

Mindfulness Therapy as a means to improve Sexual Satisfaction in Couples Living  
with Neuromuscular Disabilities

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## *Abstract*

Research regarding sexuality after neuromuscular disabilities has focused on either men or women separately, without considering the couple and how acquiring a disability may influence relationships.

The objective of this study was to investigate the effects of an 8-week modified mindfulness intervention on sexual satisfaction in couples where one or both partners are living with neuromuscular disability.

One couple (male age 42, female age 44) with the female living with neuromuscular disability (relapsing remitting MS, 11 years since diagnosis) participated in the study.

The mindfulness intervention was administered to participants via a booklet and the exercises were explained verbally after the baseline interview. The booklet contained a total of eight mindfulness-based exercises for each week of the intervention. The exercises were explained in a step-by-step manner in the booklet. The booklet also included reflection questions at the end of each exercise in order to prompt the couple to journal about their experiences and record how much time they dedicated to that exercise per week. The exercises were carried out at home.

The intervention also included a psycho-education session that was offered at week five of the intervention. The psycho-education session aimed to challenge thought patterns and negative beliefs about sex and physical abilities. It also involved a discussion about body-image as it relates to mindfulness.

Testing involved a sexual satisfaction questionnaire that was completed by each member of the couple individually at baseline and at the end of the 8-week intervention.

Also, an in-depth semi-structured phenomenological interview of the couple together was conducted at baseline and at the end of the 8-week intervention.

The results of this study showed that sexual satisfaction and sexual-self view have improved for the couple as a result of participating in the 8-week mindfulness intervention. In addition, the couple reported an improvement in communication, understanding, and awareness. Sensate focus exercises enhanced intimacy between the couple. Themes such as acceptance and feeling present in the moment were discerned from phenomenological analysis.

These findings show promise for mindfulness-based therapies to enhance sexual satisfaction and relationship satisfaction in couples living with neuromuscular disabilities.

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## **Chapter 1.0- Introduction**

### ***1.1 Spinal Cord Injury***

Spinal Cord Injury (SCI) is a life-altering event that causes a significant burden to the individuals affected, their families, and society. When the spinal cord is damaged, it results in neurological impairment that affects motor, sensory and autonomic function (Noonan et al., 2012).

Damage to the thoracic, lumbar or sacral spinal cord results in paraplegia while damage to the cervical cord results in tetraplegia (Noonan et al., 2012). Specifically, paraplegia involves loss of motor and/or sensory function in the thoracic, lumbar or sacral parts of the spinal cord with arm function still intact while, depending on the level of injury, the pelvic organs, trunk, and legs may be affected (Marino et al., 2003). Tetraplegia involves impairment of motor/sensory function in the cervical part of the spinal cord resulting in loss of function in the arms, legs, as well as the trunk and pelvic organs (Marino et al., 2003). SCI can be divided into two main types: Traumatic Spinal Cord Injury (TSCI) and Non-Traumatic Spinal Cord Injury (NTSCI).

In most cases, TSCI occurs due to external causes, such as a motor vehicle accident, fall or violence (Noonan et al., 2012). It has been reported that the incidence of TSCI ranges from 10 to 83 people per million worldwide (Noonan et al., 2012). The few studies that have examined the prevalence of TSCI have reported an estimation that ranges between 223 and 755 per million worldwide (Noonan et al., 2012).

Most of the research done on the epidemiology of NTSCI has been done in Australia (Noonan et al., 2012). NTSCI is known to occur due to spondylosis, infections or tumours (Noonan et al., 2012). In general, studies have reported that individuals with NTSCI are more

likely to be older females, have more comorbidities, and present more frequently with paraplegia compared to tetraplegia (Noonan et al., 2012). Considering the increasing incidence of NTSCI with age and Canada's aging population, it is concluded that NTSCI will be increasing demands on the Canadian health care system in the future (Noonan et al., 2012).

### ***1.1.1 Spinal Cord Injury and Quality of life***

Individuals often have multiple perspectives on what quality of life (QOL) means. Some focus on material possessions, others emphasize the functioning and integrity of the body, others focus on the quantity and quality of interpersonal relationships and some again focus on mental and spiritual well-being and life satisfaction (Dijkers, 1997). From a holistic standpoint, it is safe to state that QOL constitutes all those aspects mentioned above. SCI potentially affects an individual's ability to earn an income, the ability to become a parent, and the ability to develop a romantic, long-term relationship, or a close and supportive network of friends (Dijkers, 1997).

Furthermore, SCI may negatively impact an individual's body image, self-concept and one's understanding of self, directly or indirectly (Dijkers, 1997). In a meta-analysis by Dijkers (1997), individuals with SCI reported a lower level of subjective well-being, on average, compared to the population at large. In other words, the results of the meta-analysis demonstrated that the average person living with SCI experiences a lower QOL compared to the average person living without an injury (Dijkers, 1997). However, when resources (such as medical rehabilitation) are readily available, help with coping and adjustment, and a supportive network of friends and family, and given that public policies and environmental and social barriers do not prevent the injured person from pursuing work, education, leisure activities and other duties, the quality of life of an individual with SCI can be very similar to that of an average person who is not disabled. Some research even shows that certain individuals can experience a

higher quality of life post-injury compared to pre-injury or compared to individuals living without an injury (Dijkers, 1997).

It was concluded that it is critical to know and understand the factors that contribute most to the subjective well-being of individuals with SCI since it may help policy makers in selecting appropriate interventions that support and maximize quality of life per dollar invested. In a similar manner, knowing what factors contribute to quality of life may increase the awareness of service providers about interindividual variations and the impact of social variables, such as race, ethnic group and generation on these factors. Therefore, the perspective of individuals living with SCI should be used as a guide to where resources can be utilized in the most effective manner, since their perspective is the only perspective that matters (Dijkers, 1997).

Rehabilitation research often focuses exclusively on the consequences of SCI, while ignoring its significant impact on the individual as a member of society (Hammell, 2007). In fact, it has been shown that stigma, social norms and notions of competence and social worth can impact the sense of self for individuals living with spinal cord injury (Hammell, 2007). For example, there are many existing myths in society that claim that individuals with spinal cord injury are 'asexual' and can no longer enjoy being sexual due to their physical disability, which can be extremely harmful to the sense of self of the injured individuals. Accordingly, a recent meta-synthesis showed that individuals who adjust well after acquiring a spinal cord injury are those who redefine their values, expand the range of activities that they cherish and reduce the emphasis on physique as a reflection of self-worth (Hammell, 2007). In the domain of sexual satisfaction, this notion can be highly beneficial to individuals living with spinal cord injury by empowering them to expand their views on sexuality and what their bodies are capable of doing.

A successful rehabilitation program for individuals with neuromuscular disabilities requires a holistic approach that includes the individuals' physical, psychological and interpersonal circumstances. Thus, a critical component of rehabilitation is sexual rehabilitation for men and women with SCI. Men and women continue to be sexually active after their injury and report experiencing less satisfaction which leads to a decrease in their quality of life. Since sexual functioning is a fundamental aspect of well-being and health, sexuality after acquiring a neuromuscular disability needs to be given the same attention and consideration as other important areas. Furthermore, sexuality needs to be addressed in all rehabilitation centres and spinal units. Finally, a more holistic approach to sexuality that includes psychosocial aspects of sexuality in addition to physical aspects is needed in order for individuals with neuromuscular disabilities such as SCI to experience richer and more satisfying sexual encounters after the injury which will likely lead to an overall increase in their sexual satisfaction which can directly influence their quality of life in a positive manner.

Early research has determined that a successful sexual rehabilitation program drastically influences the overall rehabilitation outcome for individuals with SCI (Lindner, 1953). Sexual dysfunction in both able-bodied and individuals with SCI has a negative effect on QOL and interpersonal relationships (Reitz, Tobe, Knapp, & Schurch, 2004).

### ***1.2 Multiple Sclerosis***

Multiple Sclerosis (MS) is a chronic inflammatory disease that is characterized by the demyelination of the central nervous system. MS is considered the most common cause of nontraumatic disability in young adults (Wingerchuk, Lucchinetti, & Noseworthy, 2001). According to the Canadian Institute of Health Information (2007), MS is a highly variable and

unpredictable disease that puts a burden on patients, their families, healthcare systems, and societies.

A systematic review by Poppe, Wolfson, & Zhu (2008) stated that the cause of MS remains unknown. However, it appears to be associated with environmental exposures and certain genetic factors (Poppe et al., 2008). MS prevalence is known to be high in Canada with recent estimates ranging between 55 and 240 per 100,000 (Beck et al., 2005). MS usually presents in young adulthood and it has been reported that incidence is between one and a half and three times higher in women than men (Somerset, Sharp & Campbell, 2002). The level of disability correlated with MS as well as the clinical course, the signs, and symptoms are extremely variable (Thompson & Hobart, 1998). Symptoms of MS may include bladder dysfunction, spasticity, cognitive problems, and fatigue (Somerset et al., 2002). In addition, the clinical course of MS is unpredictable, ranging between 10-30 years in general. During that time, neurological disability tends to accumulate at a changing rate (Somerset et al., 2002).

### ***1.2.1 Multiple Sclerosis and Quality of Life***

Individuals living with MS live with many unmet needs. Depression is highly prevalent among individuals living with MS and is correlated with increased suicide rates compared to individuals living with other chronic illnesses (Scott et al., 1996)

Shnek et al. (1997) suggests that psychological difficulties occur as a result of the uncertainty associated with the course of MS, while a qualitative investigation by Somerset et al (2002) emphasized the importance of personal control as one of many psychological and emotional requirements for successful adaptation to living with MS.

Building a partnership with the person living with MS, healthcare professionals and loved ones may be able to aid the person who has MS to build a higher sense of control and personal

autonomy which has the potential to enhance quality of life in individuals living with MS (Somerset et al., 2002).

### ***1.3 Mindfulness***

Mindfulness was introduced to Western medicine by Jon Kabat-Zinn, a molecular biologist who applied mindfulness to people living with chronic pain (Brotto, 2018). Clinical studies that were conducted by Kabat-Zinn found that chronic pain patients who took part in an eight-week Mindfulness-Based Stress Reduction (MBSR) program reported a significant improvement in their pain symptoms and a significant improvement in their quality of life. The effects of mindfulness on chronic pain and quality of life of those patients lasted even up to four years after the initial completion of this training (Kabat-Zinn, 1982; Kabat-Zinn et al., 1985). In addition, mindfulness has been shown to improve symptoms of anxiety and depression across a comparably broad range of severity (Hofmann, Sawyer, Witt, & Oh, 2010).

Furthermore, mindfulness was correlated with increased relationship satisfaction (Kozlowski, 2013). Mindfulness training was found to improve physiological responses to sexual stimuli, physical awareness during sexual arousal, and attention (Silverstein, Brown, Roth, & Britton, 2011). Women who participated in a mindfulness-based psychoeducational intervention reported an increase in sexual desire, orgasm during sex, sexual arousal, sexual satisfaction, decrease in sexual distress, and an overall improvement in psychological well-being (Brotto et al., 2008; Brotto & Heiman, 2007).

Mindfulness is defined as the practice of observing what is happening inside of us and of being kind to ourselves in the present moment, even when it is difficult to do so (Brotto, 2018). Applying mindfulness to sexuality means encouraging individuals to pay attention, in a nonjudgmental manner, to their bodies, their assumptions about sex, and feelings related to sex

(Brotto, 2018). In fact, the fundamental aspect of mindfulness is nonjudgment. Mindfulness has been shown to ameliorate judgmental attention and, in turn, judgmental attention ameliorates sexual well-being (Brotto, 2018; Brotto et al., 2012).

Mindfulness represents a holistic treatment for sexual difficulties because of its gentleness. Thus, mindfulness encourages individuals to observe the effect of past traumatic experiences then letting them go. Paradoxically, mindfulness promotes change by not trying to change (Brotto, 2018).

Sensate Focus exercises, a widely used tool in sex therapy, were created by sex researchers Masters and Johnson (1970). Sensate focus is a direct application of mindfulness since it incorporates many aspects of mindfulness including paying attention to sensations in the present moment and refraining from judging one's own or one's partner's performance during sexual activity.

## **Chapter 2.0-Literature Review**

### ***2.1 Effect of Spinal Cord Injury on the sense of self***

The results of a meta-synthesis conducted by Hammell (2007), indicated that quality of life after SCI was related to perceived social support, accessibility of the physical environment, accessibility to healthcare, having sufficient income, being integrated in society, perceived control over one's life, feeling satisfied with relationships, participating in the community and being engaged in an occupation of choice. The results also showed that low life satisfaction is related to pain, experiencing spasticity, pressure sores, insufficient income, decreased mobility, feelings of boredom, perceptions of having decreased control over one's life, and feeling dissatisfied with one's occupation (Hammell, 2007).

Moreover, the findings of this meta-synthesis showed a correlation between perception of self-worth and the engagement in meaningful occupations for spinal cord injured individuals. The researchers argued that for most individuals, life with an able body is taken for granted before the injury. As a result, SCI seems to be experienced not only as a physical disability, but with significant changes and frustrations that disrupts life in a major manner which leads individuals to feel a significant amount of loss because their values, careers, daily activities and life plans have been disrupted (Hamell, 2007). This is referred to as 'Biographical disruption', which is comprised of three dimensions that include the body, conception of self, and time. This suggests that a spinal cord injury that results in an inability to perform daily activities that are perceived to be valuable by the individuals may lead those individuals to experience loss of certain aspects of themselves such as perceptions of competence and self-worth (Hammell, 2007). The results demonstrated recurrent findings that pertain to the relationship of the body to the self. Thus, individuals that were preoccupied with physical dysfunction as a result of spinal cord injury reported an overwhelming sense of loss since the disabled body represents a flawed sense of self to those individuals (Hammell, 2007).

As a result, it was theorized that restoration of the sense of self-worth may be critical to the experience of a life worth living. The findings of this qualitative meta-synthesis demonstrated that when individuals used their time in ways that they found meaningful and when they perceived themselves to be competent in what they do, their own sense of self-worth was enhanced. It was concluded that there appears to be a relationship between a sense of 'I can' and a sense of who 'I am' (Hammell, 2007). That is aligned with the finding that individuals with SCI defined the purpose of the rehabilitation process as the reintegration of the self (Lucke, 1997). The results of the meta-synthesis showed the importance of reshaping one's biography

after an injury in terms of priorities and values and working to achieve a sense of continuity between life before the injury and life after the injury through imagining a purposeful and productive future and promoting important relationships (Hammell, 2007). In fact, the need for the sense of continuity or connecting an individual's present and future lives to an individual's past life, before the individual was affected by the injury, has been a recurrent research finding (Spencer, 1989; Spencer, Young, Rintala, & Bates, 1995; Quigley, 1995). As a result, it has been suggested that the idea of continuity may provide a more valuable tool for rehabilitation compared to the traditional process of rehabilitation which emphasizes the concepts of loss and change. This will allow individuals to be aware that there are many important areas of their lives that have been unaffected by the injury (Hammell, 2007).

## ***2.2 Effect of Spinal Cord Injury on Sexuality***

Sexuality following SCI is a significant topic that has recently received increased attention. Most rehabilitation centres offer sexual education and counselling sessions as a part of SCI treatment routine (Alexander, Sipski, & Findley, 1993). Early research has focused primarily on fertility and male's erectile function (Alexander et al., 1993). Over the last two decades, there has been an increased emphasis on the psychosocial aspects of sexuality for men and women such as the frequency and types of sexual activity. However, it has been pointed out that the quality of sexual experiences after SCI has received less attention (Alexander et al., 1993).

### ***2.2.1 Sexuality for men after Spinal Cord Injury***

In a study by Alexander et al. (1993), it was suggested that following SCI, men generally returned to sexual involvement within 12 months. However, the frequency of sexual activity decreases dramatically after SCI. Interestingly, the results indicated that the frequency of sexual activity post-injury is correlated with the partner's desire for sex, compared to the frequency of

sexual activity pre-injury, which is correlated with both the man and his partner's desire. Furthermore, it was demonstrated that frequency of sexual activity does not appear to be related to the level and severity of the injury (Alexander et al., 1993). The findings of this study emphasized the challenges that men with spinal cord injuries face in meeting available partners who desire to have a sexual relationship with them. It has been shown that barriers related to architecture, social skills, transportation difficulties, job status, and self-esteem all play a significant role in the ability of the spinal cord injured individual to meet potential partners (Alexander et al., 1993). In addition to the dramatic decrease in sexual activity following injury, the results indicated that there is also a significant decrease in the enjoyment of penis-vagina intercourse while there is an increase in sexual activities that are related to areas above the level of the injury. It was speculated that this might be due to the difficulty that spinal cord injured men find in achieving and maintaining erections long enough for intercourse (Alexander et al., 1993). This emphasizes the importance of the willingness of the spinal cord injured individual to engage in a variety of sexual expressions other non-coital sexual experiences.

The results of the study further demonstrated that sexual satisfaction is decreased as a result of SCI. It has been reported that pre-injury, two factors were related to sexual satisfaction: frequency of sexual activity and the partner's perceived desire for sex (Alexander et al., 1993). However, both factors, as perceived by the spinal cord injured individual, are both decreased following SCI (Alexander et al., 1993).

It was concluded that since intercourse is the sexual activity that is most impacted by SCI, methods that aim to improve SCI persons' abilities to engage in intercourse such as vacuum and injection techniques should be readily available, in order to improve sexual satisfaction in this population (Alexander et al., 1993). Since Viagra (Sildenafil Citrate) was approved as a

treatment for erectile dysfunction (ED) in Canada in the year 1999, various studies have examined the effects of Viagra on treating ED in men with SCI. The existing data suggests that Viagra is an efficacious and well-tolerated treatment for ED in men with SCI (Derry, Hultling, Seftel, & Sipski, 2002). In fact, 94% of the men reported improved erections as a result of using Viagra and 72% of intercourse attempts were successful (Derry et al., 2002). In addition, it was concluded that it is important for individuals with SCI to receive sexual education and counselling post-injury when they are able to process the information effectively. Finally, it is important for spinal cord injured individuals to expand their personal definition of sexuality by engaging and finding pleasure in a variety of sexual activities other than penis-vagina intercourse (Alexander et al., 1993).

A study by Phelps et al. (2001) investigated factors that predicted sexual satisfaction in married or partnered men with SCI. The study also aimed to explore the sexual functioning, sexual activities and needs of this group of men with SCI. The findings of this study suggested that relationship factors such as satisfaction with the relationship, enjoyment of sex, and sexual satisfaction had a strong influence on the sexual lives of married or partnered men with SCI. Furthermore, sexual behaviour and satisfaction of men with SCI were significantly influenced by their partner's sexual satisfaction, satisfaction with the relationship and their level of sexual desire. In fact, it has been shown that perceived partner satisfaction with the sexual relationship is the strongest predictor of sexual adjustment in partnered men with SCI (Phelps et al., 2001). On the other hand, men with SCI who perceived that their partners were not satisfied with their sexual relationship reported a decrease in sexual activity and a decrease in sexual satisfaction (Phelps et al., 2001). Moreover, the findings of this study indicated that men with SCI are highly interested in learning how they can provide pleasure for their partner. It has been noted that the

ability to please and satisfy a partner sexually, in addition to feelings of intimacy and closeness, contribute to the sexual satisfaction of men with SCI (Phelps et al., 2001).

It has also been noted that failing to satisfy a partner was rated by men with SCI as the most important of 17 possible concerns about sexual activity and function following their injury (Phelps et al., 2001). On that note, it was concluded that providing education on different methods to sexually satisfy a partner will likely be well received by most men with SCI and may increase their sexual satisfaction, which in turn may improve their quality of life (Phelps et al., 2001).

It has also been shown that the sexual fulfillment of men with SCI is more influenced by the amount of emotional closeness in their relationship, mutual concern and a wide range of sexual activities than by physiological factors, such as erectile function or orgasmic and ejaculatory function (Phelps et al., 2001). Interestingly, the findings of this study indicated that for men with SCI in long-term relationships, sexual satisfaction does not appear to be so dependent on physiological factors. Therefore, sexual satisfaction, enjoyment, and behaviour of men with SCI in long-term relationships/marriages is strongly correlated with the quality of the relationship and the partner's sexual satisfaction, as opposed to only physiological parameters. On the other hand, it appears that sexual satisfaction in the beginning stages of relationships might be more significantly influenced by the capacity to orgasm, erectile function, and genital sensation (Phelps et al., 2001). As such, when men with SCI in long-term relationships or marriages present with sexual difficulties, it is important for medical providers to focus less on physiological factors and start exploring other potential factors that affect sexual satisfaction such as sexual desire, relationship satisfaction, and perceived partner satisfaction (Phelps et al., 2001). In fact, it was suggested that men with SCI should be provided with relationship

counselling, not only as a way to evaluate and treat relationship/marital issues, but to improve their sexual satisfaction as well (Phelps et al., 2001).

Based on the findings and the results of this study, it was concluded that when treating and assessing sexual difficulties in partnered men with SCI, clinicians are encouraged to assess sexual desire, perceived partner satisfaction, and the ability to please a partner. Clinicians are also encouraged to assess and provide education about non-intercourse forms of sexual activities (Phelps et al., 2001).

### ***2.2.2 Sexuality for women after Spinal Cord Injury***

In a study by Sipski & Alexander (1993), the effects of SCI on various domains of sexuality and sexual adjustment were evaluated in women. The results of the study indicated that sexual satisfaction decreased significantly following SCI, while sexual desire did not decrease after SCI. It was found that sexual desire was correlated with the ability to be aroused following SCI (Sipski & Alexander, 1993).

Furthermore, there was no relationship between the level and severity of injury and the type of sexual activities the women participated in. In fact, there was no significant change in preferences and the types of sexual activities post-SCI compared to pre-SCI (Sipski & Alexander, 1993). Women's self-reports of their ability to lubricate have demonstrated only a weak relationship with the type of injury. It was speculated that this may be due to inherent difficulties in the women's ability to distinguish if they can lubricate and the quality of their lubrication (Sipski & Alexander, 1993). Moreover, the ability of women to achieve an orgasm was not correlated to the type of injury. In fact, women with complete and incomplete SCI reported the ability to achieve orgasm (Sipski & Alexander, 1993). It is important to note that the physiological responses of these women during orgasm are unknown. Thus, it was suggested that

laboratory-based physiological studies are needed to understand the effects of SCI on the sexual response cycle in women. Specifically, correlates of the sexual response cycle and orgasm such as blood pressure, respiratory rate, heart rate, lubrication, and perineal and lower extremity contractions need further examination (Sipski & Alexander, 1993). Some women reported experiencing autonomic dysreflexia during intercourse in this study. This could prevent women living with SCI from enjoyment of sexual activity or achievement of orgasm. Thus, it was also suggested that the frequency of autonomic dysreflexia should be monitored in future laboratory-based studies. Future studies should consider prophylactic techniques for dysreflexia, such as the use of nitropaste before sexual activity begins (Sipski & Alexander, 1993).

A cross-sectional, mail back questionnaire study by Kreuter et al. (2011) demonstrated that most women continue to be sexually active after SCI. 392 responded to the questionnaires across Sweden, Denmark, Norway, Finland, and Iceland. The women also considered sex to be an important part of their lives. The findings of the study indicated that women experienced changes in their sexual functioning that are both of physical and psychological in nature. Physical changes as a result of SCI include lost or decreased sensations, challenges in achieving orgasms, and challenges in positioning oneself during sex (Cramp et al., 2015). In addition, the women in this study reported decreased frequency of sexual activity, as mentioned earlier. They also reported that bowel and bladder problems, pain, and other unpleasant feelings have negatively impacted their willingness to participate in sexual activity (Cramp et al., 2015). The psychological changes include feeling less attractive or feeling unattractive, decreased self-confidence, and challenges in meeting a suitable partner (Cramp et al., 2015). The women also reported that they were concerned about their ability to satisfy their partners, to cope emotionally with the changes in sexual functioning, and to help their partners cope with their sexual

limitations post-injury (Ferreiro et al., 2005). When the women were asked about what they did to compensate for the loss or decreased genital sensation, they emphasized that hugging, kissing, and caressing different body parts (including body parts with no sensation) were critical parts in enjoying their sexual experience post-injury. The women also stated that they used fantasies and memories to enhance their sexual experiences with their partners post-injury (Sipski et al., 2009).

Furthermore, the women in the study emphasized the importance of psychological satisfaction in the sexual experience, especially when physiological orgasm wasn't possible for some women to experience. Indeed, many women reported that orgasm was less intense and required a longer period of time to be achieved after the injury (Kreuter et al., 2011). This likely explains the reason why many women in the study have expressed that being shown love, closeness, romance, and warm feelings as well as feeling their partners' understanding, consideration and support were critical steps on the journey of enjoying their sexual interactions after the injury (Kreuter et al., 2011).

The women also reported that bowel and/or urinary incontinence were sources of great anxiety when it came to enjoying sexual activities post-injury (Charliefue, 1992; Jackson & Wadley, 1999; Westgren et al., 1997; Cramp et al., 2015). A bowel or bladder accident can occur and can be extremely embarrassing if it happens during sexual activity, as reported by the women in the study (Kreuter et al., 2011). The women reported taking preventative measures in order to avoid accidents during sexual activity such as emptying the bladder or bag beforehand and taping the catheter to the stomach or thigh (Kreuter et al., 2011). The women emphasized the importance of discussing those issues and anxieties with their partners and openly sharing their fears and needs. The women also emphasized the importance of having partners that were able to

react with understanding and consideration, as opposed to reacting with irritation and frustration, when an accident had indeed occurred (Kreuter et al., 2011).

Furthermore, urinary incontinence has been found to negatively affect various aspects of a woman's sexuality such as sexual desire, orgasm, and types of sexual activities (Cramp et al., 2015). Women usually experience embarrassment and negative, unpleasant feelings as a result of urinary incontinence which results in reduced sexual desire (Cramp et al., 2015). In addition, urinary incontinence influences the types of sexual activities that a woman participates in after SCI, since certain positions, movements, and even orgasm itself could potentially trigger urinary incontinence (Serati, Salvatore, Uccella, Nappi, & Bolis, 2009). Women with hypotonic bladders may abstain from sexual positions that could potentially place pressure on the bladder which, in turn, can result in leakage (Cramp et al., 2015). Some women with SCI may even avoid receiving oral sex because they are concerned about experiencing urinary incontinence during the experience, since the sensations felt before an upcoming orgasm are similar to the ones felt before urinary incontinence occurs (Cramp et al., 2015). Thus, urinary incontinence may negatively affect body image, sexual confidence of women, sexual quality of life, women's self-esteem, relationships, and sexual satisfaction, which may result in detrimental effects on QOL (Cramp et al., 2015).

Knowing what strategies women use to compensate for their physical impairment and loss and/or decreased genital sensations can assist in the sexual rehabilitation process by helping professionals in developing rehabilitation programs for women with SCI.

### ***2.3 Sexuality after Multiple Sclerosis***

Sexual problems in multiple sclerosis can emerge from primary, secondary, or tertiary sources. Primary sexual dysfunction is caused by physiological impairments directly due to the

demyelination of the lesions in the spinal cord and/or brain in MS (Foley et al., 2001). Symptoms of primary sexual dysfunction may include loss of vaginal lubrication in women, erectile dysfunction in men, and numbness in the genitals in both men and women (Foley et al., 2001).

Secondary sexual dysfunction is caused by non-sexual physical changes that resulted from the disorder, which nevertheless influence the sexual response such as pain, fatigue, spasticity, bladder and bowel dysfunction. Tertiary sexual dysfunction refers to psychological and cultural issues that result from living with MS and that interfere with sexual satisfaction, sexual performance, and how one feels about themselves as a sexual being. These psychological factors include interpersonal or communication difficulties, low self-esteem, and demoralization (Foley et al., 2001).

Valleroy and Kraft (1984) found that the most common sexual symptoms in women living with MS were fatigue, decreased libido, decreased sensation, difficulty with arousal, decreased frequency of orgasm and/or total loss of orgasm. On the other hand, the most commonly reported sexual problem in men was erectile dysfunction (Valleroy & Kraft, 1984).

Regarding the effects of MS on other aspects of intimacy such as marital communication and satisfaction, a study by Foley et al. (2001) found that counselling may improve sexual satisfaction, marital satisfaction, and problem-solving communication in individuals living with MS and their partners. These findings were deemed encouraging since issues with sexuality and intimacy are highly prevailing symptoms that negatively affect quality of life in individuals living with MS (Foley et al., 2001).

#### ***2.4 Definition and history of mindfulness***

Mindfulness has its origins in Buddhism with a history of around 3,500 years. The tradition of Buddhism began with the teachings of a man by the name of Siddhartha Gautama.

Gautama was later known as the “Buddha”, which means the “awakened one” (Kang & Whittingham, 2010).

Within the Buddhist traditions, mindfulness can be defined as “nonreactive, nonelaborative, non-refined awareness that has meta-cognitive functions, monitoring ongoing awareness and discriminating wisely between aspects of awareness content so that awareness and behaviour can be directed towards the goals of genuine happiness, virtue and truth” (Kang & Whittingham, 2010). Thus, mindfulness encourages paying attention to the present moment experience, sustaining attention on a familiar, factually consistent and positively viewed object or on systemic recollection of constructive ideas, in a way that is willingly generated or spontaneously emergent (Kang & Whittingham, 2010). In literature outside the Buddhist traditions, mindfulness has been defined as “non-judgmental, present-moment awareness and is comprised of two components: (1) self-regulation of attention so that there is focus on the current experience, and (2) adoption of a curious, open and accepting orientation to the present”. (Brotto et al., 2012).

## ***2.5 The use of mindfulness to treat a variety of disorders***

### ***2.5.1 Pain***

Mindfulness meditation has been found to ameliorate a variety of negative cognitive and health outcomes such as anxiety, depression, and stress. The health benefits related to mindfulness training are associated with improvements in cognitive control, emotion regulation, positive mood, and acceptance, each of which have also been associated with pain modulation (Zeidan et al., 2012). Since a variety of chronic conditions are associated with the experience of pain, Zeidan et al (2012) were interested in exploring the effects of meditation practice on pain. Using electroencephalography (EEG) and noxious laser stimulation, they found that greater

meditation experience was associated with lower pain unpleasantness ratings. In fact, when researchers compared the meditation group to controls, the meditation group demonstrated smaller anticipation evoked potentials in the right inferior parietal cortex and mid-cingulate, which indicates less anticipation to the noxious stimuli (Brown & Jones, 2011). It is important to note that in that study, the meditation group was not formally meditating (which means that those participants did not practice meditation outside of the study as a part of their daily life). That suggests that meditation practitioners have experienced persistent changes that allow them to process nociceptive information in a unique manner (Zeidan et al., 2012). The researchers posited that pain reduction related to mindfulness meditation is associated with increased cognitive and emotional control (which was demonstrated by the activation of the anterior cingulate cortex/ Ventromedial prefrontal cortex) produced by cultivating an attitude of acceptance towards impending stimuli (Zeidan et al., 2012).

Furthermore, Grant et al. (2011) explored the brain mechanisms involved in pain reduction related to mindfulness, using functional and structural MRI. Their results demonstrated that the meditators had a mental state where they were fully attentive to the sensory properties of the stimuli (which was showed by highly activated pain areas) but simultaneously, meditators were able to inhibit appraisal, elaboration and emotional reactivity (Grant et al., 2011). In that study, researchers found that there were structural regional differences between those who had meditation experience and those who did not. Researchers concluded that meditative practices have long lasting changes on the brain. In this review by Zeidan et al. (2012), researchers concluded that mindfulness meditation changed the contextual evaluation of pain, but it is likely that mindfulness meditation does so dynamically over time and experience. Thus, beginners

reappraise events while the most advanced practitioners may refrain from elaboration/appraisal entirely.

### ***2.5.2 Anxiety and Depression***

Mindfulness has been shown to be an effective treatment for anxiety and depression. A meta-analytic review by Hofmann et al (2010) revealed that patients with anxiety disorders and depression who have undergone Mindfulness-Based Therapy (MBT) have shown drastic improvements with large effect sizes (Hedges's  $g$ ) of 0.97 for improving anxiety and 0.95 for improving depression. Moreover, the results of the meta-analytic review have shown that for individuals with disorders other than anxiety and depression, but who had elevated symptoms of anxiety and depression, MBT was moderately strong at improving symptoms of anxiety (with an effect size of 0.67) and improving symptoms of depression (with an effect size of 0.53). The researchers that conducted the meta-analytic review posited, based on the results, that MBT improves symptoms of anxiety and depression across a wide range of severity, even when those symptoms are present as a result of other conditions, such as medical problems. Hofmann et al. (2010) speculated that MBT appears to be associated with a general reduction in stress, probably by encouraging patients to alter their perspectives about their physical symptoms so that when they occur, their consequences are less disturbing. It was concluded that while MBT may not be diagnosis-specific, it may target processes that occur in various disorders by altering a range of emotional and evaluative dimensions that underlie general aspects of well-being (Hofmann et al., 2010).

## ***2.6 Mindfulness Interventions for sexual dysfunction***

### ***2.6.1 Interventions for women who have survived Cervical and Endometrial cancer***

Since mindfulness has proven to be effective in improving chronic pain and symptoms of anxiety and depression, researchers were interested in exploring the effects of mindfulness on sexuality. However, while the effects of mindfulness on a variety of medical conditions have been the topic of multiple studies and meta-analytic reviews, the effects of mindfulness on sexuality are still novel and uncommon in the sexuality literature. The few studies that have examined the efficacy of mindfulness in treating sexual dysfunction and improving sexual function have shown promising results. In fact, mindfulness has been shown to be effective in treating sexual dysfunction in different populations. Brotto et al. (2012) explored the effectiveness of a 3-session mindfulness-based cognitive behavioral therapy intervention on female survivors of cervical or endometrial cancer who suffered from low sexual desire/arousal compared to a control group. Eligible participants randomly assigned to participate either in the immediate treatment group (T1) who received the mindfulness intervention right away or the wait-list control group (T0) who waited three months before receiving the mindfulness intervention (Brotto et al., 2012). The first session of the intervention aimed to educate women on causes of sexual difficulties, especially after cancer with a focus on sexual beliefs, body image and introductory mindfulness exercises. The women were also given mindfulness exercises to practice at home. The second session of the intervention aimed to educate the women on the relationship between mindfulness, body image, and sexuality in addition to some mindfulness exercises that were done during the second session. The third session of the intervention aimed to educate women on sensate focus exercises, the relationship between

mindfulness, sexuality, and relationship satisfaction. The women were also taught how to incorporate mindfulness into various sexual exercises (Brotto et al., 2012).

The results of the study suggest that the 3-session mindfulness-based intervention resulted in significant improvements in a variety of domains of sexual functioning which include desire, arousal, lubrication, orgasm and satisfaction (Brotto et al., 2012). The mindfulness-based intervention was also successful in improving overall sexual functioning and symptoms of sexual distress. The authors noted that these improvements were retained six months post-intervention, which suggests that the changes induced by this brief mindfulness intervention are long-lasting (Brotto et al., 2012). Furthermore, in this study, physiological sexual arousal (i.e., vaginal pulse amplitude) was measured in the laboratory setting pre-and post the intervention. The authors noted that physiological sexual arousal did not significantly change post-treatment. On the other hand, the mindfulness-based intervention led to a significant increase in women's perception of their genital arousal and they were significantly more likely to notice signs of lubrication and genital throbbing when they were exposed to erotic stimuli, compared to before the intervention (Brotto et al., 2012). According to the authors, the main goal of including this physiological measure of sexual arousal was to investigate the extent to which the mindfulness-based intervention was able to improve physical events associated with sex versus the women's ability to notice these physical signs of arousal.

The authors posited that since the mindfulness-based intervention increased women's perception of genital arousal, this suggests that an improvement in attentional focus was responsible for the increased perception of sexual arousal as a direct consequence of the mindfulness skills that the women learned during the intervention. Therefore, the intervention emphasized 'paying attention' to one's physiological sensations (Brotto et al., 2012). The fact

that women's perception of sexual arousal increased despite the absence of change in actual genital arousal suggests that the mechanisms through which mindfulness works involves cognitive/emotional change as opposed to direct physiological change (Brotto et al., 2012).

Furthermore, individuals who experience sexual difficulties tend to catastrophize their difficulties, experience a heightened attention to dysfunction, and judgmental or other negative thoughts about their sexual experience. In the case of cervical and endometrial cancer survivors, they often experience threats to their self-identity, negative reactions from their partners, body image changes, fear of recurrence of cancer symptoms, and negative sexual self-image (Nobre & Gouveia, 2006). All these experiences interact with medical factors, which impacts their sexual functioning (Brotto et al., 2012). Mindfulness appears to be ideal to manage these difficulties because its main purpose is to permanently reduce the habitual attachment to mental proliferation by teaching women to pay attention to their body's sensations in a present-moment, non-judgmental manner (Brotto et al., 2012).

### ***2.6.2 Interventions for women with Spinal Cord Injury (SCI) and Multiple Sclerosis (MS)***

Individuals with a neurological disability such as Multiple Sclerosis (MS) and Spinal Cord Injury (SCI) experience a variety of sexual difficulties, which leads to a decrease in their quality of life. Despite the fact that sexual difficulties and the importance of sexual health for individuals with SCI and MS is well documented in the literature, there are surprisingly few intervention studies that address those sexual difficulties (Hocaloski et al., 2016), and a literature review has shown that there are no mindfulness-based interventions that are designed to target the sexual difficulties experienced by men or couples with SCI or MS.

On the other hand, a recent study by Hocaloski et al (2016) offered an intervention tool for women with MS and SCI. The intervention included cognitive behavioral therapy,

mindfulness-based skills, and education and it was originally developed and found to be effective for female cancer survivors as well as a more general population of women who experienced sexual difficulties (Hocaloski et al., 2016). The authors mentioned that the existing intervention tool was modified in certain ways to match the needs of women with SCI and MS. Specifically, the modified intervention included information regarding how common sexual difficulties are in MS and SCI populations, body-mapping exercises, sensate focus or body exploration exercises, a description of female internal reproductive anatomy, and finally, a mindfulness practice of ‘observing judgments’ was added to the existing intervention (Hocaloski et al., 2016). Since women with disabilities tend to have a negative body image and sexual self-view (which refers to how a person views themselves as a sexual being in light of their disability), this exercise of ‘observing judgments’ was meant to provide women with the opportunity to become aware of the impact of negative self-talk on their own sexual self-view (Hocaloski et al., 2016).

The results of the study have demonstrated that the mindfulness-based skills that were part of the intervention have led women to become significantly less judgmental of their own inner experiences (Hocaloski et al., 2016). Therefore, as a result of the mindfulness-based skills, women were less likely to place judgments upon their thoughts and feelings after the intervention compared to before the intervention.

These results suggest that mindfulness appears to be a critical part of a woman’s experience of her sexuality (Hocaloski et al., 2016). Furthermore, the authors noted that this mindfulness-based intervention may have contributed to the process of adjustment to a disability and establishing a more positive sexual self-view. Thus, it appears that the value of this mindfulness-based intervention for women living with MS and SCI lies in its potential to improve sexual self-view (which has a positive effect on self-acceptance) and increase quality of

life rather than as a treatment for sexual dysfunction that resulted directly or indirectly from the disability or illness (Hocaloski et al., 2016).

Additional studies have been conducted in order to examine what mechanisms explain the efficacy of mindfulness in improving sexual dysfunction and distress in a variety of populations.

## ***2.7 Mechanisms that may underlie the efficacy of mindfulness in studies of sexual (Dys)function***

A review by Arora and Brotto (2017) regarding mindfulness and sexuality has included publications that focused on individuals with sex-related difficulties (such as low sexual desire/arousal), in addition to a review on mechanisms in other populations such as women with gynecologic cancer, multiple sclerosis and spinal cord injury. It is important to note that the literature review conducted by Arora and Brotto (2017) has included studies investigating the mechanisms of mindfulness in other populations, such as individuals who suffer from depression, anxiety, or chronic pain, as a means to identify mechanisms that might apply to individuals living with sexual dysfunction. When the authors combined studies that specifically recruited samples with a sex-related difficulty, they found that certain variables appeared as possible mechanisms by which mindfulness could be effective in improving sexual dysfunction. Those variables include increased relationship satisfaction, body image, interoceptive awareness, trait mindfulness, and decreased depressed mood and anxiety (Arora & Brotto, 2017).

### ***2.7.1 Relationship Satisfaction***

For the variable ‘relationship satisfaction’, it was suggested that being aware of present-moment sensations and not placing judgments on one’s own performance or one’s partner’s

performance can be a critical component in having satisfactory sexual experiences (Khaddouma et al., 2014).

### **2.7.2 *Body Image***

For the variable ‘body image’, the authors explained that mindfulness provides women with the ability to identify thoughts and feelings associated with the appearance and functioning of genitals, which may be able to decrease the mismatch between psychological and physiological sexual arousal in women (since women are less able to identify signs of their sexual arousal compared to men) (Dunkley et al., 2015). Moreover, the ability to accept internal thoughts and feelings in a non-judgmental manner, instead of ruminating on or inspecting them, has the potential to help women decrease the effects of cognitive distractions that are connected to their own body and performance on their sexual experiences (Dunkley et al., 2015).

### **2.7.3 *Interoceptive Awareness***

For the variable, ‘interoceptive awareness’, it was mentioned that in studies that used a mindfulness-based intervention, an improvement in sexual desire was mediated by changes in interoceptive awareness (which refers to an individual’s ability to sense internal sensations in their body with accuracy). In a similar manner, self-compassion increased the effect of the intervention on improving overall sexual function (Silverstein et al., 2011).

### **2.7.4 *Depressed Mood and Anxiety***

For the variable ‘depressed mood and anxiety’, it was found that decreased depressed mood and anxiety may be a significant mechanism by which mindfulness is able to decrease sexual dysfunction, since it was found in the literature that anxiety was indeed a significant psychological barrier to healthy sexual functioning (Silverstein et al., 2011).

It was found that depression, anxiety, and decreased psychological well-being are all associated with Female Sexual Dysfunction (FSD), which means that using mindfulness to improve those outcomes could lead to an improvement in sexual function (Arora & Brotto, 2017). Thus, when women are in a state of present-moment awareness, they might be able to decrease cognitive distractions and self-judgment during sexual activity and instead pay attention and focus on body sensations that allow them to better notice and enjoy their sexual arousal (Paterson et al., 2017).

### ***2.7.5 Trait Mindfulness***

Multiple studies have examined the extent to which participants experience an increase in trait mindfulness as a result of being involved in a mindfulness-based intervention. Arora and Brotto (2017) reported the results of a study that indicated that trait mindfulness significantly mediated the effects of the intervention on sexual functioning. They concluded that mindfulness appears to mediate the relation among body cognitions, perception of performance, sexual insecurities, and sexual satisfaction (Dunkley et al., 2015).

## ***2.8 Mechanisms that may underlie the efficacy of mindfulness in general populations***

### ***2.8.1 Decentering***

Another important mediator underlying the benefits of mindfulness may be decentering. Decentering refers to distancing oneself from internal emotions or feelings and recognizing that internal events are fleeting, instead of permanent representations of self. (Arora & Brotto, 2017). The authors found many studies that described decentering as a mechanism through which mindfulness interventions decrease state anxiety, generalized anxiety disorder symptoms, and negative affect (Hoge et al., 2015; McClintock & Anderson, 2013). Also, through decentering,

mindfulness interventions are able to improve psychological well-being (Joseffson, Lindwall, & Broberg, 2014).

In the context of sexual functioning, decentering may mediate the effects of mindfulness on sexual functioning by helping women and men perceive cognitive distractions, self-criticism or judgement during sexual activity as fleeting thoughts not as facts or truths about themselves (Arora & Brotto, 2017). As a result, when women and men learn to perceive negative judgmental thoughts as fleeting and transient instead of permanent, it could help women to manage those thoughts in a more effective manner, which will prevent the thoughts from interfering with their sexual experiences (Arora & Brotto, 2017).

### ***2.8.2 Neural Correlates***

Arora & Brotto (2017) also mentioned that while conducting this review, they found many studies that investigated the neural mechanisms that underlie the efficacy of mindfulness. Those studies have reported increased cortical volume in the insula and anterior cingulate cortex (which is responsible for interoceptive awareness) (Holzel et al., 2011). Moreover, the studies have reported a decreased activity in the default mode network, which is responsible for the processes of rumination. These reports have led the authors to conclude that improvements in sexual function as a result of mindfulness could be partly due to changes in the insula, since the insula is associated with interoceptive awareness (Brotto et al., 2016).

In conclusion, mindfulness has been shown to be an effective treatment for sexual problems, at least in women. The studies that have investigated the mechanisms behind the effectiveness of mindfulness found that mindfulness acts by targeting the psychological barriers to satisfying sexual experiences (Arora & Brotto, 2017). Specifically, those mechanisms include a decrease in cognitive distractions associated with body performance (Dunkley et al., 2015),

decreased depression and anxiety (Silverstein et al., 2011; Paterson et al., 2017), and improved genital self-image (Dunkley et al., 2015), relationship satisfaction (Khaddouma et al., 14), interoceptive awareness (Silverstein et al., 2011), self-compassion and self-acceptance (Joseffson et al., 2014; Arora & Brotto, 2017).

### *2.9 Challenges in adopting Mindfulness for Men*

It can be challenging to adopt mindfulness as a part of men's sexuality. Mindfulness strategies and techniques encourage men to establish new set of physical and psychological skills. In addition, mindfulness encourages men to take responsibility for their sexual well-being (McCarthy & Wald, 2013). Thus, mindfulness promotes 'good enough sex' and invites men to accept a variability in erection, intercourse and orgasm by focusing on sensual, playful and erotic interactions with their partners instead of being preoccupied by performance and outcome. The model of Good Enough Sex (GES) was introduced by Metz and McCarthy (2007) and is characterized by a practical appreciation of the importance of sex in the relationship. The GES model encourages couples to set reasonable expectations based on intimacy as the eventual focus, pleasure and function being equally important, an environment based on mutual emotional acceptance, and having playfulness, spiritual connection, and special bonding as regular parts of the sexual experience between couples. Therefore, this model emphasizes sharing desire and satisfaction during sexual experiences, rather than focusing on individual sex performance (McCarthy & Wald, 2013).

The problem lies in the fact that women (whether they are aware of this or not) reinforce the notion of focusing on performance and outcome such as whether the man was able to maintain an erection or whether the man was able to reach an orgasm during their sexual

encounter (McCarthy & Wald, 2013). As a result, it becomes challenging to integrate mindfulness into male's sexuality.

Because men's sexual satisfaction is significantly affected by their perceptions of their partners' support (Phelps et al., 2001), it is crucial for women to be supportive and refrain from making judgments about men's erection and orgasm, which is what mindfulness is essentially about. Similarly, men are encouraged to enjoy sexual feelings and emotions without focusing on reaching a certain outcome such as maintaining an erection for a certain period or reaching orgasm (McCarthy & Wald, 2013).

### ***2.10 Challenges in adopting Mindfulness for Women***

It can be equally challenging for women to adopt mindfulness strategies and techniques as a part of their sexuality. Mindfulness invites a woman to take full responsibility for her own sexuality instead of allowing the man's sexual expectations to influence her (McCarthy & Wald, 2013). In addition, mindfulness encourages women to become fully aware of their own sexual story, feelings, preferences and to be completely free to express desire, pleasure, eroticism and satisfaction (McCarthy & Wald, 2013). Relaxation, awareness and acceptance are the basic components of mindfulness, which fits well with healthy female sexuality, regardless of any illnesses or disabilities that women may suffer from. Furthermore, the concept of mindfulness and the GES model are empowering for women (McCarthy & Wald, 2013). This is critical, and yet challenging to adopt, for women because in traditional sexual socialization, eroticism lies in the man's domain, which is a concept that is strongly promoted by the porn industry. As a result, women's eroticism has traditionally focused on turning on their partners (McCarthy & Wald, 2013). Thus, mindfulness plays a critical role in women's sexuality by encouraging women to

find their own 'erotic voice' by creating personally relevant erotic scenarios and accepting a variety of orgasmic patterns that facilitate sexual satisfaction (McCarthy & Wald, 2013).

### ***2.11 Challenges in adopting mindfulness for couples***

Embracing mindfulness represents a challenge for couples. Embracing mindfulness strategies and techniques and the model of GES enhances desire, pleasure, eroticism and sexual satisfaction for couples (McCarthy & Wald, 2013). McCarthy and Wald (2013) have argued that healthy couple sexuality is based on a positive influence process (regardless of the presence of disability or medical conditions) which dictates that partners positively affect each other when they embrace mindfulness individually. On the other hand, performance pressures, demands, secrets, and power struggles have been found to decrease and negatively affect sexual desire and satisfaction (McCarthy & Wald, 2013).

When couples start embracing and practicing mindfulness skills, it is common for one partner to embrace it more than the other. It is important for couples to recognize and accept this as normal instead of struggling to convince the other partner, which represents a healthy approach and promotes mindfulness even more (McCarthy & Wald, 2013).

### ***2.12 Moving Forward***

There are currently no studies that have examined the effects of mindfulness-based interventions on couples' sexuality. Few studies have examined the efficacy of mindfulness-based interventions on women's sexuality in different populations such as women with gynecologic cancer, women with Multiple Sclerosis, women with Spinal Cord Injuries and women suffering from Female Sexual Dysfunction.

Future studies are encouraged to investigate the effects of mindfulness-based interventions on couples' sexuality in different populations. In addition, future studies should

investigate the effects of a mindfulness-based intervention on couples' sexual satisfaction in different populations, particularly for couples where one or both partners are living with a neuromuscular disability such as SCI or MS.

Based on the studies mentioned above, mindfulness represents a promising treatment for sexual dysfunction for individuals and for couples alike, whether they are able-bodied or living with a disability or chronic illness.

### ***CHAPTER 3.0- Rationale, Purpose, and Hypothesis***

#### ***3.1 Rationale***

A spinal cord injury (SCI) causes nerve damage that affects motor, sensory, and autonomic functioning. As a result, sexual function is often impaired after SCI (Biering, Sorenson, Boling & Hansen, 2012). Nonetheless, sexuality is a basic human need and is a vital component for achieving satisfaction with one's overall quality of life whether an individual is living with a disability or able-bodied (Reitz et al., 2004).

The impairment of sexual function is associated with a lower quality of life for spinal cord injured men and women, especially if the injury occurs during the reproductive period of their lives (Reitz et al., 2004). In fact, it was found that sexual function represented the highest priority for quality of life for individuals with paraplegia, while it was second highest priority (after regaining hand and arm function) for individuals with tetraplegia (Anderson, 2004). Early Studies that have examined the effect of spinal cord injury on sexuality have mainly focused on the physical aspects of sexuality such as penile erection, ejaculation, lubrication and fertility (Alexander et al., 1993). In recent years, however, there has been an increased focus and emphasis on the emotional and psychosocial aspects of sexuality for men and women such as the types of sexual activities that individuals engage in or the frequency of sexual activity

(Alexander et al., 1993). Still, there is a relative lack of research that focuses on the quality of sexual encounters and sexual satisfaction after SCI (Alexander et al., 1993).

Sexuality, specifically after SCI, needs to be approached in a more holistic manner that includes psychosocial aspects as well as physical aspects, in order for individuals living with SCI to experience richer and more satisfying sexual encounters, which will likely result in an overall increase in their sexual satisfaction and quality of life.

After MS, sexuality is modified against a basis of previous sexual encounters and experiences since the onset of MS occurs usually in younger individuals between the age of 20 and 40 (Schmidt et al., 2005). As a result, sexual dysfunctions have greater influence on their quality of life (Jonsson, 2003). In addition, the unpredictable nature of MS causes additional distress on the individual affected and their partners (Schmidt et al., 2005). MS often results in changes roles of a couple in a relationship which has a great impact on their partnership and sexual satisfaction due to the severe changes both physiologically and emotionally that an individual with MS experiences (Schmidt et al., 2005).

Mindfulness has been shown to improve a variety of negative mental health outcomes such as anxiety, depression and stress. Previous research has also linked mindfulness with favourable physical outcomes such as pain relief (Zeidan et al., 2012). The health benefits related to mindfulness training are associated with improvements in cognitive control, emotion regulation, positive mood and acceptance (Hofmann et al., 2010). Thus, mindfulness techniques and training have been incorporated into many interventions, therapies and education programs (Kabat-Zinn, 2003). It has been found that dispositional mindfulness and mindfulness practice are positively correlated with increased attention regulation, body awareness, emotion regulation, physiological arousal, empathy and open awareness (Khadoumma et al., 2015). Thus, it was

speculated that mindfulness may decrease partners' tendency towards behaviours that are often associated with sexual dysfunction, sexual distress and sexual dissatisfaction, such as inhibition, anxiety, self-criticism, and judgment during sexual encounters (Khadouma et al., 2015).

In another study by Hocaloski et al (2016), mindfulness has been shown to significantly increase sexual functioning in women with SCI and MS. In that study, the women were involved in a mindfulness intervention that consisted of five 90-minute sessions that were spaced two weeks apart and that were completed within a 10-week period (Hocaloski et al., 2016). This mindfulness group intervention was formed based on a similar intervention that has developed and found effective for female cancer survivors who struggled with sexual dysfunction, and more generally for women who suffered from low sexual desire (Hocaloski et al., 2016). One critical modification to the existing mindfulness intervention was the addition of the mindfulness practice of 'Observing judgments. This was included in this mindfulness intervention for women with SCI and MS because existing literature has pointed out that women with disabilities are more likely to have a negative body-image and sexual self-view (Taleporos & McCabe, 2003). The purpose of this exercise was to provide women with the opportunity to notice the influence of negative self-talk on their own sexual-self view (Hocaloski et al., 2016).

Despite these promising results, there is no research regarding the effects of mindfulness training when delivered to couples living with SCI or MS. Thus, the current study aims to investigate the effects of an 8-week modified mindfulness intervention to couples where one or both partners are living with a neuromuscular disability. It is hypothesized that this mindfulness-based intervention will improve sexual self-view (which has a positive effect on self-acceptance), improve sexual satisfaction and increase quality of life.

### ***3.2 Purpose***

The purpose of this study was to investigate the effects of a modified 8-week mindfulness intervention on sexual satisfaction when delivered to couples where one or both partners are living with a neuromuscular disability. The quantitative method will be used to determine if the mindfulness program improved various domains of sexual satisfaction, while the interview data will be analyzed qualitatively to help understand the lived experiences of the couple regarding sexuality and the impact of the mindfulness program.

### ***3.3 Hypotheses***

It is hypothesized that:

- 1- Sexual satisfaction in couples living with neuromuscular disabilities will increase as a result of the 8-week mindfulness training compared to sexual satisfaction at baseline.
- 2- Common themes will be discerned regarding sexual satisfaction/dissatisfaction and the effects of mindfulness on the sexual encounters of couples living with neuromuscular disabilities.

## ***Chapter 4.0- Methodology***

### ***4.1 Research Context***

This research study aimed to examine the effects of a modified mindfulness intervention on three couples where one or both partners are living with neuromuscular disability as well as explore the lived experiences of those couples regarding the influence of practicing mindfulness on their sexual encounters. This research study was completed as a Master's thesis project in the Faculty of Applied Health Sciences, at the department of Kinesiology at Brock University in St. Catharines, Ontario.

Despite the promising results that have been shown as a result of using mindfulness to enhance sexual function and sexual satisfaction, there is no research regarding the effects of mindfulness training when delivered to couples living with neuromuscular disability. In the study by Hocaloski et al (2016), when participants were asked for suggestions to improve future mindfulness interventions, they requested incorporating a partner component in the form of a handout or a guide that partners could use together to work towards a common goal. This has inspired the researcher to examine the effects of the mindfulness intervention on couples living with neuromuscular disability by including mindfulness practices to be completed individually as well as mindfulness practices to be completed as a couple.

A more holistic approach to sexuality that includes psychosocial aspects in addition to physical aspects is needed in order for couples living with neuromuscular disability to experience more satisfying sexual experiences, which represents the rationale for the present study. By examining the lived experiences of couples regarding mindfulness and its effects on their sexual encounters, the researcher will be able to identify common themes that could potentially be used to enhance future mindfulness interventions for couples living with neuromuscular disability as well as other types of chronic illnesses.

#### ***4.2 Theoretical Perspective***

It is critical for qualitative researchers to be aware and explicitly acknowledge their own assumptions before conducting their research because their own assumptions will, to a certain extent, affect how the research unfolds, since every researcher has their own beliefs and perspectives that guide and influence many aspects of the study such as the design of the study, the collection and presentation of data and even the research question that the study aims to answer (Creswell, 2017).

The worldview I operate under is phenomenology. According to Savin-Baden & Major (2013), those who operate under this worldview have a unique interest in human experiences and believe that research should aim to search for a more profound meaning. Phenomenologists attempt to bracket their experiences to the best of their ability because they believe that a researcher's experience has to be distinguished and remain separated from the participant experience (Savin-Baden & Major, 2013).

From a personal perspective, I believe that humans are sexual beings; expressing our sexuality freely contributes and is intimately connected to who we are. Thus, every human being has the right to express their sexuality safely and without feeling timid or scared of being judged.

Expressing our sexuality freely and safely contributes to personal growth which enhances quality of life. Individuals living with any type of disability such as SCI or MS are often perceived as asexual and they are usually aware of that societal bias which, in turn, negatively influences their sexual self-view, and accordingly, they start to view themselves as research commodities or individuals who need fixing; especially during the rehabilitation period that occurs after the injury. Those beliefs have motivated and inspired my interest in this area of research. In addition, when it comes to mindfulness, I practice mindfulness meditation regularly and I have personally experienced the positive effects and results that it has on my mental and physical health. My interest in mindfulness training is motivated by personal experiences as well as my interests as a researcher.

### ***4.3 Qualitative Research***

I used qualitative research to guide the research design of this study, specifically regarding gathering and analyzing data because qualitative research aims to capture lived experiences in a way that quantitative research cannot. Qualitative research is defined as social

research that has the purpose of examining the way in which individuals conceptualize their ideas and experiences (Savin-Baden & Major, 2013).

#### ***4.4 Phenomenology***

Like many qualitative researchers, I am interested in exploring human experiences. Furthermore, I am looking to understand the essence of the experience itself. The qualitative research approach used to accomplish this is phenomenology. Specifically, phenomenology is a type of qualitative research that aims to examine and explore the foundations of the human experience in order to seek the nature of lived experiences as it is for many individuals (Savin-Baden & Major, 2013). Namely, phenomenologists are essentially curious about the structures of consciousness (Polkinghore, 1989). Thus, phenomenologists perceive the lived experiences of individuals as conscious experiences (Van Manen, 1990). It is important to note that in phenomenology the idea of consciousness enjoys an elevated status; thus, it is critical that consciousness is recognized (Savin-Baden & Major, 2013).

Phenomenology is based on the philosophical teachings of Husserl or Heidegger (Savin-Baden & Major, 2013). Phenomenology attempts to reveal what several research participants who have experienced a phenomenon have in common. The purpose is to dilute the experiences in order to come up with a description of a universal core of the concept in question (Creswell, 2007; Van Manen, 1990).

There are two main types of phenomenological approaches: Transcendental phenomenology and hermeneutic (interpretive) phenomenology. Transcendental phenomenology is based on the work of Husserl and aims to describe, accurately, the subjective, lived experiences of individuals with the phenomenon in question. In order for the researcher to understand the true nature of the phenomenon in question, they must practice 'bracketing' which

the act of is becoming aware of their personal biases and the world biases and choosing to let those perspective go in order to properly understand describe the phenomenon in question (Savin-Baden & Major, 2013). Hermeneutic phenomenology is based on the work of Heidegger and the purpose of it is the interpretation of the lived experience in order to gain a deeper understanding of the phenomenon at hand (Van Manen, 1990). Hermeneutic phenomenology requires the researcher to draw from their personal experiences with the phenomenon in question. Personally, I practice mindfulness meditation regularly, however, I don't have a neuromuscular disability, and I don't have personal experiences with using mindfulness specifically with the purpose of increasing sexual satisfaction. In this study, the hermeneutic phenomenology approach will be utilized.

#### ***4.5 The interview***

In hermeneutic phenomenology, the interview is used to examine and gather information about the lived experiences that were experienced by participants in relation to the phenomenon in question in order to reach a deeper level of understanding of the phenomenon (Van Manen, 1990). Van Manen (1990) argues that the hermeneutic interview turns the individuals interviewed into partners of the research project.

#### ***4.6 Data Collection Procedures***

##### ***4.6.1 Sampling Criteria***

I utilized purposeful sampling to recruit participants for this study as only individuals living with a neuromuscular disability and their partners can contribute to the topic under investigation and share their lived experiences with mindfulness and its effects on sexual satisfaction in their relationships.

Originally, the plan was to recruit three couples where one or both partners are living with a SCI. When issues in recruitment arose due to the nature of the topic and time commitment required for the intervention, I decided to open recruitment to include couples where one or both partners are living with MS and/or Spina Bifida. Two couples where one partner is living with a neuromuscular disability decided to participate in the study. Due to personal circumstances, one of the couples decided to drop out of the study, thus only one couple remained in the study. Hence, the study became a phenomenological analysis of a single case involving one heterosexual couple where the female partner has MS. Focusing on one couple has allowed for richer and more in-depth phenomenological analysis.

Regarding the inclusion criteria, there were specific inclusion criteria the participants had to fulfill. As mentioned earlier, research regarding sexuality after SCI and MS has either focused on men or women separately and specifically research has only focused on women regarding the effects of mindfulness on sexual satisfaction. Thus, the current study chose to focus on couples' lived experiences regarding mindfulness and its effects on sexual satisfaction. Participants of this study were required to be in a romantic relationship (married or otherwise).

The level and severity of SCI or MS were not restricted; the study was open to including any couple where one or both partners are living with SCI or MS. There were no classifications or restrictions on the level or severity of SCI or MS for two reasons. First, to my knowledge, the effects of mindfulness on sexual satisfaction in couples where one or both partners are living with SCI or MS has not yet been investigated. Thus, there were no pre-existing guidelines to follow regarding recruiting couples with SCI and MS. In addition, having the study open to couples with wider range of SCI and MS had the potential to better determine the effects of mindfulness on sexual satisfaction and may help guide future research on where it should focus

its efforts. Also, since the topic of sexuality is perceived to be sensitive and private, recruiting couples willing to discuss their personal sexual experiences and intimate parts of their relationship was challenging. Hence, I was happy to include any couple willing to commit to the intervention and share their experiences. Finally, couples were required to be age of majority or older.

#### ***4.6.2 Recruiting procedures***

I recruited participants using recruitment posters which were placed at Power Cord which is located at the Brock-Niagara Centre for Health and Well-being. Participants were also recruited by word of mouth through referrals from other participants (a copy of the recruitment poster has been included in the data manual at the end of this document). Potential participants either approached me or the undergraduate thesis student who was involved in the project themselves at Power Cord or, contacted Dr. David Ditor using the phone number listed on the recruitment poster. I informed participants who showed interest in participating in the study about the details of the study and the approximate time commitment involved in the intervention. I also informed them that they would be asked open-ended questions about their experiences with mindfulness and how it affected their sexual satisfaction among other things in their relationship.

In addition, I informed them that they would be required to meet for a total of two interviews in addition to a psycho educational session offered by the clinical sexologist involved in the study. I informed them that they could refuse to answer any questions that made them feel uncomfortable and that they could withdraw from the study at any time without any consequences. Also, I made it clear that withdrawal from the study would not affect their ability to continue exercising at Power Cord.

I informed the participants that the interviews will be audio recorded so their answers can be revisited during the data analysis process, and that only myself and the main investigator would have access to the audio recording of the interviews. I also informed them that the audio recordings of the interviews would be destroyed after their content has been analyzed. In addition, I informed that the results of the study may be published in a scientific journal or presented at scientific conferences, but that their names and identities would always remain confidential; rather pseudonyms would be used when necessary.

I also informed the participants that that they would be able to review my notes after the interview and that, upon request they may view the entire interview transcript when it was ready.

I gave all potential participants a Letter of Invitation which outlined the purpose of the study, the inclusion criteria, and the rights of the participants in order to help potential participants make an informed decision regarding their participation in the study (a copy of the Letter of Invitation and Informed Consent Form has been included in the data manual at the end of this document). The participants had the opportunity to ask me and/or the principal investigator before signing the Informed Consent Form and deciding to participate in the study.

#### ***4.6.3 Sample***

I was approached by individuals living with SCI to participate in the study. However, they did not end up participating because they could not find a time where both members of the couple could be present for the interviews. In addition, some have said that the time commitment required for the intervention did not work for their schedule. When recruitment became more challenging, the study became open to individuals where one or both partners are living with Multiple Sclerosis (MS) and Spina Bifida.

One couple where one partner has Spina Bifida were interested in the study. They agreed to participate and completed the baseline interview. They were also given the mindfulness exercises booklet. However, due to family circumstances, they dropped out of the study.

One woman living with MS inquired about the study and talked to her partner about it and they agreed to participate. The woman has relapsing remitting MS and is 44 years old and her partner is an able-bodied, 42-year-old male. She was diagnosed with MS since January of 2008. They have been in an exclusive relationship for almost two years at the time of inquiry.

#### ***4.7 Ethics***

All ethical guidelines outlined in the Tri-Council Statement: Ethical Conduct for Research Involving Humans as described in Brock University's faculty Handbook on research ethics were followed. I submitted an ethics application to Brock University's Research Ethics Board. The ethics application was accepted on November 19<sup>th</sup>, 2018 (File Number 18-089-DITOR) (a copy of the REB letter of approval can be found in the data manual at the end of this document).

Participants' information collected was used only for the purpose this study. Identifying information was known only by me and the principle investigator. All the other individuals involved in this research study were only aware of the pseudonyms of the participants which ensured confidentiality and made sure that any identifying information could not be linked to data that had been collected during the study. I informed participants that participation was completely voluntary and that they had the right to refuse to answer any questions that made them feel uncomfortable. I also informed them that they could withdraw from the study at any time with no penalty. I informed participants of these rights verbally before the start of the baseline interview. I also reiterated those rights in the Letter of Invitation and Consent Form.

Since the woman knew about the study because she exercises at Power Cord at the Brock-Niagara Centre for Health and Well-being, I made it particularly clear that withdrawal from the study would not compromise her ability to keep exercising there.

The participants had the opportunity to ask me and the principle investigator any further questions before signing the Informed Consent Form. I kept the data collected in a private file on a personal, password protected computer that is only accessible to me. I deleted audio-recordings upon completion of the project. I disposed written data and interview transcripts of upon completion of the study.

#### ***4.8 Data collection***

##### ***4.8.1 Interviews***

Since I utilized phenomenology, the primary source of data collection was the in-depth interview of the people who have first-hand experience with the phenomenon (Patton, 2002).

The couple in this study completed a total of two in-depth interviews (at baseline and 8 weeks post- intervention). The interviews lasted approximately an hour and they were conducted by me and the clinical sexologist in a private room at the Brock-Niagara Centre for Health and Well-being. This ensured privacy between me and the couple and it also provided an environment that was free of distractions where the couple could feel relaxed.

Before the start of the baseline interview, participants were required to sign two copies of the Informed Consent Form. One copy was kept by the participants for their own records, and the other copy was kept by me. All the interviews were audio-recorded, and participants were told that they could take a break during the interviews if they needed. The interviews utilized an open-ended, semi-structured with interview guide approach. The couple was asked standardized

open-ended questions that were designed to address specific topics of interest. I created the interview questions with the guidance of the clinical sexologist who was part of this project.

The design flexibility of the interview guide approach allowed the freedom to explore in depth any relevant and important topics that had been unanticipated or planned (Patton, 2002). I utilized probe questions in order to gather more information regarding certain topics. This resulted in a richer, and more detailed description of how this couple experienced this particular phenomenon. Since the interview questions were created by me and the clinical sexologist who was part of this study, the questions were clinical in nature. Specifically, the baseline interview included questions about demographics of the couple, their relationship status, the type of MS the woman had, and the types of sexual activities this couple engaged in. The post-intervention interview included questions about the couple's experiences with the individual mindfulness exercises and with sensate focus. The complete interview guide for the baseline interview and the post-intervention interview can be found in the data manual at the end of this document.

I received formal phenomenological interview training prior to the start of this research study. In addition, I was trained by the clinical sexologist in clinical interviewing skills. Hence, I was aware of the format and the procedure to follow during an interview, appropriate probe questions to gain additional information, and effective ways to handle participants' emotions if they were evoked during the discussion.

I informed participants that they were able to reach out to organizations such as Distress Centre Niagara in case they felt distressed as a result of the discussions. I made that clear to the couple both before and after the interview. To my knowledge, none of the participants contacted any organization after the interviews.

I took field notes during the interviews that noted any areas of interest to revisit later in the interview, information that appeared important that had been repeated by the couple, and any expressions of non-verbal communication that could not be captured via audio-recording. I informed the participants that they had the option to see the field notes at the end of the interview in order to ensure that I did not misinterpret their responses and/or non-verbal communication, but the couple did not ask to see the field notes.

#### ***4.8.2 Sexual Satisfaction Questionnaire***

The Sexual Satisfaction Questionnaire is a 10-item tool and questions are answered on a 4-point Likert scale (1, strongly disagree, 2, disagree, 3, agree, and 4, strongly agree). The higher the score, the higher the level of sexual satisfaction. Many studies have demonstrated that the questionnaire is psychometrically sound and valid (Nomejko & Zygmunt, 2014).

### ***4.9 Data Analysis***

#### ***4.9.1 Transcription***

I listened to each audio-recorded interview and typed everything that was said verbatim including long pauses, laughter, jokes, etc.

#### ***4.9.2 Read and Jot***

The second phase of data analysis was to read through the entire interview transcript. While doing so, I noted parts of the interview that stood out to me. The purpose of the “read and jot” phase is for the researcher to become familiar with the interview transcript and to get a sense of the entire data set.

#### ***4.9.3 Sensitized Summaries***

I included a general description only for the baseline interview. The general description was created by condensing and retaining only the information that pertained to MS, mindfulness,

sexuality, and the relationship as a whole. All other information was removed from the general description

#### ***4.9.4 Phases of analysis***

For the purposes of this document, I conducted phenomenological analysis of the post-intervention interview only since the baseline interview was used to collect demographic information and explore sexual satisfaction at baseline.

I read over the post-intervention interview transcript three times. Once to gain an understanding of the sense of the whole, next to read for salience, and a third time to read for pattern. Next, I looked over the data for a second time to determine if there were patterns associated with body, space, time, and relation (BSTR), as they are phenomenologically guided lifeworld categories. Once patterns were established, I read over the data to determine salience commonalities. In addition, an undergraduate thesis student has also conducted data analysis on the post-intervention interview using BSTR. The analysis conducted by the undergraduate student was included when I categorized the themes into the four lifeworld existentials.

#### ***4.9.5 Discerned Themes***

The last phase of analysis involved utilizing the revelatory phrases in order to discover themes and patterns within the information that the informants gave me. An idea has become a theme when it had been brought up by the informants multiple times throughout the interview.

#### ***4.9.6 Lifeworld Existentials***

The next level of analysis involved examining the themes based on four existing categories: Lived space (spatiality), Lived body (corporeality), Lived time (temporality), and Lived other (relationality) (Van Manen, 1990). All human beings experience the world by

belonging to the existential ground where the four fundamental existentials of spatiality, corporeality, temporality, and relationality are perceived to belong (Van Manen, 1990). This makes logical sense, since any experience we have in the world involves these four lifeworld existentials. In addition, the phenomenological literature considers these four categories to be a critical part of the fundamental structure of the lifeworld (Van Manen, 1990).

The purpose of categorizing themes into these four categories is to gain a better insight into the lived experiences of the couple and to understand, on a deeper level, how they experienced mindfulness as part of their relationship and how mindfulness influenced their sexual satisfaction. Utilizing the lifeworld existentials leads to a deeper understanding of the ‘essence’ of mindfulness as a phenomenon regarding sexual satisfaction. Capturing the essence of a phenomenon is the goal of phenomenology.

Data Analysis was inductive in nature, done by exploring and discovering new information on the topic instead of testing or confirming a hypothesis. The post-intervention interview was analyzed and considered as its own case. In doing so, I was able to shed light on the lived experiences this couples have regarding their sexual satisfaction/dissatisfaction and the effects of the mindfulness intervention on their sexual experiences.

## **Chapter 5.0- Results**

### ***5.1 Sexual Satisfaction Questionnaire Data***

The couple were asked to complete the Sexual Satisfaction Questionnaire at baseline, and post-intervention. Participants completed the questionnaire individually.

#### ***5.1.1 Sexual Satisfaction at baseline (prior to the intervention)***

##### **Jane**

- I am disconcerted with a part of my sexual life (4)

- Sex is a source of pleasure for me (3)
- Thinking about sex generates negative emotions (1)
- I feel sexually attractive (3)
- I find myself a poor sexual partner (1)
- I don't have any problems in my sexual life (2)
- I like thinking about my sexual life (4)
- My sexual life frustrates me (2)
- I am afraid I do not satisfy my sexual partner (1)
- I find my sexual life fulfilling (3)

### **Bradley**

- I am disconcerted with a part of my sexual life (2)
- Sex is a source of pleasure for me (3)
- Thinking about sex generates negative emotions (1)
- I feel sexually attractive (3)
- I find myself a poor sexual partner (2)
- I don't have any problems in my sexual life (3)
- I like thinking about my sexual life (2)
- My sexual life frustrates me (1)
- I am afraid I do not satisfy my sexual partner (2)
- I find my sexual life fulfilling (3)

### ***5.1.2 Sexual Satisfaction post-Intervention***

#### **Jane**

- I am disconcerted with a part of my sexual life (2)

- Sex is a source of pleasure for me (4)
- Thinking about sex generates negative emotions (1)
- I feel sexually attractive (3)
- I find myself a poor sexual partner (1)
- I don't have any problems in my sexual life (2)
- I like thinking about my sexual life (3)
- My sexual life frustrates me (3)
- I am afraid I do not satisfy my sexual partner (1)
- I find my sexual life fulfilling (3)

### **Bradley**

- I am disconcerted with a part of my sexual life (2)
- Sex is a source of pleasure for me (3)
- Thinking about sex generates negative emotions (1)
- I feel sexually attractive (1)
- I find myself a poor sexual partner (2)
- I don't have any problems in my sexual life (3)
- I like thinking about my sexual life (3)
- My sexual life frustrates me (2)
- I am afraid I do not satisfy my sexual partner (3)
- I find my sexual life fulfilling (3)

### ***5.2 Levels of Data Analysis***

I organized the following chapter based on the three-phase process I used to analyze the data.

Phase one involved within data-analysis where I read through the post-intervention interview to gain a sense of the whole, for salience, and for pattern. When I read for salience, I read over the interview to determine if certain quotes were prominent. When I read for pattern, I read the interview a second time to determine common occurrences.

I summarized the interview based on the themes and patterns that were examined in phase one for data analysis. Next, I entered the data into a chart in order to analyze the themes in the couple's responses. After I established patterns, I read over the data to determine if there were themes associated with the lifeworld existentials of lived body, lived space, lived time, and lived other (BSTR). In phase three of data analysis, I separated the BSTR patterns in order to determine clusters and designations.

### ***5.2.1 Phase one- Within Data-Analysis; Reading for the Whole, Salience, and Pattern***

After I transcribed the interviews verbatim, I read over the post-intervention interview attentively three times. The first time to gain a sense of the whole interview, the second time to note salience, and the third time to read for pattern. Note that I have only provided a general description for the baseline interview since the findings and results are based on the data provided in the post-intervention interview.

### ***5.2.2 Baseline Interview***

I interviewed participants at baseline prior to the start of the intervention in order to collect demographic information about them and learn more about their relationship and about them as individuals.

Here's a summary of the information collected at the baseline interview as it relates to sexuality and MS:

**Jane and Bradley:**

Jane is a 44-year old woman and Bradley is a 42-year old man. They have been in a long-term exclusive relationship for two years and they have also known each other for two years. They plan to move in together later in the year. They said they spend more than half of the week at each other's homes. Bradley has two kids from a previous marriage so when he has the kids, Jane and he stay at his house. Bradley also mentioned that he's legally separated from his ex-wife. When he doesn't have his kids, Jane and Bradley spend majority of the time at Jane's house. They expressed that now was the perfect time to participate in the study before they move in together because changes in life can disrupt sexual activity.

Jane has relapsing remitting Multiple Sclerosis and she was diagnosed in January of 2008. She believes that she has had MS for much longer than when she was diagnosed. Jane said that she didn't know what was happening, so she continued to live her life normally. As a result, the attack that led to her diagnosis in 2008 lasted much longer than normal because she continued to work and run which, according to her, prolonged the attack and worsened the damage to her brain. Jane said that usually people rebound after a major attack, but she believes that she didn't completely rebound. She said she experiences residual symptoms that come and go based on weather, stress, anxiety and other factors. She said that she has been managing her MS symptoms for the past ten years and that she has been doing better than she used to be. Jane stopped working in 2009 and it took her a year until she started feeling somewhat normal. Then, it took her another year to adjust further. Since then, she has been focusing on working out and healthy food, which have made the biggest difference and helped her feel better overall. Jane said that she experiences neuropathic pain daily that varies on a scale. Jane mentioned that pain can be triggered by a variety of things such as the weather and lack of sleep. Jane said that lack of sleep is definitely the worst thing for her because it makes her unmanageable during the day.

She feels like she can't drive properly, think or see very well. Lack of sleep affects her greatly. In addition, she said that storms and excessive heat and humidity affect her too as well as the death of a loved one or being in a car accident. Bradley confirmed that heat, cold, and exertion trigger her. He said that she's amazing at managing her MS symptoms. Jane says that she has got managing MS symptoms down to a science. She says that she has eighty percent confidence that she can manage any symptom that occurs. Jane said that specific things have to happen for her to experience a 'flare-up'. She mentioned that storms, a fight with Bradley or eating something she isn't familiar with are reliable triggers.

When Jane was asked to describe her neuropathic pain, she described the pain as "*incredibly bad*" and "*pretty insane*". However, she mentioned that proper diet has helped decrease that pain. Jane believes she has arthritis, so she experiences arthritis pain as well. She also experiences headaches that feel like her brain is swollen and squishing against her forehead and it feels like a needle coming from behind into her eye and her ears feel swollen and her jaw feels clenched inside on the left side. She also experiences extreme muscle spasticity and it feels like her muscles are tight and can't relax or release tension. Sometimes she experiences this in certain muscles and other time she experiences it in most of her body. She emphasized that the pain varies every day and can vary within the day. She said that there is a certain pain where if she doesn't take an Advil at a certain time, there's nothing she can do to get rid of it, so it just has to take its course. She said that if she takes an Advil for it early enough then MS wouldn't get involved. Once MS gets involved, then it becomes too late to take an Advil. When Jane was asked about the severity of her pain, she said that her pain is now better managed, however it's not necessarily less severe. She said that the pain happens less often now. If she would rate her pain between one and five, her fives aren't as often as they were. She said that the pain can also

last for varying lengths from minutes to days. Jane said that if the pain is a five on the scale, there's usually nothing that she can do to relieve it. Sometimes she enjoys pressure and she believes that it's because pressure activates her nerves which she feels sends a message to her brain. So sometimes she asks Bradley to fully lay on her. At first, he was a bit surprised by her request, but she assured him that the pressure of his body weight actually helps calm her. She said that this is the only thing that works for her pain. Jane also said that she uses a weighted blanket which also provides pressure. She said that when she gets to a certain point where she's feeling extreme pain, she needs extreme pressure. She said that the pressure doesn't take away the pain, but it definitely helps. Jane also does yoga to help stretch her muscles out and uses a roller for her back because she experiences back pain. She pointed out that she feels anxiety strongly in her back, since anxiety is a symptom of MS. Jane added that hiking usually helps with the pain. She said that when her pain is five on the scale, light and noise sensitivity are an issue for her, so she has to rest in a quiet, dark room. She also has to wear sunglasses if she goes out even at night and when she's watching TV. She also prefers phones and computers to be muted. She said that she experiences sensory overload often with MS and she thinks this is the source of her pain. She always knew sensory overload was a problem, but she never connected it with pain until she was asked about it during this interview, so she said she's grateful for that.

When Jane and Bradley were asked about how conflicts are handled in their relationship and how they discuss problems that arise, they said that if the problem is extreme, they feel they're not good at handling it. Jane said that if the conflict is low-key, then they are good at handling it. She said that they're both the kind of people who don't like to stay mad so usually conflicts are resolved by the end of the day. Bradley finds that there have been a few build-up moments in their relationship. He explained that because Jane has MS, he is a little more

reserved to attack back during conflict and doesn't want to be aggressive. Jane said that she doesn't perceive it as an attack and would like Bradley to be open with her, which she feels like he isn't. Bradley describes Jane as very strong and that she wants to be open. He added that he thinks she should judge the appropriateness of the time to be open in the moment during conflict. Bradley said that Jane can become 'rammed up' during conflict and sometimes he has to retreat and shut down the conversation before they both start getting worked up. Jane said that she gets worked up when she feels like Bradley isn't listening. Bradley said that he shuts down emotionally and suggests taking a break when things get too extreme for his comfort level. He also said that sometimes he would 'blurt it back to her' at the same level. Jane said that if they are being honest, they both do it to each other. Bradley said he likes to call a timeout when things are about to boil over; that's his method of dealing with things. Jane said that sometimes she's afraid she would have an attack when things become extreme during conflict so, sometimes she leaves and goes for a walk. She said that she needs to because of MS and because she needs to manage her symptoms and not because of the fight itself with Bradley. When they were asked about fantasies, Jane said that she doesn't fantasize as much as she did and she thinks it's due to perimenopause, which she said hasn't been confirmed by her doctor. She added that she definitely has symptoms of menopause and she thinks it's crazy because of her age. She said that there has been a drastic change in her sexual 'makeup' as she called it. She said that those menopause symptoms appeared in the last two years and they didn't affect her or Bradley in the beginning but now it does affect them. Jane said that before she would see or hear things that trigger a fantasy in her, but she is not like that anymore. Bradley said that he never really thought about if he fantasizes or not and this forced him to think about it. Bradley said that his level of fantasizing is directly connected to how much sex he's having at this point in time in his life. He

added that he would fantasize more often if he didn't have a partner. Regarding the content of the fantasies, Jane said her fantasies always involved people she knew or partner she's with and she never had fantasies that involved strangers. Jane said that her fantasies include little scenarios sometimes and sometimes she'll have a scenario then it would 'die off in her brain' before it finishes which she finds interesting. She thinks this may be due to her MS. Bradley described his fantasies as 'pretty boring' as they are typical in nature. He said that sex was never the forefront of the person he is. Bradley said that he used to fantasize a lot more when he was younger. The fantasies usually involve a random, one on one occurrence with a female. When they were asked about experiencing an orgasm from fantasy alone, Bradley said that he used to have wet dreams. He also said that it happened to him when it has been a long time without masturbating or having sex with a partner. Jane said that she experienced sexual dreams where she woke up wet and turned on, but those dreams did not lead to orgasm. Bradley said that he first started exploring his body and masturbating when he was fifteen or sixteen years old, which he assumes is older than when most boys start masturbating. Jane said that she started exploring her body and masturbating around ten, eleven, or twelve years old. She said that she has always been a heightened sexual person so it's annoying that she is no longer that at the moment. Bradley said that he has always been "muted" in those terms. Jane said that when they started dating, she thought that Bradley was asexual because he was not engaging with her. Jane said that it took some time and practice, but they are good now in terms of engaging in sex. Bradley said that he required some 'training'. Jane said that after the first time they had sex, she asked Bradley to go back to the bedroom and she give him a 'tutorial'. Bradley said that Jane is very specific with everything. Jane said that because of her MS and menopause, she has to be specific. She said that when she was younger, she would put up with things till the guys figured out, however, now she

things it will take forever so that's why she's more specific now because she never used to be that way before. She used to be 'hypersexual' and she didn't really need to tell guys much because she was always multi-orgasmic, and she never had an issue with that but now the orgasms are decreasing so she needs to be specific with Bradley, so he knows what she needs. Jane mentioned that the stimulation that she requires now is different since she feels different now as a result of MS, menopause and other factors.

Supporting Quote:

- “Well there's some things that I am, that he's actually got no problem doing that like snacking my ass or pulling my hair or something like that and this is MS related though but um, and I've told you this right from the start is like it's not holding me down but it's the pressure again so if I am on my back I like it when a guy like puts his hands here and pushes down while he's yeah I don't know why I think it's just the sending the signals back to my brain again and I feel all of a sudden things on a different heightened level, it's a heightened feeling that I wasn't feeling just normally” (referring to the importance of feeling pressure and intense sensations during sexual encounters”

Jane said she's honest with Bradley and she'll communicate if she's not feeling 'it' as sometimes she feels neutral about having sex and feels like she's not wanting it or desiring it as before. She said that she feels 'neutral' while Bradley would be ready to go right away, in which case she communicates to him that he's going to have to help her get where she needs to be and sometimes it's much harder than other times. She said that if her fatigue is higher than usual then those are the times where they need to do a little bit more before sex. She said that they're figuring it out on their own as time goes on. Jane noted that it's always nice to get more help with their sex life hence why they're participating in the study.

Supporting Quote:

- “I started neutral but he will like be ready to go right away and I’m like look I’m sorry but you’re gonna have to help me get to where I need to be and like sometimes it’s much harder than other times. But I’m I’m up front with him and tell him and sometimes he just knows now if I am at that state. Like if my fatigue is higher usually those are times when we just need to do a little bit more before, yup. So I guess we are kinda figuring things out a bit on our own but it’s always nice to hear a bit more help to figure it” (referring to sexual encounters)

Jane added that in terms of masturbation, that she barely masturbates now if at all. She said that she’s done it once or twice this year. She said that she used to masturbate all the time and she was multi orgasmic but she’s not anymore and she finds that very frustrating.

Supporting Quote:

- “I don’t masturbate barely at all, if at all. I think I’ve done it once or twice this year and I used to, I was good all the time (chuckles) because I was so multi-orgasmic I needed to have orgasms, I’m not anymore...it’s very frustrating”

She noted that she had an issue emotionally and mentally with Bradley in the beginning of their relationship and she knew it wasn’t about him, it was about her. She added that now she needs a vibrator even though she never used to. Bradley said that when it comes to masturbation and self-pleasure, he’s “pretty simple”.

### ***5.2.3 Post-Intervention Interview***

In the following section, I summarized the salience and patterns found in the post-intervention interview provided by the couple I interviewed.

*Saliency***Superordinate Theme: Becoming more deeply attuned to each other****Secondary Themes:****Improved listening and understanding of partner and increased openness**

Bradley mentioned that mindfulness practice has helped him become more aware in regard to Jane's needs regarding her MS. Jane emphasized that Bradley has become more understanding of how she's feeling at a given moment and how she's affected by MS. She mentioned that Bradley listens better to her now and when she communicates that she lost touch with the intimacy between them, he doesn't find that offensive.

**Supporting Quotes:**

- "he's just more open to listening to me".
- "he's more open and understanding of why I need to..."
- "it's helpful at least that he's understanding of how I am affected or I am feeling that kind of thing"
- "there's more we've communicated there's more awareness"
- "we're communicating better like I understand you more like for sure"
- "you needed to evolve and understand my MS"

**Mindfulness Communication: responding in a kinder way to partner's needs  
and adopting a different approach to communication**

Jane mentioned that because they participated in the study, Bradley responded to her in a kinder manner when she voiced her needs, for example, when she told him that missed him. She said that it was a good moment for them because he understood what that meant to her.

Supporting Quotes:

- “Because of the study I find he responded to me that much more in kind than he had if we hadn’t done the study”- Jane
- “We work better together this way”- Bradley
- “I do find that your approach is different to me though”- Jane

**Continuing to schedule ‘date night’ is an important part of the relationship**

Another salient element was continuing to schedule time that is solely dedicated to the couple and their relationship. Jane mentioned that this is important to her because it involves ‘the anticipation’ like when they were dating. This demonstrates that relationship satisfaction is critical and is intimately connected to sexual satisfaction in a relationship. Bradley noted that taking part in the intervention with Jane was his way of showing dedication to their relationship and that he makes time for Jane.

Supporting Quotes:

- “yeah there’s an anticipation like you are still dating...even though you’re still living together you’re still...like you know what I mean you’re still like oh what are we gonna do tonight like you know it’s not like you know let’s lay on the couch and watch Netflix and...”
- “I am here!”

**Superordinate Theme: Present and grounded in the moment****Secondary Themes:**

**Sensate focus is correlated with feeling present with partner and emphasized aspects such as touch and eye contact**

They said that sensate focus exercises have helped them ‘ground’ themselves because it involves ‘taking intimacy back’ and prevented them from going through the motions of sex and intimacy which tends to happen in relationships when couples get caught in life, as Jane noted.

Supporting Quotes:

- “that (sensate focus) helps ground yourselves”
  - Grounding yourself with your partner
  - “it’s not going through the motions of intimacy and sex”
- “I am at a place yeah where it (sensate focus) I s comfortable” (sensate focus)

**Mindfulness practice is associated with intimacy in a relationship**

Jane repeated many times throughout the interview that mindfulness in her relationship with Bradley was about intimacy. It was mentioned that because life became hectic for her and Bradley, Jane felt like intimacy was compromised between them. They mentioned that mindfulness brought them back to a place where they felt intimate again because they both became more aware when intimacy was lost between them. They noted throughout the interview that if they hadn’t participated in the study, they wouldn’t have been as ‘aware’ of the state of intimacy in their relationship.

Supporting Quotes:

- “Because life changed, things between us slipped a little bit”.
- “We lost that (intimacy) in that moment”

- “It was as a couple it was intimacy that’s what (mindfulness) was really about to me”
- “Reconnect again”; “connect again”.
- “It's not going through the motions of intimacy and sex”.
- I am hugging him holding him”

### **Mindfulness involves seizing the moment**

They noted that participating in the study and practicing mindfulness have taught them to ‘go back’ and ‘dial down’ in order to reconnect and regain that sense of intimacy in the relationship.

#### Supporting Quotes:

- “brings you back” to that area where you can be intimate
- “go back”, “dial down”
- “coz it’s like you’re taking it back
- “connect again”, “reset”
- “take a time out”
- “training your brain to stop”
- “ stop that focus on the person in front of you”
- “ you get more in tune with the moment”
- “ I enjoy it because it takes you back a bit”
- “it was the slowing down part”
- “slow and then refocus”
- “go back again for a second”

### **Mindfulness practice helps partners become aware of distractions during sexual encounters**

Jane mentioned that sometimes she experiences intrusive thoughts during sex which makes her feel annoyed and out of control. This reflects how the mind wanders and the potential negative effects of being distracted on sexual satisfaction and feeling satisfied during sexual encounters. It appears that as partners practice mindfulness, they become more aware of those distractions and are able to let them go since mindfulness emphasizes non-judgmental awareness. Hence, they are able to bring their attention back to the sexual encounter in the present moment.

#### Supporting Quotes:

- “but those are the types of thoughts that I will have during sex sometimes”
- “we’ll be kissing or something and I’ll be...this thought pops into my head”
- “I don’t have control” (over the thoughts)
- “ you can’t control your thoughts”

### **Superordinate Theme: Time commitment and dedication required for mindfulness practice**

#### **Secondary Themes:**

#### **Challenging to make time for mindfulness practice**

Both Jane and Bradley acknowledged that they found it challenging to fit the mindfulness exercises in their daily lives because life circumstances changed as they had travel plans and were preparing to move in together.

#### Supporting Quotes:

- “definitely it was a challenge in my schedule” Bradley
- “ it did kinda get a little crazy” Jane

#### **Mindfulness practice is a life-long practice**

They both mentioned that mindfulness practice will always be an ever evolving process. Bradley noted that he's in the awareness stage and Jane mentioned that she considers herself 'an infant' in mindfulness.

Supporting Quotes:

- “it will be ever evolving for a while”
- “This is a lifelong thing” (mindfulness)
- “ a work in progress”
- “ this will be a very slow process” (mindfulness)
- Progress regarding mindfulness “ I am like totally in infancy”, “I am still an infant”
- “it's gonna take some time”

**Continuing to practice mindfulness beyond the intervention**

Jane decided to buy the mindfulness app Headspace and she said that she wouldn't have taken that step to buy the app if she hadn't participated in the study. Jane noted that she started and plans to continue incorporating mindfulness in different aspects of her life (using the mindfulness app Headspace) since it offers mindfulness exercises aimed at different activities such as sleeping, hiking, or running; demonstrating that applying mindfulness in one area (i.e., sexual satisfaction) inspires applying mindfulness in other areas.

Supporting Quotes:

- “I bought headspace” (a mindfulness app)
- “but it made me try some of these apps that I probably wouldn't have if I didn't do the study so...it made me end up buying “ (the app)
- “having the toolbox (mindfulness) and now having this app”

“I need guided (meditation)”

**Conversations about mindfulness during the interviews and the psychoeducation session reinforced mindfulness practice**

Jane said that she feels that they should do this (the interview) every six months. Specifically, she was referring to the importance of the conversations because they involved speaking with a sexologist who conducted the interviews (with me) and offered counselling as part of the intervention during the interview and the psycho-education session. This demonstrates the importance of including relationship/ couples counselling to sexual rehabilitation programs that aim to help individuals living with neuromuscular disabilities and their partners. In particular, Bradley noted that he felt comfortable talking about sex in the interviews because he felt like the sexologist was closer to their “age demographic”. Jane said that she appreciated how “real” he is which makes talking about sex so much easier. Bradley said that he appreciated how comfortable I was with the topic and how comfortable the sexologist was as well because it made it easier for them to open up and share their experiences during the interviews. Jane added that she felt like they were not even talking about sex because of how light-hearted the conversation was. This demonstrates the importance of building rapport with individuals regarding talking about sex and engaging in a light-hearted conversation that does not feel “clinical”.

Supporting Quotes:

- “I feel like we need to do this every six months”
- “because who you are is just so...natural and easy-going nothing about it is clinical nothing about it is taboo nothing about it makes you feel like scandalous or like you

know what I mean it's just talking and no yeah I mentioned that I think that's helped him too because he was so you know..."

"talking to you"

- "and also like all the conversations we've had umm I am aware of it more in regards to Jane"

**Superordinate Theme: Accountability was ensured by one member of the couple motivating the other**

**Secondary Theme:**

**They are more likely to continue incorporating sensate focus because it keeps them accountable**

Bradley noted that Jane often 'checked up on him' to make sure he did the individual mindfulness exercises which reflects that perhaps in a relationship someone may take on the leader role to ensure accountability and motivate the other to complete the individual exercises which is a critical component of the dedication required to take part in the intervention.

This also may explain the positive effects mindfulness has on communication and relationship satisfaction in the context of the intervention since it emphasizes working with a partner to achieve a common goal.

Jane stated that it was easier to find the motivation for sensate focus exercises since they involved the couple together because they were 'forced' to do them together. This demonstrates the importance of accountability regarding mindfulness practice in the relationship.

Supporting Quotes:

- “I would do it more as a duo”.
- “it’s easier for us coz then it holds him accountable too”.
- “She did check in on me every five minutes (laughs) to make sure I was meditating personally alone properly”
- “I would just like every week I would say we’re starting the new week and this is what’s gonna happen yeah it was for that that’s all it was you need to write your journal and this is what’s gonna happen next week that’s all it was...that’s all it was”.

*Pattern*

**1- Sensate focus is correlated with Acceptance, non-judgement and pleasure-focused sexual encounters in a relationship**

Jane repeated many times throughout the interview that mindfulness in her relationship with Bradley is about intimacy. It appears that sensate focus contributed to and reinforced that sense of intimacy in their relationship. As a result, they were able to enjoy sexual encounters while focusing on pleasure instead of performance or an end-goal, something Jane struggled with.

Supporting Quotes:

- “it’s more of a connection right it’s not just the act” (referring to sexual intercourse)
- “because I think of this like that intimacy was like no efficient sex we’re good like we were both okay with it we both enjoyed it”

- “but I am saying that if we hadn’t necessarily done the study then maybe you know how I was thinking with my brain before I might have been ugh like that wasn’t quite what I was hoping it to be or something right”
- “I was okay with whatever happened in that moment with what he did yup”
- “I accepted it and I was good with it so I guess I am evolving a little bit there

## **2- Mindfulness practice is associated with increased awareness and consciousness in a relationship**

Jane and Bradley mentioned repeatedly throughout the interview that mindfulness practice increased their sense of awareness in the relationship. They became more aware of the state of intimacy, how the mind wanders, and each other’s needs.

### Supporting Quotes:

- “I don’t think I would have been so cognizant of that (intimacy)... if we hadn’t done the study”
- “my brain is a little more wired that way now or at least aware of it”
- “you are more conscious”
- “if anything I realize now how much my mind does wander”
- “I am definitely more aware of it”
- “I am at the awareness stage”

## **3- Mindfulness practice is about stopping, refocusing, resetting**

Bradley and Jane noted throughout the interview that mindfulness is them is about training the brain to stop, resetting and taking a step back. They also repeatedly

mentioned ‘refocusing’ on each other and what’s happening in the present moment

Supporting Quotes:

- “Training your brain to stop
- “refocusing on what’s happening”
- “reset”
- “training your brain to stop”
- “yup I heard you (the thoughts) and then goodbye now moving on”
- “you get more in tune with the moment”
- “slow then refocus”

**4- Mindfulness is associated with increased comfort and open-mindedness regarding one’s sexuality**

Jane repeatedly noted that she believes that Bradley has become more open-minded and more comfortable with himself which has increased comfort between themselves in the relationship. She also mentioned that he has become more relaxed and open-minded regarding the use of sex toys such vibrators.

Supporting Quotes:

- “he’s actually more comfortable”
- He's more comfortable with himself”
- “you’re more relaxed” (regarding his sexuality and the use of sex toys)
- “I wanna say more open-minded" (regarding sexuality)
- “I am like opening up”

**5- Mindfulness is perceived as a ‘toolbox’ that couples can refer to and it requires practice and discipline**

It was repeatedly mentioned throughout the interview that mindfulness doesn't come 'naturally' to them which suggests a sense of struggle against old patterns of thinking. Jane said that mindfulness practice felt like competing with her old self. Bradley noted that even though mindfulness requires practice, he perceived it as a positive change in his lifestyle. They noted that mindfulness is a toolkit or a toolbox that they can always refer back to as part of their lifestyle.

Supporting Quotes:

- “I just don't normally naturally think of it myself”
- “it's still a new concept”
- “at times you're threatened if you feel uncomfortable with certain concepts or change or whatever”
- “but this one is a positive one” (referring to the change mindfulness brings)
- “it's a huge step for me”
- “it's a big jump”
- “compete with your old self”
- “coz then I am battling myself”
- “just wanted to make sure I said those things they're actually that was a big deal for me”

***5.2.4 Phase 2- Creating themes associated with the categories of body, space, time, and relation (BSTR)***

I reviewed the data in order to determine if there were any patterns associated with lived body, lived space, lived time, and lived relation (BSTR) since they can determine phenomenologically guided lifeworld categories. I created a chart to present the themes found in the data for BSTR categories. The interpretation of the BSTR categories will be discussed in the next chapter.

<u>Body</u>	<u>Relation</u>
<p><b>Intimacy and sex</b></p> <ul style="list-style-type: none"> <li>• “because I think of this like that intimacy was like no efficient sex we’re good like we were both okay with it we both enjoyed it”</li> </ul> <p><b>Sex toys</b></p> <ul style="list-style-type: none"> <li>• “and he was even like do I need the vibrator and I am like no actually I am good”</li> </ul> <p><b>Sensate focus</b></p> <ul style="list-style-type: none"> <li>• “that helps ground yourselves” (sensate focus)</li> <li>• Grounding yourself with your partner</li> <li>• “it’s not going through the motions of intimacy and sex”</li> <li>• “I am at a place yeah where it’s comfortable” (sensate focus)</li> </ul> <p><b>Mindfulness and the Brain</b></p> <ul style="list-style-type: none"> <li>• “Training your brain to stop”</li> <li>• “my brain is a little more wired that way now or at least aware of it”</li> <li>• More aware</li> </ul> <p>Touch; sexual touch vs. Affectionate, non-sexual touch</p> <ul style="list-style-type: none"> <li>• “please come in the room and touch me”</li> <li>• “but with me he is now like we were in Finland he was constantly grabbing my hand”</li> </ul>	<p><b>Intimacy</b></p> <ul style="list-style-type: none"> <li>• “Because life changed, things between us slipped a little bit”.</li> <li>• “We lost that (intimacy) in that moment”</li> <li>• “It was as a couple it was intimacy that’s what (mindfulness) was really about to me”</li> <li>• “Reconnect again”; “connect again”. “It’s not going through the motions of intimacy and sex”.</li> <li>• “I am hugging him holding him”</li> </ul> <p><b>Communication; Responding in a kinder way to partner’s needs; different approach; improved listening and understanding of partner; increased openness</b></p> <ul style="list-style-type: none"> <li>• “Because of the study I find he responded to me that much more in kind than he had if we hadn’t done the study”</li> <li>• “We work better together this way”</li> <li>• “I do find that your approach is different to me though”</li> <li>• “he’s just more open to listening to me”.</li> <li>• “he’s more open and understanding of why I need to...”</li> </ul>

<p><b>“Managing MS”</b></p> <p><b>Anxiety</b></p> <ul style="list-style-type: none"> <li>• “He has more anxiety than he thinks he does”</li> <li>• “he doesn’t always identify that he’s anxious”</li> </ul> <p><b>Health changes related to MS</b></p> <ul style="list-style-type: none"> <li>• “when I had my last big attack it kind of became a lot more for me and I have a lot less control over it”</li> <li>• “I am this person but MS blew it up”</li> <li>• “It’s not you it’s my MS”</li> </ul> <p><b>Headspace (the mindfulness app); technology encouraging mindfulness practice</b></p> <ul style="list-style-type: none"> <li>• “I bought headspace” (a mindfulness app)</li> <li>• “but it made me try some of these apps that I probably wouldn’t have if I didn’t do the study so...it made me end up buying “ (the app)</li> </ul> <p><b>Benefits of conversations about mindfulness</b></p> <ul style="list-style-type: none"> <li>• “talking to you” (referring to talking about mindfulness during the interviews as part of the intervention)</li> </ul> <p><b>Benefits of mindfulness; how mindfulness is experienced in the body</b></p> <ul style="list-style-type: none"> <li>• “training your brain to stop”</li> <li>• “it calms me actually to think of nothing”</li> <li>• “Relaxing and refocusing on what’s happening”</li> </ul>	<p><b>Acceptance; pleasure-focused sexual encounters</b></p> <ul style="list-style-type: none"> <li>• “ I was okay with whatever happened in that moment with what he did yup”</li> </ul> <p><b>Benefits of Mindfulness</b></p> <ul style="list-style-type: none"> <li>• “I think we both find it (mindfulness) beneficial”.</li> </ul> <p><b>Sensate focus; easier because of accountability; aspects such as touch and eye contact; being present with partner</b></p> <ul style="list-style-type: none"> <li>• “I would do it more as a duo”.</li> <li>• “it’s easier for us coz then it holds him accountable too”.</li> <li>• I think that we’ve already kind of incorporated it as a staple”(mindfulness)</li> <li>• “stop that focus on the person in front of you”.</li> <li>• “please come in the room and touch me”.</li> <li>• “looking at each other coz you have to look at each other when you do it”.</li> </ul> <p><b>Relationship; being influenced by partner’s emotions; feeling negatively affected by how a partner handles anxiety</b></p> <ul style="list-style-type: none"> <li>• “the anxiety can get me a little...”</li> <li>• Feeling negatively affected by how a partner handles anxiety “it’s not good for me (his anxiety)”;</li> </ul>
<p><u>Space</u></p> <p><b>Consciousness/ Awareness</b></p> <ul style="list-style-type: none"> <li>• “I don’t think I would have been so cognizant of that (intimacy)... if we hadn’t done the study”</li> <li>• “recognizing”</li> </ul>	<p><u>Time</u></p> <p><b>Challenging to make time for mindfulness practice</b></p> <ul style="list-style-type: none"> <li>• “definitely it was a challenge in my schedule”</li> <li>• “ it did kinda get a little crazy”</li> </ul>

- “my brain is a little more wired that way now or at least aware of it”
- “you are more conscious”
- “if anything I realize now how much my mind does wander”
- “it was the slowing down part”
- “I am definitely more aware of it”
- “I am at the awareness stage”
- “the awareness thing”

### **Cognitive experience of mindfulness**

- “refocusing on what’s happening”
- “reset”
- “training your brain to stop”
- “yup I heard you (the thoughts) and then goodbye now moving on”
- “Acknowledge what you’re feeling”
- “you get more in tune with the moment”
- “it’s more of a toolkit” (mindfulness)
- “slow then refocus”

### **The effects of mindfulness on the ‘space’ of the relationship; a Mindful relationship mindset; mindful communication**

- “because of the study I find that he responded to me that much more in kind than he had if we hadn’t done the study”
- “you can’t truly know how I feel and think unless you’re totally asking me”
- “I do find that your approach is different to me though”
- “it’s helpful at least that he’s understanding of how I am affected or I am feeling that kind of thing”
- “there’s more we’ve communicated there’s more awareness”
- “we’re communicating better like I understand you more like for sure”
- “anticipation” (regarding planning date nights)
- “you needed to evolve and understand my MS”

- “when it got kinda hectic and crazy”
- “you have to carve out time for certain things” (mindfulness practice)
- “sometimes things are hectic”

### **Mindfulness seizes the moment**

- “brings you back” to that area where you can be intimate
- “go back”, “dial down”
- “coz it’s like you’re taking it back
- “connect again”, “reset”
- “take a time out”
- “training your brain to stop”
- “stop that focus on the person in front of you”
- “you get more in tune with the moment”
- “I enjoy it because it takes you back a bit”
- “it was the slowing down part”
- “slow and then refocus”
- “go back again for a second”

### **Mindfulness practice is a life-long journey**

- “it will be ever evolving for a while”
- “This is a lifelong thing” (mindfulness)
- “a work in progress”
- “this will be a very slow process” (mindfulness)
- Progress regarding mindfulness “I am like totally in infancy”, “I am still an infant”
- “it’s gonna take some time”

### **Acceptance of the moment**

- “I was okay with whatever happened in that moment with what he did yup”

**Cognitive benefits of mindfulness; Mindful sexuality**

- “he’s actually more comfortable”
- He's more comfortable with himself”
- “you’re more relaxed” (regarding his sexuality and the use of sex toys)
- “I wanna say more open-minded” (regarding sexuality)
- “I am like opening up”

**Benefits of sensate focus; Mindful sexual encounters; intimacy-oriented/focused sexual encounters instead of goal-oriented/focused sexual encounters**

- “not going through the motions” (of sex)
- “it’s more of a connection right it’s not just the act” (referring to sexual intercourse)
- “but I am saying that if we hadn’t necessarily done the study then maybe you know how I was thinking with my brain before I might have been ugh like that wasn’t quite what I was hoping it to be or something right”
- “and I don’t think I would have been so calm with that before if we hadn’t have done this because...”
- “so I don’t think if we had that then it would have been different situation or different feelings or thoughts around it kind of thing”
- “at least for me because you guys know my brain was different than his in the beginning so...yeah” (referring to expectations during sexual encounters)
- “I was actually okay”
- “Actually I am good”
- “I accepted it and I was good with it so I guess I am evolving a little bit there”
- “I think that I am gonna go back to intimacy is maybe if I didn’t have that

with him then it would be more of an issue for me”

- “I was okay with whatever happened in that moment with what he did yup”

**Mindfulness is exercise for the brain; Mindfulness requires practice; mindfulness involves ‘mental’ struggle like exercise; perceived as positive change**

- “training your brain to stop”
- “I just don’t normally naturally think of it myself”
- “it’s still a new concept”
- “at times you’re threatened if you feel uncomfortable with certain concepts or change or whatever”
- “but this one is a positive one” (referring to the change mindfulness brings)
- “I am incorporating mindfulness not just in one aspect” (referring to incorporating mindfulness in other aspects such as sleep and hiking)
- “I am getting it” (referring to mindfulness and sensate focus)
- “I am starting to get there”(referring to mindfulness and sensate focus)
- “it’s a huge step for me”
- “it’s a big jump”
- “compete with your old self”
- “coz then I am battling myself”
- “just wanted to make sure I said those things they’re actually that was a big deal for me”

**Cognitive effects of MS; The need to ‘feel’ in control; management of MS; sense of self and MS (the use of word my)**

- “I had an issue with MS I became completely antisocial”
- “Because I can’t control my MS so it’s...making my brain go a little...”
- “she’s trying to control certain aspects coz she can’t control the MS”
- “manage MS”

- “it’s not you it’s my MS”
- “you can’t truly know what I feel and think unless you’re totally asking me”
- “you needed to evolve and understand my MS”

**The use of technology for mindfulness;  
Mindfulness apps (Headspace)**

- “but it (the intervention) made me try some of these apps that I probably wouldn’t have if I didn’t do the study...so it made me end up buying the app”
- “having the toolbox (mindfulness) and now having this app”
- “I need guided (meditation)”

**The conversations during the intervention helped in incorporating mindfulness**

- “talking to you”
- “and also like all the conversations we’ve had umm I am aware of it more in regards to Jane”

**Mindfulness correlates with Acceptance  
Non-judgment**

“I was actually okay”

“I accepted it and I was good with it so I guess I am evolving a little bit there”

“I was okay with whatever happened in that moment with what he did yup”

“you get more in tune with the moment”

**Distraction by thoughts during sex**

- “but those are the types of thoughts that I will have during sex sometimes”
- “we’ll be kissing or something and I’ll be...this thought pops into my head”
- “I don’t have control” (over the thoughts)
- “you can’t control thoughts”

**Anxiety; acknowledging anxiety**

- “my mind is so crazy”
- “anxious”

<ul style="list-style-type: none"> <li>• “he has more anxiety than he thinks he does”</li> <li>• “I don’t think he even realizes it” (anxiety)</li> <li>• “he doesn’t always identify that he’s anxious”</li> <li>• “he’s fanatic”</li> <li>• “You don’t...acknowledge it” (anxiety)</li> <li>• “you don’t acknowledge that you’re anxious”</li> <li>• “I just want him to recognize” (the anxiety)</li> <li>• “because my mind does race”</li> </ul>	

The space aspect of mindfulness constituted of awareness, acceptance, and intimacy. It appears that mindfulness is correlated with awareness and acceptance which enhanced intimacy in the relationship which in turn increased sexual satisfaction. The time aspect of BSTR revealed that even though mindfulness practice requires commitment regarding setting time aside for mindfulness, which was found to be challenging for the couple, once time ‘stops and ‘slows down’ as a couple practices mindfulness, other aspects such as space and relation take over. It appears that time ‘stops’ or ‘slows down’ via acceptance of whatever is happening in the present moment. In turn, acceptance of the present moment and ‘non-judgement’ enhance sexual satisfaction by focusing on what feels good in the present moment as opposed to anticipating outcomes during sexual encounters. The relation aspect of BSTR constitutes of communication and accountability as the main factors. It appears that mindfulness practice improved communication between the couple by emphasizing awareness and being attuned to partner’s

needs which in turn contribute to increased sexual satisfaction. Because sensate focus required and encouraged accountability between members of the couple, that may have resulted in an improvement in communication which contributes to relationship satisfaction (which is correlated with sexual satisfaction). The body aspect of BSTR included physical aspects of sensate focus such as touch, intimacy, and the use of sex toys for added stimulation. The body appears to have minimal presence across BSTR categories which suggests that mindfulness may contribute to and improve sexual satisfaction by targeting and influencing the Space, Time, and Relation aspects of BSTR. This also suggests that intimacy has little to do with the body. In other words, it appears that the Body aspect is a ‘vehicle’ through which intimacy can be experienced and expressed in the physical world.

#### **How the thematic patterns relate to each other across BSTR:**

Since one of the discerned themes was the essence of mindfulness as it relates to time (stop, refocus, reset), I believe this has led to invoking a huge expansion of space which suggests that the ‘stopping’ or ‘slowing down’ of time has contributed to the constitution of a ‘couple space’ that previously constituted of two individuals engaging with each other but still essentially separate.

In addition, it appears that the ‘body’ aspect has minimal presence across BSTR which suggests that intimacy in a relationship seems to develop out of the ‘couple space’ and as a result of the expressive communication that was enhanced through mindfulness practice.

#### **Chapter 6.0- Discussion**

The purpose of this study was to investigate the effects of a modified 8-week mindfulness intervention in couples where one or both partners are living with neurotraumatic disability such

as SCI or MS. It was hypothesized that sexual satisfaction would increase after the 8-week mindfulness intervention compared to sexual satisfaction at baseline prior to the intervention. It was also predicted that themes regarding mindfulness and its influence on sexual satisfaction would be discerned. This chapter will be used to discuss the findings in chapter five.

The following section reviews the findings that relate to the effects of mindfulness and sensate focus on sexual satisfaction and other aspects of the couple's relationship. These findings were discovered through phase two of analysis [body, space, time, and relation (BSTR)]. BSTR categories were used to guide data analysis as typically they are phenomenologically guided lifeworld categories.

### ***6.1 Sensate Focus***

The couple mentioned throughout the interview that intimacy was enhanced between them as a result of practicing sensate focus exercises. There was a theme about sensate focus benefits which include grounding one's self in the presence of a partner and reminding them not to go through the motions of sex. In addition, through sensate focus, the couple was reminded that sexual encounters are about the connection and not just the act of sexual intercourse. Sensate focus has also enhanced acceptance of the present moment, a theme that appeared throughout the interview. Specifically, they mentioned that through sensate focus, they were calmer about accepting whatever happens during their sexual encounters without placing judgment or expecting a certain outcome. Sensate focus encouraged the couple to focus on the intimacy and connection between them which fostered pleasure as opposed to focusing on performance or outcomes. They repeatedly mentioned that their perspective was completely different prior to participating in the study.

## ***6.2 The experience of mindfulness***

The couple mentioned throughout the interview that the process of being mindful involved bringing one's focus back to the present moment and 'refocusing' on what's happening in the moment. It also involved a 'reset' and training the brain to 'stop'. They also mentioned that mindfulness involved 'slowing down'. In addition, they noted that mindfulness involved acknowledging the thoughts that emerge then letting them go instead of holding on to them or repressing them. Mindfulness involved acknowledging one's feelings in the moment and getting 'in tune' with the moment.

They described mindfulness as a 'toolkit' that can be utilized and practiced whenever possible and necessary.

### ***6.2.1 Mindfulness and sexuality on the individual level***

The couple reported that on an individual level, mindfulness practice has resulted in feeling more comfortable with one's self, feeling more comfortable in one's body, and feeling more relaxed regarding one's sexuality. In addition, they reported that mindfulness has contributed to feeling more open-minded regarding sexuality and the use of aids such as sex toys. The couple reported that they both found mindfulness practice to be beneficial.

### ***6.2.2 Mindfulness and the relationship***

The couple reported that as a result of mindfulness training individually and as a couple, they responded to each other in a kinder manner compared to prior to taking part in the study. They learned the importance of checking in with each other and sharing their feelings and thoughts, especially during conflict. They said that their approach to each other and particularly regarding responding to each other's needs has become different as a result of practicing mindfulness. They reported an improvement in understanding each other's needs, improved and

increased communication, increased awareness, and better understanding of how MS affects the female partner and how her partner can support her better.

### ***6.2.3 Mindfulness and Acceptance***

There was a theme throughout the interview that mindfulness practice and sensate focus fostered a feeling of acceptance. Specifically, acceptance of whatever happened in the moment during sexual encounters. Acceptance was associated with feeling ‘in tune’ with the moment.

### ***6.2.4 Mindfulness and Awareness***

They reported an improvement in awareness as a result of engaging in mindfulness practice and sensate focus. There was a theme that they wouldn’t have been so ‘cognizant’ of the state of intimacy in the relationship if they didn’t take part in the study and practiced mindfulness. They mentioned that their brains are more ‘wired’ in a different way and they have become more ‘aware’. They also reported becoming more ‘conscious’ and noticing and realizing how much their minds wander. They mentioned that it was due to the fact that mindfulness and sensate focus encourage ‘slowing down’ which in turn promotes better awareness.

### ***6.3 Using technology for mindfulness: Headspace (a mindfulness app)***

They reported that as a result of participating in the study, they decided to purchase Headspace, a popular mindfulness and guided meditation application that contain guided mindfulness sessions for different things such as sleep, hiking, and gratitude. They noted that the app is helping them incorporate mindfulness in other aspects of life other than sexuality.

### ***6.4 Challenges with mindfulness practice***

The couple referred to mindfulness as ‘training’ and they mentioned that it’s not something that happens ‘naturally’. They said that mindfulness is still a new concept and it requires ‘competing’ with one’s old self. It was also noted that mindfulness practice was a ‘big

jump' and a 'huge step'. They reported that even though changes can be threatening, mindfulness is considered a positive change. The partner living with MS reported incorporating mindfulness in other aspects of life such as sleep and hiking, and she reported encouraging her partner to participate with her.

They noted that they found it challenging to schedule mindfulness as part of their day because life became hectic and busy for them. However, they mentioned that it required dedication and 'carving out time' for mindfulness practice.

### ***6.5 Psychoeducation***

The study included a psychoeducation session that was offered at week five of the intervention. The purpose of the psychoeducation session was to challenge thought patterns and negative beliefs regarding sexual activity and sexuality and disability. The psycho-education session was led by the clinical sexologist that was part of the project and the principle student investigator. The psycho-education session included having conversations with the couple regarding common beliefs about sexuality after disability such as "my sex life is over". "if it's different it's no good", "I am not normal", and "if it's not spontaneous, it's pointless" (Weiner & Avery-Clark, 2018).

Tepper (2000) argued that it's the way in which individuals think about touching and sex that plays a vital role in their sexual experiences and sexual function. Hence, beliefs about touching and sex have a greater negative influence on the implementation of sensate focus (Weiner & Avery-Clark, 2018). For that reason, as per the recommendation of Weiner & Avery-Clark (2018), the psychoeducation session was offered at week five of the study before the start of sensate focus at week six in order to ensure that the couple carry out sensate focus exercises successfully and reap the benefits of engaging in sensate focus. This demonstrates the

importance of including psychoeducation as part of sexual rehabilitation programs for individuals with neurological disabilities such as SCI and MS.

### ***6.6 Recruitment challenges in the study***

In terms of recruitment, it was challenging to recruit individuals living with a neurological disability such as spinal cord injury. It appears that sex continues to be perceived as a “taboo” topic and individuals living with SCI may still hesitate to discuss their sexuality. Because there was difficulty recruiting individuals with spinal cord injury and their partners, the study was opened to include couples where one or both partners are living with Spina Bifida and MS.

Another issue related to recruitment was the difficulty enrolling couples to participate in the intervention. Despite a relative interest in participating in the study from individuals with SCI and MS, they expressed that it was difficult to get their partners to join them in taking part of the study for reasons that include being busy, difficulty finding a time where both partners can be present, and a partner not wanting to discuss sexuality or not caring enough about sex as part of the relationship.

### ***6.7 Implications of findings***

The results of this study demonstrated the importance of including sex therapy as part of sexual rehabilitation programs after a neurological disability. Counselling regarding relationship issues and sexuality appears to be critical for individuals living with neuromuscular disability and their partners.

This is consistent with previous research that showed that surveyed individuals who have completed rehabilitation after SCI have expressed a need for more education and counselling on sexual health and relationship concerns as part of rehabilitation (Elliott & McBride, 2014).

Sexual rehabilitation programs need to take a different approach regarding the sexuality of partnered individuals living with neurological disabilities. This has the potential to improve quality of life for individuals living with neuromuscular disabilities and their partners. Partnered individuals living with neurological disabilities require a different type of sexual rehabilitation that considers their sexual concerns as well as relationship/sex therapy and counselling to ensure couples have the necessary skills to maintain a healthy relationship.

The results of this study demonstrated that sexual satisfaction is associated with relationship satisfaction and that targeting sexual satisfaction in partnered individuals living with neuromuscular disability cannot be separated from the rest of the relationship.

The results of this study also demonstrated the effectiveness of using sensate focus exercises (which are a direct application of mindfulness) as part of sexual rehabilitation for individuals living with neuromuscular disability.

Sensate focus is used in sex therapy frequently and its importance lies in encouraging individuals to focus on pleasure and enjoying sexual encounters in the present moment as opposed to having performance-based, goal-oriented sexual encounters. These concepts are essential for both able-bodied individuals and those living with physical disabilities. It's important to note that sensate focus operates by allowing sexual tension to build in a non-demand way and works under the belief that sex is a natural function. Hence, the more desire and arousal are not the goal, the more likely for the individual to experience sexual arousal and desire (Weiner & Avery-Clark, 2018; Masters & Masters, 1980)

This study advocates for the inclusion of Mindfulness and sensate focus as part of sexual rehabilitation for individuals with neuromuscular disabilities because they encourage the focus on pleasure in sexual encounters as opposed to focusing on sexual function, performance, and

fertility; areas that research typically have focused on. Specifically, medicine as a whole, healthcare professionals and even researchers have targeted sexual function and performance-related areas such as ejaculation, orgasm, and fertility. Weiner & Avery-Clark (2018) have argued that the field of sexuality had become ‘medicalized’ in a large measure. This is consistent with previous work by Tepper (2000) where he argued for the inclusion of pleasure when discussing sexuality after SCI and physical disabilities in general.

This study represents a direct application of the Sexual Rehabilitation Framework (SRF). One of the principles of the sexual rehabilitation framework is maximizing the remaining capabilities of the body, as a first step in sexual rehabilitation, before relying on medications or external aids. Maximizing the remaining capabilities of the body can be done using new body maps, breathing and/or mindfulness practices (Elliot & McBride, 2014). As such, sensate focus encourages sexual healing of the whole person. In addition, sensate focus emphasizes the power of touch, which is believed to be the first sensory system to develop (Weiner & Avery-Clark, 2017). Furthermore, touch is believed to possess life-giving energy which sensate focus harnesses during sexual encounters. As a result, touch is said to have healing effects on sexual responsiveness and feelings of well-being which may result in an improvement in quality of life (Weiner & Avery-Clark, 2018).

## **Chapter 7.0- Conclusions**

The findings of this study show promise for mindfulness-based therapies and interventions as a part of sexual rehabilitation for individuals living with neurological disabilities and their partners. In addition, findings advocate for the inclusion of sex therapy tools such as sensate focus in sexual rehabilitation programs. The results demonstrate the importance of psychoeducation and having frank, ‘non-clinical’ conversations with individuals with

neuromuscular disabilities and their partners regarding their sexual beliefs and thought patterns. Finally, based on the findings of this study, sex therapy and counselling should be integrated in sexual rehabilitation programs for such individuals.

Future studies should consider investigating the effects of mindfulness-based interventions and sensate focus on a larger number of couples living with a variety of neurological disabilities. In addition, future research should consider shorter mindfulness-based interventions. Finally, further research is required to investigate the effects of mindfulness-interventions on sexual satisfaction in men living with neuromuscular disability since studies have only examined mindfulness as part of women's sexuality.

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## Chapter 9.0: Data Manual

### Letter of Invitation

#### **Mindfulness Therapy as a Means to improve Sexual Satisfaction in Couples Living with Spinal Cord Injury**

Please consider this an invitation to voluntarily participate in a research investigation examining the effects of a mindfulness intervention on sexual satisfaction in couples with spinal cord injury. This study will be directed by Dr. David Ditor of the Department of Physical Education and Kinesiology at Brock University. In this letter, you will find a detailed description of the study that will assist you in your decision to either participate, or not participate in this study. Please take a minute to carefully read through this letter. Do not hesitate to ask for clarification, or to ask any questions you may have regarding either this letter or the study. Should you require further information, please contact the principle student investigator or the faculty supervisor using the contact information provided below.

**Principle Student Investigator:** Merna Seliman, Graduate Student, Department of Kinesiology at the faculty of Applied Health Sciences, Brock University.  
(289)-990-3364  
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**Research assistant:** Tim Sullivan, Undergraduate Honours Thesis Student, Department of Kinesiology, Brock University.

**Faculty Supervisor:** Dr. David Ditor, Professor, Department of Kinesiology, Brock University.  
(905) 688-5550, extension: 5338  
[dditor@brocku.ca](mailto:dditor@brocku.ca)

This study has been approved by the Brock University Ethics Board (File number 18-089-DITOR). Should you require further information regarding the ethical approval of this study, please contact Lori Walker at the Brock University Ethics Board: 905-688-5550, ext. 4876.

#### **PURPOSE OF THE STUDY**

The purpose of this study is to examine the effects of an 8-week mindfulness-based training on sexual satisfaction for couples where one or both partners has a spinal cord injury. The hope is that by investigating the effects of mindfulness on sexual satisfaction, which is often overlooked for couples with spinal cord injury, we will be able to cultivate the benefits of mindfulness training as a critical component of sexual rehabilitation for couples with spinal cord injury. Also, the results of this investigation can guide future studies by providing a foundation for future interventions that target sexual satisfaction in couples with spinal cord injury as well as provide health-care practitioners with guidance on how to counsel couples with spinal cord injury for sexual rehabilitation purposes.

#### **STUDY PROCEDURES**

Should you and your partner choose to participate in this study, which will last a total of 8 weeks in addition to a 6-week follow-up period, you will be required to complete a 90-minute interview with the researcher, where you will be asked to complete a sexual satisfaction questionnaire individually. After the first interview, you will be given a booklet that contains mindfulness-based practices that you can take home and participate in for 8 weeks. The researcher will go over these practices and will answer any questions you may have during the first baseline interview. Also, a total of 4 psychoeducational sessions (about an hour each) will be offered during the 8 weeks in order to shed light on topics related to sexuality/sexual satisfaction such as body image, how sexuality is affected by SCI and some limiting beliefs that may affect sexuality. During these sessions, some mindfulness exercises will also be

practiced, and the researcher can answer any questions you may have. In addition, during the 8 weeks, you will have the option of meeting with the student principal investigator or schedule a phone meeting with her to ask any questions you might have about the exercises assigned for that week, however, you are not obligated to do so if there are no questions or concerns. The mindfulness-based exercises are to be carried out at home. One to three hours per week are anticipated for these exercises, which corresponds to three sessions per week. After 8 weeks, you will be required to participate in a 90-minute interview where you will be asked to discuss your experiences with the mindfulness practices as well as complete the sexual satisfaction questionnaire for a second time. You will be encouraged to continue incorporating these practices for another six weeks, without obligation, while keeping in mind any tips that you will have received from the researcher during the second interview. After another six weeks, you will be required to participate in a final 90-minute follow-up interview, where you will be asked to discuss your progress and your overall experiences with the mindfulness-based practices and complete the sexual satisfaction questionnaire one final time. Throughout the period of the intervention, you will be required to keep a log of your time commitment, including the six-week follow up period. All interviews will take place at the Brock-Niagara Centre for Health and Well-being, located at 130 Lockhart Drive in St. Catharines, Ontario, in the Brock Research and Innovation Centre. All interviews will be audio recorded and transcribed verbatim. During the interviews, you will have an excellent opportunity to share your stories, your knowledge, your experiences, and any concerns you might have.

### **POTENTIAL RISKS**

Discussing experiences of a personal nature may create some feelings of trepidation, and talking about an issue of such importance may increase sensations of emotional stress. Please keep in mind that you will be able to avoid answering any questions that make you feel uncomfortable. Furthermore, the researcher has participated in a formal phenomenological interviewer training and is prepared to manage these risks.

### **POTENTIAL BENEFITS**

Potential benefits of participating in this study include the opportunity to discuss your experiences, concerns, and frustrations, as a couple, regarding a significant topic that has, for the most part, been left unstudied. You will have the opportunity to learn about a variety of mindfulness-based practices that may help increase your sexual satisfaction. You will have the opportunity to reconnect with your partner by participating in the mindfulness exercises together and working towards a common goal, which may help you cultivate a stronger relationship. The information that is revealed during this investigation will have the ability to guide future research to ensure that sexual satisfaction is targeted by researchers and health care practitioners in a manner that is based on practices that have been proven to be beneficial for couples with spinal cord injury.

### **COMPENSATION**

There will be no financial compensation for participation in this study.

### **CONFIDENTIALITY**

The information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, with your permission, a pseudo name and anonymous quotations may be used. Shortly after the interviews have been completed, you can request a copy of the transcript if you would like an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

### **VOLUNTARY PARTICIPATION**

Participation in this study is strictly voluntary and the choice whether or not to participate is up to you. You have the right to forfeit answering any question(s) you choose while still remaining in the study, as well as the right to withdraw from the study at any time without penalty.

### **ACCESSING FINDINGS OF THIS STUDY/ PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. A one page summary of the findings will be mailed to you upon completion of the study. You will also have the option of receiving a full copy of the completed paper.

### **CONSENT FORM**

I agree to participate in the study described above and I have made this decision voluntarily based on the information provided in the Information-Consent Letter. The study has been explained to me and any questions I that I had have all been answered to my contentment. I understand that I may ask additional questions in the future, and that I maintain the right to withdraw this consent at any time.

Name (please print): \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Person obtaining informed consent (please print): \_\_\_\_\_

Signature of person obtaining informed consent: \_\_\_\_\_ Date: \_\_\_\_\_

### **Baseline Interview Guide**

Demographics (age, relationship status)

Medical History

Do you experience pain?

- Onset of pain
- What provokes it?
- Can you describe the pain?
- Region pain experienced? Radiation/spreading?
- Severity (rate the pain from 1-10)
- Time (how long?)
- What helps relieve the pain?

How often do you discuss problems/issues with your partner? Close family? Friends? Anyone?

How do you benefit from sharing that information with them?

Do you have a religious affiliation? How does that affect your ability to cope with issues?  
How does it affect sexual expression?

In terms of types of sexual activity

How often do you fantasise?

What do your fantasies typically entail?

How do these fantasies affect your sexual expression when alone? With partner?

How often do you experience orgasm from fantasy alone?

How old were you when you first began to explore your own body in a sexual way?

How old were you when you first masturbated?

How do you feel safe/enjoy self-pleasure?

What techniques do you utilise? Toys? Erotic materials?

Do these increase enjoyment?

Do you use these with a partner? In what way?

Do they increase pleasure for you? For partner? How so?

How often do you experience orgasm from masturbation alone?

Do you practice

hand/genital stimulation (receiving/giving)?

Oral/genital stimulation (receiving/giving)?

Genital/genital stimulation (receiving/giving)?

Anal/genital stimulation (receiving/giving)?

How often do you experience orgasm with a partner? With each of those partnered stimulation?

How important is it for you to reach orgasm? For partner to reach orgasm?

How does sexual satisfaction contribute to your quality of life?

### **Post-Intervention Interview Guide**

- 1- How was it like to schedule the mindfulness exercises as part of your day/week?
- 2- How does being mindful 'feel' to you individually and as a couple?
- 3- How was it like to practice the sensate focus exercises together as a couple?
- 4- How did mindfulness affect your sexual satisfaction individually and as a couple?
- 5- What was it like doing the exercises individually versus as a couple? What were the benefits, challenges?
- 6- How do you see yourself maintaining what you've learned?
- 7- Would you revisit these sensate focus exercises again on your own in the future?
- 8- How did your perspective regarding your sexuality change? Do you feel intimacy is expressed between the two of you differently now than before?