Examining the psychological and emotional experience of sexuality for men after spinal cord injury

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Abstract: Sexual rehabilitation for men after spinal cord injury (SCI) has focused on physical challenges and has neglected psychosocial factors. Utilizing a descriptive phenomenological approach, the lived psychological experience of sexuality was described for six men (age 24–49) with complete or incomplete SCI (C4-T12; <1 year to 29 years post-injury) who participated in one in-depth, standardized, open-ended interview (68–101 minutes). Participants described the emergence of a new perspective of sexuality placing less emphasis on any one physical act and more importance on emotional factors. Understanding the evolving meaning of sexuality for men after SCI is imperative for delivering effective sexual health information.

Subjects: Rehabilitation Medicine; Disability; Chronic Diseases; Sexual and Reproductive Health

Keywords: male sexuality; sexual satisfaction; intimacy; sexual health; spinal cord injury

1. Introduction

Sexuality is a basic human need that is vital for achieving satisfaction with one’s overall quality of life (QOL) (Reitz, Tobe, Knapp, & Schurch, 2004). Society has strong ideals of what sexuality is and who is
allowed to participate. Sex is viewed by society as a privilege of the young, beautiful and non-disabled, thus suggesting that individuals with disabilities, including spinal cord injury (SCI) are not sexual (Sakellariou & Sawada, 2006). Individuals with SCI are told they must disregard their inherent sexual desires that are human in nature, and abandon that part of themselves (Herson, Hart, Gordon, & Rintala, 1999). However, sexual adjustment after SCI is not solely dependent on genital function or level of injury (Siösteen, Lundqvist, Blomstrand, Sullivan, & Sullivan, 1990). Despite changes in mobility and sensation, sexual desires may be unaltered and sexuality continues to be important to many individuals after SCI (Sakellariou & Sawada, 2006; Siösteen et al., 1990). Kreuter, Sullivan, and Siösteen (1996) suggest that sexuality is not synonymous with genital function, and that the emotional and sensual dimensions of sexuality may compensate for physical limitations resulting from SCI.

In terms of sexuality for men after SCI, literature has focused primarily on physical aspects of sexuality such as obtaining and maintaining an erection, and successful ejaculation. Emphasis has been placed on the measurement of these physical indicators of sexual performance (Sunilkumar, Boston, & Rajagopal, 2015), and the psychological aspects of sexuality have been largely neglected for men with SCI (Basson, Walter, & Stuart, 2003). Nevertheless, sexuality is multifaceted and due to changes in function and sensation, the psychosocial aspects may be more important than the physical factors for achieving satisfaction with sexual life in this population (Kreuter, Sullivan, & Siösteen, 1994; Siösteen et al., 1990). General anxiety, performance anxiety, negative self-concept, feeling sexually unattractive, emotional distress, fear of rejection, depression, feelings of sexual inadequacy, lack of confidence and self-doubt regarding sexuality after SCI may have a more profound negative affect on sexual adjustment than the actual genital dysfunction (Low & Tunku, 2000; Siösteen et al., 1990) and may lead to avoidance of sexual activities (Kreuter et al., 1996). Therefore, addressing the psychological and emotional concerns resulting from SCI, especially in the context of sexuality, may be just as important as physical rehabilitation (Giuliano et al., 2008). This study aimed to examine the lived psychological and emotional experience of sexuality for men after SCI.

2. Materials and methods

2.1. Phenomenology

An inductive and exploratory qualitative approach was employed. Utilizing Giorgi’s descriptive phenomenological method (Giorgi, 2009), an in-depth examination of the experience of sexuality for men living with SCI was conducted to explore their lived experiences. The goal of this study was not to predict, but to receive information.

2.2. Participants and recruitment

Phenomenology requires the participants have personal, lived experience with the phenomenon under investigation (Patton, 2002), and recognizes that only certain individuals will be able to provide information that is useful and relevant for describing the phenomenon. Therefore, purposive sampling was used to select participants based on the information they would be able to provide (Carpenter & Suto, 2008). This resulted in detailed, information-rich descriptions of experiences from men who had firsthand knowledge of sexuality after SCI (Creswell, 2007). Phenomenological investigations generally involve a small number of participants (Carpenter & Suto, 2008; Polit & Hungler, 1995) and focus on meaning, richness and depth of the data that are uncovered rather than sample size (Liamputtong, 2009). Six participants took part in this study which falls within the recommended guidelines for this type of investigation (Patton, 2002; Polit & Hungler, 1995). Individuals were eligible to participate if they were male, between the ages of 18 and 50, living in Canada with a SCI of any level or classification and were able to communicate in English. Participants were recruited via posts on relevant social media platforms, by word of mouth and through support from Spinal Cord Injury Ontario.

2.3. Interviews

Pseudonyms were chosen by each of the men who participated in this study, and they were referred to by these names throughout the entirety of the investigation. Each participant
completed one confidential, in-depth telephone interview lasting between 68 and 101 minutes in length (mean time 81 minutes). Interviews followed a standardized, open-ended approach combined with interview guide approach (see Appendix A for complete interview guide) ensuring the same topics were addressed with each participant while also allowing for further investigation into new and relevant topics that arose but were not planned for or not anticipated (Patton, 2002). The main interview questions can be found in Table 1 and included the six types suggested by Michael Quinn Patton: demographic, experience/behavior, knowledge, sensory, feeling/emotion and opinion/value (Qualitative Research & Evaluative Methods, 3rd ed, 2002), and probing questions were used to delve deeper and obtain additional information regarding certain topic areas. Interviews were audio recorded using a Sony ICD-PX370 digital voice recorder and were transcribed verbatim. Field notes were recorded during each interview. Ethical approval was obtained from the York University Research Ethics Board and the Brock University Research Ethics Board.

2.4. Analysis
Data were analyzed by means of ongoing and constant comparison to determine how one transcript may convey a message about the others. This was achieved using Giorgi’s method and adhered to the following procedure: transcription, read and jot, meaning units, first transformation, specific descriptions, general descriptions, revelatory phrases and emerging themes (Giorgi, 2009). Analysis began with unique, or within-case orientation where each transcript was examined as its own case. This was followed by a cross-case analysis and individual cases were compiled to examine the phenomenon across various contexts and relationships, and to uncover the prominent themes and patterns that emerged between them. Data were analyzed independently by two researchers and discussed until a consensus was met regarding emergent themes, and a reflective journal was kept throughout the process to track decisions (Carpenter & Suto, 2008). To stay close to the data, themes were supported by direct quotations from the participants’ transcripts. The emerging themes represent the lived experiences and prominent ideas of these particular men regarding this particular phenomenon.

| Question number | Main interview guide questions |
|-----------------|--------------------------------|
| 1.              | Can you start by telling me a little bit about yourself and your spinal cord injury? |
| 2.              | What is the meaning of sexuality to you? |
| 3.              | How has your spinal cord injury impacted your sexuality and/or sexual function? |
| 4.              | Describe a time after SCI when you felt sexually satisfied (or describe a situation that would make you feel sexually satisfied). |
| 5.              | How would you describe any body issues that you are concerned about when participating in, or thinking about participating in sexual activities? |
| 6.              | How has your spinal cord injury affected the way you see yourself? How has this affected your sexuality? |
| 7.              | Tell me a story about a time or situation when your SCI affected your sexual life. |
| 8.              | As you talk about and reflect on your sexual life after spinal cord injury, what types of feelings and emotions are you experiencing? |
| 9.              | What resources have you used or accessed (books, pamphlets, videos, support groups, etc.) to help with adjusting to your sexual life (sexuality, sexual function) after SCI? |
| 10.             | Is there anything that we didn’t talk about today that you would like to discuss now, or is there anything that you would like to add to our conversation? |
3. Results
Six men with complete or incomplete SCI (C4-T12) between the ages of age 24 and 49 participated in this study. Participants were <1 year to 29 years post-injury. All of the men identified as heterosexual. Four of the men were married, one was in a relationship and one was divorced. Three of the six men had children. Of these men, two had children prior to their injury and one had children after his injury. Table 2 outlines demographic and interview characteristics for each participant.

3.1. Themes
The men in this study acknowledged stereotypes and societal beliefs pertaining to sexuality, masculinity, disability and attractiveness and recognized that as a result of their SCI, they no longer conformed these norms. The men expressed the importance of adapting their own beliefs regarding these topics in order to find acceptance of themselves in “a world that is not all that accepting.” -Will

Elliot: Definitely I’ve fallen into stereotypes of what disability and sexuality were like until I started to investigate it more and realized that they’re not entirely true. Every part of my body and the way in which society views the norms of what a body should look like. I think I’m constantly going back to it thinking that there is something inherently wrong with my body. ... facilitating an erection can be tricky and it’s kind of the main part of many peoples’ view on what sex should look like. So if you don’t have a really great erection then obviously you’re kind of failing in one very important part of what many partners find very important.

3.1.1. Changing perspective of sexuality
When asked to describe the meaning of sexuality, all of the men in this study described feelings of intimacy and connection with themselves and/or their partner on an emotional level. The men stated that being physical and/or having penetrative sexual intercourse may play a role in sexuality, but revealed that the physical aspects of sexuality were “just a tiny little part of it.”

Table 2. Participant and interview characteristics

| Participant | “Joe” | “Elliott” | “Will” | “Steve” | “Paul” | “Peter” |
|-------------|-------|-----------|--------|---------|--------|---------|
| Interview Length | 81 min | 101 min | 83 min | 67 min | 86 min | 68 min |
| Age | 24 | 32 | 45 | 49 | 49 | 47 |
| Injury | C7 Incomplete | C4 Incomplete | T9 Complete | C4/C5 Incomplete | T12 Incomplete | T6 Complete |
| Years Post-Injury | 6 years | 15 years | 28 years | 29 years | 7 years | 7 months |
| Sexual Orientation | Heterosexual | Heterosexual | Heterosexual | Heterosexual | Heterosexual | Heterosexual |
| Relation-ship Status (current) | In a relationship | Married | Married | Married | Divorced | Married |
| Relation-ship Status (at injury) | In a relationship | In a relationship | Single | In a relationship | Married | Married |
| Participat-ion in Sexual Activities Prior to Injury | No | Yes | Yes | Yes | Yes | Yes |
| Participat-ion in Sexual Activities Post-Injury | Yes | Yes | Yes | Yes | Yes | No |
Joe: Meaning of sexuality? I guess how one feels or expresses their intimate feelings. ... it’s not all about sex at all. For me it’s more emotional.

Will: [Sexuality is] the intimacy between two people. ... it’s not defined by one particular act [intercourse]. Sexuality is everything from the intimacy between two people, their interactions, the different ways that they arouse each other and the different ways that they inspire each other in those intimate moments.

Steve: [Sexuality is] being connected with yourself emotionally and physically. And sexuality is also about being connected with your partner in that same emotional type of way. Not just in the physical sense.

This portrayal of sexuality differs from the description of sexuality these men thought they would have provided in the past. Prior to SCI, the men thought of sex and sexuality in a physical sense with emphasis on penetration and intercourse. They referred to this as the “traditional” view of sexuality. Post-injury, physical factors became less important due to decreased sensation and decreased ability to trigger an erection or successful ejaculation, as well as decreased physical function and mobility to perform various sexual activities. The men explained that sex cannot be defined the same way it was prior to injury, and that the meaning of sexuality was an evolving concept that changed and expanded over time and with new experiences.

Will: It’s a long road getting to that point where you get past what would be considered a traditional method [of sex], however you want to define it. It becomes about things that you may not have realized were quite as important before. It’s something that yes, you have to define it in a different way, you don’t really have a choice. You can’t try to define it [sexualiy] by the same way it was pre-injury.

Elliott: I think before my spinal cord injury, the way I would think of sexuality was penetration. And that was basically it. I just wasn’t really interested in a whole lot of stuff other than that. Right now, I’m more leaning towards the non-penetration side of a variety of sexual activities.

Will: It [SCI] took the focus off of the one traditional act that everyone comes to think about when it comes to sexuality, and moved it to other places, and thinking about it in other ways. And sometimes it actually doesn’t have to do with any one act or anything. It definitely becomes more emotional.

As the men let go of the idea of sex as a purely physical, penetrative experience, they became more appreciative of the psychological and emotional side of their sexual relationships, and experienced sexuality in a new way. One participant explained that he was able to reach a deeper level of intimacy which he felt he would have been unattainable without his injury. He supposed the focus on physical factors of an able-bodied person would actually inhibit their ability to reach an understanding of intimacy on that level. In his opinion, sexuality was more fulfilling within this perspective than it was prior to injury.

Steve: Sex is way different because I focused solely on genitalia [before SCI]. It took a while at the beginning because you think of sex from a physical standpoint. You don’t think from an emotional standpoint. It [SCI] just opened my mind to a whole different level of sexuality because guys are normally not taught to be emotional in any way or in contact with your own sexuality that way. And it’s much more fulfilling in my opinion to be connected with your partner emotionally than it is just the physical aspect. I honestly probably don’t think [I would have gotten to this level of sexual fulfilment without SCI] because I would have been concentrating so much on the physical aspect of it. I don’t know if that would have gotten in the way of understanding that level of intimacy. The physical aspect of feeling your genitalia and you know, wanting to have that physical release is actually in the way of your emotions. You really have to look at it from a different perspective. And you can’t look at it from your typical male perspective ... it’s not just about getting off. It’s about being...
connected. And it [SCI] really taught me that. Because that physical release, you have to find it from a different avenue of connection. And it’s more fulfilling being this way than it is being the other way.

Men who had not embraced this new perspective of sexuality struggled to find satisfaction within the traditional framework of sexuality, and in some cases, this led to decreased interest and participation in sexual activities. When asked to describe a time since his injury when he felt sexually satisfied, the most recently injured participant (<1 year post-injury) who was focused on recovery and regaining “normal” function and sensation, reported that he was unable think of a time when he had been sexually satisfied post-injury. This is in contrast with the men who had embraced the new perspective of sexuality, focusing less on physical function and sensation, and placing more emphasis on intimacy and emotional connection.

Furthermore, as a result of being unable to feel the body or pleasurable sexual sensations, including climax, in the same way they did prior to injury, all of the men in this study reported that they now placed more emphasis on their partner’s sexual satisfaction. Many of the men stated that a great deal of their own sexual satisfaction came from their partners’ satisfaction, and through their partner, they, themselves were able to feel satisfied in a sexual sense. For the majority of these men, this differed from their perspective of sexuality prior to injury as they had tended to be more concerned about themselves in their past sexual situations.

Elliott: [Before SCI] I was just basically thinking about myself a lot of the time. And I think after my spinal cord injury I’ve also learned that your partner is very, very important to think about. And you can have a positive experience from your partner’s reaction as well. [Sex] definitely doesn’t feel the same as what it used to feel like, so I think it’s very difficult for me to only focus on myself when it’s very difficult for me to get to that point [climax] so I tend to focus I think more so on my partner.

Steve: That’s how I get pleasure out of it now. Pleasuring my partner. That’s what gets me excited. That’s where I get my enjoyment from. It’s that my partner is being pleased.

Generally speaking, participants conveyed a continued importance of sexuality in their lives post-injury. The men explained that satisfaction with their sexual lives was necessary for improving other physical and psychological health issues, and that sexual satisfaction was vital for improving their outlook on life and overall QOL.

Elliott: I definitely know that I am a little bit more frustrated because that part of my life [sexual] hasn’t been as adequate or what I was hoping it would be. It definitely makes my mood a lot worse. … my thoughts about myself, and just life in general is not always the greatest, but they probably would be if my sexuality was a little bit more positive.

3.1.2. Changing perspectives of masculinity
Participants in the current investigation admitted to taking part in, or at least being aware of, society’s beliefs about the meaning of masculinity which they characterized using terms such as strength, dominance and sexual conquests. The men also acknowledged that SCI affects many of the traditional measures of masculinity in both activities of daily living as well as in a sexual sense. Again, the men in this study were able to expand their views of masculinity and redefine the concept. By placing more emphasis on the strength required to allow others to support them, the nobility in being there to support those close to them, the strength in being vulnerable, showing emotions and exposing one’s true self rather than focusing on strength in the physical sense that is often associated with masculinity, there was acceptance that they were no less of a man as a result of the injury. It was also noted that sex can be experienced and enjoyed in many ways, and having the man play the dominant role in a sexual setting is not the only approach.

Elliott: … before my injury [I had] very specific stereotypes in my head where the man was supposed to be the strong one and the man was supposed to be the dominant persona, especially like in a sexual sense. Now, after my injury, I really can’t be the physical, dominating [person] in
a sexual relationship and it plays into the way I actually feel about sexuality. And I don’t think there is any general way to look at how a man or a woman should act in this situation. I think everyone enjoys [sexuality] in a bunch of different ways.

Will: I don’t believe in the old toxic masculinity view of things. I don’t judge myself as a man by my conquests. To me, being a man is just simply what you are to your friends and family, to the people that you care about. It’s about being there to support others, it’s about being there to let them support me if and when I need it. Now that probably has changed quite a bit from prior to the injury because, yes, I did definitely judge myself by other people’s achievements, how many women had I dated etc. Yeah, I could have very much fallen into that category. But these days I don’t judge myself as a man by that aspect at all. I do find myself occasionally falling into that trap because things [penis/body] don’t work as the average man thinks they should. That does occasionally get you a little depressed, but I do try to get myself out of that by realizing it hasn’t changed who I am as a person.

Steve: ‘Oh suck it up, don’t cry, men don’t cry.’ Yeah, we do, and you should. And you should express that. And I find that I’m more of an emotional person now. And that’s a real man. The real man is someone who can show their emotions, not just anger and other things.

3.1.3. Changing perspective of disability
Spinal cord injury affects how an individual is viewed within society, and the men suggested this is because SCI is a visible disability. The men felt the injury was the first thing people saw when they looked at them and suspected that some people may not be comfortable interacting with them because of the injury. The men have felt misunderstood when people assumed they must have a mental disability as well as a physical limitation. They have felt looked at as a patient more than a person, viewed as a science project, and they have felt that people look at them with pity. The men explained that for some people, the SCI is not something they can look past. This is challenging when meeting new people in general, and also when trying to meet a new potential sexual partner. The men in this study described the importance of finding a partner who was willing to look past the injury, and who was open to getting to know them as a person.

Will: I recognize and acknowledge the fact that when you’re meeting new people for the first time, the chair is the first thing that many of them will see. Some people can’t get passed it. It’s [SCI] always there in one way or another. People are always wondering how they can help me, and if I need help.

Joe: You always feel like people are looking at you with pity, like they feel bad for you. And it’s sometimes difficult to get them past that point. You always feel like they’re looking at you as sort of a poor person that has to be looked after. So, a lot of people have this misconception that when I say wheelchair people think mental disability or that I can’t do anything below my head, stuff like that. It can be tough. You can’t really blame them for that. They just don’t have any experience previously with people in wheelchairs.

Joe: Being in the hospital, I’ve been looked at as a patient more than a person for three years. Everybody would look at me as a person with a spinal cord injury, like, ‘he’s just a patient. He’s a science project.’ So, once I was able to meet someone who looked at me as a person rather than a patient, that just made me feel completely so much better.

Steve: … those online dating sites. I was trying to go out there with a generic profile, so you get all your physical attributes and they call you and then [after finding out you have a SCI] they’re like, ‘oh, yeah never mind … ’

3.1.4. Changing perspective of attractiveness
Society has beliefs about what an ideal body is supposed to look like, and the body of a man living with SCI may not encompass that vision. Participants in this study revealed that after their injury, they felt as though no one would find them attractive. The men questioned their own appeal to another person and felt they would have to settle in terms of the partner they would end up with. This led to an enhanced fear
of rejection and avoidance of approaching new people, thereby resulting in feelings of loneliness and depression.

Elliott: At that point I had been fairly certain that like, like no one would find me attractive because of my disability and because of my spinal cord injury. I just kind of assumed that wasn’t something that was going to happen.

Joe: It takes me back a little bit to the beginning of my injury when I thought everything was over and that I’d never be able to find anyone that’s attracted to me. [At first] you just don’t feel like it’s going to be possible to find a partner or that you’d have to lower your standards to the point where you’re not even attracted to the person. It triggered depression. There are other parts of the injury that cause that too, but mainly it was a feeling of loneliness.

Elliott: I just didn’t really feel comfortable approaching anyone. It’s definitely something that’s very difficult for someone with disabilities. I think there is constantly a fear of rejection. I think it’s a lot more now than it was before my injury. It still would be just very, very difficult for me to actively engage in a relationship because of self-doubt.

One participant described a specific situation where he felt his SCI affected the way women viewed him and his level of attractiveness as a potential partner:

Steve: When I sit in my car, you can’t tell I’m in a wheelchair. I’m a good-looking guy, and all they can see is my face and my smile. I get out of my car, and they turn their head away. I’m the same guy you just looked at, like looks-wise, but now I’m in a wheelchair. So, what’s the difference?

Men described specific body image issues they experienced as a result of SCI which included a loss of muscle mass, a larger stomach, pressure sores, spasticity, restrictions on the type of clothing they could wear, bladder and bowel issues, always being in a seated position and having a flaccid penis. The men compared their current bodies to their bodies prior to injury, and described the difficulty and frustration in not being able to do anything about it. Due to the fact that they could not be as physically active as they were prior to injury and could not engage certain muscles to work, they expressed a sense of hopelessness.

Steve: Now I have a quad gut (larger stomach due to inability to engage core muscles) and my arms are skinny my legs are skinny. Like I said, I was an athlete. I was fit. That is hard for body image.

Will: I’ve got the tummy, my [legs] have withered, and unfortunately because of the nature of the injury, with the loss of strength in muscle tone of my abdomen there’s a lot of weight. It’s not even weight, it’s more just flab that has appeared just because you can’t do proper exercises in that region, the muscles don’t work all that much and I’ve gained myself a belly.

Changes to body image also enhanced their fear of rejection by a potential partner and heightened avoidance behavior.

Elliott: Just initiating any type of [sexual] activity with anyone else was terrifying and I just didn’t really want to get into it. I just found a variety of parts of my body unattractive and I felt that if I got into a situation with anyone else, they would also find me unattractive.

Joe: I was at my lowest point in confidence. Confidence in myself. Feeling that people wouldn’t be attracted to me, or confidence in approaching people, or you know, so-called ‘making a move’ or anything like that really.

One participant went on to discuss how these issues with body image affected his feelings about himself, his confidence, his self-esteem and how these insecurities caused him to fall back into the negative self-thoughts he had been able to overcome prior to his injury. Ultimately, he was led to question his appeal to potential partners.

Will: It’s hard not to judge myself, and that affects your view of yourself. I thought I had gotten over them [my insecurities] before the injury took place because I was more confident with myself. I became successful to a degree in life, and then this happens, and then you start questioning everything again. When you look at yourself, and unfortunately because you’re in a seated position...
all the time, it makes things look that much worse than if you were able to get into a standing position. It reduces what you see as your own appeal. When you layer that on top of the fact that things don't work [penis], umm, you start to, you can't help but question what your own appeal is. What would it be that would bring people to you to see you that way [as a potential sexual partner]?

Participants believed they were doubly disadvantaged as consequences resulting from SCI left them feeling unattractive, as well as feeling disabled in the sense that the body, and specifically the penis, did not function the way they believed it should. While able-bodied men may feel insecure about the size of their penis due to society's obsession with its appearance, men with SCI may feel an added insecurity in this regard due to an inability to achieve erection. When participating in sexuality activities, if the penis is flaccid, it may appear smaller than it would if it were erect adding another dimension of concern for these men.

Joe: With men obviously there's always an obsession with, everyone constantly talking about the size of your penis. That's the body image thing for men. There is always a nervousness about that, even so like it may not be small or whatever, but when you're not using it sexually all the time or getting erections all the time without medication they usually shorten because you're not exercising that stretching right? So that's definitely a concern, and always is.

Participants acknowledged the high probability that all men, able-bodied or not, are likely to have concerns with body image. However, they explained that men with SCI have to deal with all the concerns any man would have to deal with, as well as an added layer of concerns that are directly related to the injury. Two participants explained that SCI had escalated the negative body feelings they experienced prior to injury, with the injury making them more intense.

Joe: I would say [men with SCI have] the same body issues [as able-bodied men], probably a little bit worse because you're sitting down all the time. And you're limited in what kind of clothing you can wear. Or I'm limited, by like, pressure sores, so I can't wear jeans. Umm, yeah, it's a different set of body image issues but I think everyone has them to an extent. Able-body or not.

Elliott: Even before my injury I always had a hard time with various parts of my body. But they did emphasize after my injury. [SCI] definitely made a lot of my body perceptions a lot worse than they were before.

Similar to the concepts of sexuality, masculinity and disability described above, one participant suggested that people need to change their views of what they think they are looking for in a partner, expanding beyond the physical and reaching into the more meaningful, deeper connections. He explained that people put a lot of emphasis on physical attributes, but that personality and connection with a virtuous person are more important than their superficial traits.

Steve: ... people who want to be with you want to be with you regardless. So when you realize that, you are more confident. Sure, there might not be as many people you come across that want to give you that chance, but then you weed out the bad people. What does 6 foot 3 have to do with anything? Nothing. Find a guy that treats you nice. Find a guy that will be kind. And will listen. Like, a guy that has six pack abs and huge muscles, and biceps, and everything like that, you really think he's deep? Do you really think he's gonna care about your needs? Some guys might. I'm generalizing again. Some guys might, but few and far between. Find connection, and you'll be so much more fulfilled. If people would realize that, they would be so much happier.

4. Discussion

Sexuality and sexual function are of top priority for individuals living with SCI (Anderson, 2004) and play an important role in their overall rehabilitation (Sheel, Krassioukov, Inglis, & Elliott, 2005). Literature suggests that over 80% of individuals with SCI feel that their injury has altered their sexual sense of self, and that improvements to sexual function would improve their overall QOL (Anderson, Borisoff, Johnson, Steins, & Elliott, 2007). This is consistent with the present findings as
the men in this study generally felt that if they improved their sexual lives, they would improve their mood, they would feel happier and the quality of their lives would be better overall.

The top two areas of research for men regarding sexuality after SCI are erectile dysfunction and ejaculatory dysfunction (Anderson et al., 2007). Although effective treatments for erectile dysfunction and anejaculation exist, the psychological and emotional consequences of SCI on sexuality for men remain understudied (Dahlberg, Alaranta, Kautiainen, & Kotila, 2007). Sexuality is a complex physical and psychological phenomenon, and through a description of their own lived experiences, participants in this study identified an evolving meaning of sexuality in which psychosocial factors were vital to increasing sexual satisfaction. Participants generally, but to differing degrees, described the emergence of a new perspective on sexuality placing less emphasis on physical factors, specifically penetration, and more importance on psychological factors including intimacy, connectedness and emotional closeness with their partner. Men who reported embracing this perspective of sexuality reported a deeper and superior sexual experience and level of intimacy, some even more so than prior to injury, whereas the participant who had not adopted this perspective reported lower levels of sexual interest and satisfaction. This is consistent with a previous study of 134 able-bodied individuals that found greater levels of intimacy were linked to higher levels of sexual desire (van Lankveld, Jacobs, Thewissen, Dewitte, & Verboon, 2018). Furthermore, Stulhofer, Ferreira, and Landripet (2014) that found sexual satisfaction was contingent on intimacy, and similarly, a study by Pascoal, Narcisco, and Pereira (2013) found emotional intimacy to be the best predictor of sexual satisfaction in individuals with sexual arousal issues (Pascoal et al., 2013).

Masculinity was the second emerging theme and is a social construct that is closely linked to sexuality. Its clearly defined expectations may have a detrimental effect on men after SCI (Esmail, Darry, Waiter, & Knupp, 2010). Boys are taught the possession, size and use of their genitals, as well as initiating sexual activity and possessing a high sexual drive are indicators of manhood (Burns, High, Boyd, & Hill, 2009). Masculinity has been described in the literature, and by the men in this study, using words such as physical, athletic, assertive, breadwinner, dominant and sexual prowess, all of which may be affected by erectile dysfunctions and other physical limitations resulting from SCI. As a result, appropriate gender roles and sexual identity may be disrupted (Sakellariou & Sawada, 2006) making it necessary for the men in this study to alter their perspectives on the meaning of masculinity. Men focused on non-physical strengths, specifically the strength that comes from being a good person who is in touch with their feelings and emotions and who supports, and is supported by, those around him to represent the character of a “real man.”

The third theme involved perspectives on disability. The men revealed that they often felt as though people saw only the disability when they looked at them and recognized the injury was not something that everyone would be able to move past. Participants with SCI have questioned whether the attention they received from others was out of curiosity about the disability and pity, or because of interest in them as a person. In most cases, participants assumed it was the former (Potgieter & Khan, 2005). Many myths exist about people who live with a disability, and due to a general ignorance about what it means to live with SCI, people may feel uncomfortable interacting with this population and may also have an assumption that they are asexual (Potgieter & Khan, 2005). Working to educate society about what it means to live with a SCI may improve social opportunities to engage in sexual relationships post-injury.

The final theme considered physical attractiveness. An ideal body may be thought of as one that stands, and for a man, it may also include a body that is strong, lean, muscular and athletic (Blond, 2008). These ideas are reinforced in society where exposure to the male body in its ideal form and as a sexual object is abundant (Blond, 2008), making it difficult for men with a disability to escape this perspective. Blond (2008) found that exposure to idealized male bodies in advertisements and other forms of popular culture had a significant negative impact on body satisfaction, specifically for those with lower levels of body satisfaction which may include those living with a disability.
Men with disabilities are taught that their bodies are unattractive because they do not conform to the socially accepted standards of an ideal male body (Potgieter & Khan, 2005), and the men in this study were aware of the ways in which their bodies deviated from this. Physical consequences of SCI described in this study included weight gain, a larger stomach, muscle atrophy, spasticity, pressure sores, flaccid penis, being in a seated position, not being able to wear certain types of clothing and issues with the bladder and bowel. As a result, the men felt unattractive and questioned their own appeal to a potential partner. Consistent with work by Potgieter and Khan (2005), the men experienced negative emotions including loneliness and depression as a result of avoiding opportunities to meet new potential partners due to a heightened fear of rejection.

Addressing the issues identified through this investigation may lead to improvements in the lived sexual experiences for men after SCI. Suggestions include educating healthcare providers on the changed perspective of sexuality for this population so that sexual education may be consistent with the interests and priorities of the patient. Healthcare providers should be aware of the stigmas surrounding sexuality and disability, as well as their own biases regarding the topic which may influence the information they provide, and which patients they choose to provide this information to. The findings of this study highlight and further support a need for the use of a biopsychosocial approach when addressing sexuality in SCI rehabilitation (Elliott, Hocaloski, & Carlson, 2017; Pieters, Kedde, & Bnder, 2018), allowing for holistic consideration of this multifaceted and complex phenomenon, integrating both the physical and psychological/emotional aspects of sexuality.

This study recognizes its possible limitations. Participants varied in terms of injury level and classification which provided a broad view of the issues that exist for this population. While this approach was valuable for capturing the core experiences of this phenomenon across contexts and identifying factors of particular interest (Patton, 2002), it is possible that the severity of injury may affect one's perspectives of sexuality. However, the themes presented in this paper represent broad social constructs and there appeared to be no notable differences based on injury level or classification. Perspectives were influenced more by time since injury and past experiences (positive or negative). Present findings describe the lived experiences of these particular men at this particular point in time and may not be generalizable to larger populations or other instances in time. Interviews were conducted by the primary researcher who is female, and it may be challenging for men to be forthcoming with information about their sexuality with a researcher of the opposite sex. However, it has been reported that men are equally, if not more likely, to reveal concerns related to body image with a female researcher (Yager, Diedrichs, & Drummond, 2013) and that a female interviewer is generally preferred. Possible explanations may be related to social norms and expectations that women would naturally be more sympathetic (Pollner, 1998) and less critical (Derlega, Winstead, Wong, & Hunter, 1985). Additionally, all of the participants in this study identified as heterosexual and the voices of these particular men may not represent those who identify with other orientations. Future work should consider other sexual preferences.

Men disclosed they had been challenged with overcoming the stereotypes assigned to them by society, as well as their own pre-injury ideas regarding the constructs of sexuality, masculinity, disability and attractiveness. These constructs play a role in one's overall sexual experience, and Potgieter and Khan (2005) concluded that socially constructed attitudes seemed to limit opportunities to express sexuality for individuals living with SCI more than their disability. Men with SCI may be aware of their deviations from societal norms and may benefit from learning to “reject the inflexible, discriminatory conventions rather than themselves” (Potgieter & Khan, 2005). The men in this study developed an adapted understanding of four dominant societal beliefs, moving beyond traditional definitions and embracing new and expanded meanings that were more consistent with life after SCI.

An updated and holistic understanding of how men with SCI describe sexuality is important for the development of relevant information and effective interventions that may have a positive impact on their sexual experiences and contribute to an improved overall QOL.
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The authors declare that there is no conflict of interest.

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Appendices
Appendix A

Interview Guide

Hello and thank you for speaking with me today.

This study involves a demographic questionnaire and a 1 to 1.5 hour in-depth interview. During the interview, we will be discussing sexuality after spinal cord injury. As we talk about sexuality and sexual function, I want you to know that when I use these terms I am referring to anything from the emotional intimacy experienced with a partner to the actual act of sexual intercourse, and everything in between unless specified otherwise.

Your interview will be audio recorded and transcribed verbatim. The audio recording will be used during the analysis process. I will also be taking some notes during the interview to record any information that stands out to me, or topics that I may want to come back to later in the interview. You may look over these notes at the end of the interview if you request to do so.

There are no right or wrong answers to any of the questions that I ask you today. I am here to learn about your own personal thoughts and experiences. During the interview, you may choose not to answer any question(s) that make you uncomfortable, or to terminate your interview at any time for any reason with no consequences whatsoever. I have provided some resources in your information-consent letter of organizations that you can contact should our discussion today evoke any feelings of distress. The information you provide will be kept confidential, and we will be using a pseudonym from this point forward to protect your identity. Can you please think of a name other than your own that you would like to be referred to throughout the remainder of this study?

Do you have any other questions before we begin the interview?

Phenomenological Question: What is the experience of sexuality for men after spinal cord injury?

Interview Questions:

(1) Can you start by telling me a little bit about yourself and your spinal cord injury? (Demographic/Background Question)
   Probe questions:
   (a) How would you describe yourself (personality, character, interests ...)?
   (b) Can you tell me a little bit about your injury (level, classification, circumstances, interpretation of impact on life, generally ...)?
   (c) Tell me about your current relationship status (if separated/divorced what do you think caused the relationship to end? If single is that by preference? Why do you think you are single? If in a relationship that started prior to the injury how has the relationship changed since the injury)?
   (d) Prior to your injury, did you see yourself as a married person with children? And now?
   (e) What challenges do you face when establishing new relationships, both in friendship and romantic contexts?
   (f) How is, or how do you think, dating is different for someone with a SCI? (methods of meeting/dating, additional complications/challenges, qualities you look for in a partner before/after injury)?

(2) What is the meaning of sexuality to you? (Opinion/Value Question)
   Probe Questions:
(a) How is the meaning of sexuality different before versus after your injury?
(b) How did your SCI change or expand what sexuality means to you?
(c) What experiences led to these beliefs (both before and after SCI)? (society?)
(d) What role does sexuality play in your life?

(3) How has your spinal cord injury impacted your sexuality and/or sexual function?

(Experience/Behavior Question)

Probe Questions:

(a) Did you participate in sexual activities prior to your injury (the term “sexual activities” refers to a broad range of activities and does not necessarily mean sexual intercourse)?
   > Any sexual challenges prior to SCI (meaning not related to SCI; examples: medical comorbidity, sexual abuse, emotional issues, performance related issues)
   > Can we talk about what was going on at that time?

(Sexual history assessment questions to separate challenges resulting from SCI from those not related to SCI)

(b) Have you participated in sexual activities since your injury?
   > What types of sexual activities? How do these activities differ from the activities you preferred prior to your injury?
   > More emphasis on psychological/emotional factors? Closeness?
   > How long after SCI before you began participating in sexual activities? Why?

(c) Has your desire or interest in sexuality changed since the injury?
(d) Have there been changes in erection (obtaining, sustaining)?
(e) Have there been changes in your ability to reach orgasm?
(f) How have any of the changes described affected your sexual life? (ex. increased/decreased creativity/sexual exploration, development of new erogenous zones, use of sexual aids: oral medications, topical agents, injections, devices, implants, etc)

(4) Describe a time, after SCI, when you felt sexually satisfied (or describe a situation that would make you feel sexually satisfied)

(Opinion/Value Question)

Probe Questions:

(a) What made it satisfying for you?
(b) Under what conditions would you consider yourself sexually satisfied? (physical? emotional? psychological?)
(c) How satisfied are you with your sexual life?

(5) How would you describe any body issues that you are concerned about when participating in, or thinking about participating in sexual activities?

(Sensory Question)

Probe Questions:

(a) What changes regarding your body have affected your sexual life? (ie: body image, bladder, bowel, spasticity, pain, fatigue, decreased mobility, decreased sensation, skin issues, autonomic dysreflexia …)
(b) To what extent are these issues a concern for you?
(c) To what extent does your fear of these body issues affect your sexuality? to engaging in sexual activities to account for these issues/concerns?
(d) What about preparation for sexual activities? What precautions do you take prior
(e) How does it make you feel when you have to discuss these concerns with your partner? How does this affect the sexual experience?
(f) How are the concerns you have similar or different to the concerns of your partner(s)?
(g) How much disclosure do you feel is appropriate when discussing sex after SCI with a new potential partner?

(6) How has your spinal cord injury affected the way you see yourself? How has this affected
(Opinion/Value Question)
Probe Questions:
(a) How has your SCI affected your self-esteem? Body-esteem? Body image? Sexual confidence? Self confidence?
(b) How do you feel about, or how have you been affected by the societal obsession with “ideal bodies?” (social pressures, attractiveness, non-typical bodies)
(c) How do you think this is different for women with SCI than it is for men with SCI?

(7) Tell me a story about a time or situation when your SCI affected your sexual life.
(Opinion/Value Question)
Probe Questions:
(a) Positive or negative experience?
(b) Describe the worst possible case scenario that has either happened, or could happen to you related to sex after SCI.
(c) Describe the best possible case scenario that has either happened, or could happen to you related to sex after SCI.

(8) As you talk about and reflect on your sexual life after spinal cord injury, what types of feelings and emotions are you experiencing?
(Feeling/Emotion Question)
Probe Questions:
(h) Frustration? Disappointment? Sadness? Longing? Pride? Amazement?
(i) What types of feelings and emotions have you experienced in your sexual relationships?

(9) What resources have you used or accessed (books, pamphlets, videos, support groups) to help with sexual adjustment (sexuality, sexual function) after SCI?
(Knowledge Question)
Probe Questions:
(a) How useful are these resources?
(b) Where did you get them?
(c) When did you access them?
(d) How much information was provided to you regarding sexuality after SCI after your injury?
(e) What was your initial reaction to this information?
(f) What resources are you aware of that you have not used or accessed?
(g) Is the amount of information that is available adequate? What is missing?
(h) How much would you say these resources are targeted towards men? Women?
(i) Do you think there is an optimal time to begin talking about sexuality?
(j) Who would be the ideal person to talk to you about sexual issues after SCI (health care professional, peer, male, female, SCI, able-bodied)?
(k) To what extent are your Doctors/health care providers comfortable discussing sexual function with you?
(l) How comfortable were you asking health care providers questions about your sexual functioning/interventions to help with sexual functioning?
> What were some of the barriers to this conversation?
What were some of the facilitators to this conversation?

- To what extent are your Doctors/health care providers knowledgeable on the topic of male sexual function after SCI?
- Do you think there is a health profession that is more suited than others to address this?

(10) Is there anything that we didn’t talk about today that you would like to discuss now, or is there anything that you would like to add to our conversation?

(Final Question)