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## Chronic Shoulder Pain in Manual Wheelchair (MWC) Users with Spinal Cord Injury (SCI): The Lived Experience

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# Chronic Shoulder Pain in Manual Wheelchair (MWC) Users with Spinal Cord Injury (SCI): The Lived Experience

## Abstract

*Background:* Existing research on the lived experience of those with spinal cord injury (SCI) resulting in paraplegia who use a manual wheelchair and experience shoulder pain is extremely limited. This research aimed to begin the process of understanding the lived experience of this population and to describe how chronic shoulder pain impacts occupational engagement and quality of life.

*Method:* A phenomenological approach using a constant comparative method was used to analyze data and to construct and redefine themes throughout the research process. The qualitative data obtained from two semi-structured interviews with the four study participants is presented below.

*Results:* Five overarching themes emerged. The themes of putting on the brakes, intrinsic factors, extrinsic factors, hope, and resilience emerged among the participants to describe their lived experience of shoulder pain as a manual wheelchair user with SCI.

*Conclusion:* The themes presented increased the understanding of the lived experience of shoulder pain in this population. Though the experience was unique to each participant, many similarities emerged from the themes, such as the benefit of having a strong support network including others wheelchair users with SCI and demonstrating a resilient spirit.

## Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

## Keywords

chronic shoulder pain, manual wheelchair user, resilience, participation, occupation

## Cover Page Footnote

This study was approved by the institutional review boards at Towson University, Kennedy Krieger Institute, and Johns Hopkins Medicine. This project was completed in partial fulfillment of the university's post professional occupational therapy clinical doctorate degree program at Towson University. A special thank you to all the study participants for their time and willingness to share their stories to support this project. To the Occupational Therapy and Occupational Science Department at Towson University, especially Janet DeLany, many thanks for the guidance, educational growth, and unwavering support. To the phenomenal staff at Kennedy Krieger Institute, your continued support and passion for spinal cord injuries is inspiring; may you continue to improve lives.

## Credentials Display

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Chronic shoulder pain is a common secondary complication following spinal cord injury (SCI) and manual wheelchair use that affects 37%–84% of the SCI population (Mulroy et al., 2015), which, in 2020, was estimated to be 294,000 people in the United States (University of Alabama at Birmingham, 2020). The wide range in statistics is a result of the large variations in the existing literature related to diagnosis, age, level of injury, and time since injury (Alm et al., 2008). Outside of the SCI itself, shoulder pain often causes additional negative effects, including decreased occupational engagement, quality of life, and independence and increased adverse psychosocial implications. Existing literature on the high incidence of chronic shoulder pain and the increased demand on the shoulder joint(s) in this population take a mechanistic, quantitative approach and do not provide the essence of the implications on those affected. There is a significant gap in the literature about the lived experience of shoulder pain in those with SCI who have paraplegia and use manual wheelchairs. The aim of this research study was to begin to fill that void, to paint a rich picture of a sample of these individuals, and explain how their occupational engagement and quality of life is impacted.

### **Background**

The shoulder is a commonly reported site of pain in individuals with all levels of SCI. Shoulder pain occurs in 37%–84% of the population according to studies published over the last decade (Alm et al., 2008; Mulroy et al., 2011). Rice et al. (2014) reported that between 35%–78% of participants developed shoulder pain during the first 6–12 months following their SCI. Shoulder pain can develop acutely despite active participation in skilled rehabilitation where activity is more closely monitored. Mulroy et al. (2015) reported that 39.8% of participants (N = 80) developed shoulder pain over a 3-year study and that it was more frequently reported in the dominant upper extremity. Those who developed shoulder pain had decreased muscle strength and lower levels of physical activity prior to the onset of shoulder pain than those who remained pain free. The researchers also reported that even minimal increases in upper extremity demands during daily activities created an increased risk for the development of shoulder pain.

The shoulder joint was designed to allow for mobility, but it becomes a joint for stability in those who use a manual wheelchair (Hastings & Goldstein, 2004; Mulroy et al., 2015). Because of the kinematic changes with manual wheelchair usage, including repetitive transfers, wheelchair propulsion, and many other factors, this population places a greater strain on their shoulder musculature and structures to complete their daily occupations (Mulroy et al., 2015). When the shoulder musculature and structures are overworked, shoulder pain can develop and limit engagement in occupations and roles; such risks increase with age and time since injury. The onset of shoulder pain in those with paraplegia who use manual wheelchairs can vary but typically appears within the first 6 to 12 months after sustaining a SCI and almost always by 5 years post-SCI (Rice et al., 2014). At this time, there is not a standard algorithm or protocol for treatment or management of shoulder pain in those with SCI, but there are some documented strategies being used to reduce pain (Figoni, 2009; Mulroy et al., 2015).

Following an injury to the spinal cord, those affected have to adapt their means of mobility by using a wheelchair or other assistive device for easier access in their home and community environments. The physical limitations following a SCI, paired with the activity and kinematic alterations, result in a greater demand being placed on the muscles and structures of the shoulder joint. When these muscles are overworked, shoulder pain can develop. Shoulder pain can cause limitations that extend across numerous occupations, roles, and responsibilities, including increased demands on the shoulder for transfers, bed mobility, activities of daily living (ADLs), instrumental activities of daily

living (IADLs), work, and leisure pursuits (Mulroy et al., 2015). This increased work demand has proved to be too much for the shoulder joint(s) to handle, leading to shoulder pain in this population with risks that only increase with age and time since injury.

The burden of chronic shoulder pain experienced in the SCI population is associated with functional limitations, decreased independence and efficiency with ADLs, IADLs, mobility, decreased leisure pursuits, engagement, quality of life, and increased depressive symptoms (Akbar et al., 2011; Kratz et al., 2013; Min et al., 2014; Mulroy et al., 2011). Despite the significant impact of shoulder pain on the occupational engagement and quality of life in people with SCI, nearly one fourth of all cases remain untreated, likely because of underreporting (Brose et al., 2008).

Fattal et al. (2014) used the Functional Independence Measure with those with SCI and shoulder pain and found that functional limitations were present in 45 out of 63 participants and included activities such as grooming, dressing, participation in leisure activities, and mobility tasks (e.g., transfers and wheelchair propulsion). Over the study period of 1–3 years, the functional limitations remained unchanged or worsened if shoulder pain remained; conversely, limitations decreased if pain decreased. The Wheelchair User's Shoulder Pain Index (WUSPI) is a self-report questionnaire that is commonly used in research studies and in the clinical environment to determine which activities cause the most pain in manual wheelchair users (Alm et al., 2008; Samuelsson et al., 2004). When individuals with SCI experienced chronic shoulder pain and felt that they needed to change their ways of engaging in occupations, their most common response was to limit participation in social and leisure activities; they did so to accommodate for the increased time and resultant pain to complete their necessary daily activities independently (Akbar et al., 2011). Samuelsson et al. (2004) conducted a research study involving 89 community dwelling individuals with SCI and found that 37.5% of their participants had shoulder pain but found no difference in ADL performance in those with and without shoulder pain. They also found that 13 participants with shoulder pain who completed the Canadian Occupational Performance Measure identified 52 different problems with occupational engagement in daily activities. Of these 52 engagement limitations, 54% of the activities were related to self-care (ADLs and IADLs), 23% to productivity in the home and/or at work, and 23% to leisure. Furthermore, Samuelsson et al. (2004) found that all participants with shoulder pain who continued participating in ADLs and meaningful activities despite the pain presence said their engagement led to fatigue, decreased efficiency with movement, and low tolerance for prolonged participation. This study did not reveal underlying mechanisms that enabled those with shoulder pain to persist in activities despite the pain.

In their cross-sectional survey study of 527 participants with chronic shoulder pain Andresen et al. (2016) found that 77% reported that pain impacted quality of life. Using the numeric rating scale and the International Spinal Cord Injury Pain Basic Data Set and the Quality of Life Basic Data Sets, Andresen et al. (2016) reported that participants gave subjective pain interference scores of 6.5 out of 10 for quality of life and life situation, 5.5 for physical health, and 6.7 for mental health, thus providing a more quantitative view of how devastating shoulder pain can be in this population. Of the quality of life articles examined for this population, pain was the only characteristic assessed that was consistently associated with low quality of life. Other factors that have been assessed but did not correlate with quality of life included age at injury onset, education level, level and completeness of injury, gender, and functional capacity post injury.

Alm et al. (2008) used the WUSPI in their cross-sectional study of 88 participants with thoracic level injuries and found that approximately 84% of those with shoulder pain reported that their pain

interfered with their leisure participation, whether it fully or partially limited it, promoted decreased enjoyment, or had forced them to seek out less meaningful or alternative leisure pursuits than those activities pre shoulder pain. Alm et al. (2008) also reported that up to 74% of manual wheelchair users specifically reported that their shoulder pain caused difficulty pushing their wheelchair, therefore limiting their access to the community and causing decreased participation in social and leisure activities. A significant inverse relationship was found between the WUSPI and Social Interaction Inventory scores, highlighting that those with higher shoulder pain during functional tasks participated less in desired social activities; conversely, when pain decreased, social interaction increased, particularly in activities in the community (Kemp et al., 2011).

Though the recommendations are vague, a number of studies concur that education and prevention are key to understanding, assessing, treating, and preventing shoulder pain in the SCI population in the future. In their studies Akbar et al. (2011; 2015) and Alm et al. (2008) suggested that it was crucial for the rehabilitation community who work with those with SCI and shoulder pain to assist with finding ways to balance the physical demands associated with required tasks of wheelchair propulsion, ADLs, IADLs, and functional mobility with the physical and psychological benefits of participation in desirable and meaningful occupations. Existing literature has identified pain ratings and correlations in function in this population, but the literature is limited on how those with SCI perceive shoulder pain and reconcile how they participate in their daily activities despite the pain. Living with shoulder pain has significant health impacts that cannot be fully understood through the examination of pain levels and decreases in occupational performance.

### **Problem Statement and Purpose of Study**

Following a SCI, physical, social, psychosocial, and emotional changes are experienced that impact all areas of occupation, engagement, health, quality of life, and well-being. Significant attention and education are available regarding the common secondary complications of SCI; however, the resources regarding prevention and treatment of musculoskeletal pain at the site of the shoulder are limited. Literature is near absent regarding the extent and impact that shoulder pain has on those with SCI despite the knowledge that overworking the shoulder(s) with manual wheelchair use, in addition to the added stresses with other functional mobility tasks and ADLs, puts this population at high risk for debilitating shoulder pain. It is important that the health care and spinal cord injured communities and their families understand the lived experience of those with shoulder pain who use a manual wheelchair following a SCI. Without this knowledge, one cannot fully understand or explain the implications across all aspects of life, or work to develop a holistic strategy to treat and prevent shoulder pain and its debilitating effects in this population. The purpose of this study was to describe the lived experience of shoulder pain in a sample of individuals who use manual wheelchairs as their primary means of mobility following a SCI resulting in paraplegia. This study also aimed to illustrate the similarities and differences in the experiences of the study participants as users with SCI and shoulder pain, which will contribute to the understanding of the experience of this phenomenon in the study population.

### **Method**

#### **Research Design**

After receipt of internal review board approval, the study commenced at a spinal cord injury center located in an urban area in Maryland. The researcher used a phenomenological approach employing qualitative methods to uncover the essence of living with shoulder pain post-SCI and the lived experience to highlight the unique and shared experience(s) and meaning(s) among the study

participants. The study was designed specifically to target individuals with SPI with chronic shoulder pain who used a manual wheelchair as their primary means of mobility, to understand how shoulder pain may have influenced their participation and engagement in occupations. Semi-structured, in-depth interviews and observational sessions were used to collect data.

### Recruitment Methods and Sample

Inclusion criteria for the study were any individual who volunteered to participate and (a) was between the ages of 18–65 years, (b) had a diagnosis of chronic SCI occurring at least 1 year prior to enrollment in the study, (c) had chronic shoulder pain indicated by the presence of pain for at least 3 months, and (d) used a manual wheelchair as their primary means of mobility. Exclusion criteria included those (a) younger than 18 years or older than 65 years of age; (b) with a primary language other than English; (c) who used a manual wheelchair part-time; (d) with SCI because of progressive disease, such as Multiple Sclerosis or Amyotrophic Lateral Sclerosis; (e) with onset of SCI less than 1 year; (f) who had concomitant injury interfering with cognition; and (g) with pre-SCI shoulder pathology.

The participants were identified via convenience, purposeful sampling through professional contacts of the researcher. Potential participants were only considered if they were relatively unknown to the researcher to prevent potential participants from feeling pressured to participate in the study or to answer questions with potential bias. The participants did not receive compensation or incentives for participating. Possible participants were identified and contacted, and four participants consented and completed the study (see Table 1).

**Table 1**

#### *Participant Demographics*

<b>Participant</b>	<b>Age (Years)</b>	<b>Gender</b>	<b>Time Since Injury</b>	<b>Mechanism of Injury</b>	<b>Level of Injury</b>
1	51	M	3 years 6 months	Fall	T5 AIS complete
2	59	M	11 years 10 months	Fall	T4 AIS complete
3	47	M	1 years 9 months	Motorcycle accident	T6 AIS incomplete
4	24	M	6 years 11 months	Motor vehicle accident	T4 AIS complete

### Setting

The setting for all points of contact with the participants occurred at the spinal cord injury center in a private room. There were multiple points of contact with each participant, including study introduction, consent, semi-structured interviews, and member checking.

### Instruments and Procedures

Semi-structured interviews were used to obtain rich information about the lived experience of those with SCI who have shoulder pain and use a manual wheelchair. Interviews have long been used in the social sciences to obtain information that provides a deeper understanding of topics than other qualitative measures, such as surveys, observations, or checklists (Creswell, 2003). The semi-structured format allowed the researcher and participants to depart from the central questions to elaborate on a topic, feeling, experience, and much more while allowing the participant to share what is important and what may have not been considered by the researcher. Interviews were completed face-to-face, on a one-on-one basis, and were audio recorded and then deidentified and transcribed verbatim.

## **Data Storage and Analysis**

All data were handled to ensure the highest level of confidentiality. No identifying information was recorded on any of the research documents or electronic data with the exception of the study consent form that contains the participant's signature. The participants were given a participant number that was used in all research documents and in transcriptions of data. Research documents were kept in a specialized research participant folder in a locked cabinet that was in a locked office at the research site.

A constant comparative analysis procedure was used to analyze each participant's interviews as they occurred to inform the questions that were asked in subsequent interviews. The constant comparative method of analysis promoted categories of meaning and relationships to emerge and allowed for those categories to continue to be refined as the research progressed. Microsoft Excel was used to organize, code, and provide additional data from the interview transcriptions. Open coding occurred first. Transcriptions were analyzed line-by-line and grouped or separated into chunks of similar themed data. These chunks of data were then sorted by category and recoded thematically to ensure they were in the proper category. Next, similar codes were combined to reveal overarching themes. The number of times each theme emerged in the transcription was counted and used to obtain the frequency of each theme. A second coder verified the analysis and offered expert review.

## **Results**

The findings presented below are based on an observation session and two, in-depth interviews with each participant. During member checking, the participants generally agreed with all themes and acknowledged that though their experiences with shoulder pain as a manual wheelchair user were unique to them, the overarching themes fit their narratives. The participants also felt that themes could apply to their peers based on the interactions they have had with other manual wheelchair users with SCI and shoulder pain.

### **Theme 1 - Challenges, Anger, Fear, and Loss**

This theme was prominent when the participants discussed navigating difficult processes related to occupational engagement as a manual wheelchair user with shoulder pain and created negative feelings, including anger, fear, and loss. All of the participants stated that shoulder pain negatively impacted their occupational engagement in a variety of ways ranging from participation in an occupation being challenging or limited, to fully avoiding or being unable to participate in an occupation. Participant 3 stated:

Shooting pool and bowling though, I really enjoyed. I tried both of these activities from a wheelchair and they both hurt like hell. There was no joy outside of the original anticipation. Once I took my first shot and felt that pain, the joy was gone.

Challenging tasks reported across all the participants were pushing their manual wheelchair up ramps or outdoor inclines and pushing their manual wheelchair consecutively for 10 min or more. Three out of the four participants also reported pain when lifting objects down from an overhead shelf. Participants 2 and 3 expressed that they would not alert their friends and/or family to the presence of pain or accept help with the challenging occupation, whereas Participants 1 and 4 stated that they would accept assistance with pushing their manual wheelchair and some household management tasks, including laundry and making the bed.

All four of the participants expressed some frustration or anger over the challenges with working with insurance and procuring equipment related to rehabilitation equipment. Participant 3 expressed anger with his insurance and acute rehabilitation, stating that his shoulder pain was a result of having to use a loaner manual wheelchair that was not made for him while awaiting his custom manual wheelchair to be built and delivered. Participants 1 and 2 expressed frustration with insurance denying rehabilitation equipment and believed that it was limiting their recovery and promoting shoulder pain.

All of the participants reported that they learned early on how to balance their day and be selective about how they structure the day and the occupations they decide to engage or not to engage in to help manage and limit their shoulder pain while maximizing participation in necessary and desired occupations. Each of the participants also shared an activity or multiple activities that they were no longer able to participate in because of their shoulder pain. Collectively, participation in leisure pursuits and social activities were most frequently reported as lost and/or avoided activities and included bowling, shooting pool, corn hole, hand cycling, and going out with friends and/or family. Participant 1 talked about losing his ability to participate in axe throwing, stating:

I would be disappointed and likely, wouldn't go . . . watching would have been worse and reminded me of something I missed, something that I lost. There are just times where I am not willing to risk it; the risk of pain just isn't worth whatever doing the activity gives.

## Theme 2 - Intrinsic Factors: Who I Am

In an attempt to better understand each participant, how they see themselves, and what motivates them to keep working toward their goal(s), the researcher asked each participant to state or describe their motto (see Table 2).

**Table 2**

*Participant Motto – Subtheme in Intrinsic Factors: Who I am*

<b>Participant and Motto</b>	<b>Supporting Quote</b>
Participant 1: "Take on the day."	"I just look at it as not sitting back and waiting for it to come to you. Jump into it. Make the most of the opportunities. I really believe that my spirituality also plays a huge role. It has kept me on solid ground and has allowed me to withstand some setbacks that have occurred over my life, so."
Participant 2: "No surrender."	"No surrender is to continue to enjoy your family, enjoy your friends, enjoy life, enjoy food and drinks, and enjoy everything. Despite all of this [SCI and shoulder pain], life is beautiful."
Participant 3: "Finish everything you start."	"So much of our life we rely on or hope for a crystal ball or we think that we know what is going to happen. The only way that you have any control of what is going to happen is if you finish what you set out to do, no matter how big or how small. If you don't finish you will never know."
Participant 4: "A man isn't defeated when he loses, he is defeated when he gives up."	"That is how I look at things everyday, like, as long as I wake up alive I am going to get up out of bed and work it out."

Three of the four participants reported that their motto was present prior to their SCI. Only Participant 4, the youngest participant both at the time of his injury and at the time of the study, reported that he did not have a motto prior to his SCI and that it emerged during the early stages of rehabilitation. All of the participants reported that they used their motto regularly to overcome challenging experiences and to maintain a positive outlook or mindset. Participant 4 shared:

If every time I tried I was defeated and beat myself up, I likely never would try. I could go either way and I just choose to be more upbeat, see the light in every opportunity and celebrate each step of the journey.

All of the participants also stated that they regularly shared their motto with family and peers. Participant 1 stated that his spirituality aided in the development of his motto, while Participant 2 said it came from the death of his mother and the time that he spent in the Navy. Participants 3 and 4 credit their fathers for their motto, stating that their fathers used the same mottos and passed them down. Finally, shared among all of the participants was the desire to gain and maintain their independence despite experiencing chronic shoulder pain as a manual wheelchair user with a SCI.

### **Theme 3 - Extrinsic Factors: People and Places**

All of the participants reported that they had family and friends that helped motivate and support them regularly. Participant 4 stated, “I surround myself with people who I love and who love me. If I call, they are there, no questions asked. I do everything for myself everyday. If I call, it’s because I really need help and they don’t hesitate.” Though these participants stated that they had family and friends in their circle to help, all of the participants shared a similar sentiment that they could rely on their close circle to help if needed but avoided asking for assistance if it was possible. All of the participants, except Participant 3, stated that they had an extended network that included other manual wheelchair users that had shoulder pain. Those that did have the peer network stated that they were able to share stories and experiences with their peers that they believed helped them learn new or adapt existing skills to minimize their shoulder pain and its impact. These participants developed their relationships through ongoing participation in outpatient rehabilitation and personal training. Participant 3 expressed that with exception to his time in acute rehabilitation, he did not know a lot of people in wheelchairs:

I knew a guy from when I was first injured and after rehab, we all kind of went separate directions after being discharged. I valued the interaction when I was hospitalized from those who were further in the rehab process, but as I progressed closer to discharge, the resources I had were coming from a smaller pool. Without having those connections, it’s [sic] been really hard.

Similarly, Participant 4 stated:

Having friends in wheelchairs has been key . . . we can have a conversation about anything . . . just stuff that only we can relate to because we are in chairs. I’ve got a good group of friends in chairs and not and my family who always got my back.

Participants 1 and 3 also shared that their place of employment provided support and a sense of community. Both participants were able to return to the same job after their SCI and continue working, with some modification, despite their shoulder pain. Participant 1 worked at a Christian-based organization and said the following about his extrinsic supports: “People have really rallied behind me . . . my friends, family, and coworkers, they have all really carried me through.” Participant 2 experienced the opposite, a lack of support from his employer after his SCI and chronic shoulder pain. He was laid off after completing his rehabilitation but was able to fill that void with new, meaningful occupations. Participant 2 stated “I’ve been able to go skiing and scuba diving which I loved. I take care of my grandkids and am so close to them. I’ve only been able to do them because I’m not working.” Finally,

all of the participants, except Participant 3, reported that their participation in rehabilitation and adaptive sports programs supported their participation in meaningful occupations and supported relationships.

#### **Theme 4 - Hope: What Lies Ahead**

This theme emerged out of the participants' conversations about the future related to their shoulder pain, their participation, and overall life. Relating to their shoulder pain, all of the participants expressed concern that their shoulder pain would increase and would reduce their independence and participation as they aged. In addition, all of the participants stated that they were working with their therapy team and insurance to obtain or be evaluated for wheelchair modifications and equipment that would reduce the repetitive strain on their shoulders, including power assist wheelchair add-ons to reduce the impact both in the present and future. In Interview 1, Participant 2 expressed fear about his shoulder pain worsening and limiting his independence and participation, stating, "When you have pain that affects everything that you do, if you think long term, it's just going to deteriorate and get worse and end up where you can't use the [manual] chair or get out of the house." In the month between Interviews 1 and 2, Participant 2 experienced a significant decrease in his shoulder pain and an increase in his participation. His outlook on the future changed as evident by his statement:

I feel like it [participation and independence] is only going to get better. I will be able to do even more things with ease and feel like I am being even more a part of the community and adding to my family. Having less pain and being able to leave the house whenever I want and for any reason and at anytime. That has been great and I really look forward to it. With having this improvement in my shoulder pain, I am really in a wonderful place and didn't realize how much I was missing out on. In these past few weeks, I just know that I am happier and enjoying liv[ing] and the prospects in the future so much more.

All of the participants discussed short- or long-term future plans and stated that their shoulder pain impacted their thoughts or planning for these activities. Participant 2 shared that he was planning a cruise with family. As a result of enjoying his last cruise less because of his shoulder pain, he was renting a power wheelchair this time. Participant 3 discussed expanding his automotive repair business but shifting from completing the work to overseeing others and managing the business end because of pain and decreased access as a result of the manual wheelchair. Finally, Participant 4 expressed a desire to return to college to finish his degree in social work, which he stopped, in part, because of the hilly terrain of the campus that caused him pain and fatigue, thus limiting his participation and well-being.

#### **Theme 5 - Resilience**

All of the participants shared that successfully overcoming difficult experiences in the past made them feel that they could handle and/or overcome their shoulder pain as well. Participants 3 and 4 referred to adapting to their SCI and regaining independence as their past challenge. They shared that though there was a learning process, filled with trials and tribulations, their success made them realize that shoulder pain was not the end. They recognized that things could always be worse and chose to see the positives and live each day to the fullest. Participants 1 and 2 also reported that sustaining a SCI challenged them but that they experienced greater challenges prior, including the death of loved ones and going to war. Participant 1 stated:

I've overcome things that have truly changed me and have motivated me to the core, deep inside so that I could continue a purposeful, happy, and meaningful life. Not that others haven't dealt

with their hardships . . . having been through those [death of his wife and daughter] and having come out on the other side, there is still a whole life to live . . . that the day I got my spinal cord injury, it could have been my last day but I am still here. I am still here and there is a reason or purpose to that. Tomorrow isn't promised, it's not guaranteed. Everyday my job is to make the best of the day for my family, my community, and myself.

Participant 2 shared:

I was in the navy and went to war. I saw friends; my brothers lose their lives or get injured. While others I served with had post-traumatic stress, I was always of the opposite in saying how can what happened in the past help grow me now? All the challenging things in my life have helped to develop me to be who I am so having the accident [SCI], I think that I was already prepared. If anyone was going to have the accident, I'm the guy because I was able to accept it and move on. Everything that is thrown your way is part of your journey.

### **Discussion**

The results of this study illustrate that the lived experience of those with SCI who have chronic shoulder pain and use a manual wheelchair for mobility are unique but that there are shared variables across the study population. Sustaining a SCI has implications on independence, participation, and quality of life that has been well researched from a quantitative perspective. For those that use a manual wheelchair as their primary means of mobility and have the added burden of shoulder pain, additional challenges are experienced. The participants reported that the activities they engaged in that generated the strongest and most consistent experience of shoulder pain were those related to mobility in their wheelchair. This aligns with other SCI and shoulder pain studies where participants indicated the most painful activities were pushing their wheelchair up inclines and outdoors and completing transfers to and from the bed, tub, and car (Fattal et al., 2014; Hubert et al., 2013; Samuelsson et al., 2004).

In addition to the physical implications, there are psychological factors in the participants' lived experience that include fear that their shoulder pain will progress and that they will experience further negative effects, including decreased independence and participation. This fear is consistent with existing literature by Min et al. (2014) who found chronic pain has been proposed as a crucial risk factor that prevents long-term adaptation to SCI and potentially worsens the experienced disability. This population also experiences anger and mourning of the loss of engaging in occupations that were meaningful prior to their onset of shoulder pain. This study pointed to the notion that chronic shoulder pain impacts psychological and quality of life factors, including motivation for participation and self-efficacy. Consistent with this study, research by Kratz et al. (2013) found that greater mobility limitations were related to lower social role satisfaction and that activity engagement was a strong predictor of adjustment to chronic pain in those with SCI (Kratz et al., 2013).

Despite experiencing chronic shoulder pain as manual wheelchair users with SCIs, this population reported strong ties to their family and friends and, when applicable, to their place of employment, community, and other SCI populations. Three of the four participants shared the value and feeling of support from and connectedness to these networks. They stated that having solid relationships with other individuals with SCI was critical for establishing peer relationships, fostering mentorship, gaining independence, promoting positivity, and continuing their motivation to live their lives to the fullest. Participant 3 was the most recently injured participant in the study with sustaining his SCI, experiencing shoulder pain, and participating in rehabilitation at the SCI specialized facility. These

factors likely contributed to him feeling less connected to his community and the SCI population and possibly led to his prominent experiences of anger and frustration in comparison to other study participants.

Lastly, this research brought to light the concept of resilience and its presence in this population. Resilience is the ability to adapt effectively when presented with a challenge, and one requirement for resilience is that a person must have experienced and overcome difficult situations in the past. In line with resilience research by Guest et al. (2015), those with SCI who show high levels of resilience were able to appraise their life positively, see there was a second chance at life, and overcome or positively take on additional challenges, such as shoulder pain. All of the participants in this study expressed that they overcame many obstacles, shared feelings of hope and optimism for the future, had resiliency embedded in their mottos, and felt that their life had meaning and purpose despite their SCI, challenges resulting from their shoulder pain, and the uncertainties ahead.

### **Implications for Occupational Therapy**

This study improves our understanding of the lived experience of individuals with SCI and shoulder pain who use a manual wheelchair as their primary means of mobility. In this population, there is a strong sense of pride associated with being independent and a fear that shoulder pain will increase and negatively impact participation, independence, and quality of life in the future. This population also experiences positive outcomes from having a strong support network, including a network with other SCI individuals, and the presence of resilience. Consistent with existing research of the SCI population, there is a strong desire to be as independent as possible when completing ADLs, IADLs, and mobility activities despite their pain experience (Kemp et al., 2011). Though some of the participants will report difficulties to family, friends, and their medical team, others may hide them because of pride, fear, anger, or a wish to not cause an additional burden. Occupational therapists can take the findings of this research and apply it to practice by ensuring that they help promote positive coping strategies to foster resilience, focus on supporting independence with ADLs, promote occupational engagement in social and leisure pursuits, enable peer support, and open communication with patients about shoulder pain. Finally, occupational therapists working with this population can work toward developing a proactive approach to preventing shoulder pain and its negative impacts on physical and psychosocial well-being.

### **Limitations**

While several methods were used to enhance the rigor of this study, there were limitations, including the inability to generalize the results. Study participants were recruited from a single urban outpatient rehabilitation facility, and the sample size was small, both of which limit the generalizability. The inability to generalize results is a common limitation of qualitative research studies where the goal is often to share a rich experience of the phenomenon being studied. The study was able to capture the lived experience of the participants and demonstrated that there are many shared elements among the participants. Though there are numerous studies that examine these components separately, this is the first to look at these characteristics collectively. To overcome these limitations, this study and its results should be used as a springboard for future studies with larger sample sizes and across other settings.

### **Conclusions**

Shoulder pain is a common complication in manual wheelchair users that is present in 37%–84% of the SCI population (Alm et al., 2008; Mulroy et al., 2011). The lived experience of shoulder pain was unique for each participant; however, there were numerous similarities present. Activities that caused the most pain for the participants in this study were pushing their manual wheelchair up ramps or

outdoor inclines and pushing their manual wheelchair consecutively for 10 min or more, which are consistent with the SCI population. All of the participants expressed periods of fear about their shoulder pain progressing and possibly losing independence. In addition, they expressed mourning the loss of past enjoyable occupations that were limited or given up altogether because of their shoulder pain. The participants had intrinsic supports, such as a personal motto, and extrinsic supports, including family, friends, and others in the wheelchair community. Three of the four participants had strong ties to other wheelchair users with SCI, and these same participants had been active at the rehabilitation facility and injured longer than the remaining participant. The last participant, Participant 3, expressed more feelings of anger and less social ties than the other participants, which may suggest that greater time since injury and access to and support in a group of like peers may play a role in promoting a more positive lived experience for manual wheelchair users with shoulder pain. Despite experiencing chronic shoulder pain that impacted their occupational engagement, all of the participants shared their hope for the future and a strong sense of resilience. Having experienced hardships in the past and being able to overcome them, the participants demonstrated positive coping skills and quality of life. The results of this study point to the impact of shoulder pain in this population and suggest that promoting independence in meaningful occupations, enabling strong support networks with peers, and encouraging positive coping skills may foster a positive lived experience in this population.

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