

Having, Being, and Living:

Stories of Disability by Female Athletes After Spinal Cord Injury

Derek M. Zike, MS and Monna Arvinen-Barrow, PhD, CPsychol AFBPsS, CMPC, FAASP, UPV sert.
University of Wisconsin-Milwaukee, Milwaukee, WI

INTRODUCTION

- The intersection between sport, gender, and disability presents complex issues that female athletes must navigate as they exit sport with a spinal cord injury (SCI)
- Research on psychosocial adaptation of athletes with acquired SCI ($n = 18$) is limited
 - Female athletes with acquired SCI are poorly represented in the literature
 - Five studies of factors related to the psychosocial adaptation of female athletes with acquired SCI (i.e., Goraczko et al., 2020; Goraczko, Zurek, Lachowicz, Zurek, 2021; Hawkins et al., 2014; Tasiemski & Brewer, 2011; Zurek et al., 2022)
- Existing research suggests the disability experience is personal and influenced by the environmental, social, and cultural world
 - Use of inductive narrative approach (i.e., Dunn & Burcaw, 2013) is recommended as it can be used to understand “how meaning is constructed in narratives in relation to available cultural, social, and interpersonal resources” (Squire et al., 2014, p. 11)
- Lack of empirical research or consensus on what it means to have a disability, be disabled, or live with disability

KEY DEFINITIONS

- **Having a disability** – meaning assigned to possessing an impaired body as one navigates the world
- **Being disabled** – meaning assigned to disability identity and the effect that has on the relationship with self, others, and the environment
- **Living with disability** – meaning assigned to the process of adaptation to disability and the factors that affect this process

PURPOSE

- To explore the disability narratives of female athletes after SCI, and to document the meanings they attribute to experiences of psychosocial adaptation to acquired disability.

METHODS

- Qualitative, exploratory, narrative inquiry (Riessman, 2008) approach
- Recruitment carried out through purposive and snowball convenience sampling
 - Several collaborating sites assisted in distribution of recruitment materials
- Six participants ($M_{age} = 37.67$ years, age range = 19-52 years)
 - Self-identified women who acquired a physical disability due to SCI
 - At least 18 years of age, living in the United States
 - Participated in competitive organized sports around the time their SCI occurred
 - At least two years removed from the date of injury
- Participants completed a 120-minute virtual, face-to-face, semi-structured interview
- Instruments included a semi-structured interview guide, eligibility survey, demographics survey, and field notes
- Data analyzed using an iterative, inductive, dual-narrative process consisting of a categorical-content analysis and a structural analysis (Lieblich et al., 1998)
 - Utilized NVivo 14 data analysis software

“I have the worst digestive problems, and I'm constantly in discomfort in my stomach, like I'm bloated and just so bloated, and it causes, like, I get really bad burning nerve pain when I'm in that discomfort and just having to go to work and feel like, I feel like such shit. But I have to, like, pull up the bootstraps and go to work and, like, work and be the boss. So, I have to, like, I can't sit there and groan all day. I have to, like, put on a face and, you know, be there, and it's like, oh, meanwhile, I'm suffering. So, there's a lot of, like, trying to figure out how to go about life while also being in such physical pain and discomfort. Like, that's a constant challenge.” – **Irene**

“Yeah, it means I'm different. It means, in some ways, I'm special. Like, I'm still kind of like, holy shit, you don't know how hard this is, and I'm doing it like, like, that's pretty, pretty amazing. So that feeling of, like, pride. Um, and then there's also the feeling of, like. Yeah, I'd say that's probably the whole, like, I'm pretty proud of myself for what I can do, what I can do with a disabled body. But it's also, like, just this glaring thing, you know, like, I'm disabled. I'm in a wheelchair. That's very prominent in my mind as I'm doing anything in this world.” – **Irene**

“One of the biggest challenges to going home from rehab was I'd always identified myself as a runner or a cyclist and an athlete. And then my whole world revolved around that. Like all my friends, my free time, everything was about going running or cycling and then going home from rehab. I knew I would have to face, like, who am I? Who am I now that I don't have that? And I don't have the friends to, you know, what am I going to do with my time? And how am I going to identify. I think I did not want to go home from rehab. And I think that was probably why. Because I didn't want to figure... I didn't want to confront, like, who am I now? Knowing it would be so different?” – **Irene**

“I think it's just because I'm young, and that's... if I was 80 and I couldn't move, and stuff, and I literally could not be independent. I'm so independent. I think that's why I don't see myself as a disability and needing assistance, so I know putting a title to it, it's just. It's a fact, though I do have a disability. I totally get that, but when it's put into like different terms on doing things like, even when you fill out a freaking questionnaire on a hotel or room or Airbnb and you put in like has to be accessible, it literally closes down everything, and it's like no, but it has one little half inch or maybe less step that makes it not accessible. But like I think the world just needs more education behind that. So maybe I'm just like explaining it on those terms, like, because when I say I have this, then it kind of eliminates all these other options for me. But I know I can do that stuff, so I like, say, I don't have a disability because I'm super independent.” – **Jane**

“Once I got into adaptive sports. Well, once I figured out there were adaptive sports, it made me so happy and something to look forward to, to still be an athlete.” – **Jane**

“I always challenged myself. I'm, like, OK, today, I'm going to go to the store by myself for the first time, and I'd wheel all the way to the store, and I'd go grocery shopping. And it was like, Wooh! I came home, and I felt like, I'd just, like, run a marathon or had some, you know, something like, a big accomplishment, like today I'm going to go on public transportation for the first time, and it'd be really scary. And I'd be really nervous, and I'd roll out and I'd do it. And then I was like, OK, I did that. That's cool. So I was, like, always doing little things like that and that felt good.” – **Irene**

“And then I got invited to this women's para-triathlon camp. And I was really excited about it. And, then I like, hurt my shoulder right before it. And so, I was like, oh, I guess I shouldn't go, but they're like, no, no, no, come anyway. It'll still be good. You'll meet these people. You'll get a lot out of it. So, I went, and it was transformational. So, I mean, I was the newest, most newly injured. Everyone else had been, like, three years, five years, fifteen years, and they had families and boyfriends and jobs. And they were doing sports. And to just see, like, I was like, OK, if they can do it, I can do it. So, it was incredibly motivating. And it was also, just, like, so helpful to ask these questions, like, how do you deal with nerve pain? And they're like, don't worry, it gets better.” – **Irene**

“I don't want to go anywhere where people are going to, like, feel sorry for me. So, I don't like going with friends, and they all try to help me all the time or, you know, I stopped going to my Bible study because I was honestly, because I'm tired of them praying for me to get better... you could keep praying I'm going to get better, but I'm not getting. I mean, and it becomes almost like a point of frustration because I just want people to be OK with, OK, this is just the way you are now. Because then I can be OK with it too, you know? ... It makes me wish I could just meet a whole new group of people, so they didn't know me before. So now they can just know who I am now and be happy for who I am now. Because I'm. I know I'm really doing great. I am.” – **Elizabeth**