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Examining Participation among Persons with Spinal Cord Injuries and Disorders Using Photovoice

Salva Balbale

Department of Veterans Affairs; Northwestern University, salva.balbale@northwestern.edu

Keshonna Lones

Department of Veterans Affairs, k.lones1908@gmail.com

Jennifer N. Hill

Department of Veterans Affairs, jennifer.hill3@va.gov

Sherri L. LaVela PhD, MPH, MBA

Department of Veterans Affairs (VA), Center for Evaluation of Practices and Experiences of Patient-Centered Care; Spinal Cord Injury Quality Enhancement Research Initiative (SCI QUERI), Edward Hines Jr. VA Hospital; Center for Healthcare Studies, Institute for Public Health and Medicine, General Internal Medicine and Geriatrics, Feinberg School of Medicine, Northwestern University, sherri.lavela@va.gov

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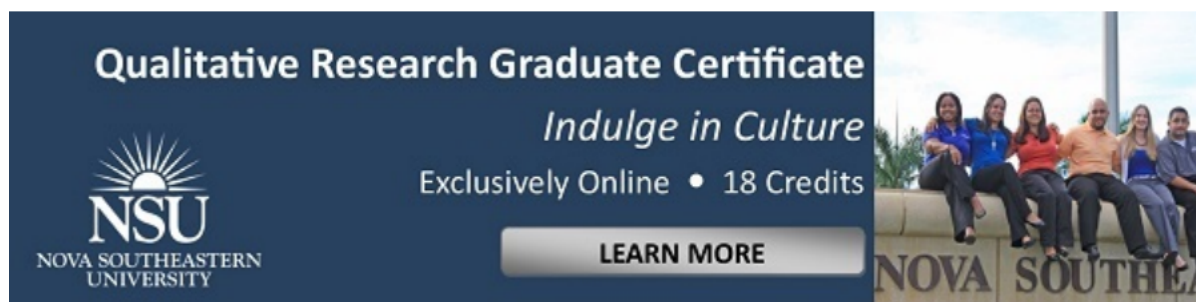


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Abstract

Participation is a significant rehabilitation outcome for individuals with spinal cord injury and/or disorder (SCI/D), yet few qualitative studies have described the social aspect of disability and community participation. We used the photovoice methodology to explore perceptions and experiences related to participation among Veterans with SCI/D. We recruited a convenience sample of individuals with SCI/D at the Hines Veterans Affairs (VA) SCI/D Unit. Participants were asked to take photographs exemplifying their experiences and activities regarding participation. Within four weeks, participants returned their photographs and completed semi-structured interviews to discuss their photographs. Interview transcripts were analyzed using an inductive coding approach to identify emerging themes. Of the 18 Veterans with SCI/D who completed the initial orientation session, 9 (50%) completed the photography phase and follow-up interviews. A majority of participants were White (67%) and the mean age was 64 years. The mean duration of injury was 21.8 years, and 75% of participants were paraplegic. Most participants (78%) were community-dwelling. All participants discussed participation as a highly relevant issue in their lives. A majority of participants (67%) described sports as an example of participation. Over half (56%) emphasized the positive effects of participation (i.e., feelings of enjoyment / accomplishment) in sports as well as engaging in faith-based activities, being outdoors, and managing business- or household-related responsibilities. Barriers to participation were mobility impairments, lack of transportation and cost. Findings from this study can be used to address environmental changes or other accommodations that influence participation, both inside and outside the health care setting.

Keywords

Spinal Cord Injury, Community Participation, Photovoice, Veterans

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Examining Participation among Persons with Spinal Cord Injuries and Disorders Using Photovoice

Salva Najib Balbale

Edward Hines Jr. VA Hospital, Hines, IL, USA
Northwestern University, Chicago, IL, USA

Keshonna A. Lones and Jennifer N. Hill

Edward Hines Jr. VA Hospital, Hines, IL, USA

Sherri L. LaVela

Edward Hines Jr. VA Hospital, Hines, IL, USA
Northwestern University, Chicago, IL, USA

Participation is a significant rehabilitation outcome for individuals with spinal cord injury and/or disorder (SCI/D), yet few qualitative studies have described the social aspect of disability and community participation. We used the photovoice methodology to explore perceptions and experiences related to participation among Veterans with SCI/D. We recruited a convenience sample of individuals with SCI/D at the Hines Veterans Affairs (VA) SCI/D Unit. Participants were asked to take photographs exemplifying their experiences and activities regarding participation. Within four weeks, participants returned their photographs and completed semi-structured interviews to discuss their photographs. Interview transcripts were analyzed using an inductive coding approach to identify emerging themes. Of the 18 Veterans with SCI/D who completed the initial orientation session, 9 (50%) completed the photography phase and follow-up interviews. A majority of participants were White (67%) and the mean age was 64 years. The mean duration of injury was 21.8 years, and 75% of participants were paraplegic. Most participants (78%) were community-dwelling. All participants discussed participation as a highly relevant issue in their lives. A majority of participants (67%) described sports as an example of participation. Over half (56%) emphasized the positive effects of participation (i.e., feelings of enjoyment / accomplishment) in sports as well as engaging in faith-based activities, being outdoors, and managing business- or household-related responsibilities. Barriers to participation were mobility impairments, lack of transportation and cost. Findings from this study can be used to address environmental changes or other accommodations that influence participation, both inside and outside the health care setting. Keywords: Spinal Cord Injury, Community Participation, Photovoice, Veterans

Approximately 276,000 individuals are living with a spinal cord injury and/or disorder (SCI/D) and about 12,500 new SCI/D cases are reported each year in the United States (US; DeVivo, 2012; National Spinal Cord Injury Statistical Center, 2015). The presence of SCI/D can result in a range of physical, psychological and social challenges (Gerhart, Bergstrom, Charlifue, Menter, & Whiteneck, 1993; Kennedy, Lude, & Taylor, 2006; Silver, Ljungberg, Libin, & Groah, 2012). An integral component of overall well-being among individuals with SCI/D is community participation (Barclay, McDonald, & Lentin, 2015; World Health Organization, 2001), which includes engagement in occupational, social

and leisure activities, as well as active involvement in an individual's environment (Magasi, Hammel, Heinemann, Whiteneck, & Bogner, 2009; Ripat & Woodgate, 2012; Van de Velde, Bracke, Van Hove, Josephsson, & Vanderstraeten, 2010). The importance of community participation among individuals with SCI/D is highlighted by recent national priorities delineated by Healthy People 2020 to reduce the proportion of Americans with disabilities that experience barriers to participation in work, school, and other community settings (US Department of Health and Human Services, 2010).

Although participation remains a significant rehabilitation and community integration outcome for individuals with SCI/D, few studies have described the social aspect of disability and community participation. Qualitative studies that evaluate experiences and perceptions around participation in the SCI/D community have been particularly limited. Data that account for the perspectives of individuals with SCI/D are needed to enhance interventions that aim to improve community participation and individual outcomes in this population (Kehn & Kroll, 2009; Simpson, Eng, Hsieh, Wolfe, & Spinal Cord Injury Rehabilitation Evidence Research Team, 2012). Furthermore, characterizing participation, in depth, is especially important given evidence that participation is driven by an individual's unique needs, lived experiences, and environment (Ripat & Woodgate, 2012; Whiteneck, 2006).

An innovative technique that can be used to obtain a comprehensive understanding of participation among individuals with SCI/D is photovoice. Photovoice is a qualitative and community-based participatory research method that has been used to identify individuals' needs around a given topic, engage communities in dialogue, and stimulate positive change (Catalani & Minkler, 2010; Wang, Yi, Tao, & Carovano, 1998). Few published studies have described the use of photovoice in a SCI/D population (Lal, Jarus, & Suto, 2012; Newman, Maurer, Jackson, Saxon, Jones, & Reese, 2009; Newman, 2010), although these studies have demonstrated the value of photovoice in extracting valuable insights about the experiences of persons with SCI/D.

Photovoice has been used in the SCI/D population to explore community participation; however, these studies focused on and were limited to environmental factors that impacted participation (Newman, 2010) and developing theory to describe the process of participation (Ripat & Woodgate, 2012). Further study using this methodology is necessary to understand the broader range of factors, beyond those at the environmental level, that shape participation, as well as perceived consequences of participation among individuals with SCI/D in community and health care settings. The purpose of this study was to use the photovoice methodology to explore perceptions and experiences related to participation among Veterans with SCI/D.

Methods

Study Design and Setting

We conducted a qualitative photovoice study at the Hines Veterans Affairs (VA) SCI/D Center. We recruited a convenience sample of Veterans with SCI/D in 2014 via flyers distributed throughout the SCI/D Center. This study was approved by the Hines VA Institutional Review Board.

This was part of a broader, mixed-methods evaluation led by Dr. Sherri LaVela, a senior research scientist, to examine the functional needs of Veterans with SCI/D. Specifically, SL conceived and designed the study; SB, KL and JH collected data; all authors analyzed data; SB prepared the initial draft of this manuscript and all subsequent revisions; all authors reviewed and approved the final version of the manuscript. This study was supported by the VA Office of Research and Development, Health Services Research and

Development Service, Quality Enhancement Research Initiative (RRP-13-248), and was intended to elicit data to support a multicomponent intervention to improve functional outcomes for Veterans with SCI/D.

Data Collection

Participants provided informed consent and attended a 30-minute orientation session at the VA. During orientation, each participant received a digital camera, memory card, and an informational packet which included guidance and instructions on taking photographs. We encouraged participants who needed help with handling the camera and taking photographs to draw upon their family members and caregivers for assistance with photographing images identified by the participant with SCI/D. All participants received safety and ethical training during the orientation. In particular, we asked participants not to take photographs of people's faces, name tags or any other identifiable information. Participants were encouraged to "tell a story" with their photographs about their experiences with living with an SCI/D. Prompts were provided to guide participant photography and encourage participants to take photographs depicting their experiences around participation overall, as well as barriers and facilitators to participation. We focused on participation experiences in SCI/D, probing participants to consider the following questions: "What activities do you enjoy participating in? Do you continue to participate in the activities you enjoy? How do you adapt when necessary? Are there things you would like to participate in, but can't, due to your injury? Have you found ways to participate in things you didn't think you'd be able to participate in?" In addition, we collected basic demographic information from each participant at the end of the orientation session.

Participants were given four weeks to take 25-30 photographs and were provided with a prepaid, self-addressed mailing envelope with bubble wrap in order to return their memory card after taking photographs. Upon receipt of returned memory cards, participants were invited to discuss the photographs they took in greater detail during in-depth semi-structured follow-up interviews.

Interviews were based on an interview guide to probe individual participant photographs (Catalani & Minkler, 2010) and narratives as they relate to participation more broadly with a SCI/D. Interview questions included:

- a. What are some things that you currently like (or would like) to participate in? How are these affected by your spinal cord injury?
- b. Can you tell me about an activity that you would like to participate in, but may have difficulty in engaging in due to your injury?
- c. In reference to a specific photograph that the participant chooses to discuss:
 - i. What is this an image of? Can you tell me what you see in this photograph?
 - ii. What is happening in this photograph?
 - iii. Probe into the significance of why the picture was taken.

All interviews were audio-recorded and transcribed verbatim for analyses. Upon completion of the photography and interview phases, participants were able to keep the digital camera used for their own photographs. Additionally, all participants received a new memory card and a \$10 monetary incentive for their participation in the study. Further details on data collection efforts for this study can be found elsewhere (LaVela, Balbale, & Hill, 2016).

Data Analysis

Interview data were entered into NVivo 8 (QSR International Ltd., 2008) for coding and analysis. We used an inductive coding approach for analysis. As described by Catalani & Minkler (2010), we did not analyze the photographs themselves. Participant photographs were incorporated into corresponding transcripts and included in the qualitative analyses. Three qualitative researchers coded the transcripts across multiple rounds to finalize emerging themes. During the first round, the coders independently reviewed three transcripts to develop a preliminary code list. The coders then collaboratively created a list of codes, coded six transcripts independently and together refined the code definitions. The final list of codes was applied to the remaining transcripts and categorized to identify prominent themes. Discrepancies were reconciled through consensus. Coded transcripts were analyzed within and across cases to develop themes.

Results

Of the 18 Veterans with SCI/D who completed the initial orientation session, 9 completed both the photography phase and follow-up interviews (representing a 50% participation rate). The mean age was 64 years, and 8 participants were male. A majority of participants (67%) were White and approximately 33% were Black. On average, duration of injury was 21.8 years. A majority of participants (75%) were paraplegic. Most participants (78%) lived in community settings; 22% lived in a residential care facility. Participant characteristics are presented in Table 1.

Table 1. Participant characteristics

Characteristic	n = 9 Frequency (%)
Gender	
Male	8 (88.9)
Female	1 (11.1)
Age	
Mean (range, standard deviation)	64 (36-86, 16.1)
Race	
White	6 (67.0)
Black	3 (33.0)
Marital Status	
Married	3 (33.3)
Divorced or separated	2 (22.2)
Widowed	2 (22.2)
Never married	2 (22.2)
Health Status	
Excellent	1 (11.1)
Very good	2 (22.2)
Good	2 (22.2)
Fair	4 (44.4)
Education Completed	
High school graduate (grade 12 or GED)	2 (22.2)
Some college or technical school	5 (55.6)
College graduate (4 years or more)	2 (22.2)

Level of Injury* (n=8)	
Paraplegia	6 (75.0)
Tetraplegia	2 (25.0)
Years Since Injury	
Mean (range, standard deviation)	21.8 (2-59, 18.49)
Patient Recruitment Source	
Residential Care Facility	2 (22.2)
Outpatient	7 (77.7)

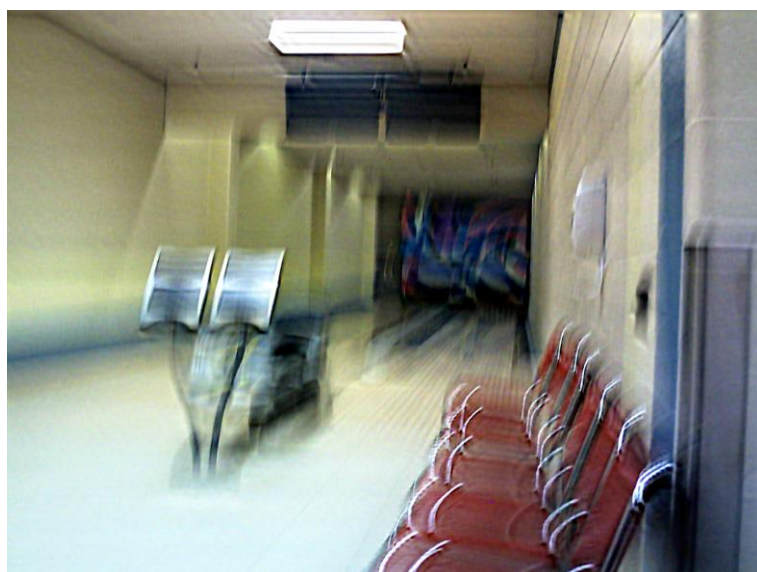
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On average, participants took 22 photographs. During follow-up interviews, all participants discussed participation as a highly relevant issue in their lives. Participant data were organized into four broad themes that described perceptions and experiences related to participation. These themes included: examples of participation, effects of participation, barriers to participation, and facilitators to participation.

Examples of Participation

Most participants (67%) described sports as an example of participation, varying from fishing, bowling, and skiing, to the VA National Wheelchair Games. One participant described his picture of an accessible bowling alley (Figure 1) and explained: “Well the one picture that’s blurry there, that’s our bowling alley here at [the VA hospital]. It’s accessible. They are in the midst of some repairs with it right now, but we do have two lanes, which are in high demand it seems like. Here [at the hospital] we have two lanes. There are lots of novices that are learning they can bowl with adaptive equipment. It’s designed as a regular bowling alley, but it’s fully accessible. There’s a lot of interaction ... team-like camaraderie.” Another participant stated: “I participate in games here [at the VA]. I played games... where you throw the bean bag into the hole. I played backgammon. I bowl here at the hospital. Then I went to the summer games. I do a lot of activities.” Many participants also described their participation in outdoor activities. One participant noted some of the activities he participated in: “Well, there’s fishing [and] I got a crossbow... Anything that has to do with the outdoors, I’m there.”

Figure 1. Photograph of accessible bowling alley



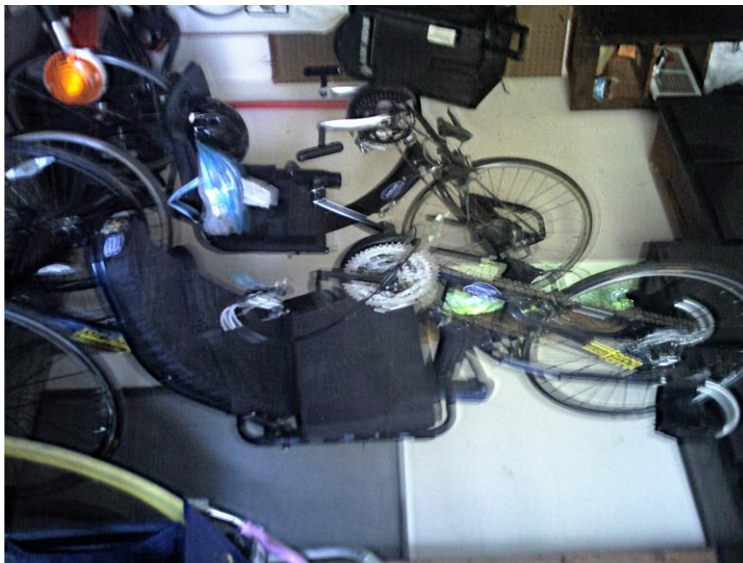
Other Veterans described their participation in the National Wheelchair Games. One Veteran commented: “We had the wheelchair games, I take part in that. It takes place once a year, usually in May. It’s a big, big deal.” Another participant explained that he was preparing himself to partake in the Games: “I’m preparing myself to participate in the National Wheelchair Games, you have to go to a lot of practices.” Other Veterans described the sports they participated in: “I do power soccer but there’s nobody here to teach us or anything. I am going to do that in the Wheelchair Games!” One participant stated: “They got air rifle and archery at the games. I do that.” One Veteran described participation in skiing: “I’ve been to Colorado a few times through the hospital. They have a winter ski clinic that was awesome. I didn’t really want to do it the first time, I hadn’t been hurt six months or nine months and they pushed me to do it. I’m so glad I went. I learned so much from all the guys.”

Figure 2. Photograph of participant’s mini-van



Other less common examples of participation ranged from traveling, using hand cycle bikes, attending church and faith-based activities, and cleaning. Fewer participants reported participation in these activities. One participant took a photograph of his mini-van (Figure 2) that he often used for travel: “I go all over the United States. Mainly from [Illinois] to Michigan or Wisconsin and maybe in the near future, Florida. So yeah, I like to travel. Depending on the situation, I drive by myself... and if I’m there for a weekend or so many days, then I have to have a caregiver go with me.”

Another participant described his photograph of hand cycle bikes (Figure 3) and their importance to his exercise participation: “These are my hand cycle bikes. They help me with my cardiovascular workout. After you get used to being in a wheelchair, you can push it all day long and you’re never really getting tired. And I notice that if I don’t do cardio, my resting pulse will be at like 100 beats/minute. That’s when you’re resting. And if I work out for a month or two in a row on the hand cycle bike and really get my cardio up, I can bring that resting heart rate down to like a 75 or 80. That’s important just to live, but this gets me out of the house, through the neighborhoods. As long as there’s a paved bike path, I can get up into the woods and ride around and it makes me very happy. You’ve got to exercise.”

Figure 3. Photograph of participant's hand cycle bikes

One participant commented on his photograph of a dishwasher (Figure 4) and his responsibilities at home: "I'm the one responsible for making sure the kitchen is clean... My wife works full time or almost full time and I'm a stay at home daddy. I do all that stuff and the dishes and the laundry... It's my responsibility."

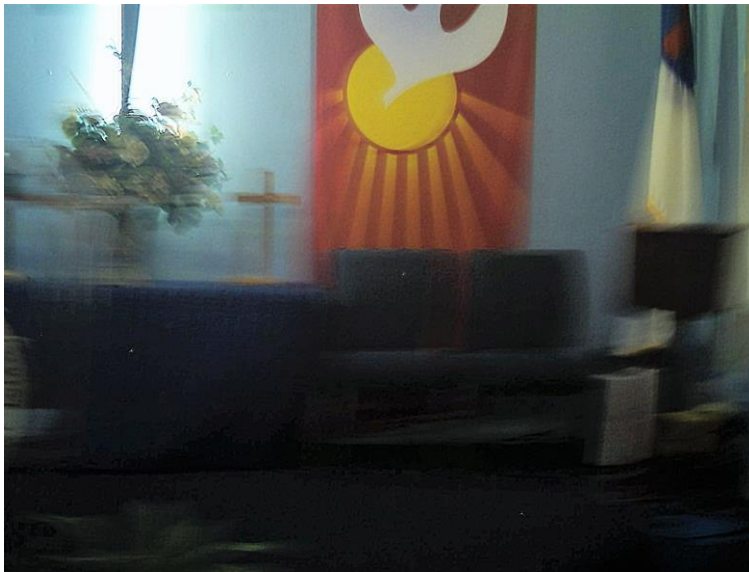
Figure 4. Photograph of participant's dishwasher

Effects of Participation

Over half of participants (56%) emphasized the positive effects of participation. The effects fell into two categories: feelings of enjoyment and feelings of accomplishment. One participant described a feeling of enjoyment from his participation in church and faith-based activities, as well as a corresponding photograph of the church (Figure 5): "Well, [church] makes me forget about my accident. I feel different when I am in church. My whole attitude just changes. So I don't stress out ... I don't worry. I just live to enjoy another day. It relaxes my mind." One participant stated: "The important thing is just to live. The bike path allows

me to get out of the house, through the neighborhoods. I can get up in the woods and ride around and it makes me very happy.” Similarly, another participant commented: “You’ve got to exercise and it gets me away from all the civilization. I’m a military guy, I like being in the woods. Not here with planes and cars... I love being outside... I really enjoy the adrenaline. I’m always trying to find ways that I can excite myself without hurting myself.” Others discussed participation in social events at VA facilities as way to meet other people and partake in activities outside of their home. One participant commented: “Whenever the [VA] has something I go... I’m going to a Christmas party... in the auditorium. It takes me out of the house... Gets you involved.” Another participant stated: “A lot of people are here [at the VA]. You see a lot of people that you know, and meet a lot of people.”

Figure 5. Photograph of participant’s church



Other Veterans described a sense of accomplishment they felt through their participation. One participant described how participating in the wheelchair games made him feel: “I like being part of the wheelchair games because it takes away from the boredom. [It] gives you some challenge and makes you feel more of a citizen when you are doing something. You feel more worth something ... and accomplishing something.” Another participant discussed a business he managed and that his involvement in the business enabled him to engage in other activities: “My business gives me money to be able to do other things ... It allows me to generate money so I can fix a car so I can drive, or buy my grandson whatever he wants. It enables me to do other things.” Finally, one participant reflected on his participation in a VA winter sports clinic soon after his injury that resulted in feelings of accomplishment and confidence in his own abilities, as well as enjoyment: “I almost think they should force people to do something like that when they get hurt to get them over that hump to realize that you can still do stuff. I wouldn’t have done it. And if I hadn’t been forced, how long would it have taken me to want to do that? It might have taken five or six years. That’s five or six years wasted. I was 19 when I got hurt. I want to have fun!”

Barriers to Participation

A majority (67%) of Veterans cited barriers to participation. Some of the most common barriers to participation were mobility impairments, lack of transportation and cost. In terms of mobility impairments, Veterans mentioned sports or social activities that were

sometimes challenging for them to participate in. One participant commented: “I used to like to go bowling... but, the way it is now since I lost use of that arm I have to keep a hand on that ramp there and drop it down, but in earlier years I used to full swing it on the chair, go bowling in my chair, and I belonged to a wheelchair bowling league... for a couple years. When my kids were smaller... every Saturday... we’d go out and do something and that was one of the things that we did, bowl. And the other thing was American Legion baseball... I got up and went with the kids to all the games and I used to... play catch with them, which I can’t do anymore.” Another participant stated: “I don’t do much socially anymore. I don’t go to BBQs or things like that because I can’t hold the plate. I can’t cut the meat. I don’t go just because... I don’t want to be a burden on [my family] and need somebody to hold this plate for me. Or I can’t cut the meat so even [when] going out to restaurants, I try to pick something that’s easy for me. A lot of times it’s finger food because I know I don’t have to cut it... I can just pick up and it may not be what I really want but... it’s something that I know I can easily eat. It makes my sister in law uncomfortable when she sees me struggling. So, I try to get something that is easy for me to eat so I don’t make others uncomfortable.” One participant commented: “I want to go visit my wife’s family... but there’s ten steps to get into every single place that you go. That gets a little challenging over time.”

Barriers to participation related to transportation challenges and cost were also discussed. “Whenever my automobile is not functioning properly, then I am just kind of shut down because the only thing I can do is call the VA to get back and forth to the hospital, but I can’t go to the museum drive here or there at my wish or desire,” said one Veteran. Another participant noted the cost associated with some of the activities he preferred to engage in: “I’d like to hunt and fish. Adaptive equipment related to that to get me to the field again... [is] out there, but they are very costly.” One participant discussed the difficulties associated with participating in sports activities, such as bowling, outside the adaptive facilities at the VA: “Outside the VA, I’ve got to take a bus, [which] drops me off in front of the bowling alley. But it’s about a half an hour ride there, and then... you’ve got the cost, and the condition of... what you can do there. The equipment is different, it’s not what we use or practice with here [at the VA]. So... you’re adapting to a new adaption.” Finally, one participant stated: “I made up my mind that I’m all done driving, I figured before I killed myself or kill somebody, I would give up my driving. And then... I couldn’t go out to eat like used to, every Monday, Wednesday and Friday night.”

Facilitators to Participation

Fewer Veterans (11%) mentioned facilitators to participation. Examples of these facilitators included accessible places, such as non-congested environments, as well as specific accommodations, such as adaptive equipment. One participant commented on a photograph of his adaptive lawn mower used for gardening (Figure 6): “This is a picture of my lawn mower. I got to buy a special lawnmower because I can’t use my feet. I can literally pull my wheelchair right up to the front and then transfer on to this part... I just do the quick hop up on to the seat and you do everything with your hands. You don’t need your feet at all... I can do it when I want.”

Figure 6. Photograph of participant's adaptive lawn mower

Another Veteran who expressed an interest in the outdoors said that the open spaces around the town facilitated participation (Figure 7): “I took these pictures because there is a lot of wide open space. I don’t like being in a congested area, this allows me to get out and around. When there’s a lot of people... it’s hard to get around. Sometimes... it can seem like thousands of people [are] in the street at one time and you can hardly get down the sidewalk sometimes. But here, I never have any trouble getting anywhere I got to go. If I want to go to the corner, the coffee shop or down the street to the cleaner, I’m not running into anybody or anything like that.” Another participant described use of an all-terrain, action track wheelchair that would allow him to participate in more outdoor activities: “I just got a new [action-track] chair. It’s got the tank tracks on it, which allows me to go even more into the woods where a regular wheelchair can’t go. This will allow me to go other places so that I can do better fishing or fishing in more places. I can go hunting.”

Figure 7. Photograph of open spaces near participant's home

Discussion

Achieving maximum participation remains a significant challenge for individuals with SCI/D (Ma, Chan, & Carruthers, 2014; Pershouse et al., 2012; Ullrich et al., 2012). This is further complicated in light of evidence that individuals with SCI/D and other disabilities are known to experience greater social isolation, poorer health outcomes, and less satisfaction

when they participate compared to individuals without disabilities (White, Gonda, Peterson, Drum, & the Rehabilitation Research and Training Center Expert Panel, 2011). To fully address participation needs and improve individual outcomes in the SCI/D population, a need exists to better characterize participation directly from the experiences and perspectives of individuals who have a SCI/D.

Through participant-generated photography and follow-up interviews, we derived several important insights that build on existing knowledge around participation in SCI/D: (1) participation is highly valued by individuals with SCI/D; (2) community and social participation often led to positive feelings of enjoyment and accomplishment; and (3) numerous barriers to participation, such as mobility and transportation challenges, currently exist for individuals with SCI/D. In addition, participants used their photographs to describe a broad variety of activities in which they participate, both in community and health care settings. These findings can be used by rehabilitation researchers and professionals to enhance our understanding of participation in the SCI/D community and develop evidence-based strategies to eliminate barriers to participation.

Previous research has found that individuals with SCI/D who engage in sports and recreational activities report feelings of enjoyment, achievement and fulfillment (Newitt, Barnett, & Crowe, 2016; Tasiemski, Kennedy, Gardner, & Blaikley, 2004). Our findings align with this and suggest, further, that persons with SCI/D may experience feelings of enjoyment and accomplishment as an effect of participation in several other activities beyond sports and recreation. Specifically, participants in this study noted that being outdoors and engaging in faith-based activities led to feelings of enjoyment, and activities such as managing business- or household-related responsibilities, in addition to involvement in sports and recreation, led to a sense of accomplishment. These data can be useful for rehabilitation efforts aiming to increase opportunities for participation in a way that also enhances feelings of enjoyment and accomplishment among individuals with SCI/D. Although existing literature broadly recognizes that increased participation can enhance individual outcomes, particularly life satisfaction among persons with SCI/D (Schönherr, Groothoff, Mulder, & Eisma, 2005; Van Leeuwen et al., 2012; Yorkston, Bamer, Johnson, & Amtmann, 2012), our findings represent early yet rich, qualitative evidence identifying specific activities and corresponding positive effects of participation that may lead to improved life satisfaction.

Although many participants appreciated social opportunities to interact with and learn from other individuals with SCI/D, it is important to note that others reported a sense of enjoyment primarily through solitary, individualized activities. This suggests that social participation may be conceptualized differently across individuals with SCI/D. In their recent analysis, Craig and colleagues (2015) found that characteristics that predicted social participation among community-dwelling individuals with SCI/D included younger age, less severe secondary medical complications such as bowel and bladder dysfunction, higher cognitive capacity, improved self-efficacy, and greater perceived social support. In light of these data, a need exists to better understand how individuals with SCI/D perceive and define participation to tailor efforts that can support participation outcomes in this population.

Facilitators of participation identified and photographed in this study included accessible environments and assistive equipment and devices; this is consistent with a recent review of social and community participation in SCI/D (Barclay et al., 2015). Given that application of assistive equipment and devices is becoming increasingly prevalent in sporting programs, this may explain why a majority of participants reported engaging in adaptive sports and recreational activities. Our findings also corroborate data from prior studies that have shown that major barriers to participation in the SCI/D community include transportation challenges, cost, mobility and health-related impairments (Hammel et al., 2008; Newman, 2010; Noreau, Noonan, Cobb, Leblond, & Dumont, 2014). Advances in

assistive technologies, as well as rehabilitation and physical therapy have been helpful in addressing mobility and health-related impairments (Barclay et al., 2015), yet transportation challenges and cost remain a significant barrier to participation. Peer or patient navigation programs tailored for the SCI/D population may be a viable strategy to connect individuals with SCI/D with useful information and available resources or services to help minimize cost and overcome transport challenges (Newman et al., 2014).

A unique aspect of this study is that our findings captured perspectives of participation among individuals with SCI/D who reside in the community as well as those living in a residential long-term care facility designed for Veterans with SCI/D. This is reflected in our findings, as participants demonstrated the importance of the health care and rehabilitation environment in their participation. Photographs and interview data underscored a range of services, events and resources that supported participation and were offered to all patients with SCI/D through VA health care facilities. In particular, veterans in this study described participation in wheelchair accessible games, sports clinics, and bowling activities facilitated by the VA, and commented, moreover, on peer-level camaraderie experienced through participation in such activities. These findings suggest that health care and rehabilitation organizations that serve individuals with SCI/D, including both outpatients and long-term care residents, may play a critical role in increasing opportunities for participation and cultivating peer-level social support, which has been established as a facilitator for participation in the SCI/D population (Gargaro, Warren, & Boschen, 2013; Sweet, Noreau, Leblond, & Martin Ginis, 2016; Van de Velde et al., 2010).

Consistent with prior photovoice studies, participants in this study were enabled to drive the data collection process, photographing aspects of participation that were most meaningful to them and leading the subsequent interview discussion by interpreting their own photographs and explaining their significance to participation (Catalani & Minkler, 2010; Wang et al., 1998). These unique insights can be directly translated into intervention efforts to enhance participation after SCI/D in a way that reflects individual needs. Participant-generated photography and narrative may be especially valuable given the need to conceptualize participation directly from the perspective of persons with SCI/D (Brown et al., 2004; Brown, 2009) and better understand the complex interactions between person, activity, and environment that shape participation (Fougeyrollas, Noreau, & Boschen, 2002; Mallinson & Hammel, 2010; Noreau, Fougeyrollas, Post, & Asano, 2005). We found that the use of the photovoice methodology allowed participants with SCI/D to visually demonstrate what matters most to them with regards to participation. Our findings align with the small number of photovoice studies in the SCI/D population that illustrate the utility of a participatory research method to capture SCI/D participant perspectives (Lal et al., 2012; Ripat & Woodgate, 2012). We build upon these studies, however, by expanding our focus beyond environmental factors related to participation, and capturing perceptions of participation in and out of community settings. Our methodological approach enabled us to extract practical and actionable insights into the participation of individuals with SCI/D, both in community and health care settings that can be integrated into interventions tailored around individual participation needs.

A majority of sports that participants reported engaging in were adaptive and elicited positive feelings of enjoyment and accomplishment. Beyond sporting activities, we also found that being outdoors and engaging in faith-based activities led to feelings of enjoyment, and activities such as managing business- or household-related responsibilities led to a sense of accomplishment. Given the importance of these activities to participation in SCI/D, targeted efforts to improve adaptations and assistive technologies beyond sporting activities may enhance community and social participation. Health care organizations, moreover, can play an important role in enhancing participation by facilitating adaptive social, sporting, and

faith-based events and providing individuals with SCI/D with patient education and resources needed to improve participation. Finally, conceptualization of participation may vary across individuals with SCI/D individuals; further examination is needed to understand how individuals with SCI/D define optimal social participation in the community and in the health care environment.

This study had several limitations. Our findings are based on a small sample size of Veterans with SCI/D, may not be representative of the broader population of persons with SCI/D (Curtin, Suarez, Di Ponio, & Frayne, 2012). Additionally, perceptions around participation were explored at a single point of time using a cross-sectional design; we did not assess changes in perceptions or experiences related to participation over time. Limitations related to the photovoice method may also have been introduced (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009; Wang & Burris, 1994; 1997). In particular, training instructions provided to participants at the orientation session may have influenced or biased participants' photography. Furthermore, data were collected across a period of two months, and in some cases participants were unable to comment on their own photographs for several weeks after taking them. As a result, some participants may have been unable to accurately recall or convey the intended meaning of their photographs during the follow-up interviews. Due to VA confidentiality policies and regulatory concerns, we were unable to validate the results of the study with participants, present the photographs in public forums, and use them to further engage the SCI/D community in critical dialogue. These are often key attributes of photovoice studies.

Increased awareness of participation from the perspective of individuals with SCI/D provides the foundation for a holistic approach to health care delivery that considers community integration. Although this study is part of an initial step to capture the unique perspective around participation among individuals with SCI/D, additional studies are needed to characterize and better understand the factors that drive participation among individuals with SCI/D. Larger qualitative studies that explore the role of participation in the lives of individuals with SCI/D in community and health care settings, as well as strategies to better facilitate participation across various levels and completeness of injury, are warranted.

Conclusion

The importance of social and community participation for individuals with SCI/D has been highly recognized in existing literature. Using photography and detailed narratives, participants in our study emphasized the importance of participation in their lives, described examples and experiences of participation in community and health care settings, and captured participation barriers and facilitators that matter most to them. We learned that: (1) participation is highly valued by individuals with SCI/D; (2) community and social participation in sports as well as faith-based activities, being outdoors and managing business or household responsibilities often led to positive feelings of enjoyment and accomplishment; and (3) numerous barriers to participation, including mobility and transportation challenges, currently exist for individuals with SCI/D. Findings from this study can be used to address environmental changes or other accommodations that influence participation, both inside and outside the health care setting.

References

- Barclay, L., McDonald, R., & Lentin, P. (2015). Social and community participation following spinal cord injury: A critical review. *International Journal of Rehabilitation Research*, 38(1), 1-19. doi:10.1097/MRR.0000000000000085

- Brown, M., Dijkers, M. P., Gordon, W. A., Ashman, T., Charatz, H., & Cheng, Z. (2004). Participation objective, participation subjective: A measure of participation combining outsider and insider perspectives. *The Journal of Head Trauma Rehabilitation*, 19(6), 459-481.
- Brown, M. (2009). Perspectives on outcome: What disability insiders and outsiders each bring to the assessment table. *Archives of Physical Medicine and Rehabilitation*, 90(11), S36-S40. doi:10.1016/j.apmr.2009.04.024
- Catalani, C., & Minkler, M. (2010). Photovoice: A review of the literature in health and public health. *Health Education & Behavior*, 37(3), 424-451. doi:10.1177/1090198109342084
- Craig, A., Nicholson Perry, K., Guest, R., Tran, Y., & Middleton, J. (2015). Adjustment following chronic spinal cord injury: Determining factors that contribute to social participation. *British Journal of Health Psychology*, 20(4), 807-823. doi:10.1111/bjhp.12143
- Curtin, C. M., Suarez, P. A., Di Ponio, L. A., & Frayne, S. M. (2012). Who are the women and men in Veterans Health Administration's current spinal cord injury population? *Journal of Rehabilitation Research and Development*, 49(3), 351. doi:10.1682/JRRD.2010.11.0220
- Devivo, M. J. (2012). Epidemiology of traumatic spinal cord injury: Trends and future implications. *Spinal Cord*, 50(5), 365-372. doi:10.1038/sc.2011.178
- Fougeyrollas, P., Noreau, L., & Boschen, K. (2002). Interaction of environment with individual characteristics and social participation: Theoretical perspectives and applications in persons with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation*, 7(3), 1-16. doi:10.1310/QDNN-8FN0-NJMG-TVWB
- Gargaro, J., Warren, C., & Boschen, K. (2013). Perceived barriers and facilitators to community reintegration after spinal cord injury: A critical review of the literature. *Critical Reviews in Physical and Rehabilitation Medicine*, 25(1-2), 101-141. doi:10.1615/CritRevPhysRehabilMed.2013007021
- Gerhart, K. A., Bergstrom, E., Charlifue, S. W., Menter, R. R., & Whiteneck, G. G. (1993). Long-term spinal cord injury: Functional changes over time. *Archives of Physical Medicine and Rehabilitation*, 74(10), 1030-1034. doi:10.1016/0003-9993(93)90057-H
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30(19), 1445-1460. doi:10.1080/09638280701625534
- Hergenrather, K. C., Rhodes, S. D., Cowan, C. A., Bardhoshi, G., & Pula, S. (2009). Photovoice as community-based participatory research: A qualitative review. *American Journal of Health Behavior*, 33(6), 686-698. doi:10.5993/AJHB.33.6.6
- Kehn, M., & Kroll, T. (2009). Staying physically active after spinal cord injury: A qualitative exploration of barriers and facilitators to exercise participation. *BMC Public Health*, 9(1), 168. doi:10.1186/1471-2458-9-168
- Kennedy, P., Lude, P., & Taylor, N. (2006). Quality of life, social participation, appraisals and coping post spinal cord injury: A review of four community samples. *Spinal Cord*, 44(2), 95-105. doi:10.1038/sj.sc.3101787
- Lal, S., Jarus, T., & Suto, M. J. (2012). A scoping review of the photovoice method: Implications for occupational therapy research. *Canadian Journal of Occupational Therapy*, 79(3), 181-190. doi:10.2182/cjot.2012.79.3.8
- LaVela, S. L., Balbale S. N., & Hill, J. N. (2016). *Experience of using the participatory research method, photovoice, in individuals with spinal cord injury*. Manuscript under review.
- Ma, V. Y., Chan, L., & Carruthers, K. J. (2014). Incidence, prevalence, costs, and impact on

- disability of common conditions requiring rehabilitation in the United States: Stroke, spinal cord injury, traumatic brain injury, multiple sclerosis, osteoarthritis, rheumatoid arthritis, limb loss, and back pain. *Archives of Physical Medicine and Rehabilitation*, 95(5), 986-995. doi:10.1016/j.apmr.2013.10.032
- Magasi, S., Hammel, J., Heinemann, A., Whiteneck, G., & Bogner, J. (2009). Participation: A comparative analysis of multiple rehabilitation stakeholders' perspectives. *Journal of Rehabilitation Medicine*, 41(11), 936-944. doi: <http://dx.doi.org/10.2340/16501977-0450>
- Mallinson, T., & Hammel, J. (2010). Measurement of participation: Intersecting person, task, and environment. *Archives of Physical Medicine and Rehabilitation*, 91(9), S29-S33. doi:10.1016/j.apmr.2010.04.027
- National Spinal Cord Injury Statistical Center. (2015). *Facts and figures at a glance*. Birmingham, AL: University of Alabama.
- Newitt, R., Barnett, F., & Crowe, M. (2016). Understanding factors that influence participation in physical activity among people with a neuromusculoskeletal condition: A review of qualitative studies. *Disability and Rehabilitation*, 38(1), 1-10. doi:10.3109/09638288.2014.996676
- Newman, S., Maurer, D., Jackson, A., Saxon, M., Jones, R., & Reese, G. (2009). Gathering the evidence: Photovoice as a tool for disability advocacy. *Progress in Community Health Partnerships: Research, Education, and Action*, 3(2), 139-144. doi:10.1353/cpr.0.0074.
- Newman, S. D. (2010). Evidence-based advocacy: Using photovoice to identify barriers and facilitators to community participation after spinal cord injury. *Rehabilitation Nursing*, 35(2), 47-59. doi:10.1002/j.2048-7940.2010.tb00031.x
- Newman, S. D., Gillenwater, G., Toatley, S., Rodgers, M. D., Todd, N., Epperly, D., & Andrews, J. O. (2014). A community-based participatory research approach to the development of a peer navigator health promotion intervention for people with spinal cord injury. *Disability and Health Journal*, 7(4), 478-484. doi:10.1016/j.dhjo.2014.04.006
- Noreau, L., Fougereyrollas, P., Post, M., & Asano, M. (2005). Participation after spinal cord injury: The evolution of conceptualization and measurement. *Journal of Neurologic Physical Therapy*, 29(3), 147-156. doi:10.1097/01.NPT.0000282247.15911.dc
- Noreau, L., Noonan, V., Cobb, J., Leblond, J., & Dumont, F. (2014). Spinal cord injury community survey: A national, comprehensive study to portray the lives of Canadians with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation*, 20(4), 249-264. doi:10.1310/sci2003-249
- Pershhouse, K. J., Barker, R. N., Kendall, M. B., Buettner, P. G., Kuipers, P., Schuurs, S. B., & Amsters, D. I. (2012). Investigating changes in quality of life and function along the lifespan for people with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 93(3), 413-419. doi:10.1016/j.apmr.2011.10.014
- Ripat, J. D., & Woodgate, R. L. (2012). Self-perceived participation among adults with spinal cord injury: A grounded theory study. *Spinal Cord*, 50(12), 908-914. doi:10.1038/sc.2012.77
- Schönherr, M. C., Groothoff, J. W., Mulder, G. A., & Eisma, W. H. (2005). Participation and satisfaction after spinal cord injury: Results of a vocational and leisure outcome study. *Spinal Cord*, 43(4), 241-248. doi:10.1038/sj.sc.3101683
- Silver, J., Ljungberg, I., Libin, A., & Groah, S. (2012). Barriers for individuals with spinal cord injury returning to the community: A preliminary classification. *Disability and Health Journal*, 5(3), 190-196. doi:10.1016/j.dhjo.2012.03.005
- Simpson, L. A., Eng, J. J., Hsieh, J. T., Wolfe, D. L., and the Spinal Cord Injury

- Rehabilitation Evidence (SCIRE) Research Team (2012). The health and life priorities of individuals with spinal cord injury: A systematic review. *Journal of Neurotrauma*, 29(8), 1548-1555. doi:10.1089/neu.2011.2226
- Sweet, S. N., Noreau, L., Leblond, J., & Martin Ginis, K. A. (2016). Peer support need fulfillment among adults with spinal cord injury: Relationships with participation, life satisfaction and individual characteristics. *Disability and Rehabilitation*, 38(6), 558-565. doi:10.3109/09638288.2015.1049376
- Tasiemski, T., Kennedy, P., Gardner, B. P., & Blaikley, R. A. (2004). Athletic identity and sports participation in people with spinal cord injury. *Adapted Physical Activity Quarterly*, 21(4), 364-378.
- Ullrich, P. M., Spungen, A. M., Atkinson, D., Bombardier, C. H., Chen, Y., Erosa, N. A. (2012). Activity and participation after spinal cord injury: State-of-the-art report. *Journal of Rehabilitation Research and Development*, 49(1), 155. doi:10.1682/JRRD.2010.06.0108
- United States Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2010). *Healthy People 2020 proposed objectives*. Retrieved from <http://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health>
- Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: Portraits of participation. *Health Education & Behavior*, 21(2), 171-186. doi:10.1177/109019819402100204
- Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24(3), 369-387. doi:10.1177/109019819702400309
- Wang, C. C., Yi, W. K., Tao, Z. W., & Carovano, K. (1998). Photovoice as a participatory health promotion strategy. *Health Promotion International*, 13(1), 75-86. doi:10.1093/heapro/13.1.75
- White, G. W., Gonda, C., Peterson, J. J., Drum, C. E., & Rehabilitation Research and Training Center Expert Panel on Health Promotion Interventions. (2011). Secondary analysis of a scoping review of health promotion interventions for persons with disabilities: Do health promotion interventions for people with mobility impairments address secondary condition reduction and increased community participation? *Disability and Health Journal*, 4(2), 129-139. doi:10.1016/j.dhjo.2010.05.002
- Whiteneck, G. G. (2006). Conceptual models of disability: Past, present, and future. In M. J. Field, A. M. Jette, & L. Martin (Eds.), *Workshop on disability in America: a new look: Summary and background papers* (pp. 50-66). Washington, DC: National Academies Press.
- World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva, Switzerland: World Health Organization.
- Van de Velde, D., Bracke, P., Van Hove, G., Josephsson, S., & Vanderstraeten, G. (2010). Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home. *International Journal of Rehabilitation Research*, 33(4), 346-355. doi:10.1097/MRR.0b013e32833cdf2a
- Van Leeuwen, C. M., Post, M. W., Westers, P., van der Woude, L. H., de Groot, S., Sluis, T., ... Lindeman, E. (2012). Relationships between activities, participation, personal factors, mental health, and life satisfaction in persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 93(1), 82-89. doi:10.1016/j.apmr.2011.07.203
- Yorkston, K. M., Bamer, A., Johnson, K., & Amtmann, D. (2012). Satisfaction with participation in multiple sclerosis and spinal cord injury. *Disability and Rehabilitation*, 34(9), 747-753. doi:10.3109/09638288.2011.619615

Author Note

Salva Balbale, MS is a doctoral candidate at Northwestern University Feinberg School of Medicine and a Research Associate at the Department of Veterans Affairs (VA) Center of Innovation for Complex Chronic Healthcare. Correspondence regarding this article can be addressed directly to: salva.balbale@northwestern.edu.

Keshonna Lones, MPH is a Social Science Analyst with VA Center of Innovation for Complex Chronic Healthcare. Correspondence can be directed to k.lones1908@gmail.com.

Jennifer N. Hill, MA is the Associate Implementation Research Coordinator (IRC) and a Social Science Analyst with VA Center of Innovation for Complex Chronic Healthcare. Correspondence regarding this article can also be addressed directly to: jennifer.hill3@va.gov.

Sherri L. LaVela, PhD, MPH, MBA is a Senior Research Health Scientist at the VA Center for Innovation for Complex Chronic Healthcare and an assistant professor at Northwestern University Feinberg School of Medicine. Correspondence regarding this article can also be addressed directly to: sherri.lavela@va.gov.

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