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Client Perspectives of Engaging in Romantic Relationships After a Spinal Cord Injury: A Phenomenological Inquiry

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By

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Author Note

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Introduction

Intimacy and romantic relationships are an integral component of an individual. Not only do intimacy and relationships provide love and support through one's lifetime, but it also serves as a built-in friendship. Social support, including that of a significant other, can increase an individual's life satisfaction, self-esteem, and well-being (Ferreira et al., 2014; Stronge et al., 2019; Umberson & Montez, 2010). Being in a romantic relationship also teaches the individual to have a sense of responsibility and a concern for others, something they may not have if they were not involved in a relationship (Ferreira et al., 2014; Umberson & Montez, 2010).

While intimacy serves many benefits, it is important to note how relationships can change after the onset of an injury or disability, particularly a spinal cord injury (SCI). A SCI can change the way that the individual looks at the world, and the intimate partner also has an altered view, especially of the relationship that they are involved in. If an individual is in a relationship at the time of injury, there is an increased risk of separation or divorce (National Spinal Cord Injury Statistical Center [NSCISC], 2020). If, though, the individual is not in a romantic relationship at the time of injury, they may feel as if they will never be involved in a relationship for many reasons, including the thought that no one will ever love them because the SCI makes the individual unattractive (Angel & Kroll, 2020; Fritz et al, 2015). While there are certainly reasons why individuals may feel as if they will never have a relationship again, there are also many reasons why being in a relationship after a SCI can be beneficial, such as having support and someone to talk to as the individual goes through the many life changes that arise from the injury (Umberson & Montez, 2010).

It has been found that many individuals want to discuss the future potential of romantic relationships and the ability to have children after a SCI, however it is not often brought up during occupational therapy rehabilitation (Lohman et al., 2017; Walker, 2020; Walker et al., 2020). Many students do not learn how to have these discussions with their future clients while in school, and therefore practitioners have no practice with it, leading them to ignore the topic in general (Areskoug-Josefsson et al., 2016; Lohman et al., 2017; Walker et al., 2020). However, occupational therapy is such a client-centered and holistic field that these discussions need to take place in order to provide the best care for clients, and so that they benefit from all the information in rehabilitation as much as possible (Walker, 2020; Walker et al., 2020). While there has been minimal standardized assessments and intervention plans specific to this topic in the past, recently there has been further development in this area of occupational therapy (Walker, 2020; Walker et al., 2020).

Literature Review

Currently, there is a vast amount of literature that describes the role that intimacy and romantic relationships can play in an individual's life, including the benefits of this type of relationship. However, intimacy looks different in individuals with a disability, specifically a SCI, as there are numerous barriers that may prevent them from participating in such relationships. Many individuals during SCI recovery have worries of engaging in intimacy, however the rehabilitation team may rarely, if ever, address these concerns.

Spinal Cord Injuries

A spinal cord injury results from any damage to either the spinal cord itself or the nerves at the end of the spinal canal. This type of injury can result in various complications and/or paralysis of different extremities (Mayo Clinic, 2019).

Prevalence

Spinal cord injuries are very prevalent worldwide. There are approximately 294,000 people in the United States currently living with a SCI and approximately 17,810 new cases are reported every year (NSCISC, 2020). This equivalates to 54 new cases per one million Americans. Worldwide, there are approximately 250,000-500,000 new cases every year (Maitan et al., 2018). In addition, SCIs more frequently occur in males than in females (Fritz et al., 2015; NSCISC, 2019; NSCISC, 2020; Putzke et al., 2001). According to the NSCISC (2019), approximately 80.4% of all SCIs occur in men, although depending on the state, that percentage can range from 61.4% to 87.0%. One reason that SCIs are more likely to happen to men are because men are more apt to participate in riskier behavior, and therefore are more likely to get injured doing these risky actions (Putzke et al., 2001).

While SCIs can happen in a variety of ways, there are certainly leading causes. The three leading causes of SCI are vehicular accidents (38.6% of cases), falls (32.2% of cases), and violence (14% of cases; NSCISC, 2020). The most common type of violence that leads to a SCI is a gunshot wound (NSCISC, 2019). Maitan et al. (2018) also found that automobile accidents and violence were two leading causes of SCI, however they also found that a lack of work safety programs is also a leading cause of injury. Therefore, a SCI can occur in a variety of settings, including an individual’s workplace.

Finally, there are many complications that can result from a SCI. The most prevalent complications include urinary tract infections, bowel and bladder complications, and pressure sores or ulcers (Conti et al., 2019; NSCISC, 2019). Two other less common complications include pain and spasticity (Conti et al., 2019). While each individual experiences a different recovery process, there are usually consistent complications that every individual with a SCI is at higher risk of developing, such as the three listed above.

Timeline of Spinal Cord Injuries

The majority of SCIs occur during early to middle adulthood (Fritz et al., 2015; NSCISC, 2019; NSCISC, 2020). Almost half of all SCIs occur between ages of 16 and 30 years (NSCISC, 2019). However, the mean age of injury has been increasing throughout the past 50 years. For example, the average age of a person sustaining an initial SCI in the 1970s was 29 years, while the average age of a person sustaining a SCI now is 43 years (NSCISC, 2020). While the average age of an individual with a SCI is older than it has been in the past, a large proportion of injuries still occur during the most common childbearing ages (Fritz et al., 2015; NSCISC, 2019). Therefore, many individuals are trying to work their way towards starting a family when this major health change occurs. This may drastically change the timeline for settling down with a significant other and creating a family (Fritz et al., 2015).

Based on the data from the NSCISC (2020), relationship statuses are likely to change throughout the 45 years after the SCI was acquired. For instance, 44.6% of individuals are single when the SCI is obtained (NSCISC, 2020). When data was analyzed, the NSCISC found that this number of single individuals continued to decrease throughout those next 45 years, ultimately landing at 24.7% of individuals with a SCI who are single at 45 years post injury (NSCISC, 2020). While being single decreased, marital status also changed. The percentage of individuals with a SCI that are married decreased as well throughout rehabilitation. Upon the initial SCI, 37.4% of individuals are married, however that number steadily decreased to 33.6% of individuals at 20 years post injury (NSCISC, 2020). After that initial decrease, the percentage of individuals who are married with a SCI increased to 44.2% at 40 years post injury (NSCISC, 2020). This data is supported by the rate of divorce after a SCI. At the time of injury, only 8.6% of individuals are divorced. However that number steadily increased to 20.1% of individuals who are divorced ten years post SCI. That number then stabilized and stayed at approximately 21% up to 45 years post injury (NSCISC, 2020). Based on the retrospective statistics provided by the NSCISC (2020), there is a greater chance of getting a divorce within the first ten years of a SCI, however, if the couple is able to make it through that initial period of distress, they are not as likely to change their marital status.

Spinal Cord Injury Levels and the American Spinal Injury Association Scale

The severity of a SCI depends on the level and scale of the injury acquired. For instance, typically, the higher on the spinal cord the injury occurs, say the cervical region, the more severe an injury is, meaning the more tasks may need to be modified or adapted for the individual (Bashar and Hughes, 2018). Therefore, an individual with a SCI at the cervical level will typically require more assistance or adaptations than someone with a SCI at the lumbar region. The American Spinal Injury Association (ASIA) has classified SCIs into five levels, outlined by the ASIA Impairment Scale (AIS; Bashar & Hughes, 2018). These five levels are broken down into AIS A, B, C, D, and E (Table 1; American Spinal Injury Association [ASIA], 2015). In addition, SCIs can be categorized as to whether they are complete or incomplete injuries. If the individual does not have motor control or sensation in the genital area or sacral vertebrae S4-S5, then they have a complete SCI, whereas if the individual does have voluntary control or sensation in the same area, it is classified as incomplete (Bashar & Hughes, 2018).

Table 1

Classification of Spinal Cord Injuries Using the American Spinal Injury Association Impairment Scale (AIS)

AIS A (complete)	No motor or sensation in vertebrae S4-S5
AIS B (sensory incomplete)	Sensation, but no motor control under the level of injury, which includes vertebrae S4-S5
AIS C (motor incomplete)	Motor function below the level of injury, and over half of the muscles below the level of injury have a manual muscle testing score of less than three, or fair
AIS D (motor incomplete)	Motor function below the level of injury, but at least half of the muscles below the level of injury have a manual muscle testing score of three or greater
AIS E (normal)	Typical sensation and motor control below the level of injury

(ASIA, 2015)

Intimacy and Sexuality

Intimacy and sexuality are two very broad terms that have been defined differently throughout the literature. When someone usually thinks of intimacy and sexuality, one of the first aspects that comes to mind is the physical part of a relationship (Angel & Kroll, 2020). McGrath & Sakellariou (2016) define human sexuality broadly, as “a concept that encompasses gender identities and roles, eroticism, sexual orientation, intimacy, sex, and reproduction” (p. 7001360010p1). However, intimacy refers to more than just the physical aspect, it encompasses the emotional side as well. For instance, Ferreira et al. (2014) defined emotional intimacy as “a multidimensional construct consisting of self-disclosure, closeness, expression of affection, personal validation and trust” (p. 391). To better understand the relationship between these terms, Rowsell & Coplan (2013) defined intimacy as the “closeness and interdependence, affection and warmth, and the extent of self-disclosure within a romantic relationship,” while sexual satisfaction refers to “the thoughts and feelings, personal and sociocultural attitudes, and biological variables that contribute to an individual’s positive sexual experiences” (p. 288). Furthermore, Walker (2020) provides an even broader definition of sexuality by saying the following:

> The nature of sexuality is complex and encompasses sex, gender identities and roles, sexual orientation, intimacy, and reproduction; is influenced by the interplay between psychological, biological, social, economic, political, cultural, legal, historical, religious, and spiritual factors; and is expressed in attitudes, values, beliefs, behaviors, practices, roles, and relationships. (p. 5)

Occupational Therapy Definitions

The American Occupational Therapy Association (AOTA) has worked to expand their own definitions of intimacy and sexuality within the past few years. As shown by the following definitions, sexuality is often used as an umbrella term, which intimacy falls under. In 2013, AOTA defined sexuality as more than an integral part of a person, by stating the following:

> [Sexuality] is a state of mind, representing our feelings about ourselves, what it’s like to be male or female, how we relate to people of our own gender and those of the opposite

> gender, how we establish relationships, and how we express ourselves. (MacRae, 2013, p. 1)

As shown by this definition, sexuality is a state of being, not just the physical aspects of sex. Further in the article, the author mentions that “holding hands, flirting, touching, kissing, masturbating, and having sexual intercourse are just some of the ways in which sexuality can be expressed” (MacRae, 2013, p. 1). While these are mostly all still physical aspects, it highlights that intimacy and sexuality are more than the physical act of having sexual intercourse.

The Occupational Therapy Practice Framework (OTPF) III, an official AOTA document that summarizes the scope of occupational therapy practice, did not specifically highlight intimacy and sexuality throughout the document, but instead covered it briefly (American Occupational Therapy Association [AOTA], 2014). For example, sexuality is mentioned in the definition of occupation, but in a very broad sense: “Occupation is used to mean all of the things people want, need, or have to do, whether of physical, mental, social, sexual, political, or spiritual nature and is inclusive of sleep and rest” (AOTA, 2014, p. S6). Sexual activity is specifically mentioned once as an occupation listed under ‘Activities of Daily Living’ and is defined as “engaging in activities that result in sexual satisfaction and/or meet relational or reproductive needs” (AOTA, 2014, p. S19). This definition only focuses on the physical aspects of sexuality and does not mention any of the emotional characteristics discussed above. The only other time that sexual activity is mentioned explicitly in the OTPF III is in the terms of social participation. The document states that participating with a peer or friend can be “engaging in activities at different levels of interaction and intimacy, including engaging in desired sexual activity,” (AOTA, 2014, p. S21). There are no further mentions of sexual activity, sexuality, or intimacy.

The newly released OTPF IV has an expanded view of intimacy and sexuality in two very prominent ways. First and foremost, the definition of sexual activity has been revised to read: “engaging in the broad possibilities of sexual expression and experiences with self or others (e.g. hugging, kissing, foreplay, masturbation, oral sex, intercourse)” (AOTA, 2020, p. 30). While the focus here is still on the physical aspects of sexuality, it expands the viewpoint to include not only the actions of sex, but also hugging and kissing, two broader areas of intimacy. The other main distinction between the OTPF III and IV is that now ‘intimate partner relationship’ has its own section under social participation, which is a change from the OTPF III, which listed intimacy under the friend or peer section. As there is a new category, there is also a new definition, which reads “engaging in activities to initiate and maintain a close relationship, including giving and receiving affection and interacting in desired roles; intimate partners may or may not engage in sexual activity” (AOTA, 2020, p. 34). This view expands the idea to include both physical and emotional aspects of intimacy.

Furthermore, the OTPF IV goes into more discussion of sexuality and intimacy as it is discussed more throughout the document. For example, sexual orientation, which encompasses both sexual preference and sexual identity, is now perceived as a personal factor of the client, which is typically an important attribute of the client (AOTA, 2020). Therefore, AOTA recognizes that sexuality and intimacy are integral parts of a person’s identity and that it is important to recognize this while treating a client for occupational therapy. In addition, this new document recognizes that past sexual experiences may shape the individual differently. AOTA acknowledges that someone with a traumatic sexual experience may view and react to sexual intimacy differently than others (AOTA, 2020). Ideally, through expansion of the definitions of sexuality, the OTPF IV allows occupational therapy practitioners, students, and other healthcare workers to think more about a client’s sexuality and intimacy needs and will promote more open conversation with their clients.

Benefits of Intimacy and Relationships

Intimacy and romantic relationships can have an effect on individuals’ life satisfaction, self-esteem, and wellbeing, which is strongly tied to the quality of an individual’s social support system (Ferreira et al., 2014; Stronge et al., 2019; Umberson & Montez, 2010). This means that if an individual has a stronger social group, they are more likely to have higher well-being (Stronge et al., 2019). In fact, a romantic partner often serves as the main social partner for an individual and so whether or not someone is in a relationship can play a major role in how much socialization the individual receives. Stronge et al. (2019) found that individuals who are divorced, separated, widowed, or single typically have lower happiness, life satisfaction, and self-esteem, and greater depression than those who are in a relationship.

Romantic relationships can lead to further social ties, especially when two friend groups can be merged together. For example, in a qualitative study that examined the link between college students’ shyness, romantic relationships, and well-being, findings showed that individuals in a relationship tend to be less shy and more outgoing than single individuals of their same age (Rowsell & Coplan, 2013). Here, researchers used the Revised Cheek and Buss Shyness Scale (RCBS), which associates higher scores with higher levels of shyness, and discovered that those students currently involved in romantic relationships scored a 2.87, while those not involved in a relationship scored an average of 2.98, which has been deemed statistically significant. Therefore, being in a relationship can help an individual break out of their shell, make new friends, and spend more time with them.

It is also physically beneficial to have high levels of social ties, because too few social ties can actually be harmful (Umberson & Montez, 2010). For example, the fewer the social ties, the more likely an individual may be at risk for being diagnosed with health conditions such as cardiovascular disease, a heart attack, high blood pressure, atherosclerosis, and even cancer. These conditions have been found in higher frequencies among individuals who have fewer social ties as compared to individuals with lots of social relationships, including romantic partners (Umberson & Montez, 2010). Furthermore, prospective studies show that the risk of death of an individual with fewer social ties is over twice as high compared to adults with higher social ties (Umberson & Montez, 2010). One reason that the authors give for this linkage of social ties and physical health is that spouses or other social partners can help monitor and promote health behaviors, such as making sure the individual is taking their medications, eating healthy, and exercising (Umberson & Montez, 2010).

In addition to the physical benefits of being in a relationship, there are also certain psychological benefits (Ferreira et al., 2014). Because an individual is no longer thinking solely about themselves, but instead thinking of the well-being of someone else as well, there tends to be an increased sense of responsibility and concern for others (Ferreira et al., 2014; Umberson & Montez, 2010). Considering someone else’s needs before your own also helps to give an individual a better sense of meaning and purpose in their life (Umberson & Montez, 2010). In addition, relationships can also reduce the stress in someone’s life, which could be due to the idea that the burden is not only on one person, but instead split between two or more people, making the situation more easily handled (Umberson & Montez, 2010). This interaction between two people also tends to make an individual feel more stable and more in control of their life and life situations than their single counterparts (Ferreira et al., 2014).

Stronge et al. (2019) also provided insight into the difference in well-being between the males and females. For example, men in a relationship showed more well-being benefits than females in a relationship, and that men have lower well-being when they are not in a romantic relationship compared to when they are in one. This may be linked to the fact that men typically have fewer social confidants outside of a relationship, whereas women typically have lots of other friends and coworkers of which they spend their free time (Stronge et al., 2019).

Intimacy in Disability

The literature suggests that intimacy is beneficial in relationships, however those with a disability, specifically a SCI, often experience intimacy quite differently than the rest of the world. After someone acquires a SCI, he or she needs to learn new ways of being intimate with their partner, both physically and emotionally (Angel & Kroll, 2020). Being paralyzed after any injury can also affect the individual's self-esteem, making the individual feel unattractive and not worthy of an intimate partner. It can make the individual with the SCI believe that no other human could want to spend time with them, let alone be intimate with them (Angel & Kroll, 2020; Fritz et al., 2015). Hwang et al. (2007) found that 10 out of 32 single individuals with a SCI wanted to date more, but they did not know how to find someone, or even where to begin. Furthermore, Fritz et al. (2015) found that 75% of their female participants (15 out of 20) wished to be more intimate and sexually active, regardless of whether or not they were in a relationship at the current time. This led researchers to conclude that even if individuals with a SCI are in a relationship, they still might not be as intimately involved as their uninjured counterparts in society. Here, some women mentioned that while they want to be more sexually active, their counterpart seemed to limit their own sexual satisfaction, meaning the partner did not desire to be as sexually involved as the woman would have liked, which made the women cycle back to their thoughts of being unattractive to others (Fritz et al., 2015).

Not only is intimacy something that is hard to begin after a SCI, but it is something that can last for a lifetime in some instances (Hwang et al., 2007). For example, Hwang et al. (2007) found that marriage is less likely for individuals with a SCI than the rest of the general public. If an individual is married at the time of the acquired SCI, divorce is also more likely, however if the couple is able to push through this high-risk time, divorce rate lowers to the normal rate of the rest of the population. One woman in a qualitative study conducted by Fritz et al. (2015) spoke about her divorce after she acquired a SCI. While she did not blame the divorce solely on her SCI, she did discuss that since the injury, she was unhappy with their level of intimacy and was sexually dissatisfied. She and her ex-husband did not understand how they could be intimate with her impaired sensation, which led to a general stop of engaging in any type of intimacy.

Many individuals develop the same barrier in being intimate with their partner after a SCI: physical intimacy with one another if sex is no longer possible. Studies have found that after an acquired SCI, there is a lack of sensation which leaves some individuals with the feeling of not wanting to try to be intimate if they will no longer feel anything (Angel & Kroll, 2020; Fritz et al., 2015). In many relationships, after the loss of a typical sex life, there can be a lack of intimacy all together, including personal touch, attention, and quality time spent together (Angel & Kroll, 2020; Engblom-Deglmann & Hamilton, 2020). However, just because an individual can no longer have sex, or no longer feels as if sex is something that is worth their time, does not mean that there can no longer be any form of intimacy in a relationship (Angel & Kroll, 2020). Couples can still lead intimate lives through touching each other, such as holding hands, caressing each other, kissing, and so forth (Angel & Kroll, 2020).

Finally, when asked to define their own definitions of intimacy, individuals with a SCI answered in varying ways. For example, Fritz et al. (2015) documented how one 55-year-old female participant, who was 40 years post SCI, replied to this request with “I really don’t know for sure; when your body parts are really involved with each other?” which depicts a more physical definition of intimacy (p. 6902260030p3). However another female participant, 40 years old and 13 years after SCI, defined intimacy in a different way, saying “just having a normal life, a married life, and being able to smile… it means making love, the closeness and all of the good things that go with it” (Fritz et al., 2015, p. 6902260030p3). For this individual, intimacy is about both the emotional bond between two individuals and living a happy, healthy life, as well as the physical behaviors that accompany it.

Benefits of Intimacy and Sexuality

There are many benefits to engaging in intimacy and romantic relationships, both psychological and physical.

Psychological Benefits. While intimacy often looks different in people with disabilities, there are certainly benefits that can increase their chances of seeking and/or continuing a relationship. For example, Engblom-Deglmann & Hamilton (2020) found that males with a SCI wished to have a romantic partner so that they could be experiencing the new changes together, instead of the men having to go through all their life changes alone. According to Stronge et al. (2019), males have fewer social supports in their life, so having a romantic partner can really increase the amount of time that they spend with someone. Females typically have many supports, whether it be from family, friends, or even coworkers; however, males tend to struggle to make deep connections and tend to spend more time alone, making a romantic partner one of few resources to go to when going through a rough patch of life (Stronge et al., 2019).

In addition, psychological health and quality of life can increase when the individual with a disability knows that they are not going through it alone (Chen et al., 2008; Conti et al., 2019; Putzke et al., 2001; Umberson & Montez, 2010). Being in a close social relationship with someone can also provide the individual with a purpose, or sense of responsibility, in a time when they may feel as if they have no purpose in their life anymore (Umberson & Montez, 2010).

Physical Benefits. In addition, having close social ties, such as a romantic partner, can increase health and wellness in general (Umberson & Montez, 2010). Umberson & Montez (2020) do not speak directly about having a romantic partner, but instead discuss having a close social relationship. They found that having a partner who is around throughout the day can help the individual with a disability, whether a SCI or another disability, in various ways. The major areas of help include reminding the individual to take their medications at the proper times, practicing safe transfer techniques, and encouraging positive health behaviors overall (Umberson & Montez, 2010). Furthermore, if the individual has few social connections, there is a higher chance of the individual facing another diagnosis, such as high blood pressure, cardiovascular disease, stroke, and wounds that are slow to heal (Umberson & Montez, 2010).

Another major benefit to pursuing romantic relationships is proper education and knowledge of the individual’s capabilities after a SCI (Fritz et al., 2015). According to Fritz et al. (2015), one of the best motivations for women after a SCI is if they are informed that they can still become pregnant despite their impaired sensation. Fritz et al. (2015) completed a study with 20 women after acquiring a SCI, and most of these women were fortunate enough to be told that they could still become pregnant, which instilled hope of not only being intimate with someone in the future, but also hope for their future life. One woman in particular discussed that she did not care as much about whether she'd ever be able to walk again, but she cared much more about whether or not she would be able to fulfill her dream of becoming a mother (Fritz et al., 2015).

Barriers to Intimacy and Sexuality

While there were numerous benefits of engaging in intimacy and romantic relationships, there are also various barriers that prevent individuals with a disability, specifically a SCI, from engaging in such relationships.

Lack of Support, Education, and Social Interaction. Those with a SCI often experience barriers to initiating a new romantic relationship, and some do not know how to go about starting one (Angel & Kroll, 2020; Hwang et al., 2007). For instance, Hwang et al. (2007) found that 10 of their 47 participants would like to date more than they currently do, whereas zero participants stated that they wanted to date less than what they currently do. This was due to various factors such as difficulty attracting potential partners and forming a romantic relationship (Hwang et al., 2007). For others, it is difficult to begin a new relationship due to difficulty meeting new people. Some participants noted that they spend less time in social and community settings, such as bars or clubs, where they could have met people prior to their SCI (Angel & Kroll, 2020). Since their social interaction is lower, people with a SCI tend to not spend their time meeting new people, which serves as a barrier for initiating new relationships. Furthermore, some individuals felt as if they were forced to learn how to re-integrate into the community on their own, and that they had no help with the process from their care team (Barclay et al., 2016). Women specifically noted that they feel as if they have a lack of support and education from their care team or family members that prevent them from gaining the needed information about how intimacy will continue to develop after their SCI (Fritz et al., 2015).

Body Image. Another prominent barrier for romantic relationships is that those individuals with a SCI may feel ‘unattractive’ and not worthy of a relationship (Angel & Kroll, 2020, p. 108; Fritz et al., 2015). Sometimes, after developing a SCI, the individual begins to have low self-esteem and a negative self-image of themselves, which can lead them to believe that others see them in the same light (Angel & Kroll, 2020). One individual noted that even though her husband reassured her that she was attractive and beautiful, and that he loved her, she could not believe it and still thought of herself as having a less attractive body (Angel & Kroll, 2020). In her case, she was already married, however single individuals who do not believe others will find them attractive may not want to initiate a relationship in fear of being turned down or risk receiving some sort of negative stigma (Angel & Kroll, 2020; Barclay et al., 2016; Fritz et al., 2015). In a study conducted by Fritz et al. (2015), multiple women addressed the idea that women tend to ‘age faster’ after a SCI, and that aging deters potential partners (p. 6902260030p5). Because of these factors, some individuals stop trying to begin a romantic or sexual relationship, regardless of whether they still want to try and find love (Angel & Kroll, 2020).

A more specific factor that oftentimes serves as a barrier for romantic relationships is whether or not the individual with a SCI has bowel and bladder control. If an individual does not have this function, they tend to be more self-conscious in general, but specifically around a potential partner (Angel & Kroll, 2020; Fritz et al., 2015). One specific woman spoke about how she did not engage in a romantic or sexual relationship because she “didn’t think a guy would be interested in having sex with me [because] I was dealing with complications like bladder management problems” (Fritz et al., 2015, p. 5). Another main concern for individuals without bladder control is the risk of having an accident at any time, and how that is stressful and exhausting to think about (Angel & Kroll, 2020). This lack of self-esteem and mental anxiety, regardless of whether it is from bowel and bladder management or the SCI in general, can leave the individual unaccepting of themselves before they even allow a potential partner to accept them as they are. However, this acceptance of self comes with time, and the courage to take part in a romantic relationship eventually comes to the individual, although each individual is on a different timeline (Angel & Kroll, 2020).

Psychological Barriers. In addition to the anxiety that comes along with bladder control, many individuals also suffer from depression and other aspects of anxiety, that may stop them from pursuing a romantic relationship. After obtaining a SCI, some individuals tend to become more isolated, not going out to new places with new people, but instead spend more time alone, participating in activities such as watching television, building puzzles, or reading a book (Barclay et al., 2016). If the individual does spend time with others, it is typically only with people they feel completely comfortable around, at least during the beginning stages of the SCI rehabilitation (Barclay et al., 2016). This decrease in social participation can lead to considerable depression, and the thought of spending time with people they do not know can cause anxiety as well (Barclay et al., 2016). Furthermore, some individuals with a SCI may feel as if they are a burden to their family or significant other, which may cause deeper depression, thus affecting the relationship as a whole (Angel & Kroll, 2020). These factors, especially when all the other factors are considered as well, can serve as a barrier for individuals wanting to initiate or maintain a romantic relationship.

Physical Barriers. Despite the psychosocial barriers that may prevent someone from entering or continuing a romantic relationship, there are also many physical aspects that may do the same. This population typically has more pain compared to others, and thus may be unlikely to spend time with a significant other during these painful episodes (Angel & Kroll, 2020). In addition, individuals with a SCI must exert more effort doing an everyday task compared to the general population. Therefore, these individuals get tired quicker than others and are exhausted at the end of the day (Angel & Kroll, 2020; Fritz et al., 2015). Most dates happen in the evenings, but by that time, individuals with a SCI may be too exhausted to go out, and sexual relations may require too much energy (Angel & Kroll, 2020). Thus, going through a full day of work or activities may decrease an individual with a SCI's desire to spend time with a significant other during the evening (Angel & Kroll, 2020; Fritz et al., 2015). Furthermore, some individuals have lack of complete sensation after a SCI, specifically in their genital region, and thus do not feel as if participating in sexual relationships would be beneficial if they could not physically feel the penetrations (Angel & Kroll, 2020).

Caregiver Burden. Caregiver burden is one of the most prominent risks of being in a relationship after a traumatic injury such as a SCI, where the partner takes the role of being the individual's primary caregiver. This phenomenon is defined as "the extent to which caregivers recognize that caregiving has hurt their emotional, social, financial, physical, and spiritual functioning," (Conti et al., 2019, p. 271). When a spouse or a romantic partner acquires a SCI, one of the first instincts may be for the other partner to want to help as much as they can, taking on the role of the primary caregiver. However, when the romantic relationship turns too much into a caregiving role instead of a romantic partner role, there can be many difficulties associated with it (Isaksson & Hellman, 2012).

Caregiver burden can lead to many physical and psychological problems for the caregiver (Conti et al., 2019; Dickson et al., 2011; Maitan et al., 2018). For example, the caregivers tend to get stressed out frequently, and therefore they require increased need for formal or informal psychological support (Maitan et al., 2018). Because of their increased stress levels, caregivers also tend to have decreased life satisfaction and more depressive symptoms than they previously had (Conti et al., 2019; Dickson et al., 2011). If this caregiver burden creates tension in the relationship, it also leads to increased symptoms of depression and anxiety (Dickson et al., 2011). All caregivers deal with this stress differently, as some let all of the stress and emotions build up to the point of a breakdown, while others understand when they need to take the break and remove themselves from the situation in the moment so that the feelings do not build up (Dickson et al., 2011). However, any way that someone deals with this burden, it does not go away, and instead they learn to live with it (Dickson et al., 2011). Caregivers who experience caregiver burden also have to deal with constantly being mentally drained, which may lead to reduced cognitive functions, which have been found to contribute to increased levels of depression and anxiety (Conti et al., 2019).

Regardless of which approach caregivers take, they all seem to have the same thing in common which is the fact that they do not get to do as much as they did before caregiving (Dickson et al., 2011). The caregivers do not get to spend as much time socializing with other friends or engaging in their favorite hobbies. Instead, they spend more time caring for the individual, especially towards the beginning of the rehabilitation process (Dickson et al., 2011). This can lead the caregiver to experience a loss in their sense of identity. They no longer engage in their passions and interests they had before the SCI, and now, all of their efforts are focused on the individual instead of themselves (Charlifue et al., 2016).

The level of caregiver burden experienced strongly relates to the level of SCI and the amount of caregiving that is required (Conti et al., 2019; Maitan et al., 2018). Maitan et al. (2018) found that the higher the injury, or the more assistance that the individual required, correlated to higher caregiver burden. In addition, there tends to be higher caregiver burden when there is a complete SCI as compared to an incomplete SCI (Conti et al., 2019). There is also a correlation between the amount of caregiver burden and the amount of caregiving required for the individual. Conti et al. (2019) found that the highest levels of caregiver burden are among individuals who have cared for an individual for three years or longer, and who have provided care for eight or more hours per day. Therefore, if caregiving is someone's full-time job, there tends to be higher rates of burden. Furthermore, if the individual with a SCI experiences frequent urinary tract infections and/or bowel and bladder dysfunction, there tends to be higher amounts of caregiver burden (Conti et al., 2019).

Transportation. A less commonly discussed barrier to relationships for those with a SCI include lack of appropriate transportation and accessible locations to visit and socialize. Barclay et al. (2016) found that adults with a SCI identified not wanting to participate in community activities due to challenges finding public or private transportation. Public transportation is difficult to coordinate getting on the proper time and some may feel as if they are inconveniencing the bus driver and other riders when taking longer to embark and disembark the bus (Barclay et al., 2016). Additionally, individuals who can drive independently spoke about difficulty getting gas into their vehicle, as it is a process that requires assistance from others and takes longer than they would like (Barclay et al., 2016). The complexity of coordinating public transportation, or the trouble with pumping gas can lead an individual to not socialize frequently, leading to fewer social relationships, which may also impact romantic relationships (Barclay et al., 2016). However, the main barrier that was identified dealing with transportation was the difficulty of finding accessible parking. These accessible parking spots need to be the correct size and design, as well as in an appropriate location, such as next to a curb cut. In addition, individuals with a SCI have identified the thought that there are too many people that have an accessible parking permit. While they do not typically see people without a permit parking in the accessible spots, multiple individuals have spoken about how there are people that have the permit that do not truly need the spot, and that takes away from those who truly do need the accessible spot closer to the entrance of the building (Barclay et al., 2016). The use of either public or private transportation has been identified in the literature as a barrier to engage within the community. While not specific to the idea of dating and romantic relationships, the added burden of transportation may have an impact on seeking such relationships (Barclay et al., 2016)

Barriers from the Romantic Partner. While there are many barriers that affect solely the individual, there are also barriers that can come from the individual's romantic partner, if there is one. One surprising fact is that individuals with any sort of disability are more likely to be in an abusive relationship compared to the general public (Hwang et al., 2007). This may be due to the romantic partner feeling stressed from caregiver burden, and the individual with a disability being scared of leaving a relationship in fear of not knowing what they would do without their partner's help, however the exact cause is unknown (Hwang et al., 2007). Another reason that relationships may not be healthy after a SCI is if the romantic partner is not supportive of their loved one (Putzke et al., 2001). If the partner or spouse is not present during rehabilitation, it may lead to stress for both people, as well as the individual with a SCI not recovering as well as they could. For example, if the partner is unsupportive, they may provide too much assistance to the individual instead of helping them learn to be independent (Putzke et al., 2001). It can also be very difficult to be in a relationship with someone if they do not understand what the other is going through, which may lead to a point of contempt in the relationship (Isaksson & Hellman, 2012). For example, if the couple was together before the SCI was acquired, both people need to cope with the disability, although only one person is physically affected by the SCI. This lack of complete understanding can lead to a power struggle or other problems within the relationship (Isaksson and Hellman, 2012). Although this is not something experienced in every relationship after a SCI, it is certainly something that, if experienced, can be a barrier to intimacy.

Benefits of Romantic Relationships

Although it may be difficult for individuals to date after acquiring a SCI, it has been found that there are many benefits to being in a relationship both during rehabilitation and after the initial therapy has ended. One of the biggest benefits to relationships are the increases in life satisfaction and psychological well-being (Fritz et al., 2015; Isaksson & Hellman, 2012; Putzke et al., 2001). A quantitative study by Putzke et al. (2001) examined multiple differences between individuals who were single versus married one-year post SCI. Those who were married had greater life satisfaction than the single individuals, as indicated by responses on a survey. In addition, those who were single one-year post SCI had decreased independence and social interaction (Putzke et al., 2001). Furthermore, Fritz et al. (2015) discussed how women engage in sexual relationships because having positive relationships with their partner increase their sense of well-being and quality of life after the injury. Some women believe that they may always have a lower quality of life initially after they acquire their SCI, but after participating in a romantic relationship, their self-esteem can increase and lead to higher life satisfaction (Fritz et al., 2015). For instance, one woman stated the following:

> I thought I'd never have a relationship again. I thought I'd never have sex again. And finding someone who is sensitive enough to be there for the need is a challenge. And you have to have enough confidence to allow yourself to go there, too, so I have to be all right

> with me in order for people to be all right with me. You know, ‘cause the shock value when they see you, it’s like, “Oooh … myyy … God, she’s so pitiful,” you know? (Fritz et al., p. 7).

However, later in life, this woman felt more comfortable in her own skin and felt more confident in pursuing a romantic relationship and even motherhood (Fritz et al., 2015).

More benefits of being in a relationship after a SCI relate to the rehabilitation process itself. For example, when the family and/or romantic partner is involved with the rehabilitation process, there are typically enhanced experiences and increased results than if the individual were to go through treatment on their own (Isaksson & Hellman, 2012; Ward et al., 2007). For example, a qualitative study by Ward et al. (2007) followed several individuals throughout rehabilitation after a SCI. One female participant stated, “I really think that my family and friends were what really motivated me to still be myself and still do the things that I always did” (Ward et al., 2007, p. 153). These experiences tend to be more positive for both the individual going through the rehabilitation as well as the family, or people who are surrounded by the individual. When involved in the process, the family learns what the individual with a SCI is capable of doing independently and also learns how to help where they can (Isaksson & Hellman, 2012).

In addition, Barclay et al. (2016) found that having family, regardless of whether it was a romantic partner or another family member, present during the rehabilitation process can make the transition to community mobility and social participation easier. When the individual has a romantic partner present, they are more likely to spend more time out in the community instead of staying alone in their home (Barclay et al., 2016). This idea helps the individual know they are not alone after the injury and that they are still capable of what they could do before, it just may need to be in a modified fashion (Barclay et al., 2016).

Furthermore, during the rehabilitation process, there are lots of new emotions and experiences that can be scary and intimidating for the individual to go through alone. However, when a romantic partner is there during the recovery, it makes the entire process and necessary adjustments easier (Engblom-Deglmann & Hamilton, 2020). For example, after a SCI, there are many adjustments and adaptations that need to be created, which can overwhelm an individual, but when there is someone to go through these emotions with, it makes the process smoother. One male participant highlights how stressful the ever-changing rehabilitation process can be, but mentions that he is going through it with somebody by stating the following:

> I think just going through that difficult time together, and the difficult time is the adjustment time … and then you think ‘this is the way life is going to be now’ but then, more adjustments are needed. Constant changes, it’s just constant changes. (Engblom-Deglmann & Hamilton, 2020, p. 256)

One positive aspect of having a romantic partner during recovery from a SCI is one that is not typically brought up, which is the idea of positive caregiver burden. This concept includes positive aspects that come out of someone caring for an individual after a serious injury such as a SCI. Some of these benefits of caretaking include an increased sense of compassion, the feeling of being appreciated, and increased family cohesiveness (Charlifue et al., 2016). Here, some caregivers have recognized that while they are caring for their loved ones, they see a shift in their outlook of life, including making them more compassionate. Others appreciate the fact that their loved ones are so appreciative of the help that they are giving, although not all caregivers have this experience, as shown by caregiver burden. Finally, some caregivers mention the idea that caring for an individual after a SCI takes the entire family, and therefore it increases the family dynamic, making the whole family closer together (Charlifue et al., 2016). One participant spoke about their positive experience of being a caregiver by stating “I find it very rewarding. I feel like, in a way, I gain as much as I give,” (Charlifue et al., 2016, p. 733).

Finally, some individuals identify intimacy and relationships as integral to their life and therefore, being part of a romantic relationship is something that is of high importance (Fritz et al., 2015). Fritz et al. (2015) discussed the idea of intimacy with twenty females. Of these participants, most discussed how they either did engage in romantic and sexual relationships, or wished they could, but did not have a partner. In addition, they mentioned how sexual and emotional intimacy is a very important part of life. One woman, a 31-year-old 14 years post-SCI, spoke about how she “viewed sexual intimacy as an essential human need and desired behavior that was, in her mind, physiologically necessary for stress relief” (Fritz et al., 2015, p. 6902260030p3). Therefore, this woman spoke about how intimacy and being part of a romantic relationship was essential and necessary for her life.

Occupational Therapy’s Role

Occupational therapy is a very client-centered, holistic field that works with each client on an individual basis to decide what is best for each client. Since intimacy and sexuality are integral parts of an individual’s identity, it is important to focus on these aspects throughout therapy (Angel & Kroll, 2020; Fritz et al., 2015; MacRae, 2013; McGrath & Sakellariou, 2016; Walker et al., 2020). After an individual suffers an injury, illness, or health condition change, their sexuality and intimacy may be affected in numerous ways, and it is important that occupational therapy practitioners address all aspects of life that were altered after the health condition occurred (Walker et al., 2020). Even though this may be an uncomfortable topic for some practitioners to address, the therapists need to come to terms with talking about this aspect of an individual’s identity in order to stay true to the client-centered practice of occupational therapy (McGrath & Sakellariou, 2016).

One way to discuss intimacy with clients is to be sure to bring up the topic during treatment sessions. If the therapist makes the client aware that they are comfortable speaking about this topic, the client is more apt to open up and discuss their true feelings on the subject (MacRae, 2013). One author spoke about a man with a SCI whose first thought after injury was how he was going to have sex with his wife, but the topic was never brought up throughout his rehabilitation, and therefore he never got any information, recommendations, or ways to adapt to this new form of intimacy (Walker, 2020).

Reasons Intimacy and Sexuality are not Being Addressed

There are many reasons for why intimacy and sexuality are not being addressed within occupational therapy; however one of the main reasons is because the practitioner feels uncomfortable or embarrassed when bringing up this topic (Areskoug-Josefsson et al., 2016; Fritz et al., 2015; Lohman et al., 2017; Walker et al., 2020). This is because it is a personal topic and sometimes the practitioner or the client can be scared to bring up the topic first. However, during therapy treatments, the client and therapist take part in even more intimate aspects of life such as toileting, that should make both the therapist and client feel more comfortable when addressing intimacy (Lohman et al., 2017). Other therapists feel uncomfortable addressing this topic due to their own religious or cultural beliefs (Lohman et al., 2017).

The other major reason that intimacy and sexuality are not addressed in treatment is due to lack of education and experience with the topic. Lohman et al. (2017) created a research study to determine how much education was devoted to this subject. They sent out a survey to occupational therapy professors who do address sexual activity and intimacy and asked them to report the amount of time that is devoted to this subject. Of those who responded, the average amount of time spent on it was 3.48 hours throughout the entire semester. That is equivalent to one lecture throughout a fifteen-week semester. It is important to keep in mind that this survey was only sent out to those who did identify that they devoted time to this subject, and therefore did not include professors that skipped the subject all together. Therefore, the actual average of class time spent on this topic is drastically lower than what was reported (Lohman et al., 2017).

Areskoug-Josefsson et al. (2016) did a similar study, which looked at students' perspectives of how comfortable they felt discussing intimacy and sexuality with their clients. The study consisted of 186 participants, made up of occupational therapy, physical therapy, and nursing students, many of whom reported that they were comfortable having the discussion, however they felt as if they were unprepared for these conversations and wanted more education and training on the topic before doing so (Areskoug-Josefsson et al., 2016). In addition, occupational therapy students felt 1.8 times more comfortable discussing intimacy with their clients than physical therapy students, which may be linked to the idea that occupational therapy is more holistic and client centered than physical therapy (Areskoug-Josefsson et al., 2016). Also noteworthy is that students with more positive attitudes towards intimacy and sexuality tend to be more comfortable discussing these topics with their future clients (Areskoug-Josefsson, et al., 2016). Therefore, the literature suggests that during school, students feel willing to discuss these personal topics with their clients, however with the little time that is devoted to it throughout school, the students feel unprepared and therefore unwilling to have these conversations once they enter practice.

There are other, less common reasons for not discussing intimacy with clients throughout occupational therapy sessions. For instance, there seems to be a lack of time within the treatments, and the therapists prioritize other aspects of sessions before sexuality, and therefore it never gets addressed (Areskoug-Josefsson, 2016; Lohman et al., 2017). Some therapists also simply do not believe that addressing intimacy and sexuality are as important as addressing some of the other aspects of rehabilitation, such as dressing, feeding, and toileting (Lohman et al., 2017). Other therapists do not feel the need to address this topic because they believe another discipline will discuss it with the client (Krantz et al., 2016). While this topic is clearly within the scope of occupational therapy practice, some therapists do not see the importance and would rather discuss other aspects of rehabilitation and leave the more uncomfortable topic of intimacy and sexuality for another therapist to discuss.

Occupational Therapy Assessment

One of the most popular models of how to address intimacy and sexuality during occupational therapy is using the permission, limited information, specific suggestions, and intensive therapy (PLISSIT) model, which is a four-step approach (Annon, 1976; Walker et al., 2020). The first three levels can all be done during brief therapy, whereas the final step is only done during intensive therapy. The first step, permission, is all about assuring the client that they are experiencing normal feelings and giving them permission to discuss any aspects they would like throughout therapy, including intimacy and sexuality (Annon, 1976). The second step, limited information, consists of providing the client with small amounts of relevant information that may help answer their questions. For instance, if someone is wondering if they will ever be able to have children, providing the client with limited, yet specific information about how they can still be fertile would help give them hope of starting a new family (Annon, 1976). The third step, specific information has multiple parts to it. First, the therapist needs to obtain specific information from the client about what they had tried before and their specific concerns for the future. Next, the therapist needs to obtain a sexual problem history, which consists of a description of the current problem, the onset and course of the problem, the client's concept of cause and maintenance of the problem, past treatments tried and their outcomes, and the current expectations and the goals of treatment. Finally, the therapist uses all the information gathered to provide specific suggestions to help the client reach the goals discussed earlier (Annon, 1976). Lastly, step four, intensive therapy, is the time in which trained therapists provide detailed, specific treatments with the client and help them reach their desired goals (Annon, 1976).

While the PLISSIT model has been used in the past by many practitioners, the model also has its limitations. This model merely serves as a means to help start the conversation between therapist and client and does not give ways of actually solving the problems or concerns voiced by the client (Annon, 1976; Walker et al., 2020). The *Sexual Assessment Framework* (SAF) was created to help guide assessment of sexuality in clients after a major health condition change such as a newly acquired SCI (Walker et al., 2020). The SAF consists of seven main concepts: sexual knowledge, sexual behavior, sexual self-view, sexual interest, sexual response, fertility and contraception, and sexual activity, all of which have a heavy focus on sexuality (Walker et al., 2020). Based on the information from the SAF, the *Occupational Therapy Sexual Assessment Framework* (OTSAF) was developed, specifically for assessing intimacy and sexuality within the field of occupational therapy (Walker et al., 2020). The OTSAF consists of nine main concepts, most of which are pulled from or slightly altered from the SAF: sexual knowledge, intimacy, sexual self-view, sexual expression, sexual interest, sexual response, sexual health, family planning, and sexual activity (Walker et al., 2020). As shown in the main topics, the OTSAF expands upon sexuality and includes aspects of intimacy as well, incorporating a larger portion of the occupational therapy scope of practice. In addition, the OTSAF also looks at the individual first, then expands to view the performance, occupations, and contexts surrounding the individual (Walker et al., 2020).

The OTSAF and the PLISSIT models were then combined and influenced the creation of the *Occupational Performance Inventory of Sexuality and Intimacy* (OPISI; Walker et al., 2020). Before this new assessment tool was created, there was a clear need for a formal program, as there was not one previously (Lohman et al., 2017; Walker et al., 2020). The OPISI has the purpose to "comprehensively screen, assess, and measure performance related to the complex occupational nature of sexuality and intimacy" (Walker, 2020, p. 3). This assessment consists of a thirteen-item screening tool and in-depth self-assessment which the client completes on his or her own and then returns to the occupational therapist. The OPISI also includes a four-item performance measure for each of the pertinent categories discussed in the OTSAF. The occupational therapist uses this measure to gain "a baseline and detect self-perceived change in ability, satisfaction, understanding, and confidence in skills and ability to improve occupational performance associated with sexuality and intimacy over time" (Walker, 2020, p. 3). Furthermore, the OPISI specifically addresses intimacy and defines the term as "a person's ability to initiate and maintain close intimate relationships which includes the ability to give and receive affection needed to successfully interact in the role as intimate partner" (Walker et al., 2020, p. 4).

The goal is for the OPISI to expand the role of occupational therapists with intimacy, as it provides a direct assessment tool that practitioners can use to help gain a better understanding of the individual client's needs and concerns in this area of functioning (Walker, 2020). The OPISI accomplishes this task by providing the therapist with an extensive inventory of questions to ask the client in order to gain insight on the client's self-perceived sexuality and intimacy. These questions directly correspond to the main components of the OTSAF (Walker, 2020; Walker et al., 2020). While the OPISI can be administered at any point during occupational therapy services, the earlier it is implemented, the more likely the client will receive the necessary intervention and ultimately reach their desired goals.

Occupational Therapy Intervention

Occupational therapy intervention for intimacy and sexuality requires lots of empathy, sensitivity, and openness, since it will develop into a very personal conversation (MacRae, 2013). While these aspects are needed for occupational therapy in general, it is especially important to use these skills when discussing intimacy (MacRae, 2013). This is because of the personal nature of the discussion and the client may be closed off and not quite willing to discuss these details with someone they do not feel comfortable with. Therefore, the therapist needs to use their therapeutic use of self in order for the client to open up and discuss these topics. In addition, intervention can take place in any setting, which may help the client feel more comfortable (MacRae, 2013). Depending on the setting of the therapist, they may have multiple options of where to address these topics in order to facilitate the most discussion. For instance, if the client is in an acute rehab center, the therapist may be working with the client in a large therapy gym, but may opt to have these private conversations in the client's room behind a closed door, if the client would feel more comfortable there. Likewise, if the therapist is working via home health, the client and therapist may choose to go to a different room of the house that gives more privacy for these discussions.

There are various ways that a therapist can incorporate intimacy and sexuality into their intervention plans. Since intimacy is more than just the physical act of having intercourse, there are many different aspects to address. For instance, the therapist could help the client work on effective communication between the client and their significant other during rehabilitation to carry over into a healthy relationship (MacRae, 2013). The therapist could also work with the client to determine and improve upon certain leisure activities that could be used as date ideas, which would help create a relationship that is still active and fun (MacRae, 2013). Finally, the therapist could also work to create a sexual education program and incorporate strategies of how individuals are still able to participate in the physical aspect of sex, and even child rearing, if so desired (Fritz et al., 2015; MacRae, 2013; Walker et al., 2020). This program could help break the ice between the client and therapist as the therapist already may have a structured idea of how to start an intervention program with a client who is interested in returning to prior sexual functioning. Social and emotional support is so integral to rehabilitation, that it has the potential to impact the rehabilitation progress and the health and wellbeing of an individual after a SCI. Therefore, it is important to prioritize social and romantic relationships throughout the rehabilitation process to make sure that the client as well as the significant other are on the same page about their relationship, where it stands, and what they each do to support the relationship currently (Isaksson & Hellman, 2012).

Problem Statement and Research Questions

Intimacy, sexuality, and romantic relationships are integral to people with disabilities, especially those with a SCI; however, there are a variety of barriers that may influence an individual’s ability to fully engage in such a relationship. Some of those barriers include a lack of social support and interaction, having a negative body image, and the risk of caregiver burden

(Angel & Kroll, 2020; Barclay et al., 2016; Conti et al., 2019; Dickson et al., 2011; Fritz et al., 2015; Maitan et al., 2018). Nevertheless, there are also many benefits of being in a romantic relationship after a SCI, such as an increase in life satisfaction, a gained sense of responsibility, and better rehabilitation outcomes (Ferreira et al., 2014; Stronge et al., 2019; Umberson & Montez, 2010). Despite the known benefits of romantic relationships, intimacy is still under addressed in occupational therapy practice (Areskoug-Josefsson et al., 2016; Fritz et al., 2015; Lohman et al., 2017; Walker et al., 2020). Having a better understanding of facilitators and barriers to engaging in intimacy after a SCI will help occupational therapists better incorporate this into treatment. Therefore, the purpose of this study is to better understand the personal perspectives and experiences of individuals with a spinal cord injury related to engaging in intimacy and romantic relationships. In addition, the researcher anticipates that the results of the study will provide a better understanding of how occupational therapy can help individuals with a spinal cord injury engage in relationships. Thus, the following research questions will be addressed:

1. What are the personal experiences of individuals with a spinal cord injury engaging in romantic relationships?
2. What are the reported facilitators and barriers of engaging in romantic relationships for individuals with a spinal cord injury?
3. How do individuals with a spinal cord injury think that occupational therapy can better support their engagement in romantic relationships?

Methodology

This study used a qualitative, phenomenological inquiry approach to gain a deeper understanding of the participants' lived experiences with intimacy and romantic relationships.

This type of research strives to understand the perspectives of the participants and how they perceive their own experiences (Carter et al., 2011; Lester, 1999). Therefore, this approach will allow the researcher to emphasize the personal perspectives and lived experiences of individuals with a SCI and how their relationships have changed due to the injury (Carter et al., 2011; Lester, 1999). Prior to participant recruitment, this study was approved by the Elizabethtown College Institutional Review Board (IRB) as an expedited review.

Participants

Eligible participants for this study included male and female individuals, at least 18 years or older, with a SCI who were able to provide informed consent. Purposeful sampling, when participants are intentionally recruited because they meet the specific requirements of the study, was used because the student researcher needed participants who would be able to share their distinctive experiences and perspectives surrounding relationships and intimacy as a person who experienced an SCI (Knapp, 2017; Creswell, 2009). Participants were recruited from various support groups within the central Pennsylvania area as well as out of state. Furthermore, these participants were recruited through their respective organization via a flyer that described the title and purpose of the study, eligibility requirements, and the student researcher's contact information (Appendix A). It should be noted that the original recruitment flyer was recruiting individuals aged 18-35; however, due to lack of interest within this population, the student researcher opened the study to any individual aged 18 or older who had a SCI and was interested in participating. The flyer was presented by the group representative at meetings and/or posted on the group's social media account for individuals to explore. In addition, the student researcher was invited by two separate group representatives to attend their respective SCI support group's online meeting to discuss the research purpose and answer any common questions. Interested participants were instructed to contact the student researcher for additional information about the purpose of the study and to provide informed consent.

Data Collection

Semi-structured interviews were used to explore the participants' perceptions on engaging in intimacy and romantic relationships, from their perspective of before and after their SCI. The interview guide was developed based on extensive review of the current literature, the research purpose, and the research questions (Appendix B). Interview questions and skills were then reviewed with the faculty mentor to ensure clarity, understandability, and that questions were not leading. Semi-structured interviews were used as they allow for more follow-up questions and are most appropriate when the responses are more abstract or open-ended in nature (Carter et al., 2011; Lysack et al., 2017). In addition, semi-structured interviews allow all listed questions to be answered, but not in a specific order, instead following the flow of conversation (Carter et al., 2011). Furthermore, semi-structured interviews start with an open-ended invitation for the participant to share their story, thus supporting the phenomenological approach (Carter et al., 2011). However, these semi-structured interview questions were used as a loose guide as the phenomenological approach strives to go deeper into the participants' responses by asking follow-up questions aimed at eliciting the stories and experiences of the individuals (Carter et al., 2011; Lester, 1999).

Informed consent (Appendix C) was gained from each participant either via email or mail before scheduling the interview, which was scheduled at a time convenient to the participant. These interviews occurred via Zoom video conferencing, and the student researcher was alone in a room to maintain confidentiality. All interviews were recorded and then transcribed using

Microsoft Stream. Transcripts were compared to audio recordings and cleaned by the student researcher to ensure accuracy.

Data Analysis

Each participant was assigned a unique identifier and all transcripts were de-identified for confidentiality. Each interview transcript was coded, and emerging themes and subthemes were identified by the student researcher and the faculty mentor. Both individuals reviewed and coded all interviews independently and then collaborated to triangulate client interview data. This process of triangulation was used to make sure the results were coded consistently and accurately (Carter et al., 2011). All data was kept on a password protected computer and only accessible to the student researcher. All electronic and written transcripts, as well as the audio recordings of the interviews, were deleted or shredded at the conclusion of the study.

Results

Participants

In total, there were five participants who agreed to participate in the study and complete semi-structured interviews (Table 2). Three participants were male and two were female. Participants varied in terms of current age, time since onset of initial injury, and level of injury. The average time since onset of their SCI was 20.4 years.

Table 2

Participant Demographics

Participant	Gender	Age at injury (years)	Current Age (years)	Time since SCI (years)	SCI level (if known)	Relationship Status at time of injury
Participant 1	Male	39	42	3	T12-L1 Incomplete	Single
Participant 2	Female	19	30	11	C4-C5 Incomplete	In a relationship
Participant 3	Male	53	57	4	T12	Single
Participant 4	Female	46	80	34	L3-L4 Incomplete	Married
Participant 5	Male	16	66	50	C5-C6	Single

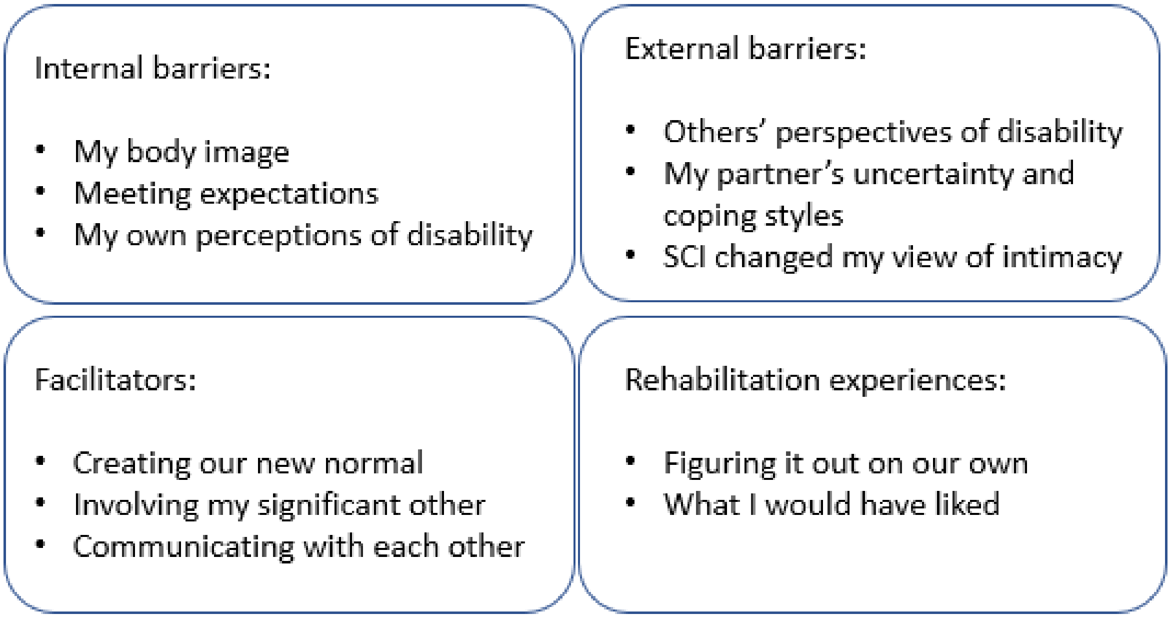
Note. Summary of demographics of the five participants involved in the study. Includes gender, age at injury, current age, time since injury, spinal cord injury (SCI) level, and relationship status at the time of injury.

Interview Results

Interviews with each participant ranged from 28-58 minutes in duration, with an average time of 48 minutes. Several themes and subthemes emerged, including internal and external barriers to engaging in intimacy, facilitators to engaging in intimacy, and the difference in what was discussed during rehabilitation regarding intimacy and romantic relationships versus what the participants would have appreciated throughout the recovery process (Figure 1).

Figure 1

Themes and Subthemes



Internal barriers:

- My body image
- Meeting expectations
- My own perceptions of disability

External barriers:

- Others' perspectives of disability
- My partner's uncertainty and coping styles
- SCI changed my view of intimacy

Facilitators:

- Creating our new normal
- Involving my significant other
- Communicating with each other

Rehabilitation experiences:

- Figuring it out on our own
- What I would have liked

Note. Summary of the themes and subthemes that emerged from the client interviews.

Internal Barriers to Intimacy and Romantic Relationships

All participants discussed a variety of internal barriers to engaging in intimacy and romantic relationships, including body image insecurities, the fear of not meeting their own or their partner's expectations, and their own perceptions of disability. While each participant emphasized different aspects, they all discussed how these barriers have affected their current relationship or their ability to engage in new relationships.

My body image. Throughout the interviews, one theme that emerged was the internal barrier of body insecurities and being self-conscious of some aspect of their new bodies. Four of the five participants explicitly stated reasons that they were self-conscious of their bodies after the SCI, with the two women more heavily speaking of this topic. One female, Participant 2, spoke about her own body insecurities when she said "I hated [my body] for a long time and I hated the way it looked. I remember saying things to him like 'Do you really find me attractive?... I just can't imagine anyone being attracted to me." Furthermore, Participant 1 spoke more about how his own body insecurities affected his dating life by stating:

> I still have a foot drop on my left leg. So that made me really nervous. After our first date, I didn't walk her to her car. I got there before her so that I could be at the door, so I didn't have to walk in front of her.

In addition, these body insecurities and internal thoughts can cause an individual to have heightened fear of losing their significant other. Participant 2 spoke of this concept below:

> I think my parents expected him to split. Actually, I think most people expected him to hightail it out of there. I certainly gave him plenty of outs because, in my emotional processing, I was like 'no one would want this.'

Meeting expectations. Another prominent internal barrier discussed with the participants was the idea of being anxious and nervous about their sexual performance with a partner. Individuals spoke of being scared that they would not perform as well, and that they would not be enough for their partner. In addition, participants mentioned not meeting their own or their partner's expectations. Four of the five participants spoke in depth about the emotional toll that this had taken on them, either on an individual level or affecting the relationship as a whole. Participant 4 voiced these concerns as she mentioned "I was always afraid that I wasn't going to measure up so to speak, and life would never be the same. I think he thought that would be the way it would be as well."

Male participants especially spoke about the idea of the SCI taking away from their masculinity, as all three male participants spoke of sexual performance being their biggest concern regarding relationships after the SCI. Participant 1 spoke of his concerns regarding sexual functioning after he was asked about his emotions once he started to date again after his injury. He responded with "Nervous especially about sex… it was an iffy type situation as far as was I going to perform or not perform so that made me nervous." Furthermore, Participant 3 spoke of his experience by explaining what it felt like to realize that his sexual performance was not consistent with what it was prior to the SCI:

> You talk about psychological trauma. For me, it was just completely devasting. I pretty much rolled over in a ball inside and I was going to leave, and I didn't cry, just don't want to do it because it's your pride and joy. You could have sex, you were very good at it, but then… you don't feel like a man because that's what makes the man.

My Own Perceptions of Disability. The last internal barrier that emerged throughout the majority of the interviews was the individuals' own perceptions of those with disabilities. Multiple participants spoke about the stigmas that are associated with people with disabilities in general, and especially the stigmas around people with disabilities engaging in intimacy and romantic relationships. For example, Participant 2 spoke about her own experience with this stigma when saying "There's this idea in society that disabled people are sort of nonsexual or infantilized in a way. I guess I kind of assumed that too, like oh, I guess sex is over." In addition, Participant 1 spoke about how he did not like talking about his injury due to the stigma around disabilities by saying "telling anybody that I met what actually happened was embarrassing."

In addition to their own perceptions of disability, multiple participants spoke of their fears of others' perceptions. Relating to negative body image, many participants spoke of the idea of how others saw disabilities as 'unattractive,' even if the significant other did not in fact have those anticipated opinions. Participant 2 spoke to this idea when she said, "I was like 'If you wanted to leave me, I would understand,' and he would get really upset when I said things like that 'cause he was like 'that's not even a question, I love you.'" Participant 2 further spoke about this same experience when she said "At first, I was like my body looks so different, it's not attractive, how could he be attracted [to me]? And he was kind of like 'I don't understand this line of thought that you have.'"

External Barriers to Intimacy and Romantic Relationships

In addition to the internal barriers, all participants also discussed a variety of external barriers to engaging in intimacy and romantic relationships after a spinal cord injury. These external barriers included, but are not limited to, others' perspectives of disability, their significant other's coping style, as well as differing views of intimacy after obtaining a SCI.

Others' Perspectives of Disability. Three individuals in particular spoke of their experiences with being stigmatized from outside individuals based solely on their disabilities. Participant 2 spoke of many times when people first met her and her husband, or just one of them, and their first impression was that he was solely her caregiver and must experience high amounts of burden. She spoke of these experiences below:

> And I'm like, OK, so the reason you say that is because he's married to a woman who's disabled, so, let's rethink that. There's a lot to unpack there, right? Like if he's with me,

> he must be an angel, like this view that someone that spends their life with someone with a disability must inherently just be the most angelic, wonderful person on this planet.

She was not the only one to speak of being stigmatized by others, though. Participant 4 spoke of a similar experience where her community did not know how to communicate with her after her SCI. Her experience is below:

> I had just been able to learn to drive again and I had an accommodated car, and I had these Lofstrand crutches and I'm walking around, and nobody spoke to me. None of the people that I knew spoke to me at all, not even said hello, goodbye, anything. And I left and thought 'Well that's just so strange.' I mean I knew all these people in this town. But, when I saw one of the girls next week, I said it was so odd to have nobody talk to me. Well, she's the only one that didn't. She said 'Well, they had a lot to say about you when you left.' So I think that's the way people are. They have a hard time.

My Partner's Uncertainty and Coping Styles. Another external barrier that was identified by multiple participants was that their partner did not know how to help them, especially immediately after the injury. This experience was outlined by Participant 2 as she shared:

> He was scared, and he was sad, and he was lonely because he didn't really know exactly. No one really knew how to support him or to support us… It was really overwhelming for everyone and that includes him overwhelmed. I think he was overwhelmed and scared and just didn't know exactly what to do.

In addition, varying coping styles can elicit different reactions from the individual and their significant other. Participant 4 spoke about her husband's avoidant coping style, which ultimately hurt the relationship, as well as her self-esteem. Participant 4 outlined her experience by saying, “I was just very, very, very not myself. So my husband actually distanced himself at the time from me. I thought we had a pretty tough time in the beginning. Really tough.”

Furthermore, Participant 4 spoke about how her relationship was really tested after the SCI because of their different coping styles, which led to a lack of communication between her and her partner. She spoke of how hard it was to not have these necessary conversations and how the relationship might have gone more smoothly had they had these open conversations throughout the process. She detailed these feelings below:

> [My husband] was not a person who liked to talk about things that didn't go well. He was never that way… I think it would have been better and would have gone more smoothly and maybe if we’d have a one-on-one with the counselor in the hospital just for the two of us, the three of us together we could have talked it through and maybe, but it never happened.

On the other hand, some individuals who were not in a relationship at the time of injury had a hard time coping with their injury alone. Participant 3, who was single at the time of his SCI, spoke about how he fell into a depression after the injury and how he would have appreciated someone being by his side during the rehabilitation. His spoke of this experience below:

> I was in depression for two years. I was not here for two years. I always wanted to date someone, but I knew I wouldn’t be able to do it in the state I was in ‘cause, you know, you’re depressed. You’re not a normal human being. After [the injury], that’s all I needed. It’s a lonely life.

Of those in a relationship at the time of injury, some spoke about how they were able to cope with their injury because they had someone by their side and were not recovering alone. Therefore, while having a significant other with an adverse coping style can be a barrier to romantic relationships, having a partner who has a similar coping style can serve as a facilitator. Participant 2 spoke about her experience with coping with her injury below:

> I did struggle with my mental health after the accident… I didn't know how to cope, and I think I very easily could have just sort of drawn into myself and isolated and I can look back and see it going that way if I didn't have someone like his sort of undying love and support.

SCI Changed my View of Intimacy. After experiencing a SCI, the individual as well as the significant other, experienced romantic relationships in a different light. Engaging in acts of physical intimacy was often more difficult and took more time to set up, which led to less acts of physicality. For example, Participant 5 spoke of how much more effort had to go into intimacy after the SCI compared to the spontaneity that occurred beforehand by saying "It was always up to her to initiate. When I'd want to, she wouldn't be feeling right. And she had to get me prepared for it. So that always had to be in consideration." In addition, the individual may not feel as comfortable with the physical aspects of intimacy and may prefer more emotional intimacy. Participant 1 spoke of this change in his romantic life after SCI below:

> So I don't know if it's because of the sex or whatever, but I'm more touchy, more verbally, emotionally type and cuddly and stuff like that. Before I was not touchy… I was sexually driven before, but now I'm more emotionally connected than sexually driven.

However, it is important to note that not all the participants noticed a decline in their physical relationships. Participant 4 spoke of how she believed her romantic relationship was enhanced after the SCI. She equated it to her and her significant other being so thankful that she survived, that they were closer and more intimate with each other afterwards. Participant 4 described this phenomenon below:

> We'd always been very intimate and had a wonderful healthy relationship, so once it was resumed, I felt like… it was better than it had even been …It was more complete, just better… So I just thought isn't this amazing that this, for a person who has this problem, it's better than it was.

Facilitators to Intimacy and Romantic Relationships

While there are certainly barriers to engaging in intimacy and romantic relationships after SCI, many participants spoke of facilitators as well. All participants, whether in a current relationship or not, spoke of strategies they found to work well when continuing or initiating a relationship, some of which include adapting when needed, involving their significant other in rehabilitation, and continually communicating with their significant other.

Creating Our New Normal. Because there are so many changes after SCI, including those that affect solely the individual as well as those that affect the couple, many participants spoke of ways that they were able to adapt their relationship to continue to engage in them. For example, some participants spoke of ways that they were able to alter specific aspects of the relationship to match their new needs and challenges. Participant 2 spoke of one such way to adapt hand holding in an inter-abled relationship below:

> The holding hands, my hands are paralyzed, but he would just stretch out my fingers and, we still do, and then we’re able to interweave our fingers, but he just kind of moves my hand so that we could hold hands that way. So, yeah, I don’t know, I think we just kind of figured it out.

While there were certainly specific examples of ways to adapt relationships to meet the individual at their new level of physical functioning, most individuals spoke of the general need of adaption in the relationship. One physical change that can affect the individual after a SCI is having to complete transfers to get from the wheelchair to a different surface. Participant 5 spoke about how his girlfriend felt comfortable helping with these transfers years after the injury. He says “She was comfortable moving me around and getting me to places. So, that took a little bit of strength and agility.”

In addition, some participants spoke about how it was difficult to continue to go on dates when there were issues with accessibility. When Participant 5 and his girlfriend went to restaurants that lacked accessibility, they tried to adapt and educate the staff on this topic. He explains this process below:

> We tried to stay with accessible places that we knew of, but we did run into places where there was no accessibility and we had to complain and try to help us out when we pointed out the problem to the owner and try to educate him about the [accessibility], so we taught him how to and who to contact… We educated them and they got an education from us.

However, some participants spoke more about their experiencing adapting to their new situations and continuing to make their dating life as close to normal as possible. Participant 2 spoke about her experience returning to dating below:

> It was awkward at first just because I didn’t know how to navigate the world in a wheelchair. So there was a lot of just figuring things out. And [my boyfriend] has this way of making anything fun, making anything an adventure, making anything an opportunity to bond and spend time together so you know when I was with him, I truly was comfortable, like I didn’t feel self-conscious.

As the participants were mentioning, if the individual or their significant other could not find new ways of engaging in intimacy, the relationship may not last; however, if there were attempts to work as a team, the relationship will be more stable. Participant 1 highlighted this idea by saying “As long as your spouse or significant other is willing to work with you, there are still ways to be sexually and intimately connected and fulfilled.”

Involving my Significant Other. Another facilitator of romantic relationships and intimacy after SCI identified by the participants is the idea of involving the significant other as much as possible during rehabilitation. Of the two participants who were in a romantic relationship during SCI rehabilitation, both had their significant other involved in the rehabilitation process quite heavily. Participant 4 discussed her husband’s involvement below:

> He was very much involved in talking to the doctors and nurses… He came to all the meetings at the hospital that I attended. He was there for them. They were family meetings, and he was always involved in them.

In addition, Participant 2 discussed how much she appreciated having her significant other involved in her rehabilitation. She spoke about how her mother was not allowed into rehabilitation with her, however her significant other was, which helped reinforce the strength of the relationship and the support of her boyfriend. Participant 2 explained this by saying “They would let him [come to therapy] because I think they knew how much it meant to me. So, you know, he was sort of as involved as the PT or OT allowed him to be.”

Communicating with Each Other. The final facilitator of romantic relationships and intimacy after SCI that emerged from the participants was being open, honest, and communicative with their significant other. As going through a SCI was a new process for both the individual and those around them, this is a process that needs to include everyone in order to help the individual recover and thrive. For example, Participant 2 spoke about how this open communication helped her relationship after the SCI by saying that “We’ve always been communicative in every space of our relationship, including our sex life, and just communicating… or just being open and having some patience about it.”

Participant 3, who was single at the time of SCI and recovery, also spoke about how open and honest communication is essential in starting a new relationship. He offered “I’ll probably spill the beans right away just to get it over with so I can relax… My physical difference is what she needs to be prepared for. You don’t want her to be shocked.”

Rehabilitation Experiences Involving Intimacy and Romantic Relationships

Each participant outlined their conversations, or lack of conversations, revolving around intimacy during rehabilitation. Some participants noted that they had no mention about the topic, while others stated they had very limited conversations, or material was dropped off but never spoken about. All participants also had their own opinion as to what was helpful at the time and what would have been most helpful if they had to go back and do it again.

Figuring it out on our own. One commonality between all five participants was that there was very little, if any, conversation about engaging in intimacy and romantic relationships during rehabilitation. Participants 4 and 5 mentioned that they were not given any conversations face-to-face, but instead they were provided with reading materials and nothing else was mentioned. Participant 4 shared about this experience by saying “In the hospital, they gave you a book, and that’s all you ever had. You really didn’t have any other preface to resuming your romantic life again…. [The book] was dropped off and not spoken about.” Participant 1 reported no memory or neither verbal conversations nor written materials being mentioned throughout rehabilitation. Participant 3 spoke of his very limited experience with this type of conversation. After being asked about whether there was any discussion regarding intimacy and relationships, Participant 3 responded with “Not really. We had a class. One. They went to the manual and sort of said what was in the manual and that was it. Any questions? No? Ok.” Therefore, there is very limited conversation around this topic, if at all.

Many of the individuals spoke of how they would have liked to have further discussion about how to engage in intimacy and relationships after SCI but were never given the chance. Participant 2 spoke about how she really appreciated having the conversation with the counselor, of a specialty she could not remember, and that she thought one conversation was acceptable, although she recognizes the need for further dialogue to continue for other individuals that may need more facilitation. Participant 2 speaks of this below:

> Having that information, having those talks, I think it depends on the person. I feel like I was good with the one talk, but someone else might need more space to talk about it and I

> think that should be an option. Some people maybe don't want to talk about it at all or aren't ready to talk about it yet.

As Participant 3 pointed out, one reason that there was a lack of conversion with this topic could be because the therapists were uncomfortable and did not know what to say. These therapists, most likely, have not experienced a SCI themselves and do not have the personal connection to it. Participant 3 continued with this rationale by stating "I remember having the sex discussion with the OT and PT and they don't get it. It's just something they had to do." This individual felt as if the therapists were checking off the check box instead of really trying to engage the individual in purposeful conversation.

What I Would Have Liked. The final commonality regarding discussions over engaging in intimacy and romantic relationships was the idea that these conversations need to continue throughout the entire recovery process, instead of a one-and-done conversation at the beginning of rehabilitation. Participant 2 talks about her experience with only one conversation below:

> The only place that [intimacy] was discussed was at the initial [rehab hospital]. You were assigned to a counselor there and she made a point to talk about it with me and bring it up and sort of give permission for me to talk about it, to ask questions, because sex is such a taboo topic for a lot of people and I think sometimes people just need a space where they're given permission to talk about it, because then if they know it's OK, the questions come flooding out… That was in the first month or two after the accident, so it was very early on, and then no one ever gave the opportunity to really talk about it again.

Other individuals also mentioned that this discussion needed to be initiated during rehabilitation, but it also needs to be a continuous process and re-examined at different stages. Participant 3 shared “At that point, you need to hear about it, but it’s still too early. This needs to be repeated later on when you’ve calmed down a little bit and your chemicals flattened out a little bit [from the medication].”

Of the individuals who did receive talks and conversation on this topic, all of them took place within the beginning stages of rehabilitation, as discussed above by Participant 2. These individuals reported that they had other priorities at the time, and that they would have gained more out of the conversations if they had happened later in the recovery process. Participant 1 spoke of his priorities when he stated “One, I feel it was too soon [in rehab] and two, my focus was more on being able to walk… If my leg could work properly, I would not care if I could never get an erection again.” Participant 3 also discussed how he had other priorities on his mind during rehabilitation, specifically revolving around his mental health. His story is below:

> Sex was not even in the mind [in rehab]. I wasn’t here. My brain was connected to my consciousness. I was clinically depressed. Because breathing and waking up and not crying was an issue and let alone think about anybody else or sex. When you’re that depressed, nothing else matters. Eating doesn’t matter. Taking a bath doesn’t matter, so I don’t think, you know, sex is higher up in the hierarchy of needs of a human being. I’m not even close to that. I was at basic needs.

In addition, the participants had many suggestions as to how to make these conversations more meaningful and for the patients to get more out of them. For instance, one idea that kept emerging was the fact that the therapists who were addressing these topics were not personally affected by a SCI and therefore could not provide their own struggles and solutions. Participant 3 outlined this idea below:

> [The discussion] should be with peers and the PTs and OTs. Peers who have been there, done that, type of deal, who can talk the right kind of language to you… I want a male and female peer there who had this actual experience in their new bodies to be able to temper discussion, to say ‘look, this is what I do, it’s not a big deal. You’re gonna be alright, it’s just going to be different.’

Other participants, though, spoke of how they would be nervous to have these intimate conversations with a larger group, instead of a one-on-one discussion. Participant 4 explained these feelings by stating “I think in support groups there were just too many people to do it. I don’t think people want to confess their fears to a big group.” While the exact method of having this type of discussion seemed to vary between participants, they all agreed that there needs to be a new way of continuing the conversation in a way that is better able to reach each individual at their preferred level.

Discussion

This study aimed to better understand the personal perspectives and experiences of individuals with SCI to engaging in intimacy and romantic relationships. In addition, this study examined the perceived facilitators and barriers to engaging in intimacy, as well as the role that occupational therapy (OT) can play in this type of rehabilitation. All participants, regardless of age and injury level, experienced a variety of emotions after SCI, although their facilitators and barriers remained common.

Barriers

Similar to current literature, participants in this study noted that negative body image was a significant barrier in pursuing relationships. While body image is something consistently cited in the literature as only pertaining to women, this study found that both male and female participants experienced feelings of self-consciousness and low self-esteem regarding their new bodies (Angel & Kroll, 2020; Barclay et al., 2016; Fritz et al., 2015). While males spoke more of their insecurities revolving around sexual performance and females spoke more of insecurities surrounding their physical appearance, all participants spoke of this being the biggest barrier to engaging in romantic relationships. Therefore, it is critical for occupational therapists to address self-concept and body image with all individuals after SCI, regardless of their age or gender.

The current research discusses how depression and anxiety can affect engagement in intimacy; however, it was not a prominent barrier identified (Angel & Kroll, 2020; Barclay et al., 2016). The present study does go into more depth as to the negative effects that a mental health battle can play when trying to engage in intimacy. This new information acknowledges that individuals experiencing depression and anxiety after a SCI are limited in their ability to pursue romantic relationships. In addition, the SCI affects the significant other as well, and they may experience mental health struggles as well, regarding accepting and understanding their new role. Therefore, addressing the patient’s and possible significant other’s mental health cannot only help the person psychologically recover from the SCI, but it can also help the individual better engage in their current relationship or initiate a new relationship if they would like.

Facilitators

The current research suggests that involving the family and significant other in an individual’s SCI rehabilitation has several benefits, with a focus on the physical benefits in recovery, such as more improvement over a quicker period of time (Barclay et al., 2016; Isaksson & Hellman, 2012; Ward et al., 2007). However, the present study expanded on the psychological benefits of involving the significant other during this emotional time. It is important to note the distinction between solely involving the significant other in the recovery process and examining how the significant other is reacting and coping with the SCI. While the SCI physically affects just the individual, it plays an emotional toll on everyone around the individual, and therefore, this idea of working with the individual and the significant other cope with the injury is crucial to promote healthy engagement in intimacy and romantic relationships.

In addition, the present study acknowledges the importance of open and honest communication within the romantic relationship after SCI. Whether or not the individual was in a relationship at the time of injury, all participants spoke of how maintaining an open line of communication was crucial when continuing or initiating a relationship. Therefore, it is important to address these communication skills while in rehabilitation. If there is a significant other present, therapists or other professionals can work to encourage a safe space and open communication between the two individuals. On the other hand, if the individual is not in a romantic relationship at the time of injury, or the significant other is not available during rehabilitation, the therapist can work with the individual to develop skills to set the standard of open communication. Having these talks that revolve around intimacy, relationships, expectations, and sexual performance can be difficult and uncomfortable; however if the individual is taught ways to feel more comfortable opening up with their current or future significant other, there is a greater chance of a more stable, healthier relationship that continues to grow with time.

Occupational Therapy's Role

The current literature suggests that intimacy and romantic relationships are rarely addressed in rehabilitation due to therapists feeling uncomfortable, not having proper education on this topic, or the prioritization of other aspects of recovery (Areskoug-Josefsson et al., 2016;

Fritz et al., 2015; Lohman et al., 2017; Walker et al., 2020). The present study confirmed that this topic is seldomly addressed, and when it is, the therapists seem uncomfortable with it. When the therapists display this subconscious message that intimacy is uncomfortable to discuss, patients will not be willing to unload their true feelings and concerns, and without disclosing this information, therapists may not realize this topic is of primary concern, and the patient will be discharged without any knowledge or suggestions on how to continue to engage in romantic relationships. Even if the individual is not ready to have this type of conversation, simply bringing it up can help the individual feel as if therapy is a safe place and that they can ask their occupational therapist any questions they may have. This will increase rapport between the client and therapist, ultimately helping the individual be more successful in therapy in general.

In addition, if this topic is discussed, it is often brought up too little and too early in the recovery process. Most of the participants spoke about how having one conversation at the beginning of rehabilitation is not enough and is too soon. Instead, these conversations need to be continued throughout recovery, so that the individuals can truly get the most information out of it and regain confidence in themselves and their bodies.

Occupational therapy can implement new, effective ways of initiating this conversation that may be more comfortable for both the therapist and patient. Throughout the interviews of the present study, many participants had differing views of how this conversation should be addressed. One of which was by having the patient watch a video that begins to address this topic. By allowing the individual to initially process this topic on their own, they could begin to develop any questions or concerns they may have, and the initial conversation with the therapist may not be as shocking and tense. Other suggestions included having an intimate conversation between simply the therapist, the individual, and potentially the significant other, saying that they would be more willing to share their true emotions and concerns, instead of divulging this information to a room of strangers. However, other participants mentioned wanting to have a larger conversation with peers that have gone through this process before so that it is more practical and helpful than having a therapist who has never personally been in this situation before.

Since every individual has their own opinions as to what would best address the needs for the general population of adults with a SCI, OTs should recognize that these conversations need to be based on an individualized approach so that each individual feels comfortable with whichever type of discussion is taking place. This may mean having multiple options, such as a video or reading material, one-on-one conversations, and a peer support group. The individual can then choose whichever approach they believe would be the most beneficial to them at the current moment. It is also important to note that all clients come from different cultures and walks of life, which may affect their willingness to participate in these conversations, and that needs to be respected. The discussion should be offered in case the individual feels as if it would be beneficial, however, as for other aspects of therapy, this should not be forced to any client, rather mentioned and discussed to each client’s personal preference.

Limitations

While the present study uncovered new information to add to the literature, there are several limitations. Due to a smaller sample size of five participants, there is limited ability to generalize these conclusions to all individuals with a SCI. In addition, since the ages of the participants ranged from 30 to 80 years old at the time of interview, viewpoints of those 18 to 30 years of age were not captured. Furthermore, while the student researcher utilized active listening and reflection during the interviews, there was no formal member check or follow-up interview.

Considerations for Future Research

While the present study served as a foundation for addressing intimacy and romantic relationships with individuals after a SCI, additional research needs to be done to continue this conversation. For example, future research could investigate whether heterosexual and homosexual relationships elicit the same facilitators, barriers, and experiences after obtaining a SCI. The present study only had participants who were either part of, or looking to initiate, heterosexual relationships, and in order to best understand how to approach these conversations, understanding any potential differences in these individuals' views of intimacy need to be examined. Additional research could study teenagers' and young adults' experiences after SCI and compare it to older adults, as the current study does not specifically look at one population over another. Additionally, future research could investigate what is specifically being offered by way of relational content in therapy and beyond from the perspectives of OT practitioners in rehabilitation, outpatient, and home health contexts as timing of this content along the recovery continuum is an important factor. A practice implication could incorporate one of the participants' ideas of coordinating with SCI patients to create a more comfortable way of addressing this topic in rehabilitation, such as creating a video that shows individuals with SCI and how they were able to adapt and continue engaging in intimacy after SCI. This video could be used to first broach the subject of intimacy and romantic relationships, which may help future patients feel more comfortable discussing this topic with their rehabilitation team, which could ultimately help these individuals feel more confident in their own skin before they leave rehabilitation.

Conclusion

Occupational therapy is a holistic field, that strives to address all aspects of a person's identity, however intimacy and romantic relationships is often overlooked when working with individuals during the SCI rehabilitation process. While the research suggests there are little to no conversations surrounding this area of practice, many individuals discuss wanting to have some sort of acknowledgment and discussion regarding this topic throughout their recovery process. The present study expanded and added to the current literature regarding this topic and has the following implications:

1. Engagement in intimacy and romantic relationships is important to individuals who have experienced a SCI, regardless of whether they mention it during rehabilitation.
2. Occupational therapists need to be competent and comfortable having conversations revolving around intimacy and romantic relationships with their clients to promote client-centered and holistic rehabilitation.
3. Conversations regarding intimacy and romantic relationships after SCI need to be continued throughout rehabilitation and beyond, as the patients may have more questions and concerns throughout recovery.
4. Discussions surrounding intimacy and romantic relationships need to be individualized to meet the needs and preferences of each patient. There should be several different approaches, including who is involved, to best meet each patient at their current level of mental and physical functioning.

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Appendix A

Recruitment Flyer

Opportunity to participate in a research study!

Client perspectives of engaging in romantic relationships after a spinal cord injury

Purpose of the study:

- To better understand the personal perspectives of individuals with spinal cord injury related to engaging in intimacy and romantic relationships
- To develop a better understanding of how occupational therapy can help individuals with a spinal cord injury engage in relationships

We want to hear YOUR story!

Am I Eligible?

- Individuals with a spinal cord injury
- Between the ages of 18-35
- Willing to participate in a 60-90 minute interview via phone or video chat about your experience with intimacy and romantic relationships after the spinal cord injury

I am interested! Who do I contact?

Reach out to the student researcher, Kaitlyn Edinger, at edingerk@etown.edu. This study is being completed with Gina Fox, OTD, OTR/L, faculty advisor.

Appendix B

Interview Guide

This interview guide was developed based on extensive review of the literature about what questions need to be asked to obtain deeper insight into the lived experiences of individuals with a spinal cord injury engaging in romantic relationships. The guide includes examples of potential prompting questions; however these may be modified slightly pending participants' responses.

Before the interview starts, I would begin by saying:

> "Hi, I'm Kaitlyn and I am a senior occupational therapy major at Elizabethtown College. How are you today? … I know you already signed the informed consent, but just to review, I am here to have a conversation about intimacy and romantic relationships both prior to and after your SCI. I am really interested in your experiences, so if you have any stories you want to tell to really get the point across, please do so. I do have some questions here to ask, but I may also ask some follow up questions to make sure that I am understanding you correctly. I'll do my best to make you feel as comfortable as possible, but any time that you feel uncomfortable or would prefer not to answer a question, please let me know, and we can just skip it. Does that make sense? … Perfect. I am also going to record the session so that I can reference this interview later to make sure I accurately portray the information, is that alright? … Thank you. Any questions for me before we get started?"

Then I would begin asking questions and listening to the participant's experiences and stories.

Demographics:

- Do you identify as male or female?
- What is your age?
- What level is your SCI?
- When did you acquire your SCI? How old were you at the time?

1. Were you in a relationship at the time of your SCI?
    a. If in a relationship at the time:
        i. Can you tell me about how your significant other reacted to your SCI?
            1. I'm hearing it was certainly an adjustment for both of you. Can you elaborate as to the role he or she played after the injury?
        ii. Can you describe their role in the rehabilitation process? Were they very involved or more removed?
            1. I'm so glad to hear they were involved! Can you elaborate on how he or she was involved in therapy?
            2. So they did come to therapy with you, that's great. Can you elaborate on how you think their presence affected therapy, if at all?
        iii. Can you explain how the relationship changed after the SCI in terms of going on dates?
            1. I'm hearing that while you were still the same people, the relationship shifted a bit. Did you find that you were able to go out as much as you had in the past?
            2. I know you mentioned loving to go out to different restaurants together. Can you tell me how that may have changed after the SCI?

        3. I know you mentioned really enjoying a night on the town. Were you still able to visit all your favorite places or did you find new places to go?
    iv. Can you discuss how the relationship changed physically? This can include holding hands, touching each other, cuddling, kissing, sex, etc.
        1. I'm hearing that you used to cuddle a lot, but that kind of stopped after the injury. Can you explain why that was or how you felt about it?
    v. Were you ever scared of losing your significant other during the rehabilitation process? Can you explain these feelings?
        1. I understand it was a very scary time with lots of adjustments and there were times you were scared of what the future held. Can you explain a little more about how these feelings affected the relationship at the time?
    vi. Are you still currently with that partner?
        1. I'm glad to hear you two are still together. Can you elaborate on what factors helped you stay together through the process?
        2. I'm sorry to hear that. Can you elaborate on what factors contributed to the breakup?
b. If not in a relationship at the time:
    i. Can you tell me about your process of re-integrating into the dating world?
        1. I'm hearing you found it really difficult to put yourself out there. Can you tell me how long after your injury you think you started going on dates again?

    ii. Have you been in a relationship, or on dates with someone since the injury?
    iii. Can you tell me about how you found potential dating partners?
        1. I understand you met people out in the community, did you consider or use online dating apps?
        2. I see you mostly used online dating apps to meet new people. Did you ever get set up with a mutual friend or meet someone in the community as well?
    iv. Can you describe what was scary about starting to date someone new?
        1. I understand it is scary to go on a first date with someone you've never met. Can you elaborate on what you were afraid of?
    v. Can you describe what was difficult during the dating process?
        1. I'm hearing the first few dates were always the hardest for you. Can you describe how you did with coming up with date ideas, such as where to go and what to do?
    vi. Can you describe what was difficult physically, such as holding hands, touching each other, cuddling, kissing, sex, etc.
        1. I understand it is difficult to initiate physical touch in any relationship. Can you elaborate on how much physical touch was in the relationship both prior to and after the SCI?

2. Are you in a relationship currently?
    a. If yes: Can you tell me about how is this relationship different than previous relationships you've had?

        i. I know you mentioned you really liked going to the river, are you still going there?
        ii. So you're not able to make it to the river that often, have you found new favorite spots in town?
        iii. I know you mentioned lots of physical touch in past relationships, do you currently hold hands, cuddle, kiss, etc. as much as you had in the past?
        iv. Are you happy with the amount of physical touch in the relationship? Do you want more or less? Can you elaborate?
    b. If no: Have you had a relationship since your SCI? Can you describe that relationship?
        i. I know you mentioned you really liked going to the river, were you still going there during this relationship?
        ii. So you weren't able to make it to the river that often, did you find new favorite spots in town?
        iii. I know you mentioned lots of physical touch in past relationships prior to your SCI, did you hold hands, cuddle, kiss, etc. as much in this relationship as you had in the past?
        iv. Were you happy with the amount of physical touch in the relationship? Would you have liked more or less? Can you elaborate?

3. Can you describe what makes it easy to be in a relationship or to start a relationship?
    a. Would you describe yourself as a more outgoing person or more reserved?
        i. Do you think that this has helped you begin or stay in a relationship? Can you elaborate?

    b. Can you describe your support system with family or friends?
        i. I'm hearing you have a large group of friends. Can you touch on how your friends are involved in your relationships? Do you all hang out together?
        ii. I'm glad to hear everyone gets along well enough to hang out together. Can you discuss whether your family and friends' opinions of your girlfriend or boyfriend are important to you?

4. Can you describe what makes it more difficult to be in a relationship or start a relationship?
    a. I'm hearing it is difficult you get around town. Can you explain how you get around? Do you currently drive, use public transportation, rely on friends?
    b. I understand you feel unsure of yourself and self-conscious sometimes. Can you elaborate on how this affects your relationships?
5. When you were in rehabilitation after your SCI, did anyone ever discuss intimacy with you?
    a. If yes:
        i. Can you explain who or what discipline discussed it with you?
            1. So the occupational therapist had this talk with you, ok. Can you elaborate as to when it was discussed? What point in rehab was it brought up?
        ii. Can you explain what was discussed at the time?
            1. I'm hearing they discussed ways that you can still have sex. Can you elaborate as to how you took the information at the time? Were you ready to receive this information? Did it feel overwhelming?
            2. I'm hearing that it was a lot of information to take in all at once. Can you discuss when you would have preferred to have the conversation?

        iii. Can you explain who was with you at the time?
            1. Was your significant other with you? Another family member? Alone?
            2. I understand you were alone at the time. Can you elaborate as to whether you appreciated having the privacy or if you would have preferred to have a support system there?
            3. I'm hearing you had your girlfriend there during the discussion. Can you elaborate as to whether you appreciated having the social support or if you feel like you would have preferred some privacy?
        iv. Can you discuss if the information provided helpful at the time?
            1. I'm hearing it was very helpful and informative. Can you explain if you remembered the information after rehab?
    b. If no:
        i. Would you have liked to discuss it?
            1. I understand you would have liked something to have been said. Can you elaborate as to what you would have liked to have been discussed?
            2. I'm hearing you would have liked some information about how to still be intimate with your partner. Can you explain when you think the best time would have been for the topic to have been brought up? Right after injury or later in rehab?

Appendix C

Informed Consent Form

Title of Research: Client perspectives of engaging in romantic relationships after a spinal cord injury: A phenomenological inquiry

Principal Investigator(s): Kaitlyn Edinger, OTS and Dr. Gina Fox, OTD, OTR/L, Faculty Advisor

Purpose of Research:

The purpose of this study is to better understand the personal perspectives of individuals with spinal cord injury related to engaging in intimacy and romantic relationships, including the facilitators and barriers. In addition, the study will develop a better understanding of how occupational therapy can help individuals with a spinal cord injury engage in relationships.

Procedures:

As a participant, I will engage in an interview with the student researcher to share my experience with intimacy and romantic relationships after my spinal cord injury. The interview will take place via a phone or video call. My responses to interview questions will be audio recorded, but all information will be kept protected and confidential. Audio recordings will be transcribed verbatim, and transcriptions will be analyzed for common themes.

Risks and Discomforts

I understand that there is minimal to no risk anticipated from my participation in this study. I may begin to feel uncomfortable discussing personal aspects of my intimate relationships. However, I recognize that all of my responses will be kept confidential, and the student researcher will make every effect to help me feel comfortable throughout the interview. I also understand that I have the right to skip any question that I do not feel comfortable answering.

Benefits

I understand that there will be no direct benefit to me; however, the information I provide may contribute to occupational therapy practice. This information may help therapists better understand the facilitators and barriers of engaging in intimacy and romantic relationships after a spinal cord injury, and how occupational therapy can better support individuals with a spinal cord injury.

Compensation

I understand that I will not receive any compensation for participating in this study.

Confidentiality

The information gathered during this study will remain confidential, and all records will be kept private and locked in a file during the study. Only the researchers listed on this form will have access to the study data and information. The results of the research will be published in the form of an undergraduate paper and may be published in a professional journal or presented at professional meetings. In any report or publication, the researcher will not provide any information that would make it possible to identify me.

Withdrawal without Prejudice

My participation in this study is strictly voluntary; refusal to participate will involve no penalty. If I initially decide to participate, I am still free to withdraw at any time.

Contacts and Questions

If I have any questions concerning the research project, I may contact the principal investigator Kaitlyn Edinger via email at edingerk@etown.edu or the faculty mentor Dr. Gina Fox via email at foxg@etown.edu. Should I have any questions about my participant rights involved in this research I may contact the Elizabethtown College Institutional Review Board Submission Coordinator, Dr. Susan Mapp, at (717)361-3766 or via email at mapps@etown.edu.

Statement of Consent:

☐ I am 18 years of age or older.

☐ I have read the above information. I have asked questions and received answers. My organization is willing to participate in this study.

☐ A copy of this consent form has been provided to me.

Participant Signature ____ Date ________

Investigator Signature ____ Date _________