

## Client perspectives on reclaiming participation after a traumatic spinal cord injury in South Africa

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### Abstract

**Background.** The development of rehabilitation services promoting participation in people living with a traumatic spinal cord injury (TSCI) is of major concern for physical therapists. What the client sees as effective participation, barriers, and facilitators might be different due to their particular context. This study was conducted to gain insight into the experiences of attaining an important outcome in a developing context.

**Objective.** The aim of this study was to explore the experiences of reclaiming participation in community-dwelling people with TSCI in South Africa.

**Design.** This was an explorative, qualitative study with inductive content analysis.

**Methods.** Individual semistructured interviews were conducted with 17 adults living with a TSCI in order to explore their experience of participation. The verbatim transcripts were analyzed, and the end result was an overall theme that included 4 emerging categories.

**Results.** The theme “participation possibility” denotes the eventual involvement in life situations. Within this theme, there were 4 categories that emerged as a representation of essential aspects along the continuum of reclaiming participation: (1) dealing with the new self, (2) a journey dominated by obstacles, (3) the catalyst of participation, and (4) becoming an agent. Dealing with and recognizing these intervening conditions seem critical for clients to reconstruct the meaning that is necessary for a broader conception of participation.

**Limitations.** The transferability of these findings to dissimilar contexts may be limited.

**Conclusion.** Client perspectives on reclaiming participation after injury affirm the notion of eventual participation, with each person finding strategies to succeed. In order to help clients reclaim participation, health professionals should develop contextually sensitive programs that include peer mentoring and reduce the influence of hindering factors.

Like many unforeseen medical emergencies, traumatic spinal cord injuries (TSCIs) cause an unprecedented change in a person’s perception of self, alteration in body functioning, and change in social interactions.<sup>1–3</sup> Tasks and roles that were previously performed with little

cognitive demand and effort suddenly require careful planning and prearrangement.<sup>2,4,5</sup> In the absence of strategies to manage these changes, people living with a TSCI may never return to full functional capacity.<sup>3,4,6</sup>

The *International Classification of Functioning, Disability and Health* (ICF) model provides the conceptual foundation for evaluating the influence of disease on activity limitations and participation restrictions in people with impairments.<sup>7</sup> It further acknowledges the unique contribution of the environment on the experience of living with a health condition. Survivors of TSCI experience a perception of living in a “changed world,”<sup>4</sup> which affects their participation or involvement in life situations.<sup>7</sup> For these clients, the lived experiences of the past cannot be similar to the new interactions between the body and environment following a TSCI.<sup>4</sup> When attempting to reclaim their full participation in society, people living with a spinal cord injury (SCI) are presented with a variety of challenges.<sup>6,8</sup> For example, they must reconstruct the meaning of living in a society that is designated for and dominated by people who are able-bodied and may not be accepting of people with disabilities.<sup>4</sup>

Globally, the incidence of TSCI does not seem to decline, and in South Africa, it was found to be among the highest (76 per million people) in the world, highlighting it as both a global and public health concern.<sup>9</sup> South Africa, like numerous developing countries forming part of the United Nations member states, ratified the United Nations Convention on the Rights of Persons With Disabilities (UNCRPD), with its core vision of full and effective participation in society through, among others, ensuring accessibility (article 9), providing comprehensive habilitation and rehabilitation (article 26), and promoting national implementation and monitoring of the policy (article 33).<sup>10</sup> In addition, South Africa has developed its own National Rehabilitation Policy (NRP), with core principles that focus on enabling people with disabilities to enjoy equal opportunities, participate socially, and become integrated members of society.<sup>11</sup>

Although the concept of participation has gained prominence in rehabilitation and medical contexts, little is known about how it is conceived, characterized, and influenced.<sup>7,12,13</sup> An additional complication is the fact that participation does not occur in a vacuum but is influenced by the unique physical, social, and attitudinal environment in which the individual exists. However, there is limited evidence on the efforts made to understand and facilitate participation following a TSCI. When deciding to embark on such an exploration, the evaluation of participation—from concept development to the translation of evidence—should emphasize the involvement and experiences of those living with an SCI.<sup>13</sup> Therefore, this qualitative study aimed to develop an understanding of the experiences of

reclaiming participation in community-dwelling adults living with a TSCI in a developing context.

## **Method**

### **Study Design**

This study made use of interviews and qualitative description to explore the experiences of clients in reclaiming participation after TSCI. Qualitative description is a low-inference method that is well suited to gathering facts about the experiences of people living in their natural setting, which is necessary for providing a thick description of a particular phenomenon.<sup>14</sup> The researchers remain close to the data to ensure that the findings are grounded within the descriptions provided by the participants.<sup>15,16</sup> With the lingering debate concerning the conceptualization and experience of participation, qualitative description is an appropriate method that could assist with the authentic evaluation of participation and may further inform programs to address factors that affect the experience of participation.

### **Study Setting**

This study was conducted in the metropolitan area of Cape Town, a part of the Western Cape Province of South Africa that is home to approximately 3.7 million people. Cape Town was chosen because of its ethnic variety, which includes people of black African, white, and mixed-race descent,<sup>17</sup> and the catchment area is one of the largest in the country, including both urban and peri-urban settings. Peri-urban areas are former “rural” localities that are now directly in the path of urbanization due to the rapid expansion of metropolitan areas and major towns. They lie officially outside of the “urban edge.”<sup>18</sup> The only specialized acute SCI (tertiary level) hospital in the country providing comprehensive care for people with SCI is situated in Cape Town. In addition, a specialized high-intensity rehabilitation center is available for people with SCI.<sup>19</sup>

### **Participants and Their Recruitment**

Seventeen participants having firsthand experiences of living with a long-term TSCI were purposively selected as key informants. The mean age of the participants was 34 years (range=19 – 47), and the mean survival time after injury was 10.5 years (range=3–21). Of the total participants, 11 had paraplegia. Participants had to be community-dwelling adults (>18 years) living with a TSCI for at least 3 years and must have made a transition from rehabilitation to their home and community environment. Additional background characteristics are shown in the Table.

Participants were recruited from a registry kept by a nonprofit organization rendering services and support to people living with a TSCI. With the aim of obtaining a broad insight into individual experiences of reclaiming participation,

maximal sampling variation was sought with regard to classification of SCI (paraplegia and tetraplegia), sex, age, socio-economic status, and ethnicity (people of African, mixed-race, and white descent). All participants provided written informed consent.

Table.  
Participants' Information<sup>a</sup>

Participant No.	Sex	Race/Ethnicity	Age (y)	Classification of SCI	Survival Time (y)	Employment Status (Socioeconomic Indicator)
1	Male	Mixed-race	43	Paraplegic	13	Ad hoc peer support trainer (volunteer)
2	Male	Mixed-race	37	Tetraplegic	12	Chairperson of nonprofit organization (volunteer)
3	Male	Mixed-race	23	Tetraplegic	3	Unemployed
4	Female	Mixed-race	36	Paraplegic	17	Unemployed
5	Female	Mixed-race	19	Paraplegic	4	Unemployed
6	Male	Mixed-race	23	Paraplegic	5	Ad hoc peer support trainer (volunteer)
7	Male	Black African	47	Paraplegic	6	Data capturer
8	Male	Black African	35	Paraplegic	14	Unemployed
9	Male	White	43	Tetraplegic	21	Research consultant
10	Female	Black African	38	Paraplegic	8	Unemployed
11	Male	Mixed-race	30	Tetraplegic	5	Police officer
12	Male	White	35	Tetraplegic	19	Self-employed and promotional work
13	Female	Mixed-race	27	Paraplegic	5	Unemployed
14	Male	Mixed-race	32	Paraplegic	4	Volunteer peer supporter (volunteer)
15	Male	Mixed-race	42	Tetraplegic	21	Administrative work (printing)
16	Female	Mixed-race	48	Paraplegic	18	Unemployed
17	Female	Black African	27	Paraplegic	5	Unemployed

<sup>a</sup> Participants 1, 2, 9, and 13 were interviewed twice. The first was an individual, in-depth interview, and the second was individual member checks that afterward included their participation in a focus group discussion to verify the overall theme and categories.

## Data Collection

Face-to-face, semistructured interviews were conducted by the first author (C.J.), a physical therapist with 7 years of experience in SCI rehabilitation, between January and September 2014. The interviews were conducted in either English (12 participants) or Afrikaans (5 participants). The interview guide consisted of the following broad questions: (1) In what way did the TSCI affect you? (2) What life areas and situations were affected after the TSCI but were not affected or difficult to do and maintain preinjury? (3) What strategies did you adopt to be involved in life situations? and (4) What are the major barriers to and facilitators of reclaiming involvement in situations. Probes were used to deepen the discussion of each focus area until each individual was able to articulate his or her conceptualization of "life areas" contained in the terms "involvement in life situations," "personal aspects critical to reclaiming involvement," and "strategies used to be involved in life situations." In this approach, the term "participation" was not used during the interviews to prevent participants from seeking an operational definition of the word, allowing us to gain insight into the meaning of "full participation."

Depending on the participant's preference, the interviews were conducted either in the participant's home or at the headquarters of the nonprofit organization. All 17 interviews were audio recorded and lasted between 42 and 69 minutes.

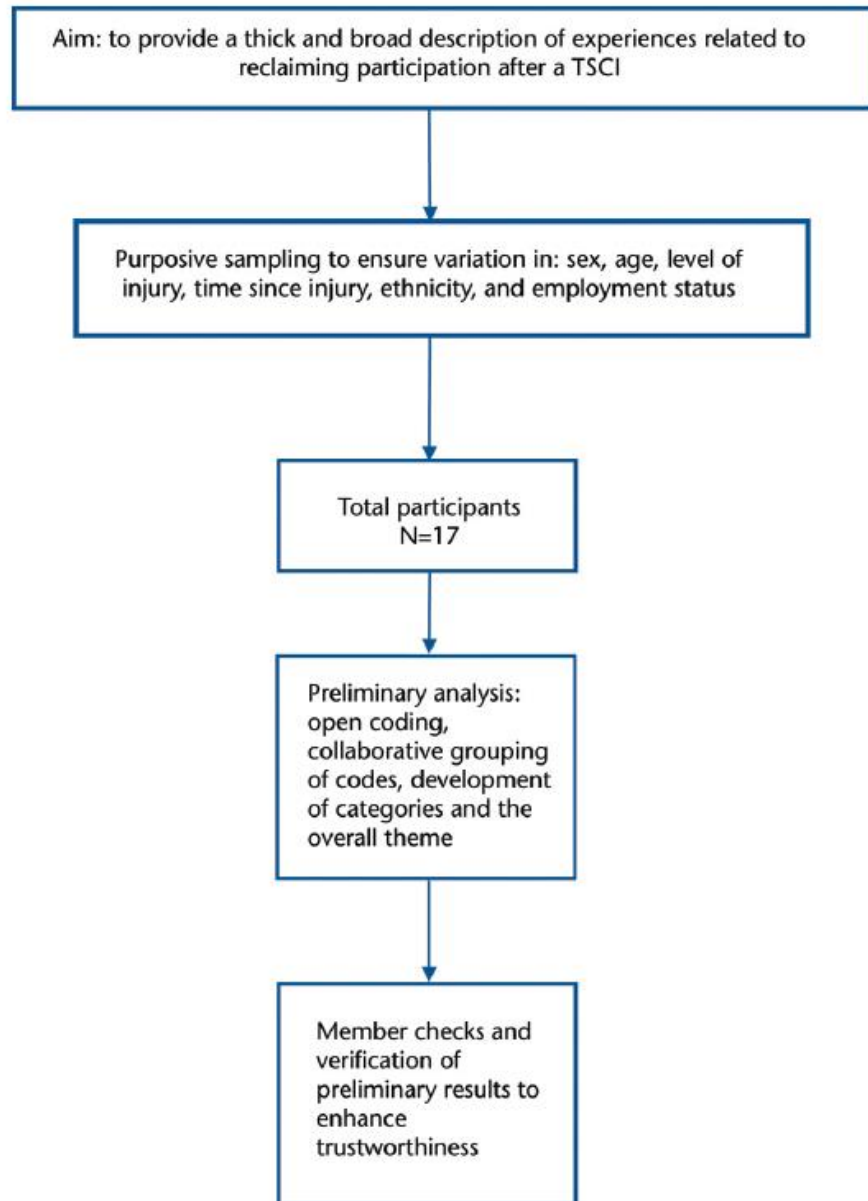
### **Data Management**

All interviews were transcribed verbatim by the first author, providing the data for analysis. The transcripts were imported into a Web-based qualitative analysis tool called "Saturate" (<http://www.saturateapp.com/>), which enabled collaborative coding, grouping of codes, and the development of categories.

### **Data Analysis**

An inductive analysis approach was used to capture a deeper understanding of the participants' journey to reclaiming participation after TSCI in the context of the environment.<sup>20</sup> Initially, 2 of the authors (C.J. and L.N.W.) (reading only the English transcripts) read the interviews several times for familiarization of content and to become immersed in the data.<sup>21</sup> Once familiar with the data and with the preparation phase, meaningful passages and concepts were freely identified and thereafter condensed.<sup>20,22</sup>

After coding, the first author and senior authors collaboratively developed the categories and subcategories. The constant comparison technique was used throughout the process to compare statements between protocols, which guided the development of categories while keeping the research aim in mind.<sup>16</sup> The categories contained similar properties of experiences related to reclaiming participation after injury, and each category was labeled based on content characteristics that were abstract enough to include all related experiences of the participants. Finally, the categories were found to represent a continuum along the path of reclaiming participation that led to the development of an overall theme.



**Figure 1.**  
Data collection and analysis procedure. TSCI=traumatic spinal cord injury.

Following the analysis, the in vivo Afrikaans quotes used in the study were translated into English twice—first by the first author and a second time by an independent translator. The 2 translated versions were evaluated to ensure that the meaning was captured as experienced within the cultural context. The Afrikaans quotations also underwent a few grammatical changes in order to improve readability. For each quote shown in the Results section, the participant number and survival time (in years) are shown in brackets.

## **Methodological Rigor**

Trustworthiness of the analysis was improved by considering credibility, transferability, dependability, and confirmability during the process.<sup>23</sup> To enhance the credibility of the findings, the researchers engaged with the data for prolonged periods and held peer debriefing sessions with the coauthors and the qualitative analyst. During these sessions, the credibility of findings and the process of reflexivity were addressed by having the first author and senior author disclose their personal experiences, biases, and assumptions that may have influenced their interpretation of the data. To further enhance the credibility of the interpreted findings, both member checks and validation of the overall theme were performed via a sub-group of the initial sample, consisting of 4 participants (participants 1, 2, 9, and 13). First, the 4 participants checked whether their perceptions and experiences were conveyed as intended by reviewing the verbatim transcripts.<sup>24</sup> Second, they attended a group discussion to verify the categories and theme to ensure an appropriate abstraction of the social process identified throughout all of the interviews (Fig. 1).<sup>16</sup> To assess the transferability of the findings, a broad description of the study setting, health care context, and included participants was provided. To ensure dependability and confirmability,<sup>23</sup> an audit trail keeping track of the conceptualization of the study, recruitment of participants, and analyses of the data was maintained and reviewed by the senior authors.

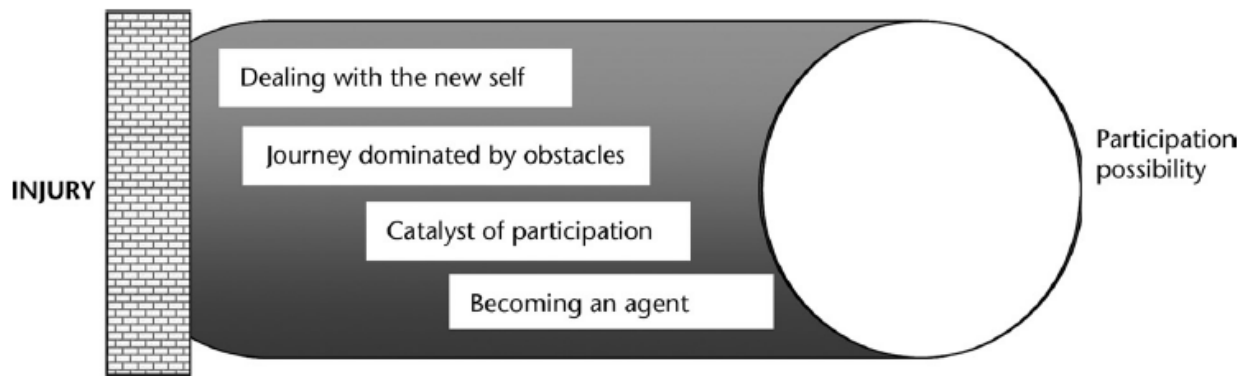
## **Results**

### **Overall Theme: Participation Possibility**

The analysis resulted in an overall theme that consisted of 4 categories and 11 sub-categories. Reclaiming participation following injury was described as a diverse range of activities and social and occupational roles and tasks. The participants described participation as a not-taken-for-granted experience because of its relative absence during the acute stage of injury. Reclaiming and becoming reinvolved in the activities and roles of the past, that is, preinjury, required the negotiation of barriers along the path of recovery and living with the injury (Fig. 2).

Participants described “dealing with the new self” (category 1) as the initial aspect to reckon with on the journey of reestablishing meaning, that is, imagining situations of the past in the current and the future. Once participants had imagined a possible life in the presence of the injury, they then described the seemingly endless “journey dominated by obstacles” (category 2). This perception was primarily due to the changes in their body functions and the inconducive environment. Careful negotiation of barriers was necessary for continuing the journey to reclaiming participation. Participants claimed that the recognition of facilitators—“the catalyst of participation” (category 3)—in the form of peer support was critical to the development of strategies and a sound knowledge base to

overcome barriers in the course of reclaiming participation. Lastly, “becoming an agent” (category 4) emerged as the mediating attribute that validated the participants’ reconstructed meaning and purpose and their ability to develop strategies to continue broadening the breadth and depth of their involvement in situations of life.



**Figure 2.**  
Illustration of reclaiming participation.

### **Category 1: dealing with the new self.**

This aspect emerged early on in the expression of participants’ experiences of reclaiming participation, as they described this devastating event in their lives. These experiences were subcategorized as: (1) negative emotional responses, (2) coping and adjustment, and (3) finding new meaning.

The TSCI set in motion a wide range of negative emotional responses as participants explicitly expressed the sense of not being in control of their lives, emotions, and futures. Their perception of the loss of control over their lives during the acute stages of the injury had severe consequences. In particular, during the early stages of recovery, participants reported that they had considered committing suicide: “I couldn’t believe what happened, I was even in that space where I even said I can take my own life.” [Participant 7, 6 years] Most participants further stated they knew of at least one person who committed suicide following TSCI.

Most participants described the day of injury as the most unexpected, unwelcome experience of their lives, changing it forever. Participants differed with regard to their mind-set around moving on with their lives, with some feeling that they needed to accept what had happened in order to make a positive adjustment, whereas others felt that acceptance was not possible and that they needed to learn to live with what has happened: “I have accepted it, and me being disabled is just like in another life for me, I would never have imagined it. . . . How can I put this, your life just comes to a standstill, your life stops immediately.” [Participant 3, 3



years] With regard to learning to live with an SCI, one participant said, “There is absolutely nothing I can do to change the situation; I just learnt to live with what life throws at you.” [Participant 11, 5 years]

In the third subcategory of dealing with the new self (ie, finding new meaning), participants described their experiences in symbolic terms, attempting to imagine situations prior to their injury. Participants adopted strategies for coping with the events leading to their substantial disability, which seemed to be a pre-requisite for finding new meaning: “I need to accept from now on that I am a physically challenged person. There are number of obstacles and challenges that I have to face, and I said to myself, facing these, I have to understand the kind of disability that I have in order to move forward.” [Participant 7, 6 years]

### **Category 2: a journey dominated by obstacles.**

Participants reported a perception of living in a changed world as a result of different interactions following changes in their bodies after the TCSI. In one accord, participants echoed the experiences of negotiating life after a TSCI as “an uphill journey,” with obstacles in all spheres of human encounter. This category emerged and consisted of 2 broad subcategories: (1) challenges due to health condition (internal factors) and (2) challenges due to the environment (external factors). These subcategories were further subclassified for challenges due to health condition as (1) psychological impairments and (2) diminishing life areas and for challenges due to the environment as (1) physical environment, (2) negative attitudes, and (3) system deficiencies. The psychological and emotional vulnerability of participants seemed to have been triggered throughout the continuum of reclaiming their involvement in life situations. One participant said, “But it was because of my own emotional, psychological well-being at that time that I refrained from doing things, and, in the process, I excluded myself.” [Participant 2, 12 years] To illustrate the dimensional nature of psychological well-being, the outlier case shows how favorable mental health could aid participation and general health: “Emotionally, the spinal injury didn’t bother me much at that time, and mentally, I was focused on becoming an active guy in my wheelchair. I used to attend the gym a lot after hours, and it helped me to find meaning.” [Participant 6, 5 years]

Participants reported that their injuries caused a heightened level of disability. One participant with tetraplegia described how his life areas were affected: “I can’t wash myself anymore. That is one of the biggest things for me. I don’t have control of my hands anymore. My sex life has changed, understand, sex life has changed a lot. Feeding myself has changed.” [Participant 3, 3 years]

All participants expressed that their social interactions with family and friends changed after the injury. Maintaining relationships with friends seemed to be most trying and difficult. As one participant said, “At first, they were with me every day.

I am talking about every single day they were with me. But now it is almost like, if we get to him, you have to go into his room, or if you go to him, you just have to go sit in the house. If you go to him, he is going to ask us to do this for him.” [Participant 3, 3 years] One of the participants experienced changes in another form of relationship: “Even my relationship with my dog changed. Now, he doesn’t listen to me anymore. I think it is because I can’t feed him anymore or take him for walks. I want to improve my relationship with my dog.” [Participant 11, 5 years]

The main process responsible for suboptimal levels of participation was the negotiation of the interaction between the “new self” and the uncondusive environment. Related to the first subcategory (ie, the physical environment), participants expressed an experience in which they felt restricted by the built environment. Many participants started by highlighting the physical challenges in their place of residence. Most of the concerns were related to the lack of adaptability of the outside terrain leading to their homes and the surfaces inside the homes, making it difficult to execute their normal duties as before. Similarly, participants also expressed barriers in society: “One of the other things that really had gotten to me when we go into shops and malls is the small spaces. That really bugs me; it made me angry because it makes you feel automatically excluded.” [Participant 2, 12 years] Participants felt that the government authorities were not responsive enough to facilitate the inclusion and participation of people with disabilities. Their perception stemmed from the negative attitudes of others and systems: “I went to public affairs building, and the toilet wasn’t for us disabled. I asked the security where the disabled toilet was, and he asked, ‘What are you talking about?’ I said, ‘I’m physically challenged.’ He said, ‘No, this is the only toilet.’ I took it up with the manager, and do you know what he said to me? He said, ‘Take it to government.’” [Participant 1, 13 years]

Participants expressed the negative attitudes experienced as they “forcefully” attempted to participate socially. Many participants felt that the negative attitudes of an able-bodied society originated from a lack of sensitization around disability: “They are talking that we smell, we are dirty, we are in a wheelchair, and we can’t go with them. . . . They think less of us, even push us out of the line.” [Participant 10, 8 years]

The final lower-level concept was “system deficiencies.” The most-cited barrier was the lack of adequate transport that left individuals unable to participate in religious and civic duties, leisure activities, and work activities. “The fact is that transport is a major problem. . . . The taxis discriminate; they don’t stop when they see you are in a wheelchair. If they stop, you have to pay double.” [Participant 7, 6 years] To further accentuate the transport issue and the influence it has on participation and engagement, another participant said, “One of the big problems is transport. You might get transport to the interview and get the job, but you won’t have access to accessible transport every day—that is a fact.” [Participant 9, 21

years] Besides public transport as a central issue, many participants expressed the lack of urgency in the provision of adequate housing to people with disabilities by the government: “Another problem is when they say that these houses are for people with disabilities, but there are no special needs in the house for it to be adaptive for the person with disabilities.” [Participant 1, 13 years]

**Category 3: the catalyst of participation.** This category emerged as participants acknowledged the mediating influence of the peer-mentoring program on their ability to cope with or accept the TSCI, negotiate barriers, and, finally, reconstruct new meaning for a future life. The peer support received was described as “a blessing in disguise” from a standpoint that peer supporters have already made a positive adjustment to life after the SCI and that the information was from another insider, that is, a person having firsthand experience of living with a TSCI. The subcategories were: (1) information sharing, (2) equal-minded friends, and (3) becoming a role model.

The impact of peer mentoring in the study was emphasized in terms of education about SCI and its manifestations: “The peer support just gave me a sense, an idea, of what is going to happen and what can be expected in the future concerning my disability.” [Participant 14, 4 years] The space to talk about sensitive issues was appreciated by participants, with one noting: “It is where the peer-to peer model also comes in. You feel much more free to discuss your personal issues.” [Participant 2, 12 years]

The second subcategory that emerged was “equal-minded friends.” In the aftermath of disintegrated relationships with friends and family from the past, many participants spoke about befriending their peer supporter. Becoming friends was described as a natural process that was built on appreciation. As one participant said, “Thanks to Mr K again, as he opened my eyes. I’m glad that I can speak to some people about disabilities who are my friends now.” [Participant 3, 3 years]

“Becoming a role model” was the last subcategory. Not all participants in this study participated in the peer-mentoring component of rehabilitation, which was evident in their expression of future life meaning. The participants who were peer-mentored later became peer supporters themselves because of their own experiences in the program. Participants also noted that the peer-mentoring program highlighted the lack of information on SCI and disability, as well as the lack of governmental and institutional urgency to advance the agenda of people with disabilities: “Able-bodied people have very little information about the needs of persons with disabilities and us with spinal cord injury. . . . I advocate that we take charge of our agenda and start nonprofit organizations to raise awareness and educate others.” [Participant 9, 21 years]

#### **Category 4: becoming an agent.**

This category emerged as participants shared their success stories, highlighting the breadth and depth of their participation and sense of inclusion after overcoming all of the barriers they had faced. All participants noted that reclaiming participation was not an easy endeavor, nor was it a once-off event. Participants felt that participation was possible regardless of the barriers and lack of governmental commitment. The data supported the emergence of 2 types of agency: (1) agent for own life and (2) agent for others. The first type was understood as a person who took charge of his or her life alone, whereas the latter type stretched, conceptually, beyond the needs of the individual and included the collective agenda of those living with an SCI. Agency was found to be instrumental and was categorized as: (1) necessity of reconstructed meaning, (2) resistance to exclusion, and (3) becoming a strategist. Reconstructing meaning was essential for redefining participation. Because most participants were still employable, many felt that furthering their education was essential and that obtaining a job would instill a sense of meaning: “I have excluded myself for almost 20 years, just being indoors. I need to further my education and do something good for me and others with disabilities.” [Participant 4, 17 years]

Participants reported that the successful negotiation of obstacles following a TSCI instilled the sense of achievement that was necessary for developing both internal and external motivation to continue reclaiming the lives they had envisaged for themselves. These achievements proved to be critical for resisting the urge to withdraw from participating in life situations in the future: “You can’t say that you feel included in community, you have to enter by force basically. I have become involved in community. I went out, did things, and made sure that others observed my entrance and respect one another. Most of the guys in wheelchairs expect things to come to them, but you have to pursue it if it is important to you.” [Participant 12, 19 years]

In the last subcategory (ie, “becoming a strategist”), participants described the development of strategies to succeed and to get things done. It involved the development of methods to succeed in one’s life and to advance the agenda of people with disabilities: “There are always barriers, some big, some are small. You know, I’ve got the mind-set where you just have to work around it, analyze the situation, and find a good solution, a solution you can share. That’s why I can say that I integrated myself well into society.” [Participant 6, 5 years] There is an urgency and need to get things done for people with TSCI; therefore, activists and organizations are playing crucial roles in keeping state authorities accountable for advancing equal opportunities: “We have decided that we are going to take government to court regarding the housing issue. . . . We know that 10% of each housing project should cater for people with disabilities. . . . This will ensure that 10% of houses are allocated to people with disabilities, and government will save lots of money.” [Participant 2, 12 years]

## **Discussion**

To our knowledge, this was the first qualitative inquiry that explored the experiences of community-dwelling people living with a TSCI in a resource-constraint context on their journey to reclaiming participation postinjury. Participants described their involvement in life situations after the injury as a contested journey, first by adjusting to the “new self” and thereafter navigating the barriers while being aware of the need for support, and finally demonstrating agency that led to reconstructed meaning.

Participants expressed negative emotional responses toward the injury and having to deal with it. However, all participants expressed an urgency to the necessary adjustment in dealing with the new self in the process of regaining meaning in life and involvement in life situations. Adjustment entails a timeless negotiation of coming to terms with the losses and limitations associated with a devastating health condition.<sup>25</sup> In our study, however, it was evident that the nature of time alone did not heal all wounds, as many participants knew of at least one person with a TSCI committing suicide after injury. Thus, the initial phase of living with a TSCI seems critical for the development of coping strategies that are necessary for continuing the process of reclaiming participation. Adjustment implies acceptance; however, this was contested by some participants who expressed their nonacceptance in terms of “tolerating” the injury. Similar findings were found in qualitative studies exploring coping mechanisms after an SCI in Sweden and Denmark.<sup>26,27</sup> In the Swedish study, a participant stated, “I don’t accept what has happened to me, but I have learned to live with it.” As participants either accepted or learned to live with a TSCI, we observed a variety of coping strategies that initiated the process of regaining meaning—in other words, when a person is able to imagine a future containing some of the important elements from the past.<sup>28</sup>

Participants in this study described a wide spectrum of involvements in day-to-day life situations, including self-care activities, mobility and domestic tasks, sports, and recreation. However, the extent of participating in these activities was restricted by both the external environment and internal factors. Participants were concerned about the physical environment (the physical spaces in which they live) that was not designed for them, highlighting the contradiction where, even though the government had adopted policies to increase participation for people with disabilities, they had not been implemented. One participant stated that public spaces (even government buildings) were not accessible, toilets for people with disabilities were unavailable, housing for these individuals was similar to that provided to able-bodied citizens, and desks reserved for use by people with disabilities (at banks, stores, and so on) were still operated by able-bodied employees. Another participant explained how society and government could

respond by having people with disabilities work at institutions or facilities where special conditions apply to them, claiming that it could alleviate the high unemployment rate among these individuals and enhance the peer-to-peer model that seems to be instrumental in this context.

Other major barriers raised by participants were the lack of public transport and the attitudes of society that devalued people living with a TSCI, aligning with well-documented findings in the literature.<sup>5,29,30</sup> Cultural beliefs and attitudes are different; therefore, addressing integration and participation requires contextually sensitive social action plans. To highlight this difference in context around transport problems, a number of participants who use wheelchairs noted that public taxis do not stop when observing a wheelchair user. On the rare occasion that they do, the person has to pay double to use the service. Such negative attitudes not only restrict participation of the individual but also cause embarrassment and an increase in the lack of faith in services and systems.

The combination of the categories as discussed provide evidence for the theme that emerged from participant responses, which is that while participation is a possibility, there are some barriers to achieving it. Participants expressed the importance of a peer mentor/supporter throughout the process of dealing with the new self and of finding ways to minimize barriers to involvement. They expressed that peer mentors provided a cultural perspective of what it is to heal and recover within the local context. Furthermore, participants placed explicit value on the role of peer mentors as being instrumental in providing expert information about what to expect. Perhaps most striking, mentors and mentees extended their “professional relationship” toward friendship, an aspect that needs further investigation. We suggest that the diminishing social interactions with friends and family, accompanied by the lack of concern from able-bodied citizens, opened a space for building friendships with those who are like-minded. Additionally, participants indicated their willingness to accept the advice and recommendations of the peer mentor more readily, compared with health professionals. The notion of the “similar other,” in which aspects of credibility, equitability, mutuality, acceptance, and normalization between the mentor and mentee provide favorable conditions for success.<sup>31</sup> Other studies showed similar positive outcomes of peer-mentoring programs in addition to improved self-efficacy and lower medical complication rates following a TSCI.<sup>32,33</sup>

Participants expressed their path to reclaiming participation as an underlying process of continuous introspection of functioning goals, dreams, and challenges. Agency, which encompasses will-power, motivation, determination, and strength to explore pathways and goals, was important to reconstruct meaning, incorporating life involvements of the past into the current and the future.<sup>34</sup> Thus, it is

important to facilitate the construction of meaning early on to address the needs of each individual living with an SCI.

Rehabilitation appears to be among the most neglected services of many health care systems, which is especially true in developing countries.<sup>35</sup> With the achievement of high levels of participation as one of the hallmark features of health care, the findings of this study provide some insight into the challenges that people with SCI face in achieving this outcome. Improved rehabilitation for people with SCI could be enabled by providing support services during the acute stage. The findings suggest that rehabilitation services, such as physical therapy, should extend into the phase where clients have returned to their communities. The concept of lifelong follow-up (rehabilitation), as part of many health care systems in developed countries, should be considered by policy makers as a critical service, which may assist with the breakdown of patient- and context-specific barriers.

### **Limitations**

The participants were restricted to one context, that is, community-dwelling people living with a TSCI in one region of South Africa. In addition, these participants received public-funded health care services, thus omitting those from the private sector. Due to the structural and procedural differences between systems in South Africa and the rest of the world, the transferability might be appropriate given the similarities of other contexts. We observed the initial process of dealing with the TSCI, in terms of coping and acceptance, reconstructing new meaning, and overcoming barriers and negative attitudes, as having outcomes similar to those described in other studies.<sup>26,27,36</sup>

Recall bias was introduced due to the nature of the study, in which participants were asked to share their experiences that go back to the first days of injury. However, in this study, the overall theme and categories contained critical aspects that, according to the participants, influenced the process of reclaiming participation. The results of this study might have relevance to the experience of reclaiming participation around the world; therefore, it is essential to tailor and implement aspects of findings according to the need of the individual in the global context.

### **Implications and Future Studies**

Participants in this study reported that participation was indeed an end-point outcome. The voices of those who had successfully reclaimed participation may contribute to the development of health services, including rehabilitation and peer-mentoring programs. There is a need to understand the similarities and differences related to the conceptualization of full and effective participation that can guide the authentic evaluation of participation across countries and

continents. This deeper understanding, in turn, may result in the development of global rehabilitation strategies that could optimize participation.

For physical therapists and other health professionals involved in the management of TSCI, understanding the insider's view and experience of participation could assist with the design of therapeutic interventions that may result in improved participation by taking into account individual goals and influencing conditions. In addition, the development of outcome measures that better target the local concept of participation may positively influence patient outcomes. Future studies in other contexts should further expand on the experiences and conceptualization of participation of sub-groups in the SCI population in order to better respond to the needs of people living with a TSCI. Furthermore, we need to improve our understanding of how health services must align themselves with the needs of the individual along the journey of reclaiming participation.

In conclusion, participants' accounts of reclaiming participation after a TSCI affirm the notion of eventual involvement in life situations, with each person demonstrating agency to combat negative intervening conditions and identify favorable ones. The path to reclaiming participation requires that actions of remediation be implemented in order to overcome obstacles as they appear on the journey. Furthermore, the widespread implementation of peer-mentoring programs should be considered to augment participation.



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