Groah, Gilmore, & Neri, 2008).

A holistic view of rehabilitation seeks to look beyond the physical impairments of the individual and address the social and environmental factors that create disabling situations. The best people to identify these factors are individuals with disabilities who

encounter these barriers or supports daily. Research efforts, rehabilitation services, and programs supporting community participation are most effective when they are conceptualized as "a process in which people with disabilities are intimately involved, rather than a product to be dispensed" (Stewart & Bhagwanjee, 1999, p. 339).

Community-Based Participatory Research

The fundamental principles of community-based participatory research (CBPR) position the community as an equitable partner in all phases of the research process, from identification of a research question to knowledge dissemination and social action. The processes of CBPR provide a platform upon which to build upon the strengths or opportunities in a community, ensure local relevance, and promote local capacity building (Israel, Eng, Schulz, & Parker, 2005). CBPR projects have the potential to address issues affecting the community participation of individuals with SCI. The nature of CBPR allows the identification and documentation of environmental barriers and facilitators from the unique perspective of individuals who use a wheelchair as their primary means of mobility.

In this article, we describe a CBPR project that implemented the Photovoice method with a group of 10 people with SCI to gather evidence of the environmental factors affecting their participation in the community in and around Charleston, SC. The project design

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supports CBPR through participatory data collection, analysis of findings, prioritization of issues that were revealed in the analysis, and movement to social action. The International Classification of Function, Disability and Health (ICF; WHO, 2001) is applied as an analytic framework with which to code and categorize the issues identified in the participants' photographs and interviews. This application of the ICF demonstrates the relevance of this tool to rehabilitation nursing by directing attention to the social world to which people must return upon discharge from the inpatient rehabilitation setting (Kearney, 2005). The specific aims of this project were to

- engage people with SCI in a CBPR approach that uses the Photovoice method to gather and analyze data on environmental barriers and facilitators to community participation
- create an evidence base of environmental barriers and facilitators to community participation through analysis of data based on the ICF taxonomy of environmental factors to categorize and identify priority issues
- use the findings of this project as a foundation for evidence-based advocacy as determined by the project participants.

Background

SCI and Community Participation

SCI is a life-altering event that can result in varying degrees of paralysis depending on the level and completeness of injury. Statistics relative to the epidemiology of SCI demonstrate a consistent trend showing that SCI typically occurs in the potentially most productive years of one's life, making the need for the implementation of programs facilitating community participation for survivors of SCI even more compelling. Presently, 87.9% of all people with SCI who are discharged return to private noninstitutional residences in the community (NSCISC, 2008).

The fact that people with SCI face environmental barriers to community participation is well established (Brown, Gordon, Spielman, & Haddad, 2002; Dijkers, Yavuzer, Ergin, Weitzenkamp, & Whiteneck, 2002; Schonherr, Groothoff, Mulder, & Eisma, 2005; Whiteneck, Harrison-Felix, et al., 2004; Whiteneck, Meade, et al., 2004). The existence of barriers in the environment promotes discrimination, prevents participation, restricts choice, and frustrates attempts at independence of those with SCI (McClain, Medrano, Marcum, & Schukar, 2000). The increased emotional distress often associated with SCI may not necessarily stem from the individual's limitations, but rather from encounters with barriers in the environment that inhibit participation in life activities and access to necessary services (Paralysis Task Force, 2005). Commonly cited reasons

for lack of community participation by those with SCI are physical environmental barriers such as the presence of stairs and lack of curb cuts in sidewalks. Decreased mobility significantly impairs one's ability to participate fully in social settings (Brown et al., 2002). Social barriers to community participation after SCI include public attitudes related to those with disability and the associated discrimination that often occurs.

The biopsychosocial model of disability increases attention on the environment and its contribution to disability (WHO, 2001). Environmental factors form the context of a person's life and include the physical, social, and attitudinal environments in which people live and conduct their lives. These factors are external to individuals and influence their ability to carry out day-to-day tasks and, ultimately, their level of community participation (WHO). Although progress has been made in promoting the accessibility of the built environment with the passing of the Americans with Disabilities Act in 1990, people with disabilities continue to report widespread and persistent barriers to employment, education, health care, and social, recreational, and political activities (Taylor, 1998). An investigation of the accessibility of public buildings revealed that a person with SCI who relied on a wheelchair for mobility consistently had more difficulty completing tasks such as entering buildings and using the restroom, drinking fountain, or telephone than people with an ambulatory mobility impairment, a visual impairment, or no impairment (Thapar et al., 2004).

Photovoice

As a CBPR method, Photovoice entails providing study participants with cameras, allowing them to record, discuss, and communicate to others the realities of participants' lives as seen through their eyes (Wang & Burris, 1997). The production of a photograph and the photographer's description of the photo provide immediate data and the foundation for effective participatory sharing of expertise and knowledge. Photovoice has the potential to strengthen research quality and validity by using the expertise of participants to generate new understanding about issues the participants consider important, as well as provide the opportunity to share this knowledge with influential people to whom the participants may not usually have access (Lopez, Eng, Robinson, & Wang, 2005).

Photovoice is gaining popularity and credibility as a CBPR method (Carlson, Engebretson, & Chamberlain, 2006; Schwartz, Sable, Dannerbeck, & Campbell, 2007). The initial application of Photovoice occurred in the Yunnan province of China (Wang & Burris, 1994, 1997) and has since been used to a limited extent with people with disabilities. Jurkowski and Paul-Ward (2008)

engaged people with intellectual disabilities to use Photovoice to address health-promotion disparities. Individuals with paraplegia in Australia and Cameroon used Photovoice to document factors influencing their health status in their respective settings (Allotey, Reidpath, Kouamé, & Cummins, 2003). The important role of participants with SCI in research activities addressing community participation, including planning and identifying priorities and assessing relevance to the "real world" and circumstances of daily living, cannot be overstated.

Methods

Partnership with Community

A partnership with the community is an essential element of any CBPR project. The principal investigator (PI) established a relationship with the staff of the Disability Resource Center (dRC) in North Charleston through volunteer activities and attendance at dRC social functions before introduction of the project proposal. This engagement supported the development of a partnership and familiarity with the organization and the consumers served by them. The dRC is a Center for Independent Living (CIL) founded with the mission to empower people with all types of disabilities to reach their highest level of independence. CILs are community-based programs primarily funded through the Rehabilitation Services Administration that provide essential resources to enable community participation and independent living of individuals with disabilities (McKinley & Meade, 2004). The dRC is consumer controlled because the people who best understand life with a disability are those who have disabilities themselves.

In preparation for this project, meetings were held with the leadership and staff of the dRC. The PI introduced the Photovoice method to the group and discussed potential benefits of the method and a strong interest in using Photovoice to document actual community experiences of people with SCI. An initial brainstorming session was held with the staff of the dRC to identify potential areas of interest or concern that could be addressed effectively through Photovoice. The general theme of this discussion centered on issues of accessibility, whether related to healthcare services such as the dentist office or general community access for leisure activities. Based on group consensus, the project was to investigate and evaluate general issues of accessibility in the community, with a focus on identifying barriers and facilitators for potential interventions. Two attendees of this meeting became participants in the Photovoice project.

Key Practice Points

1. Community participation is commonly considered the ultimate goal of rehabilitation.
2. Spinal cord injury (SCI) typically occurs during a person's most productive years, making the implementation of programs facilitating community participation for survivors of SCI even more important.
3. The increased emotional distress often associated with SCI may not necessarily stem from a person's functional limitations, but rather from encounters with barriers in the environment that inhibit full community participation.
4. A holistic view of rehabilitation looks beyond the physical impairments of the person and seeks to address the social and environmental factors that create disabling situations.

Role of the Researcher

This project represents an initial engagement of community members with SCI in a CBPR project by the PI. One major unwritten goal of this project was the cultivation of trust and relationships between the PI and the community that can support future projects reflecting the principals of CBPR in all phases of the project. In this project, the PI was responsible for the initiating the meeting to discuss a potential research partnership with the dRC. Both the PI and the representatives from the dRC defined the purpose of the project collaboratively. The PI was responsible for grant writing, procurement, and management of funding for the project. The participants held the primary responsibility of data collection, issue selection, and identification of dissemination and advocacy strategies. The PI provided support to facilitate these activities and sought to maintain a neutral, flexible role in the progression of the project. The PI will be identified as project facilitator in this article to reflect this role.

Sample

Participant recruitment occurred as a collaborative effort between the project facilitator and the peer counselor at the dRC. The goal was to create a diverse, purposive sample (Patton, 1990) of 10–12 individuals meeting the following inclusion criteria: (a) age 18–65 years old, (b) chronic paralysis due to SCI, (c) level and severity of paralysis requiring locomotion with a wheelchair, and (d) duration of disability resulting from SCI longer than 1 year. The dRC peer counselor and the project facilitator extended an invitation to participate in the project

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Table 1. Sample Characteristics

Participant	Gender	Race	Age	Years Since Injury	Level of Injury	Education (Years)	Primary Transportation
1	F	AA	27	12	T 11-12	14	Own
2	M	W	60	36	C 7	14	Own
3	F	W	61	7	T 9-10	12	Own
4	M	AA	20	20	C 6-7	15	Family
5	M	W	40	13	C 6-7	16	Own
6	F	AA	48	2	T 4-5	16	Paratransit/family
7	M	W	49	36	T 4-5	14	Own
8	M	AA	50	15	T 10	13	Own
9	M	W	42	18	T 6	13	Paratransit
10	F	AA	24	11	T 12	12	Paratransit/family

to 14 people meeting the enrollment criteria. Twelve people responded and agreed to join the project, and ultimately 10 among this group participated in data collection and analysis. Two individuals withdrew; one due to medical issues before engaging in any portion of the project, and another person who never initiated data collection for unspecified reasons and ultimately withdrew from the project. Among participants, 40% were female, 60% male; 50% African American, 50% White; age range 24–61, with a mean age of 42.1; and an average 13.9 years of education. Average time since injury was 17 years with a range of 2–36 years (Table 1).

The Medical University of South Carolina Institutional Review Board approved this project as exempt human research status; 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.

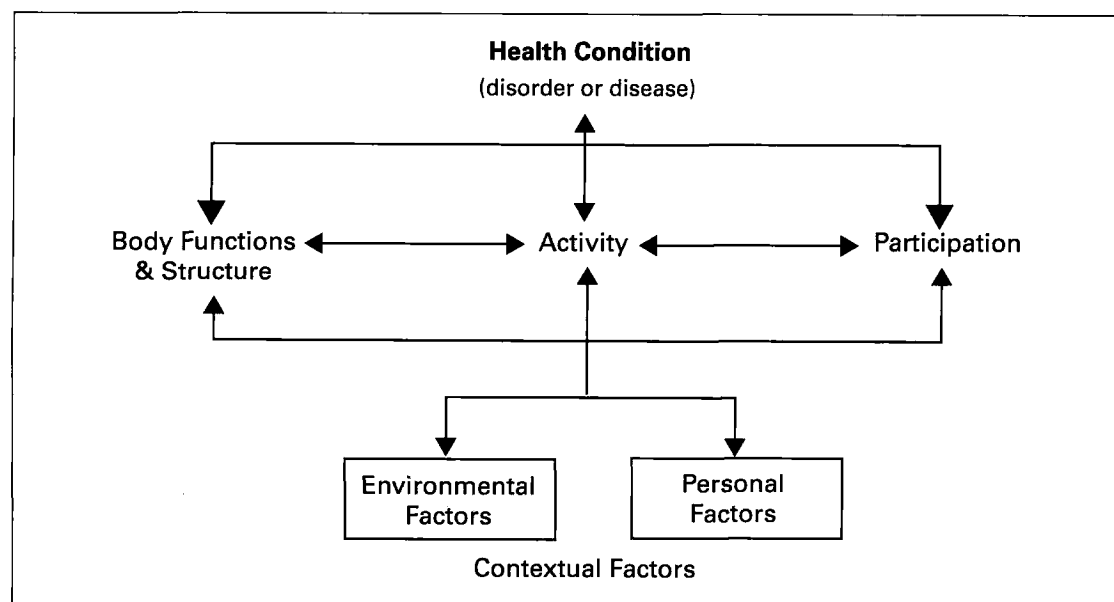
Data Collection

The project facilitator conducted introductory Photovoice training sessions for the participants as recommended by Wang and Burris (1997). A primary purpose of these sessions was to develop rapport and trust with the study participants. These sessions also helped to ensure that participants felt safe and had opportunities to ask questions before deciding to continue their participation in the study. Participants' transportation needs were assessed and addressed in conjunction with staff from the dRC. During the initial training session, information about the purpose and aims of this project was reviewed with the participants. The project facilitator presented an overview of the Photovoice

method, its history, development, and strength as a CBPR method, as well as examples of previous studies using Photovoice. During this session, the project facilitator engaged in discussion with the participants with the questions "How do you define community?" "What helps you go where you want to go and do what you want to do?" and "What prevents you from going where you want to go and doing what you want to do?" These questions were used to engage the participants in a brainstorming session on potential issues relevant to their lives that could be addressed using Photovoice.

The second session provided training on the actual implementation of Photovoice. A discussion of the ethical issues of using a camera (with emphasis on personal safety) and acquiring written permission from people with release forms before taking their photograph occurred during this training session (Wang & Redwood-Jones, 2001). Participants were provided with a digital camera that they were allowed to keep at the conclusion of the project as compensation for their participation. 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. The mechanical aspects of camera use, as well as basic photographic techniques, were discussed. The participants were provided with the opportunity to practice taking pictures and using the release form that is required before taking someone's photograph. The participants also were provided with a binder containing a copy of the Information for Participants sheet, the photo assignments, release forms, and contact information for the project facilitator. The binders also contained the instruction booklet for the digital camera, a notebook for taking notes, and plastic sleeves for storage of photographs.

Figure 1. Biopsychosocial Model of Disability (WHO, 2001)



Participants collected data by taking pictures as guided by photo assignments and were encouraged to take at least 10 pictures for each assignment and jot notes about the pictures as they took them. They were also encouraged to write about any pictures they decided not to take. The themes for the assignments included (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 one day you were out participating in your community life. Participant data collection initially was to occur during 3 months, with one of the three photo assignments occurring each consecutive month. However, because data collection occurred during a holiday season, an additional month was given for participants to complete their data collection. Participants were given 2 weeks to complete the photo assignment designated for that month and then were asked to contact the project facilitator to schedule an interview once the assignment was completed. Five of the project participants completed all three assignments and interviews. Four participants completed only two cycles of photographing and interviews. One participant completed only one assignment and interview, stating he could not think of anything else to photograph. Another participant contributed a fourth interview at her request because she had photographed more situations in the community that she wished to discuss.

Data Analysis

The initial stages of the Photovoice participatory analysis process were accomplished through semi-structured individual interviews between the project facilitator and each participant. The option of indi-

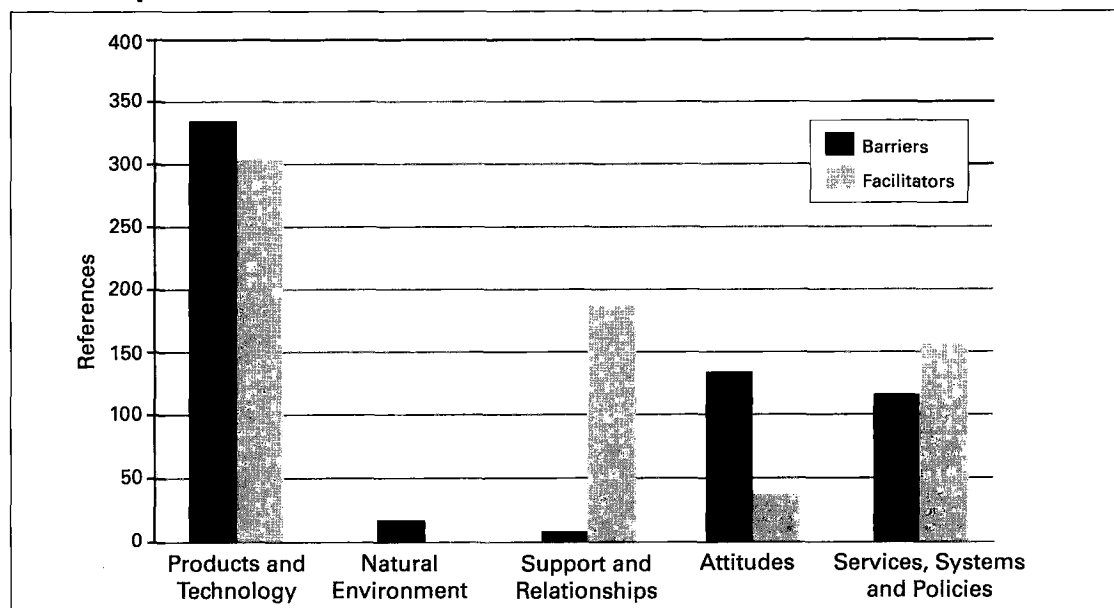
vidual interviews was selected over group discussion at this stage of data collection and analysis to minimize potential participant transportation issues. At the interview session, the project facilitator downloaded the participants' photographs from his or her camera into a laptop computer and configured them so that they could be viewed on the computer screen. The participant was asked to share his or her general thoughts about the assignment. The interview proceeded with the participant being shown the photographs they had created for the assignment sequentially. They were asked 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. Participants were also asked about any photographs that they did not take. The project facilitator provided the participants with hard copies of their photographs at the conclusion of the interview. Participants generated more than 560 photographs.

Interviews were digitally recorded and transcribed verbatim. The project facilitator reviewed 100% of the resulting transcripts in their entirety on audio with simultaneous comparison to the text copy. Participants' photographs were then added to their transcripts at the appropriate points containing discussion about the particular photo. These transcripts were imported into NVivo 8 (QSR International, 2008) for data management, coding, and analysis. Twenty-five interviews were completed.

The final stage of analysis in the Photovoice process is to identify issues or themes or develop theories that are anchored in data generated during the participatory analysis of the photographs. This stage

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Figure 2. Frequency of References to Barriers and Facilitators by ICF Chapter



of analysis began with the project facilitator making an initial interpretation of the information obtained from the individual interviews through application of the ICF framework to categorize responses, and concluded with an interactive group discussion session with the entire group of project participants to validate the facilitator's categorization.

Analytic Framework: ICF

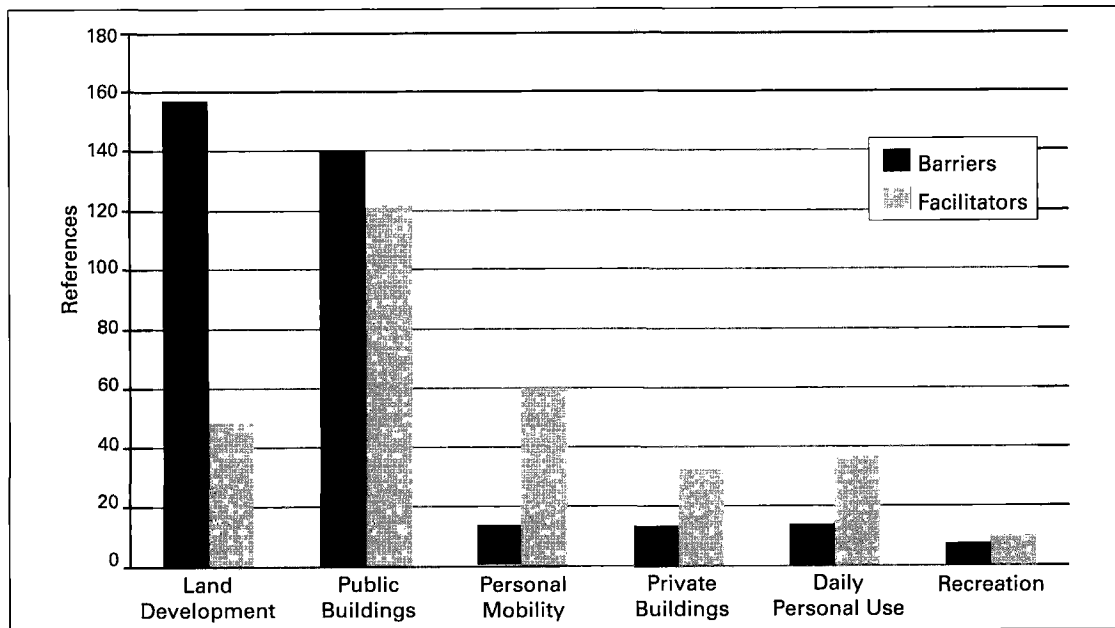
Disability is a complex phenomenon resulting from an incorporation of the features of the individual and the environment in which the individual exists. The WHO ICF uses a biopsychosocial model of disability that blends elements of the medical and social models. The incorporation of contextual factors influencing the three levels of human functioning into the model reflects this shift in the definition of disability. Environmental factors denote the physical, attitudinal, and social environment in which the person lives. Personal factors refer to the characteristics that have an effect on how a person perceives disability (WHO, 2001; Figure 1)

One of the ICF's principal uses is to enhance disability advocacy efforts (WHO, 2001). Interventions that seek to improve levels of participation of people with disabilities are a primary goal of disability advocacy. The ICF facilitates collection and coding of data on environmental factors impeding community participation, whether it is in the presence of a barrier or the absence of a facilitator. These data are vital to the development of viable interventions and influencing policy change (WHO).

Presently, no classification of personal factors exists in the ICF. This deficit is recognized as a limitation of the model; however, developing a taxonomy of personal factors is controversial (Whiteneck, 2006). The ICF identifies personal factors as characteristics of the individual that are not related to health condition or health status (WHO, 2001). Such factors include gender, age, and race. The inclusion of factors such as personality and behavioral and psychological patterns becomes contentious. Whiteneck (2006) suggests the inclusion of these characteristics may again spark concern from disability advocacy groups if the model suggests that individual motivation or compliance with treatment contributes to disability. The voice of people with disabilities was crucial to the development of the environmental factor taxonomy; consequently, the inclusion of individuals with disabilities is essential in activities to complete the ICF model through the development of a taxonomy of personal factors.

The taxonomy of environmental factors consists of five chapters: Chapter 1—Products and Technology, categorizes "products, equipment or technology...that are gathered, created, produced, or manufactured" (WHO, 2001, p. 173); Chapter 2—Natural Environment and Human Made Changes to Environment, addresses elements of the environment (e.g., climate, geography, flora and fauna, air quality) as well as characteristics (i.e., demographics, population density) of the other people that live there; Chapter 3—Support and Relationships, focuses on people or animals that provide physical or emotional support; Chapter 4—Attitudes, addresses the attitudes of people who

Figure 3. Frequency of References to Barriers and Facilitators by Category in Chapter 1: Products and Technology



are external to the person whose situation is being described; and Chapter 5—Services, Systems, and Policies, categorizes structured programs or operations, the administrative control over them, and the rules and regulations that govern them. A second level of categories is presented in each chapter to further refine classification of environmental factors. For example, Chapter 1 includes categories such as design and construction of buildings (for both public and private use) and land development, as well as products for personal mobility and transportation, personal use in daily living, education, and employment (WHO).

The ICF taxonomy of environmental factors was recreated in NVivo 8 (QSR International, 2008) as a tree node classification system. The project facilitator coded each individual interview using this taxonomy. The coding of the situations depicted in the photographs was based solely on the participant's description that occurred during the interviews. Often, the photographs were classified in more than one chapter or category. For example, a photograph of a situation of inaccessible parking may have represented a barrier in land development (e.g., parking lot design and construction), the attitudes of strangers (using the space without a placard), and civil protection services and systems (lack of enforcement of regulations related to accessible parking). After all of the photographs and interviews were coded, the results were shared with the group in a presentation organized around the chapters of the ICF. A brief overview of the ICF and its use was provided to the participants. During the presentation, participants were able to discuss their

photographs with the group. The participants were also provided the opportunity to address any concerns they had with the coding of the situation by the facilitator. No participants verbalized disagreement with the coding of the situations reflected in their photographs during this session. Further verification of coding was achieved through individual meetings with two of the participants who selected photographs and coded them based on the ICF taxonomy. Their coding was then compared to that of the facilitator and there was agreement in coding.

Qualitative Rigor

Lincoln and Guba (1985) identified criteria of trustworthiness in qualitative research as credibility, transferability, dependability, and confirmability. In this study, prolonged engagement and the development of a relationship with the dRC and the participants of this project created mutual respect and trust that enhanced credibility. Transferability was attained through the creation of a descriptive account of the context of the project and through the photographs, field notes, and annotations; this will allow others to consider the appropriateness of transferring generalizations to another context. Dependability was established by scrutinizing the accuracy of transcripts produced from audio files and providing participants with the opportunity to provide feedback on interpretations and coding. Confirmability was supported by the audit trail created from the raw data and products of analysis maintained in an electronic database.

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Results

Creating the Evidence Base

Analysis revealed an almost even number of references to barriers ($n = 554$) and facilitators ($n = 556$) contained within the interviews. Barriers and facilitators occurred most frequently in the classification of products and technology (Figure 2). These factors are representative of the physical environment, although different categories of this chapter were found to be more problematic or more supportive (Figure 3). Land development was the most problematic area, with numerous barriers encountered in the exterior environment, which includes parking lots, sidewalks, ramps, and curb cuts. Problems with accessible parking were common (Figure 4).

Photographs of barriers of the products of land development also reflected problems with services, systems, and policies of open-space planning (Figure 5).

The design and construction of buildings for public use was the second most frequent source of barriers (Figure 6).

Although the construction of public buildings was often problematic, this category also represented the most frequent occurrence of facilitators in the products and technology classification (Figure 7).

One participant took the opportunity to share some tricks of the trade with newly injured individuals through his photographs (Figure 8). He "wanted just to show people [who] are newly disabled things that they can do they might not realize they can do—like hunt, fish, go on trips." Along with his pictures of hunting and fishing trips and vacations on a cruise ship, he created a humorous series of photographs showing accessible and inaccessible products that are used in everyday life.

The environmental factors classified under "natural environment" received relatively little attention from the participants and only barriers were identified. The most frequent barrier in the natural environment was related to climate, specifically wind and rain. Participants also identified the challenges of navigating around overgrown landscaping that blocked accessible pathways.

Although the physical aspects of the community environment received the most attention from participant photographers, interactions and relationships with people were also reflected in the photographs and interviews. These interactions could be both problematic and supportive. Support and relationships revealed a high frequency of facilitators. Community members and peers, immediate family, and friends were the most common sources of supportive relationships.

There are more students than before in wheelchairs in college. So, we, we've come together and talk about

Figure 4. Barrier—Products and Technology of Land Development



This was the only spot I could find. You need an extra 3 foot beyond the end of your ramp on the van, and, and if you don't have...let's say about at least 5 foot space from that yellow line to the curb, you're going to run into a curb, and then that's a problem. —Participant 8

Figure 5. Barriers—Products and Technology of Land Development; Services, Systems, and Policies of Open Space Planning

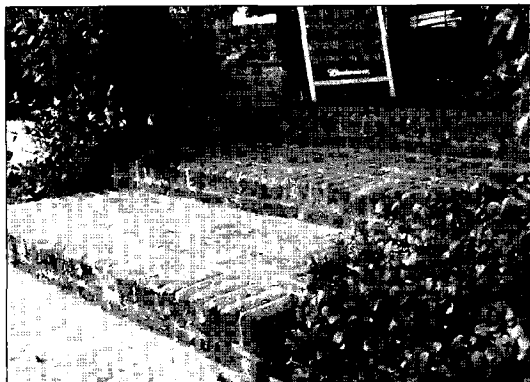


What I'm showing here in this neighborhood, it's not an affluent neighborhood. You've got a series of really bad sidewalks, no curb cuts, bad curb cuts. But then you go to the more affluent or more populated neighborhood downtown, and they're great. —Participant 2

it and we're thinking about starting up like a group of some sort to just talk about issues and, and sort of be supportive to each other. —Participant 4

No barriers were coded in this category, which is most likely a reflection of the intent of this classification to represent supportive, nurturing relationships (WHO, 2001). The most frequent barriers related to

Figure 6. Barrier—Design, Construction, and Building Products and Technology of Buildings for Public Use



These aren't just any steps. At the top of these steps sits a local bar/restaurant and all around local hangout favored by many of my coworkers. Why am I showing them to you? I mean, I know you've seen steps, and while these are really nice brick steps, they don't appear to be anything special. But they are! These steps provide access to much of the social interaction between my friends at work. These steps hold the insight to private jokes and conversations of people whose company I really enjoy. These steps lead to the way for me to interact with friends. These steps stop me in my tracks. There is no ramp. These steps are my enemy. —Participant 7

interactions with other community members occurred in attitudes, with the attitudes of strangers, society in general, and people in positions of authority being most problematic. The frequency of barriers resulting from attitudes of others in the community almost equaled the barriers encountered in accessing public buildings.

I wonder sometimes if I'm the only person in a wheelchair that ever has to go in this particular building. Same thing with these other ones, you know. Somebody else had to complain about this before, so the owner just desired to do nothing about it, or they don't care about wheelchairs, you know. —Participant 8

The attitudes of peers, colleagues, community members, people in positions of authority, and health professionals were most supportive (Figure 9).

Analysis of references classified in services, systems, and policies captured a wide variety of services in the community. The most barriers were seen in services and systems related to open-space planning. This finding reflects the numerous barriers seen in the classification of the products of land development. Services and systems related to transportation and health care were reflected evenly with an approximately equal number of barriers and facilitators reported in each. Stories

Figure 7. Facilitator—Design, Construction, and Building Products and Technology of Buildings for Public Use



That's heaven for somebody in a wheelchair. It is huge. I don't have to worry about bumping into the sink ... there's plenty of room for my wheelchair to get in there ... they've got grab bars up there and everything. And when you close the door it's almost big enough to do a small figure eight in there, because I did. —Participant 3

about accessibility of health care are of special interest to rehabilitation nurses and other rehabilitation service providers. Generally, health professionals were seen as supportive and services were accessible, although not ideal. The seemingly simple barrier of an inaccessible exam table has profound implications for the health of people with SCI. The primary care clinic visited by a participant with a chronic pressure ulcer that incapacitated him for 6 months does not have an accessible exam table. The consequence of this barrier is that the physician is unable to assess the status of the pressure ulcer because the participant is unable to transfer out of his wheelchair to the exam table.

I deal with pressure sores a whole lot, and in order for the doctor to see the pressure sore I'd have to be up on that table ... And with just him talking to me and taking my word ... I think it's not an accurate diagnosis of what he's going to put down in his chart ... and there might be an infection there, and he never gets to see it because I never get up on the table. —Participant 8

This participant must be referred to a specialty clinic for assessment and treatment of his wound. The 2006 national bill for treating pressure sores in the United States was approximately \$2.18 billion (Agency for Healthcare Research and Quality, 2006).

Movement to Action

Participants are using the results of this study to stimulate social action. The group has identified

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Figure 8. Tricks of the Trade: Inaccessible and Accessible Appliances

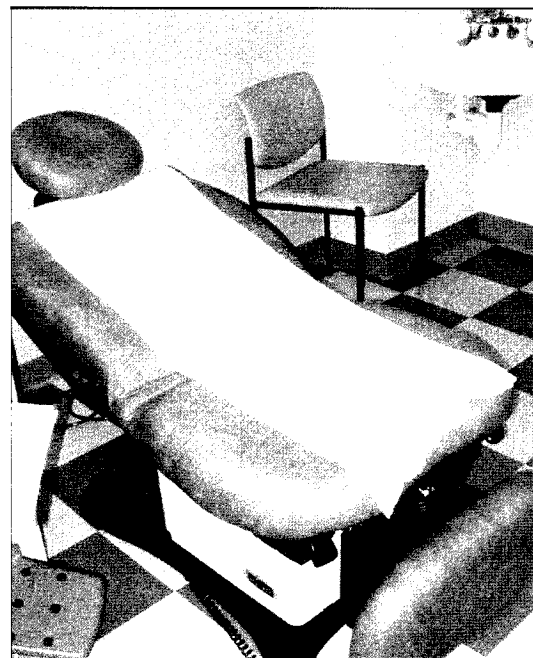


accessible parking as a priority issue and is working on addressing policies and pending legislation that will affect the availability of accessible parking areas. Findings in the project support this issue as one of the most problematic areas for this group. The participants used their photos to supplement written testimony presented to the South Carolina Senate Transportation Committee in support of a proposed bill to strengthen accessible parking laws in the state.

The local Charleston newspaper has published several stories, including participant photographs, about the project, with a focus on accessible parking issues identified by the participants during the course of the project and their subsequent legislative advocacy activities (Menchaca, 2008, 2009). Two participants independently used their photographs to create videos that were posted on YouTube. Future dissemination plans include a gallery exhibit of participants' photographs and stories, as well as further engagement of various local media sources, including print and television.

This Photovoice project paves the way for grassroots disability advocacy and has led to the development of a coalition of citizens sharing common concerns. The participants engaged in this project have begun to share with the public and policy makers—at the local and state level—knowledge and visual evidence of issues affecting citizens who use wheelchairs. This sharing of knowledge provides policy makers with the expertise needed to make decisions about legislation that affects people with disabilities (American Public Health Association, n.d.)

Figure 9. Facilitators—Attitudes (Health Professionals); Services, Systems, and Policies



This is the first time I've been on a table that raises up and down, and I can place myself from the wheelchair onto the table and actually get positioned for my examination, so that was, that was very exciting... The staff presents more willingness to assist if needed. ... the doctor that read the ultrasound said his wife had a T-12 injury, so already I know that I don't have to be on my guard, I can relax here because you know what I'm dealing with, you won't ask me to do something that you know my body's incapable of doing, so the knowledge and the sharing seems to be better at accessible facilities. —Participant 6

Discussion

Evaluation of Photovoice as a CBPR Method

The results of this project demonstrate that Photovoice is an effective method of engaging people with SCI in CBPR projects to address environmental factors affecting their community participation. The structure of Photovoice lays the foundation for participants to function as partners and eventually leaders as the participatory research process progresses. In this study, the project facilitator was primarily accountable for initiating the project, providing the tools to implement the research, and facilitating the research process. It is possible that a different research agenda may have developed if the project originated within the participant group rather than with the researcher. The data-collection process of Photovoice placed power in the hands of the participants and gave them control over the issues that were photographed and discussed. The photographs formed a visual evidence base to facilitate the prioritization of issues by the participants and support their advocacy endeavors. This process resulted in shared power between the "traditional academic researcher" and the community, fostered trust, and promoted a sense of ownership in the community, which in turn builds capacity for social change.

Modification of Method

The principles of CBPR require that researchers be flexible and adaptable to a community's particular needs and goals, and this may require modification of a prescribed means of data collection and analysis (Green et al., 2003). Photovoice methods are traditionally defined to include a collective participant group discussion after each photo assignment (Wang & Burris, 1997). Because of the unique transportation needs of a population with SCI, individual interviews were conducted with each participant after each photo assignment was completed to minimize the inconvenience to participants who relied on others for transportation. These individual interviews also provided a more intimate setting for participants to share their thoughts with the facilitator, and potentially resulted in much richer interview data than if initial discussion of the photographs had been conducted in a group setting.

An additional modification of the interview process involved allowing participants to comment on all of their photographs rather than selecting one or two they thought were most important or liked best as described in the traditional Photovoice methodology (Wang & Burris, 1997). A primary goal of this project was to conduct a comprehensive assessment

of the community's perspective of environmental factors that affected community participation. Limiting participants to discussion of one or two photographs would have impeded the collection and analysis of the full range of issues that were captured in their photos. The volume of data that resulted from this approach necessitated initial analysis and organization of data by the project facilitator, who then presented the full assessment to the group at a collective discussion session. During this session, participants could see the common experiences shared by members of the group and begin to prioritize issues to be addressed.

Limitations

The characteristics of this sample limit the applicability of the findings of this study to all individuals with SCI. The racial and ethnic characteristics of the study's participants reflect the population served by the dRC based upon information in the center's consumer database. Consequently, the findings may not reflect the needs or priorities of people in other racial or ethnic groups not represented in our sample. The participants' years of education (12–16 years, mean 13.9 years) suggest access to socioeconomic resources because the majority of participants owned their own adapted vehicle. Although the perspective of those without transportation who are less mobile in the community was not as broadly represented as the perspective of those with transportation, the predominance of mobility in the participant population allowed a comprehensive assessment of many aspects of community life. The participant whose sole means of transportation was the public paratransit system completed only one photo assignment and interview cycle. He was provided with opportunities and encouragement to continue his data collection, but he expressed that he had taken photographs of all aspects of the community that were relevant to him. This observation suggests that relying on paratransit services may limit community participation of people with disabilities.

The nature of photography presents unique restrictions to data collection because there are limits to what is observable and can be captured on film (Castleden, Garvin, & Huu-ay-aht First Nation, 2008). During the interviews, participants were prompted to discuss any pictures they did not take to help mediate this limitation. Photography makes it difficult to capture intangible issues; however, the analysis of the photographs in this project demonstrates that participants found effective ways to illustrate these concepts (e.g., attitudes). Participants also capitalized on the creative aspects of photography to portray personal feelings such as altruism, hope, and personal growth.

Evidence-Based Advocacy: Using Photovoice to Identify Barriers and Facilitators to Community Participation After Spinal Cord Injury

This information will help set the stage for creating a taxonomy of the personal factors—which the WHO has yet to develop in the ICF—that affect community participation after SCI.

Conclusion

Rehabilitation nurses are an integral part of the rehabilitation team whose primary purpose is to help individuals with disabilities, such as SCI, achieve their optimal level of functioning and lead more socially connected and productive lives (Association of Rehabilitation Nurses [ARN], 2004). An essential component of the role of rehabilitation nurses is to engage in advocacy on the behalf of their patients (ARN, 2009). Regardless of the location in which rehabilitation nurses practice, attention must be given to the community setting in which people with disabilities ultimately return to carry out their lives. Rehabilitation nurses, as well as other members of the interdisciplinary rehabilitation team, are better prepared for this role by gaining insight into the experience of living as a person with SCI in the community. This knowledge can be gained through projects that use creative methods to identify factors in the community environment (as perceived by people with SCI) that affect community participation.

Awareness of the issues that face people with SCI in the community is critical to the rehabilitation nurse's fulfillment of the advocate role. The short amount of time spent in the acute-care setting by individuals with newly acquired disabilities only makes this awareness even more critical as we try to facilitate the transition from the acute setting back to community life. Understanding the issues from the unique perspectives of those who have experienced this transition and are now living in the community helps keep rehabilitation professionals in touch with the real world.

The bill to strengthen the accessible parking laws in South Carolina (S.126) was passed by the South Carolina House and Senate and subsequently signed into law by Governor Mark Sanford on June 2, 2009. On January 1, 2010, the SC Department of Motor Vehicles began issuing new parking placards and license plates for people with disabilities.

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References

- Agency for Healthcare Research and Quality. (2006). H-CUPnet, 2006 National statistics principal diagnosis only. Retrieved February 1, 2009, from <http://hcupnet.ahrq.gov/Hcupnet.jsp>.
- Allotey, P., Reidpath, D., Kouamé, A., & Cummins, R. (2003). The DALY, context and determinants of the severity of disease: an exploratory comparison of paraplegia in Australia and Cameroon. *Social Science & Medicine*, 57(5), 949–958.
- American Public Health Association. (n.d.) APHA legislative advocacy handbook: A guide for effective public health advocacy. Retrieved July 14, 2008, from www.apha.org/NR/rdonlyres/6AF958C0-17EF-4E26-A37D-C9D4B6AC-CD98/0/Advocacyhandbook4web.pdf.
- Association of Rehabilitation Nurses. (2004). The home care rehabilitation nurse: Role description. Retrieved June 15, 2008, from www.rehabnurse.org/members/pdf/HmCrRhbNr.pdf.
- Association of Rehabilitation Nurses. (2009). *ARN Health Policy Toolkit: Chapter 2 What is health policy advocacy?* Retrieved February 17, 2009, from www.rehabnurse.org/pdf/ToolKitChapter_2.pdf.
- Brown, M., Gordon, W., Spielman, L., & Haddad, L. (2002). Participation by individuals with spinal cord injury in social and recreational activity outside the home. *Topics in Spinal Cord Injury Rehabilitation*, 7(3), 83–100.
- Carlson, E. D., Engebretson, J., & Chamberlain, R. M. (2006). Photovoice as a social process of critical consciousness. *Qualitative Health Research*, 16(6), 836–852.
- Castleden, H., Garvin, T., & Huu-ay-aht First Nation. (2008). Modifying Photovoice for community-based participatory indigenous research. *Social Science and Medicine*, 66, 1393–1405.
- Centers for Disease Control and Prevention. (2000). Healthy People 2010: Healthy people with disabilities. Retrieved November 6, 2006, from www.cdc.gov/ncbddd/factsheets/DH_hp2010.pdf.
- Department of Education. (2006). National Institute on Disability and Rehabilitation Research-Notice of Final Long-Range Plan for Fiscal Years 2005–2009. Retrieved November 20, 2006, from www.ed.gov/legislation/FedRegister/other/2006-1/021506d.html.
- Dijkers, M., Yavuzer, G., Ergin, S., Weitzkamp, D., & Whitenack, G. (2002). A tale of two countries: Environmental impacts on social participation after spinal cord injury. *Spinal Cord*, 40(4), 351–362.
- Green, L., George, A., Daniel, M., Frankish, J., Herbert, C., Bowie, W., et al. (2003). Guidelines for participatory research in health promotion. In M. Minkler & N. Wallerstein (Eds.), *Community-based participatory research for health promotion* (pp. 419–428). Jossey-Bass: San Francisco.
- Israel, B., Eng, E., Schulz, A., & Parker, E. (2005). Introduction to methods in community-based participatory research for health. In B. Israel, E. Eng, A. Schulz, & E. Parker (Eds.), *Methods in community-based participatory research for health* (pp. 3–26). San Francisco, CA: Jossey-Bass.
- Jurkowski, J., & Paul-Ward, A. (2008). Photovoice with vulnerable populations: Addressing disparities in health promotion among people with intellectual disabilities. *Health Promotion Practice*, 8(4), 358–365.
- Kearney, P. (2005). The ICF and rehabilitation nursing: Emphasizing the social. *Journal of the Australian Rehabilitation Nurses Association*, 8(1), 9–16.

- Kroll, T., Groah, S., Gilmore, B., and Neri, M. (2008). Consumer-directed teaching of health care professionals involved in the care of people with spinal cord injury: The consumer-professional partnership program. *The Journal of Continuing Education in Nursing*, 39(5), 228-234.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. London: Sage.
- Lopez, E., Eng, E., Robinson, N., & Wang, C. (2005). Photovoice as a community-based participatory research method. In B. Israel, E. Eng, A. Schulz, & E. Parker (Eds.), *Methods in community-based participatory research for health* (pp. 326-348). San Francisco: Jossey-Bass.
- McClain, L., Medrano, D., Marcum, M., & Schukar, J. (2000). A qualitative assessment of wheelchair users' experience with ADA compliance, physical barriers and secondary health conditions. *Topics in Spinal Cord Injury Rehabilitation*, 6(1) 99-118.
- McKinley, W. & Meade, M. (2004). Community integration following SCI. *NeuroRehabilitation*, 19, 79-80.
- Menchaca, R. (2008, June 25). Caught in the act: Disabled people use Photovoice project to show how violators' abuse disrupts their lives, mobility. The Post and Courier, p A1,A7. Available at www.charleston.net/news/2008/jun/24/watchgroupweb45383/.
- Menchaca, R. (2009, January 29). Parking advocate presses case. The Post and Courier, p B1,B6. Available at www.charleston.net/news/2009/jan/29/parking_advocate69932/.
- National Spinal Cord Injury Statistical Center. (2008). Spinal cord injury: Facts and figures at a glance. Retrieved June 10, 2008, from <http://images.main.uab.edu/spinalcord/pdffiles/Facts08.pdf>.
- Paralysis Task Force. (2005). A public health action plan for paralysis and similar mobility impairments. Retrieved January 22, 2006, from www.spinalcord.org/news.php?dep=1&page=0&list=645.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage Publications.
- QSR International. (2008). QSR NVivo. Retrieved January 7, 2010, from www.qsrinternational.com/.
- Schönherr, M., Groothoff, J., Mulder, G., & Eisma, W. (2005). Participation and satisfaction after spinal cord injury: Results of a vocational and leisure outcome study. *Spinal Cord*, 43, 241-248.
- Schwartz, L., Sable, M., Dannerbeck, A., & Campbell, J. (2007). Using Photovoice to improve family planning for immigrant Hispanics. *Journal of Health Care for the Poor and Underserved*, 18, 757-766.
- Stewart, R., & Bhagwanjee, A. (1999). Promoting group empowerment and self-reliance through participatory research: A case study of people with physical disability. *Disability and Rehabilitation*, 21(7), 338-345.
- Taylor, H. (1998). Americans with disabilities still pervasively disadvantaged on a broad range of key indicators. The Harris Poll #56, October, 1998. Retrieved November 20, 2006, from www.harrisinteractive.com/harris_poll/printfriendly/index.asp?PID=152.
- Thapar, N., Warner, G., Drainoni, M., Williams, S., Ditchfield, H., Wierbicky, J., et al. (2004). A pilot study of functional access to public buildings and facilities for persons with impairments. *Disability and Rehabilitation*, 26(5), 280-289.
- Wang, C., & Burris, M. (1994). Empowerment through Photo Novella: Portraits of participation. *Health Education Quarterly*, 21(2), 171-186.
- Wang, C., & Burris, M. (1997). Photovoice: Concept, methodology and use for participatory needs assessment. *Health Education and Behavior*, 24(3), 369-387.
- Wang, C., & Redwood-Jones, Y. (2001). Photovoice ethics: Perspectives from Flint photovoice. *Health Education and Behavior*, 28(5), 560-572.
- Whiteneck, G. (2006). Conceptual models of disability: Past, present and future. In M. Field, A. Jette, & L. Martin (Eds.) *Workshop on disability in America: A new look* (pp. 50-66). Washington, DC: National Academies Press.
- Whiteneck, G., Harrison-Felix, C., Mellick, D., Brooks, C., Charlifue, S., & Gerhart, K. (2004). Quantifying environmental factors: A measure of physical, attitudinal, service, productivity, and policy barriers. *Archives of Physical Medicine and Rehabilitation*, 85, 1324-1335.
- Whiteneck, G., Meade, M., Dijkers, M., Tate, D., Bushnik, T., & Forchheimer, M. (2004). Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 85, 1793-1803.
- World Health Organization. (2001). International classification of functioning, disability and health. Geneva, Switzerland: Author.

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