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Relationships and Spinal Cord Injury:
Occupational Therapy's Role in Facilitating the Transition Post-Injury

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Abstract

OBJECTIVE. The purposes of this study were; 1) to identify the impact of spinal cord injury on areas of partner and/or marital relationships post-injury, and 2) to identify the role of the occupational therapist in facilitating the transition of partner relationships post-spinal cord injury.

METHOD. Six men with acute spinal cord injuries participated in two focus group discussions approximately two hours in length. The discussions were voice recorded, transcribed, and analyzed by three researchers using a code-recode procedure called thematic analysis. Following an independent analysis of the focus group results, the notable similarities and differences were highlighted.

RESULTS. The outcome regarding the impact of spinal cord injury on partner and/or marital relationships varied amongst the participants based on individual experiences. Participants identified a vast amount of areas affected by their injury, including; emotional status of themselves and/or their partner, sexuality, role changes, finances, dreams/future plans, fertility, support systems, and their views on relationships. As a result of these factors, it is important to be aware of individual differences and relationship dynamics to best prepare a couple for success and life after rehabilitation.

CONCLUSIONS. Occupational therapists must use clinical judgment when initiating intervention plans focusing on relationships after a spinal cord injury, as each couple will have individual preferences to receiving the information. To optimize successful outcomes, therapists must be educated on the spinal cord injury recovery process and comfortable answering any questions that may arise on sensitive topics in order to facilitate a positive transition post-injury for the patient and his or her partner.

Relationships and Spinal Cord Injury: Occupational Therapy's Role in Facilitating the Transition Post-injury

Individuals with a spinal cord injury will experience changes in all areas of their life. For those individuals involved in a committed relationship, this could be one of the most difficult adjustments to make. Unfortunately, this is an area of concern not always addressed during the initial rehabilitation process. This paper will begin with an introduction to spinal cord injuries and a discussion of the effects it has on the areas of a person's life. Second, the current role of occupational therapy in the treatment of spinal cord injury will be explored. The effects spinal cord injury has on a person's relationships and the role of occupational therapy in facilitating the transition for the patient and his or her partner post-injury will be reviewed. Finally, the current study will be presented.

Spinal Cord Injury Etiology and Statistical Data

There are two main categories of spinal cord injuries: complete and incomplete (Miller, 2012). When a person sustains a complete spinal cord injury, his or her cord is completely severed, resulting in a loss of all sensory and motor function below the level of injury (Miller, 2012). An incomplete spinal cord injury occurs when the cord is not completely severed and there is still some voluntary function and/or sensation below the level of injury (Miller, 2012). For both categories, the degree of injury will vary in terms of functional outcome depending on which level (cervical, thoracic, lumbar, or sacral) of the spinal cord is affected. Typically, with incomplete and complete injuries, there is a 6-month period post-injury where patients will get the most return of function, both motor and sensory (Waters & Yoshida, 1996).

Spinal cord injuries are further classified to describe the impact of the injury. There are several terms used, including quadriplegia, paraplegia, and tetraplegia (Miller, 2012). Miller

describes quadriplegia as an injury where there is impairment or limited function to all of the extremities, resulting typically from a cervical cord injury. Tetraplegia is similar to quadriplegia in that it results in impairment of the upper and lower extremities, but refers to the loss of function as resulting specifically from damage to neural structures within the spinal canal and does not include damage to structures outside of the canal. Finally, paraplegia refers to functional impairments to the legs and trunk. This is a result of an injury to the thoracic, lumbar, or sacral regions of the spinal cord. According to The National Spinal Cord Injury Statistical Center, the most common neurologic category of spinal cord injury is incomplete tetraplegia with 40% of people reporting this level of disability (2013). This level was almost double compared to the other levels reported, including complete paraplegia (18%), incomplete paraplegia (19%), and complete tetraplegia (12%).

More than 12,000 people per year are affected by spinal cord injury (National Spinal Cord Injury Statistical Center [NSCISC], 2013). Of those affected, 81% are males with an average age of 43 at the time of injury (NSCISC, 2013). In 2013, it was estimated 238,000 to 332,000 people were living with a spinal cord injury in the United States. Of the people living in the United States with a spinal cord injury, a wide variety of races/ethnicities are represented including Caucasian (67%), African American (24%), Hispanic (8%), Asian (2%), and Native American (<1%).

Spinal cord injury results primarily from traumatic accidents. Of the traumatic spinal cord injury cases reported since 2010, 37% were caused by a motor vehicle crash, followed by falls at 28%, and acts of violence at 14% (NSCISC, 2013). Although the majority of spinal cord injuries result from traumatic accidents, they are not limited to traumatic causes. Some occur as a result of developmental or acquired conditions, including spina bifida, scoliosis, bacterial/viral

infections, embolisms, and thrombosis (Miller, 2012). A spinal cord injury causes not only physical disabilities, but also affects every aspect of a person's lifestyle. This area will now be discussed.

The Impact of Spinal Cord Injury on Areas of Life

The impact of spinal cord injury varies, depending upon level and degree of impairment. The impairment usually involves performance difficulties in all areas of occupation including; occupations of daily living, instrumental occupations of daily living, and socialization with others. Occupations of daily living, such as grooming, oral hygiene, eating, bathing, dressing and toileting, can pose performance problems for people with spinal cord injury with the degree of difficulty varying based on the level of injury. According to Miller (2012), it is difficult for a person with spinal cord injury to complete these occupations because he or she may need a significant amount of assistance from another person or rely on the use of a wheel chair for functional mobility. It will be an adjustment for a person to get back into a regular routine with occupations of daily living post-injury.

Instrumental occupations of daily living make up a significant amount of a person's lifestyle. Instrumental occupations of daily living are defined as, "multistep activities to care for self and others, such as household management, financial management, and childcare" (Brayman et al., 2004). There are usually no cognitive deficits accompanying spinal cord injury that interfere with socialization/communication; however, architectural, environmental, and transportation barriers can pose problems in many of these areas (Miller, 2012). These barriers, which are out of a person's control, along with decreased endurance and increased reliance on others, may present challenges to a person with a spinal cord injury in getting back to his or her

pre-injury social habits. There are many changes resulting from a spinal cord injury; however, this study is focusing on relationships and that will be the emphasis of the next section.

The Impact of Spinal Cord Injury on Relationships

Relationships, the focus of the current study, are dramatically impacted by a spinal cord injury. According to The National Spinal Cord Injury Statistical Center (2013), 52% of people are single at the time of injury, while the other 48% are in relationships. That 48% will be forced to find new balance and equality in their relationships and their partners will be thrown into a role he or she never expected to be in. These relationships are put in jeopardy, “whenever equity and equality - about finances, parenting, maintenance or planning - are compromised and one partner is heavily dependent upon the other” (Cornucopia of Disability Information, n.d.). Therefore, relationships may be strained and individuals may have concerns regarding the stability of their relationships post-injury.

Yoshida (1994) conducted a study to examine the effect spinal cord injury had on meeting potential partners and developing intimate/marital relationships. The researchers conducted semi-structured interviews with 28 males with paraplegia in a cross-sectional study. The participants had been living in the community for an average of 9 years at the time of the interviews. There were five major themes upon which potential relationships were considered: partner acceptance, assistance with accessibility, altered division of labor, sexuality, and future plans. The results showed that of the 28 participants, 43% were single before the injury and were still single at the time of the interview, 21% were single or co-habiting before the injury and then married at the time of interview, and 14% were single at the time of injury and engaged or co-habiting at the time of the interview. Eleven percent of the participants were married or engaged before the injury and were still married at the time of interview, 7% were married before the

injury and later separated or divorced by the time of the interview, and 4% were divorced before the injury and were still divorced at the time of the interview. The results of this study varied based on individual experiences and often conflicted within the group. For example, when looking at the issue of meeting others, some reported it was not a problem and others reported it was difficult. This study demonstrates the potential difficulty of meeting partners and continuing a successful marriage post-injury based on the statistics presented. It also shows there is a need for more research on the impact of spinal cord injury on areas of partner relationships.

Chan (2000) conducted a study to examine the impact of spinal cord injury on family and marital relationships. He used semi-structured interviews with 66 people with a spinal cord injury and 40 of their spouses to get both perspectives of the couple. There were six emerging themes during the interviews including; family/marital stress, marriage maintenance, divorce/separation, life satisfaction, social roles, and leisure. For the individuals with spinal cord injury the biggest issues were functional ability, role changes, and health problems. For their spouses, the biggest areas of concern were their partners' attitudes and reactions to the injury. The results of the impact of spinal cord injury varied based on how each person perceived the injury; however, Chan found there were interrelated aspects between the couples, such as how they both experience a similar adjustment process to the injury. Therefore, the health care provider should treat the patient and his or her partner as a single unit during interventions to address aspects like functional independence, caregiver burden, and communication between the couple to make the transition smoother post-injury.

Karana-Zebari, de Leon, and Kalpakjian explored the relationship between demographics, injury characteristics/physical functioning, self-rated health, and life satisfaction to marital longevity in 2,327 people with spinal cord injury (2011). They compared these

characteristics to the duration of marriage with people who were married at the time they were injured. They studied this in a prospective cohort design where they interviewed the couple four times: 1, 5, 10, and 15 years post-injury. The main outcome variable was marital longevity, which they described as, “the non-occurrence of divorce after spinal cord injury” (pp. 121). Injury level/function, independence, and mobility did not play a significant role in determining marriage longevity. The authors found the most influential predictors of marriage longevity to be maintaining social connections and improved or stable self-rated health of the person who sustained a spinal cord injury. These two areas are ones that should be addressed by a health care provider with a person with a spinal cord injury and his or her spouse during the rehabilitation process.

Kreuter (2000) conducted a scientific review to summarize the effects of spinal cord injury on partner relationships. Kreuter reviewed articles from Medline, Psychlit, and Cinahl databases and compared them on aspects of partner relationships and spinal cord injury including; “divorce, the emotional quality of the SCI person’s relationship, comparisons of relationships existing when the injury occurred and relationships established after the injury, the able-bodied partner’s personality characteristics, and single SCI persons’ possibilities to find and attract a partner” (pp. 2). There was found to be a higher rate of divorce in spinal cord injury relationships in the first 3 years post-injury. After 5 years of marriage post-injury, the rate of divorce averaged out to be around the same as the general population. Divorce rates were found to vary from 8% to 48% following a spinal cord injury. Marital status was found to be a strong predictor for independent-living variables based on the strong support the partner provided during the rehabilitation process. There is a need for more systematic research that addresses partner relationships and spinal cord injury that puts the problems of the couple into perspective.

It is important for health professionals to address relationships and all areas of life impacted by spinal cord injury to provide quality, holistic care during rehabilitation. One health care provider who is integral to the rehabilitation process is the occupational therapist and the focus will now be turned to examine the relationship between occupational therapy and spinal cord injury.

Spinal Cord Injury and Occupational Therapy

Occupational therapy is defined by the American Occupational Therapy Association as, “the art and science of applying occupation as a means to effect positive, measurable change in the health status and functional outcomes of the client by a qualified occupational therapist” (2002, pp. 668). They play a vital role in multiple settings of the care process in treating persons with spinal cord injury including; acute care, inpatient rehabilitation, and community reintegration. Throughout this spectrum, most of the treatment principles stay the same; however, the focus of care changes. The therapist will have initial contact with the patient within 24 hours of admission. In the acute care setting, the focus is on patient/family support and prevention of medical issues, such as pressure sores and range of motion limitations (Atkins, 2008). This is a very intense time for the patient as he or she may be undergoing surgical and medical procedures. The occupational therapist must be flexible and conscious of the pain and fatigue levels of the patient, as these will typically be high during this time. The main goals focused on in the acute care setting are providing environmental control and helping maintain upper limb range of motion to prevent deformities (Atkins, 2008). Therapists can work on this by performing positioning and range of motion exercises with the patient in bed.

During the inpatient rehabilitation phase of recovery, the focus is on support, education, and meaningful occupations (Atkins, 2008). The occupational therapist will continue to educate the patient and family on aspects of care and communicate with them about home modifications,

environmental accessibility, self-assertiveness, travel, and driving (Atkins, 2008). Occupational therapists will work on increasing function in performance areas that are meaningful to the patient, such as occupations of daily living, instrumental occupations of daily living, leisure, and work (Protos, Stone, & Grinnell, 2009). They may also begin to introduce self-efficacy and self-management skill interventions to encourage the patient to take an active role in his or her care. Close to discharge from rehabilitation, the therapist will assist the patient in choosing and learning how to operate the appropriate assistive equipment to ensure optimal functional mobility, including wheelchairs, bathroom equipment, and a bed (Atkins, 2008).

Recovery for a patient with spinal cord injury does not stop after rehabilitation. When leaving the hospital, the patient should feel comfortable going home and beginning to integrate back into a routine/lifestyle. The occupational therapist also has a role in reintegrating the patient back into the home and community. He or she might need to do a home evaluation to make sure it is accessible and safe for the patient's return (Atkins, 2008). The therapist will also offer a variety of occupations during therapy the patient may encounter in the community and have the patient evaluate his or her confidence in performing those occupations (Atkins, 2008). The patient may continue to receive therapy in an outpatient facility for several weeks or months after discharge. An occupational therapist needs to be an advocate for his or her patient, both in the hospital and in the community, to ensure safety and self-sufficiency. As evidenced, the occupational therapist is connected to every aspect of a person's life and relationships should be just as important. Since relationships are the focus of this study, the role of occupational therapists with relationships will now be discussed.

Role of Occupational Therapists with Relationships

Occupational therapists are experts in helping patients resume their roles and occupations of daily living, which includes their relationships; thus, occupational therapists should be prepared to address partner relationship concerns as they arise in the clinical setting. There is a plethora of research available on the effects of spinal cord injury on sexuality; however, sexuality is only one aspect of a relationship. Healthcare professionals have a responsibility to support healthy interpersonal relationships for persons with spinal cord injury and their partners. According to the Consortium for Spinal Cord Medicine, “in addition to the emotional support, information, education, and counseling related to sexuality, social skills, and interpersonal relationships, they can help in facilitating a return to the family and community” (2010, pp. 329). By working on these areas, the person can have assistance when adjusting to his or her new role in an intimate partner relationship.

The occupational therapist should encourage individuals to discuss any concerns they have about their relationship and give ample opportunities for the partner to be involved to discuss his or her concerns with the role changes that may occur as a result of the injury (Consortium for Spinal Cord Medicine, 2010). The Consortium for Spinal Cord Medicine suggests these concerns may be with sexual desires and abilities, dependency, fertility/parenting, intimacy, caregiver burden, or any other issues which either partner may have anxiety or stress over. The occupational therapist should help the couple to facilitate open communication in all aspects of their relationship and should provide the couple with accurate information about how the injury affects those aspects (Consortium for Spinal Cord Medicine, 2010). For those who are interested in a sexual relationship, the Consortium suggests the health care provider offer education on positioning, bladder management, mobility, sensation, self-care, and arousal. There

should also be discussions about some of the nonsexual challenges the couple might face, such as transportation, financial issues, medical treatments, reintegration to the family, childcare, and personal care for the person with a spinal cord injury from someone other than the romantic partner (Consortium for Spinal Cord Medicine, 2010). All of these areas can and should be discussed with the patient and his or her partner during and after rehabilitation once the couple has had a chance to assimilate back into their routines and figure out where any problems may arise.

As the results of the aforementioned studies suggest, the topic of partner relationships post-injury can be complicated and there is currently very little research out there addressing this topic. Areas such as relationship status, stability, stress, marriage maintenance, life satisfaction, caregiver roles, social integration, and health perception all need to be considered. This needs to be a concern for the patient, his or her partner, and the occupational therapist.

Current Study

Lohrer (2009) studied the timing of sexual education services following a spinal cord injury and the role of occupational therapy in sexual rehabilitation. Lohrer conducted two focus groups with individuals with spinal cord injury: one with five men and one with three women. The outcome of when to initiate sexual education services post-injury varied based on individual experiences. There were many factors which impacted one's readiness for sexual education including; relationship/marital/dating status, age, sexual drive, previous enjoyment of sexual activity, health concerns, level of acceptance, and level of function. Lohrer found individual differences need to be taken into consideration when initiating a sexual education discussion. The sexuality aspect of a relationship was the main focus and the study did not address other aspects of relationships. Therefore, the current study will broaden the scope of this study in the

hopes that more results can be found about how spinal cord injury impacts all aspects of a marital or partner relationship.

Marital and/or relationship stability was found to be a major area of concern in the care of spinal cord injury (Kreuter, 2000). There is a need for more systematic research that takes into account the perspectives of the patient and his or her partner due to the lack of research including the partner's perspectives. The role of the occupational therapist in facilitating the transition of partner relationships post-injury will be investigated by examining the impact of spinal cord injury on areas of the relationship. Crewe and Krause (1991) discussed the limitations of the existing research on the impact of spinal cord injury on relationships and lack of qualitative studies on the different aspects of partner relationships post-injury. Most of the current research focuses on divorce rates, how sexuality changes after a spinal cord injury, and other similar statistical reports that do not take the patient's experiences into perspective. Therefore, the current study seeks to provide therapists with the research-based knowledge regarding the best way to prepare the patient and his or her partner for the challenges they may face post-injury, which could potentially weaken the relationship if not properly addressed.

The purposes of this study were; 1) to identify the impact of spinal cord injury on areas of partner and/or marital relationships post-injury, and 2) to identify the role of the occupational therapist in facilitating the transition of partner relationships post-spinal cord injury.

Method

Participants

According to Krueger (1994), the ideal focus group is comprised of 6 to 10 participants. The original recruitment goal was thirty participants, however, the location and recruitment of a special population, for example persons with spinal cord injury willing to discuss their

experiences with relationships, limited the number of participants. Participants were recruited through local spinal cord injury support groups, personal contacts, referrals, email, flyers, and by word of mouth.

Once the participants were recruited, each of them or a representative for the group, was contacted by email to confirm participation and to remind them of the date/time they had been assigned. To participate in this study, participants had to meet the following inclusion criteria; (a) be a male or female who has sustained a traumatic spinal cord injury; (b) be at least 18-years of age; (c) must have been in a committed partner relationship (heterosexual or homosexual; sexual and/or nonsexual) at the time of injury (may or may not currently be in the relationship); (d) show no significant cognitive impairments; (e) able to attend focus groups and communicate with other participants/researchers in coherent conversation; and (f) willing to openly engage in a discussion about personal issues related to partner relationships post-injury.

Rationale for Method

According to Krueger (1994), focus groups are an effective method to collect data for research that intends to discuss factors pertaining to complex, multi-faceted behavior. They also provide in-depth insight into challenging topics, such as spinal cord injury and partner relationships, where certain beliefs and aspects may be uncertain. Unlike more structured methods, focus groups create an environment where open-ended comments and discussions are encouraged. Krueger also says focus groups should be considered when there are limited resources available or the research is an exploratory or preliminary study. This method is appropriate for the current study due to the lack of adequate resources identified by the literature review. Focus groups can also be helpful in acquiring individual opinions regarding future

interventions and practice in a topic area. Thus, this was the method chosen for carrying out this research study.

There are several reasons focus groups were chosen as the mode to collect data for this study. First, they allow participants the opportunity to socially interact with others who have gone through similar situations in a real-life setting to increase open communication. Participants can listen to one another and respond with their own viewpoints and opinions (Krueger, 1994). Second, focus groups allow increased flexibility compared to other methods of data collection. It allows the researcher the ability to probe into unanticipated issues that arise that may not have been possible in a more structured environment. Third, there is high face validity for focus group discussions. The discussion allows the researcher to get individual insights and opinions that may have been overlooked or impossible in structured sources. Finally, focus groups permit the researcher to obtain large and rich amounts of data from a group of participants, in a quick, relatively low cost manner as compared to the time and resources needed for individual interviews (Krueger, 1994).

Procedures

By using the focus group interview method, opinions and suggestions regarding the impact of spinal cord injury on partner relationships and occupational therapy's role in facilitating the transition post-injury was explored. The protocol questions were developed using Krueger's (1994) guidelines for question development. The questions were developed to reflect the purposes of the study: the impact of spinal cord injury on partner and/or marital relationships and occupational therapy's role in facilitating this transition post-injury. The complete focus group protocol and questions can be found in Appendix A.

Arrangements were made with The University of Toledo Main Campus and the Ann Arbor Center for Independent Living in order to reserve a wheelchair accessible room for the focus group meetings and handicap accessible parking. The first focus group was conducted on June 15, 2013 and the second on September 24, 2013. In order to optimize the group's attention, the focus groups lasted approximately 2 hours in length. Prior to the focus group meetings, the table arrangement, temperature, lighting, and background noise were assessed in order to create a comfortable, accessible environment for everyone participating (Krueger, 1994). The chairs were set up for the primary and assistant moderators and the rest were stored in another place in the room so the participants had easy access to the tabletops. The assistant moderator was present to take hand written notes, assist with logistics, and obtain clarification and/or elaboration if necessary.

Once the participants arrived, they were greeted and asked to fill out an informed consent agreement. After they gave consent, the participants were given a nametag for their first name only (Krueger, 1994) and a demographic questionnaire to complete (Appendix B). The questions covered information such as each participant's age, race, marital and familial status, level of injury, years since injury, sexual orientation, employment, education, and other related details. Once the demographic questionnaire was completed and all the participants arrived, participants were asked to find a place around the table and place their nametag visibly on the front of their shirt or on the table in front of them. After all of the paperwork was completed and collected, introductions were made and the primary moderator gave an overview of the study and discussed a few ground rules for the focus group meeting.

Since a digital voice recorder is a fundamental component of data collection with focus groups, it was introduced to participants prior to beginning the study as a tool to help capture

their comments and opinions. There were two digital voice recorders used for this study. Participants were encouraged to speak one at a time (Krueger, 1994). Only first names were used during focus group discussions; however, each participant was given a number to be used during the transcription process and data analysis. Also, the group was informed during the introduction of the study on the importance of maintaining confidentiality throughout the entire discussion. The assistant moderator took notes on the seating arrangements, noteworthy quotes, and provided insight the digital voice recorder couldn't capture, such as body language and other nonverbal aspects of the participants (Morgan & Krueger, 1998).

Results

Data Analysis

A vertical analysis was completed due to the purpose and design of the study, which means each of the focus group discussions were analyzed separately with similarities and differences addressed at the end of the study (Morgan & Krueger, 1998). Based on the recommendations of Krueger (1994) and Morgan and Krueger (1998) for data analysis and report writing, the following plan of action will be used for data collection.

1) In order to analyze the data, an audio recorder procedure was used. The primary researcher then listened to the recordings and prepared unabridged transcripts while also consulting any field notes taken by the assistant moderator, the debriefing discussion, and any summary comments made following the focus groups. The transcripts were prepared to reflect the responses of each group organized by question.

2) After making the transcripts, three researchers read through each focus group's transcript independently. They considered the words, context, internal consistency (flow of opinion changes and possible triggers), frequency (how often comments were made),

extensiveness (how many participants commented on a question), intensity (strength or depth of viewpoint), specificity (responses based on experiences made with a great degree of detail), as well as reflected on the overall purpose of the study to capture any big ideas (Krueger, 1994).

Primary themes were identified by each of the three researchers through a process of reading and highlighting any key findings and quotes as well as notes on the transcripts.

3) The researchers met to discuss themes and patterns found, negotiate categories, and develop a preliminary coding scheme.

4) Using the preliminary coding scheme, the researchers then independently coded the data. They noted any statements and passages appearing un-categorizable or categorizable into multiple thematic categories. These were then discussed when the researchers met.

5) After each of the researchers individually coded the data using the preliminary coding scheme, they met a second time to review their results and discuss any modifications. A final coding system was then developed to reflect the relevant themes.

6) Each of the researchers then used the revised themes to re-code the data. Discrepancies in the coding of specific statements or passages were resolved through further discussion until all researchers arrived at a consensus.

In order to complete a scientifically robust qualitative research study, several critical principles were used. First, a systematic, disciplined process was defined prior to data collection. Second, the results of the focus group discussions must be verifiable; therefore, quotes were selected verbatim with a systematic trail of evidence documented for replication (Krueger, 1994). Lastly, credibility was established through the use of a code-recode procedure called thematic analysis. Therefore, mechanisms were put in place to protect the integrity of the participants'

responses in order to ensure high quality results contributed to the occupational therapy profession.

Participant Demographics

The current study included six males with spinal cord injury. The participants ranged in age from 29 to 72.5 years ($M = 47.75$, $SD = 16.37$). All of the participants identified Caucasian as their race on the demographic questionnaire. In terms of highest level of education, three of the men completed a bachelor's degree, one participant had attained his master's degree, one completed high school, and the other participant identified his education level as under 12th grade. Four of the men were single before their injury and two were married. Of the participants who were single before their injury, two were still single and the other two participants were married at the time of the focus group discussions. Of the two men who were married before their injury, one was still married and the other was divorced. Two of the men had children prior to their injury, two had children after their injury, and the other two participants did not have any children before or after their injury. Four of the men reported having the potential to have children after their injury, one reported not having the ability to have children post-injury, and one participant did not answer the question. In terms of living situation, five of the participants reported living with family and the other participant lived with a friend/roommate. Three of the men identified themselves as currently employed, two were unemployed, and the other participant was retired. Furthermore, four of the men currently employed a paid personal attendant and two did not.

The etiology of five of the men's injuries resulted from a vehicular accident or a fall, while the other participant choose "other" as the cause of his injury. The men classified their level of injuries as C4, C5, C5-C6, C7, T5 and T5-T6. The six participants identified

neurological classifications of incomplete tetraplegia, complete tetraplegia, and complete paraplegia on the questionnaire. The average age of injury onset was 31.83 years ($SD = 14.93$, $Range = 19-57$). The average amount of time since their injuries was 15.58 years ($SD = 8.53$, $Range = 2.5-26$). All of the men reported being sexually active before their injury, but two reported they had not been sexually active post-injury. Additionally, all six participants reported participating in occupational therapy services, however, only two reported having a discussion about relationships post-injury with a healthcare provider. During the focus group discussions, neither of the two participants reported having this discussion with an occupational therapist during their rehabilitation.

Focus Group Themes

Fifteen themes were identified during the analysis of the two focus group transcripts. The themes identified by participants include; pre-injury relationship perceptions, grieving, abandonment, end of relationship, sexuality, caregiver role, caregiver conflicts, financial burdens, dreams/future plans changed, positive changes post-injury, new appreciation for relationship, new meaning and purpose in life, relationship/sexual education, therapeutic relationship, and need for resources and peer support. Each of the fifteen themes will be discussed in more detail throughout the remainder of the section. Significant quotes capturing the impact and importance of each theme were selected to highlight the context from which the themes were developed. Additionally, some information has been added to clarify the responses and will be included in brackets [text], while the omission of trivial words and/or phrases have been designated by the use of ellipses (...).

Pre-Injury Relationship Perceptions. The participants had a broad range of perceptions on the relationships in their lives prior to their spinal cord injury. Many of the men were in

different places in their lives when the injury occurred, so perceptions varied based upon what life stage each of them were in. Thus, this theme was created to capture the wide gamut of pre-injury perceptions, which formed a foundation for how the men felt about their relationships without the complications of a spinal cord injury.

For instance, when asked if they would have considered their relationship strong at the time of their injury, one participant responded,

“Yeah, we had our arguments, uh, two people are always going to have differences. I believe a successful marriage is compromise and we learned to do that. Um, most of the time we did, it was pretty fun. We had a good time. As my son puts it, we had a good run at it.”

Another participant, who was in a relationship with his college girlfriend at the time, responded,

“I would say it was probably fairly strong. We communicated a lot. We still talk maybe every other week.”

One of the other participants, who was in a serious relationship he saw progressing to marriage, commented on how physical activity was a major way he and his girlfriend connected and kept the relationship strong,

“Until basically the day I was paralyzed, I had a great relationship with the girl. We were basically active. We did things. She played soccer, I played soccer. We played sports together, we hunted together, cared for farm animals, and just did a whole bunch of things.”

Grieving. Throughout the focus group discussion, the topic of grieving came up several times among the men when talking about the initial reactions to their injury. Many of the

participants described going through a period of grieving after their injury when they were trying to come to terms with the severity and impact of sustaining a spinal cord injury.

One of the participants described the grieving process he went through post-injury,

“Because there is a grieving process that everybody goes through regardless of whatever that point is. At some point in the future, they’re going to look back at that and they’re going to remember it. A good example is, I had a quadriplegic who said, “You’re going to be paralyzed the rest of your life, so get used to it.” I was 19. When you’re 19, you have the idea that you’re going to get better and you have a 2-year window to get anything back. So, I was in denial. There is a denial phase of the grieving process, but I look back now and think, he was right. He came in my room and said the truth. He knew that a complete injury means you’re not going to walk again. He knew...everything he told me was right, but I didn’t want to face the truth.”

Later in the discussion, he went on to sum up what a few participants had said about the trauma they experienced,

“Just because, like [Participant #6] had mentioned, the trauma around that. When you have an accident like that at that point of life...it’s like a part of me died. So, I always tell people, that was a small death in my life and now I have been given this new way of living and now I am writing a new chapter.”

Abandonment. The issue of abandonment surfaced several times throughout the duration of the focus group discussions. The men had very different experiences with the relationships in their lives following their injuries. Many of the men experienced strain on their relationships and felt abandoned by friends, family and significant others at a time when they needed them most.

One of the men expressed the abandonment he felt by friends he thought would always be there for him,

“Friends I’ve had for years, um, all of a sudden...if I don’t go see them then they don’t come see me and I can’t drive.”

Another participant talked about the strain his injury put on his relationship with a girl he was casually dating,

“In pretty short order, she went away. I can’t blame her a bit because I was a mess. I wasn’t very independent and it was a big change from where I was the minister of death to, um, quad about town and the biggest thing for me was where does a quadriplegic go to meet girls? That was just horrifying.”

In addition, one of the other participants commented on the initial and long-term effects his injury had on the relationship with his girlfriend,

“Um, relationship wise, I was dating at the time and it definitely brought me close at the time, but now, it has just kind of fallen at the wayside. It seems like everyone, on that side – the relationship side, of dating it just kind of, everyone just kind of moved on...”

End of Relationship. The majority of the men expressed the negative experiences their spinal cord injury had on the relationships they were in when the injury happened. This was a central theme expressed many times throughout both of the focus group discussions. Many of the men experienced the end of a dating relationship, as well as one of the participants experiencing the end of his marriage. Each participant expressed individual struggles they had as a result of the injury and how it led to the end of their relationships.

One participant described how his personal struggles in coming to terms with his injury ultimately was the reason for the end of his relationship,

“I wasn’t making anything simple. I was making everything real hard. The first few years of my injury was me beating my head off of a wall and trying to think of why I wanted to live, ya know? It was just not what I wanted. So, she put herself in a big mess and stood there and took it to where I knew she would’ve a little bit, but a couple years into that she ran. That was sort of a big wake up call for me. That is when I sort of started realizing things weren’t always going to go...because before that it wasn’t very hard to get a young lady and I didn’t treasure nothing when it came to a woman. That made me wake up cause that was someone I liked and then it all went sour. That was a big wake up call and made me start doing a lot of things different.”

Another participant explained how the initial complications of his injury affected his relationship,

“...so between going to the hospital and surgery for that and with her just graduating and trying to start a career, ya know, there’s... I felt there’s no place for a relationship like that.”

While one of the other men commented how circumstances right after his accident negatively impacted the relationship,

“She got there right after I wrecked so she walked up and saw me newly injured. It really, um, it really wrecked her ‘cause like, we had been together for 3 years and she saw me like that and then got hauled away to the hospital for 2 months and those 2 months of not being with her are really kind of what put our

relationship over the edge because during that time her parents never let her come see me.”

Finally, a participant described the gradual demise of his marriage to his wife of over 20 years,

“Yeah. I filed for a legal separation when she told me she was leaving to go to [City X] to work at [a hospital] down there...we were going to marriage counseling but I said, “Well you’re not moving any closer to coming back home. You’re moving away.” So I filed that legal separation so, what that does is make her responsible for the debts she incurs and me responsible for the debts I incur. But, she countered with an absolute divorce due to gross neglect of duty, which I don’t know what she really meant by that.”

Sexuality. The theme of sexuality and intimacy was obvious throughout both focus group discussions and an overarching theme that emerged amongst the participants. Many of the men talked about the sexual encounters they experienced before and after their injuries both in and out of relationships. The impact of their spinal cord injury on intimacy and sexuality was one of the biggest concerns and issues post-injury, as well as one of the areas seldom addressed during rehabilitation. All of the men had differing viewpoints on readiness for a relationship/sexual encounters post-injury, however, the majority of them were affected by sexuality concerns in their relationships, at least in the beginning stages of recovery. Several subthemes emerged within the theme of sexuality, including disappointment with assistive devices and conception/starting a family.

One participant discussed the intimacy complications his injury created in his marriage, which he felt was a contributing factor to his divorce,

“Um, it was alright when I wasn’t paralyzed, I’d say we had a good sex life, but um, afterwards it, um, like I said, twice in 3 years was our only attempts at it so that’s what she meant I guess about gross neglect of duty when she divorced me. But um, ya know, that was something I couldn’t change. If I could have, I would have by now.”

Another participant discussed how sexual relations became an unimportant part of his marriage to his wife of 34 years based upon a mutual decision they came to after realizing there was much more they valued about their relationship,

“We had 34 years of great sexual relations and building a life together...children, and everything like that. So, we still had all this other aspects of our life together. We’re still together... We don’t have sexual relations and talking with her about it, she says, “We have more stuff to our relationship and that doesn’t have to be part of our relationship.”

That same participant later went on to say,

“In talking about sexual relations with my wife and she said, “Ya know, that’s not necessary for me and if you can’t really feel that sensation...why would I want to get into that because I wouldn’t be able to get the enjoyment of it myself.” So, she was fine with basically just deleting that. I think I am fortunate in that sense. I can’t compare it to any other women that were in a comparable situation to me.”

Another participant explained how his injury changed his views on relationships and sexuality in a positive way,

“That’s what you’re looking for, the other stuff. Not so much the sex. My sexual life is still just as good and I’m sure others are as well. My young lady is very

happy and things are great. We will probably talk a little more here, but yeah, very satisfying on both ends. I have been in relationships where both people are saying it's fine, but I just feel it's the best terms I've ever been in."

The theme of disappointment with assistive devices surfaced as a subtheme within the theme of sexuality. Many of the men had experience with a device intended to help make sexual intercourse easier and were disappointed when it did not provide the opportunities they had hoped,

"In the magazines, there's an advertisement for this Ferticare stimulator to get an erection. So I got one of those and I went and saw the doctor...could it work...and yes, demonstrated that. I did have an ejaculation. I couldn't feel it though, but he signed off for getting one of these things. I tried using it, but I couldn't feel the erection actually and I also started to get a little bit of pains in the neck indicative of [autonomic]dysreflexia. I thought, I don't want to get into that so I basically just put it away in the box."

Another participant responded to that by saying,

"My experience was very similar, um, where the device...I thought that was going to be a help with our relationship. I was thinking, oh great, I can ejaculate again. This is going to be great. But, I quickly realized that it is so much work to get to that point that it wasn't really going to benefit."

The topic of conception/starting a family also appeared to be a subtheme of sexuality in the focus groups. Some of the men had differing levels of awareness of their ability to start a family post-injury. The participants explained they were not all educated on the possibilities and options available relating to fertility/conception after a spinal cord injury.

One participant explained how he was able to conceive with the help of a fertility device,

“My wife and I had a daughter 2 years ago and without the Ferticare we wouldn’t have been able to do it. I did also have the [autonomic] dysreflexia as well, but I was given the device and told I could do it at home. It was wild, but I knew the symptoms that when I was having them I knew how to cater to them.”

Another participant discussed the importance of increasing awareness in the spinal cord injury population about fertility post-injury,

“It might be important to let people know that, yes, you can have children. Have them talk to somebody and let them know it is possible. I think this would be a big factor when looking for a potential husband. It’s different, adopting, than having your own...that there be a reassurance that this probably is possible and it doesn’t necessarily have to involve \$10,000 or more.”

Caregiver Role. A discussion on role changes post-injury prompted the emergence of this next theme. The men all had different experiences with caregivers; depending on if they were family members, a significant other, or a paid personal attendant. Some of the men expressed the challenges when role changes occurred in their relationships and the caregiver role landed on the shoulders of their loved ones,

“Well, um, for me...yes, it does affect us because she is my caretaker in terms of...if I have a pressure ulcer on my butt, then I go to the hospital for wound care, but in between, she does the dressing. She has learned how to do it expertly, so she has taken over the role of being a caretaker. If I...it’s been very rare that I have taken a fall on the floor, but she is there to help me. I try not to do that, and I am good at not doing that, but I have become dependent on her.”

Another participant commented on his negative experience of relying on a girlfriend as his caregiver,

“Those mothers, girlfriends, wives, that’s the only role they can play. Someone has to fill that role and it’s mom or somebody... It’s supposed to be taboo, ya know, don’t allow this because once they do go, if they go, or if you get in an argument...you lose your wife or your girlfriend...you lose your caregiver, your support team, your everything, so it’s really a chuck out the door when they go. I’ve had that happen many times. The girlfriend is always taking care of me and they leave... it’s starting all over again. It’s really starting all over again.”

Finally, one of the other men responded by sharing his experience when he was preparing to marry his wife,

“She understands there is a balance... I did make it clear when we were getting married that I wasn’t marrying her to be my caregiver.”

Caregiver Conflicts. A similar theme emerged when the participants discussed the conflicts that can occur within a relationship as the result of having a paid caregiver come to the home. The men explained how issues could arise when an outside caregiver is helping with intimate aspects of their care, such as bathing and dressing, especially when that personal caregiver is a woman.

One participant summed it up in a concise statement,

“The tension between a woman caregiver and a girlfriend...”

Another man in the group elaborated on the previous statement by recalling a personal example demonstrating this tension,

“That’s where...do I want my girlfriend to be my caregiver...no. It just seems to be that’s what fits. Have I tried to replace it? Yes. What happens? She is lying next to me and the aide comes to get me up. We’re waking her up, we’re in the shower, we’re giggling...ya know...it’s like, Well I can’t sleep when that shit is going on so why don’t I [girlfriend] just continue doing it.”

Financial Burdens. The cost of a spinal cord injury can have devastating effects on a person’s life and personal savings. The participants all experienced some degree of financial burden as a result of their injury, whether it was for equipment, personal caregivers, medical bills, hospital stays, or fertility. For example, one gentleman said,

“Well, I made a lump sum settlement with workers comp and it didn’t include, um, medical. Little did I know, at the time, the cost of, ya know, being a quadriplegic.”

Another participant added,

“They’ll give you \$1100 a month but that isn’t enough...I need someone to roll me at night. There’s a lot that goes on.”

Lastly, one of the other participants mentioned the unplanned costs of needing a fertility device when he was ready to begin a family with his wife,

“The Ferticare was \$900 out of pocket and then, being that my wife works at [healthcare system], was a bonus because the only other out of pocket was just clinic time for her to make sure everything was okay.”

Dreams/Future Plans Changed. Many of the participants expressed the difficulty they experienced when adjusting to their new life post-injury. They discussed the dreams and plans they had for their futures and how those changed drastically after their injury, for better or worse.

When asked how the injury affected his lifestyle, one of the men said,

“It’s been an adjustment for me because I used to like working in the yard, mostly in the lawn. I did a lot of things outdoors. I don’t do a lot of those anymore because if it’s over 80-82, I’m too hot. Looking back, I’m happy with the way things turned out, but looking back 27 years, it’s not what I would’ve planned.”

The subject of children was brought up within several different themes during the focus group discussions. This participant, who was nineteen at the time of his injury, commented on how his feelings about children evolved following his injury,

“It’s not something you look forward to at 19 but after I had my accident I wanted to have children more than I thought... but the kid thing is something I really probably missed out on that I would’ve really enjoyed, ya know? Seeing what child I would have had. All of that good stuff that goes a long with...what they would look like, how they would act...”

He later went on to talk about his dreams and how they changed after his accident,

“It was nothing I ever would’ve imagined. No dreams that I had then are dreams that I am doing today. A dream that I do have is I have a woman that I am attracted to and loves me. I feel that passionately great love, but my lifestyle is nothing what I thought it would be or my dreams where I thought they would be.”

Positive Changes Post-Injury. There is always a silver lining in times of misfortune and that is a quality each of the participants embodied. All of the men were able to talk about something positive that happened as a result of their injury, something that may or may not have occurred if they had not had an accident. For example, when talking about his family, one man said,

“I get to spend a lot of time with my grandchildren, but they don’t...they don’t look at me as though there’s something wrong with me because they’ve never know me any other way.”

Another participant talked about meeting his wife, whom he adores, after his injury when he had almost given up on love and relationships,

“I was lucky I found my wife 2 years post-injury because she ended up proving all of the things I thought...why girls wouldn’t like me...she proved them all wrong. Good things come out of it.”

One of the other guys discussed how his injury changed his view on relationships,

“It makes you into a better person. I don’t know if it came with age, but I definitely started getting down to what a relationship is, what it should be, um, a sexual relationship, a money relationship. I like not making a whole bunch of money and not having a whole bunch of things because I sort of have a feeling I am loved for the right reasons. But, I see things and they help me a lot, strengthen me and make me a better person. So, I saw a lot of good things came from my injury in terms of that department because it made me understand real stuff, ya know, not just sexuality.”

A subtheme of increased support and closeness also emerged within this theme during both focus group discussions. Several of the men talked about how their families were supportive throughout their recovery and it made those relationships stronger. One participant, who had the most recent injury, talked about the overwhelming family support he has received,

“I think in time of injuries, or anything that has to do with health, can either bring a family closer or separate. For my immediate family, it brought everyone real

close. I mean you'd like to expect that family would reunite in a time like that and they definitely did...But with family, I mean, its gotten better. I was still close with them before, but now we are even closer...I am very blessed and lucky to have that. So I think things have gotten, they're definitely a different direction than it was before."

He later went on to describe the supportive relationships with the friends who were involved in the motor vehicle accident with him,

"Yes and I didn't have a scratch on me, so everyone was almost untouched. The car flipped three times and everyone made it out almost untouched, which is kinda crazy, but um relationships with them are great. They always help out with fundraisers and they're always around to call and check up on me."

New Appreciation for Relationship. Along with the increased support, a couple of the participants described the new appreciation they found for their loved ones and significant others. Some of the men discussed appreciation for the relationship they had at the time of their injury and others commented on new relationships with girlfriends and wives they met after their accident. One participant in particular really captured the views of the men on this theme when he said,

"I had an even greater appreciation of what my wife could do. The way she was able to take over things. Not just care of me, but management of our finances. She is right on top of all that...She is on top of family relations everywhere, in terms of not ticking off any divisions in my siblings. She is a very good counselor in terms of my stepping out of the fray of some of the sibling things there. My wife is much better at knowing what to not say to siblings or to other people. I have

learned to listen to and take her advice on these things. I messed up some things because of not having the right attitude about things so I don't do that much anymore. If there is a question about things, I ask her what her take is on it. So, I appreciate her even more than I did before."

After more discussion between the other participants about similar situations in their lives, he went on to add this about his wife,

"It's a trauma. It changed life and how we relate to each other. I mean, I am in a dependent situation, um, in terms of her doing X, Y and Z for me. Used to be I ran the show more, now she runs it more. I can't say, "Well, I'm out of here." She is my most valuable asset. She is still my sweetie. We're coming up on 49 years now. I still very very much...she's my sweetie."

New Meaning and Purpose in Life. This theme emerged to capture how the participants capitalized on their spinal cord injury and embraced the new opportunities that arose. For example, one participant said,

"I've been kinda focusing more on going and educating people about the injury and telling my story. I feel a little bit more effective doing that [than working full time]."

He later went on to discuss his coaching role at a local high school, which was a pre-injury role he was able to get back into after his injury. This role gives him meaning and purpose in his life that he feels he could not get elsewhere,

"So just being more interactive with those guys and keeping the coaching role and I'm educating... So, they kinda wanna get me more involved and that's mainly the purpose of why I don't wanna work. If I do, between doing that and my

rehab that I am doing twice a week up in [City X], it would take a lot of time away from that.”

Another man commented on a new opportunity he was given as a website designer, arising as a result of a hobby he took up post-injury,

“They pay me \$100 per month to make changes on it so, um, yeah I am making \$100 more than I used to so, ya know, that gives me a purpose to do something.”

Relationship/Sexual Education. This theme was developed to highlight the long discussion on the education the participants received during their inpatient rehabilitation. The men reviewed the education they received, or did not receive, about relationships and sexuality after their injury. The majority of the men felt they were not ready for an intervention on these topics immediately after their injury, but looking back they wished they had known more before leaving the hospital. The participants wanted their preferences acknowledged and respected, however, this led to many of them feeling unprepared and left with unanswered questions upon return home.

One participant explained his lack of education on relationships by saying,

“The subject of relationships never came up in the many hours of OT I did have.”

Another gentleman described a common situation when a couple is not prepared when they leave the hospital and how that can lead to a relationship’s demise,

“And I see, I do, you see so many people who are inpatient and they’re with someone and then you hear like 2 years later they’re not with that person. You hear that so often. You also hear the success stories as well, but you hear far more of the relationships that just don’t work out. So with that, if they can just create a manual that would say, well these are some things to look for...these are

some stories of people. There are so many different situations too. There are so many different types of resources and that has got to affect a relationship.”

That same participant later went on to talk about his experience with occupational therapy during his rehabilitation,

“I was actually one on one with my occupational therapist during my stay and my experience with that was more or less them teaching me how to cook and care for myself. They didn’t really talk to me about relationships, however, they did give me a giant book that was...had basically everything in it. It was through the spinal cord network or something like that. The spinal injury association and in there was an actual chapter on relationships.”

Another participant talked about the educational opportunities available to him during his hospital stay,

“When I was up there...on Tuesdays, we had patient ed, which everyone knew about. I think it was at 7pm. I think the doctor may have talked to me about the hardware, the equipment aspects, but not as it relates to the relationship part of the relationship.”

He later went on to discuss the evolution that occurred as he found out more about what was affected after his injury and his readiness for that information,

“I don’t remember when it was, but I think for me...later. I did my acute care at [hospital] and when I was getting ready to get discharged from there, one of the doctors came in and gave me some suggestions about rehab and then he started talking about what they have done with penile implants and fertility. At that point, I thought, “Oh, that’s paralyzed too, huh?” At age 28, I just thought...Oh no! If

God was truly merciful, he would have put that in the brain stem instead of the sacral. But that's what 20-year-old guys think about."

He also commented on how his occupational therapist provided him with some sexual education options for when he was ready to accept and deal with all of the changes he would experience,

"It was very different when I was going through rehab. They were doing penile implants, the rigid ones, the inflatable ones and I was thinking, "That isn't right." I guess I was hoping there would be another answer by the time I became sexually active again and thankfully that happened. I didn't mind looking through the catalogue with...I think it was my OT. I was perfectly comfortable with that, but I also knew I didn't have to make a decision right then and there. Saying okay, here are some options."

Finally, one of the gentlemen talked about the timing of receiving education,

"Here is the bad thing about too soon, too late...sometimes you wait too long and you never see that person again. They take off and they never come back. So, you almost have to catch them with something before they get out."

Therapeutic Relationship. This theme covered a broad array of issues related to the ideal type of person to deliver information on aspects of relationships after a spinal cord injury. Each of the men shared their personal experiences they had in rehabilitation, as well as some of their preferences for receiving this type of information. Specific qualities of a therapist, knowledge/experience level, and comfort level to discuss sensitive topics were all addressed as important characteristics to foster the therapeutic relationship.

One man talked about his gender preference for the person to broach these topics,

“The camaraderie from guy to guy. I think it would be a totally different experience and I mean that’s not to say that females are bad. I think the females are more, ya know, they have that caring, emotional side where more guys are coming from an athletic background and we were able to connect better.”

Another participant commented on his experience with a lot of therapists not being comfortable talking about sensitive issues, such as intimacy and sexual intercourse, so they did not get brought up in the acute phases of therapy,

“PTs/OTs are afraid to go there. Not everyone is ready to go there. A lot of people don’t want to hear that shit right out of the gate.”

Additionally, a participant expressed the need for occupational therapists to have experience with the spinal cord injury population and understand what patients are experiencing during the recovery process,

“In order for that OT, or any OT, to answer those questions properly, or to really know what the injury process is and what the recovery is from being in the hospital to any type of rehab...Unless, I mean if you don’t know, it’s almost like being in the shoes of the patient. You really can’t answer their questions properly and I think that’s the biggest thing. After the injury, I mean, no one knows, the family or whether it’s a significant other. It can be scary.”

He later mentioned this about how therapists could help,

“I’d probably say that, ya know, definitely if an OT was able to...not necessarily consult, I mean you’re not gonna be there to be a psychologist, but to be able to give them [patients] an overview of what to expect.”

Need for Resources and Peer Support. This theme developed from the passion of the participants to prepare and educate clinicians and people affected by spinal cord injury. Most of the men are advocates for spinal cord injury rehabilitation and half already volunteer as peer supports at a local inpatient hospital to help better prepare newly injured persons. They all had an opinion about the need for more resources, such as a spinal cord injury manual, and peer support and how those two things could have had an enormous impact on the recovery process. For example, one gentleman discussed the need for occupational therapists to have specialized knowledge about spinal cord injury,

“So, an OT, I know they can go into specialized areas, but having someone there to be able to educate on the struggles or the challenges of what a spinal cord brings. You really have to walk through the injury process to know how to answer those questions and obviously not every spinal cord injury is the same. It’s not the same footprint so being educated on, even the type of catheter stuff, I think is huge. Ya know, ventilators and even the technology side. Just having a broad view of what that might bring, or what a spinal cord injury might bring.”

That same participant later went on to add how a spinal cord injury manual was his family’s saving grace after his injury and how beneficial it would be for therapists to create that resource for patients and families. He talked about the importance of involving family members, friends, and significant others into the rehabilitation process so they are prepared for life after discharge,

“Okay, but how does that incorporate into your home life and how can you make it better? How can your family members be incorporated into it, and your friends? Like I was talking about that bible that we have, ya know, has range of

motion. If they're coming in from home, they aren't going to be in therapy with you, but if they come home they can have that reference to look at. I think maybe that's where an OT can come in and have something like that...something like that where you could provide that and be that reference point for the family and family members."

Another participant discussed the importance of having peer supports, who have experienced the rehabilitation process firsthand, come in and talk to a person who is in the acute phase of recovery,

"I like involving people in chairs. It's very hard for you to get across to me what the hell I am feeling and going through. So, when you get [Participant #3] in front of me, I can't come at him with 10,000 eff you's because he is just sitting there trying to be a person. You are a different person in my eyes. [Participant #3] is looking at me a little different than you are. I don't know why, but that is just a little bit how we feel and I can relate to people in chairs much better than the OTs and PTs... We're all people who have experience and it's the credibility. They see it up there too, the therapists. They're like, "Back up, we can't tell you what these guys can." That is why I enjoy what I do. Seeing these kids listening and wanting to go to the next stage."

Finally, one of the men volunteered some advice for therapists to give to their patients in the beginning stages of rehabilitation,

"Tell people it really sucks if you want it to. At some level you make a decision of whether you're going to make the best of it and be positive about things."

The results of this study, regarding the impact of spinal cord injury on partner and/or marital relationships, varied amongst the participants based on their individual experiences. All of the participants identified numerous areas of their lives which were impacted by the injury, including; emotional status of themselves and/or their partner, sexuality changes/concerns, role changes, financial burdens, dreams/future plans, fertility, support systems, and their views on relationships. Thus, it is imperative that occupational therapists be aware of individual differences and relationship dynamics in order to best prepare a couple for success after rehabilitation.

Discussion

The aim of this study was to identify the impact of spinal cord injury on areas of partner and/or marital relationships in order to determine the role of occupational therapy in facilitating this transition post-injury. As the current study discovered, the impact of a spinal cord injury on relationships and marital status varied based upon individual experiences among the participants. For example, some of the factors impacting relationships revealed in the focus groups included; pre-injury relationship status, acceptance of the injury, sexuality and conception, caregiver conflicts, role changes, financial burdens, attitudes and reactions to the injury, future plans, meaning and purpose in life, divorce and separation, and support systems pre- and post-injury. Due to these identified factors, the significance of considering and acknowledging individual experiences and situations becomes of utmost importance when determining how a relationship is impacted by spinal cord injury and how to address this transition in therapy. Participants in other studies reported similar impacts of spinal cord injury on partner relationships. When Chan (2000) interviewed 66 persons with spinal cord injury and 40 of their spouses, he found that family/marital stress, maintenance of marriage, divorce and separation, life satisfaction, role

functioning, and leisure activities had the biggest impact on relationships. It was concluded that the effects of spinal cord injury manifested in different, yet interrelated aspects between the participants and their spouses. Yoshida (1994) interviewed 28 men with paraplegia on their experiences regarding relationships. The men reported changes in relationship status post-injury, difficulty meeting others, changing viewpoints on how they assess relationships, caregiving and altered divisions of labor/roles, sexuality, and long-term plans. Thus, as can be seen by the aforementioned studies, the impacts of spinal cord injury are complex and depend heavily on individual experiences. Therefore, it is imperative to recognize and respect individual preferences and incorporate various options into rehabilitation post-injury.

While the current study revealed a broad range of factors impacting relationships after spinal cord injury, the results also highlighted the issue of relationship/marital status changes post-injury. Five out of the six participants in the current study disclosed their relationship/marriage ended as a result of their injury, while only one participant remained married post-injury. The time frame for the end of the relationships varied amongst participants; however, all five of the participants cited their injury as the main cause for it ending. Three participants experienced the end of a serious dating relationship, one went through a break-up of a casual dating relationship, and the last participant experienced a divorce as a result of his injury. Similar findings have been reported in studies focusing on relationship/marital status and adjustment to spinal cord injury. In a scientific review by Kreuter (2000), the divorce rate after a spinal cord injury was higher than the average population, ranging from 8% to 48%. El Ghatit and Hanson (1975) studied the outcome of 333 marriages that were intact at the time of the male's spinal cord injury. Of those marriages, 27% resulted in divorce. The highest risk factors for divorce included; being young, being female, being African American, being nonambulatory,

having no children, being injured less than three years, and having a previous divorce (Kreuter, 2000). Many of the participants in the current study fell into at least one of these at risk categories in the months and initial years following their injury, resulting in the termination of their relationships.

Other outcomes of this study revealed the need for relationship education and provided desirable qualities and requirements needed for an effective therapeutic relationship to develop between a newly injured patient and an occupational therapist. A positive therapeutic relationship is essential in order to best facilitate readiness for this education. Of the six participants in the study, only two revealed they received any type of relationship discussion and/or education during their rehabilitation and neither felt it was suffice to prepare them for the challenges that occurred in their relationships post-injury. Calhoun et al. (n.d.) emphasizes occupational therapists should take a developmental and holistic approach to relationship education, focusing discussions on body image, self-esteem, and sexuality, but not forgetting to consider the patient's personal beliefs, values, and attitudes. Incorporating a peer support, someone who has experienced a spinal cord injury and understands the recovery process, was another suggestion the participants found to be beneficial. Several of the participants reported their therapist set up a meeting with a peer support during their inpatient hospital stay and it changed their outlook on their injury, as well as their attitude towards life. One participant said involving peer supports helps in a way therapists cannot understand and it was a valuable adjunct to therapy. The participants varied in their readiness to discuss/receive education on these sensitive topics during rehabilitation. It was determined that offering the opportunity for these discussions early in rehabilitation was important, however, therapists should consider each patient on an individual basis and be aware they may not be receptive to the information initially.

In order to better prepare a person with spinal cord injury and their partner for life after injury, the participants suggested a reference manual be given to newly injured patients. A manual could educate and prepare couples for the challenges that may arise in daily life after an injury of this magnitude. Chan (2000) emphasized the importance of treating the couple as a single unit to facilitate increased understanding and preparedness following spinal cord injury. All of the participants in the current study described several important considerations and topics to be included when developing this type of resource for future patients. For example, participants suggested including topics on medical management (e.g. range of motion, catheter management), occupations of daily living (e.g. bathing, dressing, eating), and relationship challenges (e.g. financial implications, sexuality, support/closeness). Thus, participants proposed the development of a manual as a valuable resource for therapists to provide the couple at some point during the acute stages of rehabilitation.

To further expand on the topic of relationships and spinal cord injury, a discussion of the implications for occupational therapy will highlight the second purpose of the current study; which sought to identify the role of the occupational therapist in facilitating the transition of partner relationships post-spinal cord injury. Additionally, the limitations of this study will be discussed, as well as suggestions for future research.

Implications for Occupational Therapy

Identifying the role of the occupational therapist in facilitating the transition of partner relationships post-spinal cord injury was an additional focus of this study. Although the impact of a spinal cord injury on areas of relationships varied based upon individual experiences, the results of this study are still applicable to occupational therapy practice. As previously discussed in the review of the literature, occupational therapists are experts in using occupation as a

modality to elicit positive, measureable change in the health status and functional outcomes of persons with spinal cord injury, including interpersonal relationships (American Occupational Therapy Association, 2006). Occupational therapy clinicians specialize in providing a holistic approach to patients across all aspects of care, including; physical, cognitive, and psychosocial changes that may occur following an injury.

The Consortium for Spinal Cord Medicine (n.d.) expounds upon the effects of a spinal cord injury on relationships by saying, “the medical complications associated with the injury as well as the mobility and sensory changes can easily affect feelings of self worth and self-esteem” (pp. 329). Initially, they suggest people with a spinal cord injury may find social interactions and relationships with intimate partners strained or more intimidating and challenging. Occupational therapists are experts at developing rapport with patients and analyzing situations in order to address specific performance problems and provide occupations with the just right challenge. This skill can be used to address relationship issues following a spinal cord injury by encouraging the couple to openly communicate and discuss concerns they may have regarding their relationship. Therapists should encourage open communication as a positive way to alleviate undue stress and anxiety commonly experienced by a couple in the acute phase post-injury (Consortium for Spinal Cord Medicine, n. d.).

As the results of the current study and many other studies suggest, no two patients are the same and therapists need to recognize and respect individual experiences and situations when preparing client-centered treatment plans focusing on relationships. Chan (2000) suggests rehabilitation professionals include family members, especially spouses, into intervention programming. Therapists need to customize personal goals and treatment plans to each individual and/or couple in order to provide meaningful occupations addressing all aspects of

relationships and better prepare the couple for the challenges they may encounter. Occupational therapists may need to facilitate discussions for patients and their partners regarding intimacy, sexuality, fertility/conception; assist with education and problem solving for couples interested in sexual relationships; discuss maintenance of pre-injury interpersonal relationships and development of social skills to promote healthy relationships post-injury; encourage maintenance of positive relationships with children; provide the couple with the support needed for the patient to reintegrate into the family; and find resources for caregiver assistance from an outside agency to prevent caregiver burden on the partner or spouse (Consortium for Spinal Cord Medicine, n.d.). These occupations should be planned while taking into consideration the comfort level of the couple, as well as addressing personal goals of the patient. In conclusion, the results of this study imply the importance of personalizing occupations and rehabilitation services to meet the needs of the patient and his or her partner to optimize successful outcomes.

Strengthening a partner relationship can have a positive effect on rehabilitation outcomes for persons with spinal cord injury. Kreuter (2000) found the strength and quality of a patient's relationship is related to better outcomes in rehabilitation following a spinal cord injury. Therapists should design interventions with the goal of decreasing relationship/marital stress resulting from the injury and promote positive conditions to facilitate improved outcomes. Many of the participants in the current study had feelings of abandonment by their partner or spouse post-injury, which had a negative effect on their emotional status and acceptance of their injury. The participants in this study challenged therapists to be fully educated on spinal cord injury rehabilitation and the recovery process, continue to stay up to date on the latest advancements and equipment available to patients, and increase their comfort level with sensitive topics, such as relationships and sexuality, in order to provide the best means for eliciting positive results in

therapy. Occupational therapists should be prepared to initiate relationship discussions as a routine part of their treatment plan to facilitate a positive transition and prepare the couple for the challenges they will encounter following a spinal cord injury. In conclusion, clinical judgment is of utmost importance when initiating relationship interventions, as each couple will have a different comfort level and readiness to receiving these services.

Limitations of the Study

Although the researchers employed techniques and strategies when designing the current study to enhance its quality, limitations were unavoidable. First, using focus groups as the method for data collection comes with several limitations. The primary researcher was inexperienced with facilitating focus group discussions and this may have led to gathering less in-depth information from the participants during the groups. Additionally, there were both strong and passive participant personalities in each group and this may have led to some of the participant's opinions being overshadowed.

Second, the vertical analysis method used to analyze qualitative data from the focus groups may have led to bias in the current study. Although measures were taken amongst the analysts to prevent erroneous assumptions, as well as including an analyst not affiliated with the data collection process, the results of the study still rely on human interpretation. Therefore, this method could've been subject to potential bias and or varying degrees of interpretation.

Third, a limitation of the current study is the small sample size. Including a larger sample size would've been beneficial in providing more evidence and added to the opinions and suggestions of the participants in this study. Additionally, there was a lack of diversity in the sample size, as all of the participants lived in the Midwest area. This could have led to bias of individuals in this region and their experiences versus people from other geographic areas.

Several other potential participants contacted the primary researcher with interest, however, were not able to make accommodations to attend one of the focus groups due to travel restrictions.

A fourth limitation existed secondary to some of the participants knowing each other prior to the focus group session. This appeared to be a positive factor, enhancing group participation and discussion; however, some participants in the group who did not know the other participants may not have shared as openly as a result. Thus, this may have hindered the extent to which some people felt comfortable participating.

A fifth limitation of this study is the lack of inclusion of women. Efforts were made to recruit women who met the inclusion criteria; however, there was not enough interest to form a focus group. During the recruitment process, one woman contacted the primary researcher expressing her interest, but no other female participants were found to form a woman's group. Not including the female perspective in the study limits the range of the results. Women who have experienced a spinal cord injury may have a different perspective on relationships and how they were affected post-injury.

Finally, the current study was retrospective in nature and included participants with varying demographic characteristics, ages, injury levels, and time since injury. This provided many different experiences, however, might explain the individualistic nature of the results. Comparing participants of more similar backgrounds may have led to more homogeneous results that indicated more precise implications for occupational therapy.

Future Research

Several recommendations for future research have surfaced as a result of this study in order to better understand the complexity of the impact of spinal cord injury on relationships and how to facilitate a positive transition post-injury. First, further exploring this topic with a larger

sample size across different geographical areas is supported to see if the results are generalizable across the spinal cord injury population. Second, a study should be conducted with women who meet the inclusion criteria to get their perspective and compare the results with the current study. Third, a study exploring patient and/or couple readiness to receiving relationship information and intervention in the acute stages of rehabilitation after a spinal cord injury. Finally, a study exploring the development of a manual as a resource to assist therapists with better preparing a couple for the transition home following rehabilitation.

Conclusions

The findings of this study regarding the impact of spinal cord injury on areas of partner and/or marital relationships should help fill the gap in the current literature concerning a lack of knowledge on this topic and expand on the studies relating to relationship/marital status post-injury. While the impacts were not universal and relied heavily on individual experiences, participants revealed many similar factors, which should provide therapists with knowledge of potential areas to evaluate and address when initiating couple-centered intervention plans regarding relationships. Occupational therapists specialize in utilizing a holistic approach to address all aspects of care, including; physical, cognitive, and psychosocial, all of which can be altered after a spinal cord injury and have tumultuous effects on interpersonal relationships. The results of this study illustrate the need for occupational therapists to take an active role in the facilitation of positive relationship transitions post-injury for individuals with spinal cord injury and their partners. The results also provide guidance on how therapists can approach this sensitive area with more confidence and create an individualized treatment plan for their patients.

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Appendix A

Focus Group Protocol

Relationships and Spinal Cord Injury: OT's Role in Facilitating the Transition Post-injury

Introduction Outline

- After arrival, participants will be greeted, checked-in, asked to fill out an informed consent agreement, and given a nametag with their first name only.
- Once consent is obtained, the participants will be given a demographic questionnaire to complete.
- After the questionnaires are collected, participants will be encouraged to visit the refreshment table and socialize amongst themselves until all the participants arrive.
- Once all the participants arrive, they will be asked to find a place around one of the tables that are set up in the room.
 - Welcome (Morgan & Krueger, 2008):
 - Thank participants
 - Introduce the primary and secondary moderators
 - I will only be here to guide discussion amongst everyone; the assistant moderator will be taking notes periodically and seeking any necessary clarification/elaboration of your responses.
 - Overview of the study
 - You were chosen because we believe you can provide essential insight into the lived experience of relationships during and after spinal cord injury.

- The results will be used to meet requirements of my scholarly research project for the completion of my occupational therapy doctorate degree from The University of Toledo.
- Establishment of general guidelines and ground rules
 - There are no correct or wrong answers.
 - This discussion will be voice recorded so please speak one person at a time.
 - We are only using first names to emphasize confidentiality.
 - If at any time you become uncomfortable, please feel free to stop and/or excuse yourself from the discussion. There will not be any penalty or loss of benefits if you choose to do this.
 - You do not have to agree with everyone in the group, however, we do ask that you listen to everyone when they share their experiences and respect their opinions.
 - Please turn off your cell phones. If you must answer or respond, please do so quietly and return to the group as quickly as possible.
- Opening question: The first question is intended to be an icebreaker and encourage all the participants to share. It can be risky to ask the group for questions during the introduction period. Therefore, an invitation for questions from the group will not be given, however, if any of the participants bring up a question, it will be addressed (Krueger, 1994).
- **Introduction Script** (Krueger, 1994)

- “Good afternoon and welcome to our focus group today. Thank you for taking the time out of your schedule to join us for the discussion of relationships and spinal cord injury. My name is Sarah Stamps and I am an occupational therapy student at The University of Toledo. Assisting me today is my assistant moderator. I am here for the sole purpose of guiding the discussion and the assistant moderator will be taking notes and asking for clarification of responses, if necessary.
- Our aim is to find out more about the challenges a partner relationship faces during and post-spinal cord injury and how occupational therapists can have a role in easing that transition post-injury. We’ve invited people with spinal cord injury to share their experiences and insights into this topic. We are interested in your experiences and opinions because they will benefit spinal cord injury rehabilitation and education in the future.
- You were chosen to be a participant in this study because we believe you can provide essential insight into the lived experience of the challenges of partner relationships during and post-spinal cord injury. There are no correct or wrong answers, just different experiences and views. Please feel free to share any insights you may have, even if it is different from others’ views. The results of this study will be used to meet requirements of my scholarly research project for the completion of my occupational therapy doctorate degree from The University of Toledo.
- Before we begin the discussion, let me provide some ground rules. This is a research project. Please speak loudly and only one person at a time. We will be voice recording this discussion because we don’t want to miss any of your

comments. If more than one of you are talking at the same time, the voice recorder will get garbled and we might miss the comments. We will be referring to everyone by their first name only tonight, however, in later reports, no names will be attached to the comments. Your confidentiality is of utmost importance to us and we will make every effort to preserve it. We are aware that you will be sharing information with us as well as the other participants present; therefore, we ask you respect the privacy of everyone here. You do not have to agree with everyone in the group, however, we do ask you listen to everyone when they share their experiences and respect their opinions. Please keep in mind we are interested in your negative comments as well as your positive ones. Sometimes, the negative comments are just as helpful in making modifications in the future. Lastly, we ask you please turn off your cell phones. If you must answer or respond, please do so quietly and return to the group as quickly as possible.

- This discussion will last about 2 hours. Let's start. We'd like to begin by going around and asking everyone to tell us your first name, where you received your rehabilitation post-spinal cord injury, and if you received occupational therapy services.
- Potential Probes (Krueger, 1994)
 - Does anyone see it differently?
 - Are there any other opinions?
 - Would you explain more?
 - Would you give another example of what you mean?
 - Would you explain further?

- Please describe what you mean.
- I don't understand, would you explain?

Purpose

- The purposes of this study are; 1) to identify the impact of spinal cord injury on areas of partner and/or marital relationships post-injury, and 2) to identify the role of the occupational therapist in facilitating the transition of partner relationships post-spinal cord injury.

Introduction Questions

1. We'd like to begin by going around and asking everyone to tell us your first name, where you received your rehabilitation post-spinal cord injury, and if you received occupational therapy services?
2. When you hear the topic of partner relationships mentioned what comes to mind?
 - How is this different from your pre-injury perceptions?
 - How does a spinal cord injury affect your feelings of masculinity?

Pre-Injury Relationship Questions

3. How long had you been with your partner at the time of your injury?
 - Probe: length, married or not, cohabitation
4. Would you consider your relationship/marriage strong at the time of your injury?
 - Were there any other difficult situations you were experiencing?
 - Probe: challenges, divorce, separation
5. What were the strengths in your relationship prior to injury?
 - Were there any weaknesses or areas of concern?

Post-Injury Relationship Questions

6. How did your injury affect roles in your relationship with your partner?
 - What role changes did you experience? Please explain.
 - Was your partner your primary caregiver after rehabilitation or did you have an aide?
 - If your partner was the main caregiver, how did that affect your relationship?
 - Probe: social roles, family
7. How did your injury affect intimacy and/or sexual experiences with your partner?
 - Initially, what were your greatest concerns?
 - What were your partner's concerns?
 - Probe: physical functioning, psychosocial issues, body image
8. How did your spouse adjust to your injury?
 - What was the hardest adjustment for him or her?
 - How did their adjustment affect your relationship?
 - Probe: acceptance, adaptations
9. How did your injury affect your long-term plans with your partner?
 - Probe: fertility, children, finances
10. How did your injury affect your relationship/marriage status with your partner?
 - Are you still with the same partner you were with at the time of your injury?
 - Did you get married (if you weren't at the time) or get divorced/break up?
 - If not still with that partner, why?
 - Probe: challenges
11. Were there any other challenges your injury forced onto your relationship that were difficult for you and your partner?

12. What positive outcomes did your injury have on your relationship?
 - Do you think they would've happened without the injury?

Occupational Therapy Involvement Questions

13. What kind of skills do you think an occupational therapist needs in order to have a role in helping with the transition of partner relationships post-spinal cord injury?
 - Probe: education, gender, qualities
14. How could an occupational therapist prepare a couple for the challenges they will face that could affect their relationship post-spinal cord injury?
 - What can a therapist do to prepare the partner for living with a person who has a spinal cord injury?
 - What topics need to be addressed with the couple?
 - Probe: educational sessions, handouts, finances
15. Did you receive any services during your rehabilitation addressing the challenges you may face as a couple and how your injury would affect your relationship?
 - If so, what did you receive and who provided the information?
 - How was the information delivered to you?
 - Was your spouse involved?

Closing Questions

16. Ideally, how would you suggest an occupational therapist prepare someone for a healthy, successful partner relationship after spinal cord injury?
 - When would it have occurred: timing during rehabilitation?
 - Who would have initiated the experience: profession, gender?
 - Who would be involved: other patients, partners, professionals?

- Where would it occur: group vs. individual sessions?
- What kind of materials would you want: videos, handouts, discussion?
- How long would it last?

17. Give summary, is this an adequate summary?

18. Give overview, have we missed anything?

Appendix B

Focus Group Demographic Questionnaire

Relationships and Spinal Cord Injury: OT's Role in Facilitating the Transition Post-injury

Please answer the following questions:

1. What is your age and gender? _____ years _____ Male _____ Female

2. What is your race?

_____ Hispanic _____ Caucasian _____ American Indian

_____ African-American _____ Asian-American _____ Other (please specify)

3. What is the highest level of education you have completed?

_____ Under 12th grade _____ Bachelor's Degree _____ Master's Degree

_____ High School Diploma _____ Doctoral Degree

4. What was your marital status before your injury?

_____ Single _____ Stable partnership non-cohabitating

_____ Married _____ Stable partnership cohabitating

_____ Separated _____ Widowed

_____ Divorced _____ Other (please specify)

5. What is your current marital status?

_____ Single _____ Stable partnership non-cohabitating

_____ Married _____ Stable partnership cohabitating

_____ Separated _____ Widowed

_____ Divorced _____ Other (please specify)

6. Did you have children before your injury? _____ Yes _____ No

7. Did you have children after your injury? _____ Yes _____ No

8. Do you have the potential to have children post-injury? _____ Yes _____ No

9. What is your current employment status?

_____ Employed _____ Retired _____ Student

_____ Unemployed _____ Volunteer _____ Other

10. How would you classify your living situation?

_____ Lives Alone _____ Assisted Living

_____ Lives with family _____ Nursing Home

_____ Lives with friend/roommate _____ Other

11. Do you currently have a paid personal attendant? _____ Yes _____ No

12. What was the cause or etiology of your injury?

_____ Vehicular accident _____ Sports/Recreation _____ Fall

_____ Gun Shot Wound _____ Other (please specify)

13. What is your neurological classification?

_____ Paraplegia-Incomplete _____ Paraplegia-Complete

_____ Tetraplegia-Incomplete _____ Tetraplegia-Complete

14. What level is your spinal cord injury (e.g. C6, T11, etc.)? _____

15. What was your age at the onset of your injury? _____ years

16. How many years since your injury? _____ years

17. Had you been sexually active before your injury? _____ Yes _____ No

18. Have you been sexually active after your injury? _____ Yes _____ No

19. Have you ever participated in occupational therapy services? _____ Yes _____ No

20. If you have participated in occupational therapy services, did they discuss the challenges that could affect your partner relationship post-injury? _____ Yes _____ No