



Personal and Cultural Factors Associated with Functional Independence in SCI

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BACKGROUND & OBJECTIVES

- Although functional status is an important outcome after SCI injury, there has been little research attention focused on racial/ethnic group differences.
- Understanding the subjective and objective measurement of the variation in the degree to which racially/ethnically diverse groups engage in functional independence is critical to developing culturally-sensitive targeted interventions for diverse groups of persons living an SCI.
- Explore racially/ethnically diverse persons with SCI perceptions and life experiences to identify the personal, cultural and contextual factors that may impact their engagement in functional independence activities.

METHODS

Design: A cross sectional qualitative study using focus groups.

Setting: Northern New Jersey Spinal Cord Injury System (NNJSCIS).

Participants: A total of 15 participants participated in three focus groups (5 per group) that were stratified by race/ethnicity: Non-Hispanic White, Non-Hispanic Black, and Hispanic. Participants were men living with chronic SCI (duration of injury at least 2 years) who used a manual wheelchair as their primary means of mobility.

ANALYSES

Qualitative content analyses organized participants' responses into themes related to personal and cultural factors that facilitate or hinder the maintenance of their self-care and mobility activities.

FUNCTIONAL INDEPENDENCE

Non-Hispanic White	Non-Hispanic Black	Hispanic
<i>That's what I'm proud of, right there... I been able to take care of myself...being independent, but physically and, and take care of my body.</i>	<i>The people that actually wanna be independent, we don't want somebody pushing us around. We wanna still be able to do things on our own 'cause it's, it's better for our mental-- I'm a man at the end of the day. I'm not going to ask anybody to do something for me that I could do for myself--cause I don't wanna be looked at as, uh, I'm disabled or I'm some victim.</i>	<i>...day by day, you're getting better on your own. You try by yourself because you are-- An individual has to--As an individual, you gotta do your thing. Even if you have a wife, a sp-- a spouse, children, or even family, no, that's-- you gotta do your thing.</i>

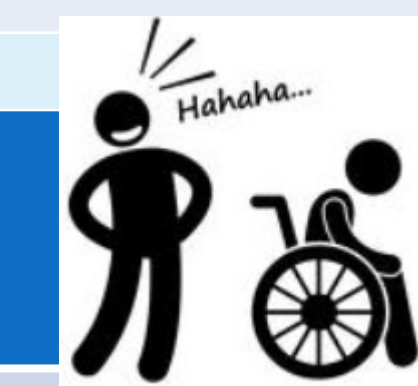


SELF-CARE

Non-Hispanic White	Non-Hispanic Black	Hispanic
<i>I was really scared to do a lot of stuff on my own, you know, after-- when I first left inpatient... you get like yourself set up the way you want to get set up at your own home. And then everything just, like, all that worries kind of melt away when it comes to like the certain things like the bathing, and the dressing, and the, that stuff.</i>	<i>I don't have to worry about peeing on myself. I don't like having that long-- what they call that? Catheter? It's a catheter but it stays in you.</i>	<i>Yeah, I saw when he was doing the toilets and, uh, Yeah. I can do it. I got to try. So yeah. One day to day, "Okay. I'm gonna try," you know. And I, I did it first time. Say, "Okay. I gonna keep it that way." --It's good now. I feel good. Yeah, yeah. Bowel program...So I don't need n-- someone help me like this.</i>

MOBILITY

Non-Hispanic White	Non-Hispanic Black	Hispanic
<i>I had a regular manual chair but then I got my car, so that became the, the obviously, the obvious independence, but then this is a standing wheelchair. And, uh, so it gave me that much more independence that I don't have to ask people to do a lot of thing just because they were out of reach before, so.</i>	<i>Like, now I know I can drive, stick shift and all, but it just that-- but man, when he let me drive, man, I was like-- the hand controls down and-- aw, man. it was a good feeling--- -feeling. I never thought I would be, like, doing this stuff, like-- and it-it's, it's like you fearless now, like.</i>	<i>I need to dr-- uh, start driving because you-- it's gotta be a l-- much better for you. Yeah. You need to because you can go everywhere.</i>



DISCRIMINATION

Non-Hispanic White	Non-Hispanic Black	Hispanic
Employment Discrimination <i>I also wanted to add that, me personally, have also experienced some discrimination at work...because, prior to, you know, to me getting injured, uh, I traveled quite a bit...apparently there was a perception that because I'm in a chair that that's not going to happen any more so how am I going to demonstrate value to the organization?</i>	Racial Discrimination <i>I'm a black man so they gonna pull me over regardless [laughter]...first thing they tell you is, "Step out of your vehicle." ... if you can't-- "I'm paralyzed, officer. I can't walk." "Really? How do you drive?" To some officers, it's new...I don't think they know about people being paralyzed driving or whatever the case might be.</i>	Disability Discrimination <i>I knew I had to go back home in a wheelchair-- I hated when people stared at me. So imagine when you're in a wheelchair. You know, that's instant, you know. So when I got home, you know, I was learning to adapt to that, people staring at me.</i>

CONCLUSIONS

- The experiences of racially/ethnically diverse men living with an SCI in a manual wheelchair suggest that they struggle with some similar personal factors that impact their functional independence; however, cultural factors vary across racial/ethnic groups.
- Understanding participants' experiences is critical to the development of interventions to manage discrimination as well as culturally-relevant interventions that encourage functional independence across all racial/ethnic groups living with SCI.

TABLE 1. PARTICIPANT DEMOGRAPHICS

	Total (n=15)	NHW (n=5)	NHB (n=5)	Hispanic (n=5)
Age Enrolled Mean (± SD)	42.8 (10.0)	51.6 (8.4)	36 (6.3)	41 (9.1)
Single (%)	10 (66.7)	2 (20.0)	5 (50.0)	3 (30.0)
Born outside of the United States (%)	6 (40.0)	1 (16.6)	1 (16.7)	4 (66.7)
Years post injury Mean (± SD)	8.2 (5.4)	8.3 (6.0)	12.8 (3.5)	3.7 (1.5)
Gunshot wound	6 (40.0)	0 (0.00)	4 (66.7)	2 (33.3)
Paraplegia	13 (86.6)	5 (38.4)	4 (30.1)	4 (30.1)