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An Investigation of Patient Readiness: Helping Occupational Therapists Initiate a Sexual
Discussion Post-Spinal Cord Injury

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Abstract

OBJECTIVE. The purposes of this study were: 1) to identify when sexual education services should be initiated following a spinal cord injury, and 2) to facilitate the role of occupational therapy in the sexual rehabilitation of individuals post-spinal cord injury.

METHOD. Five men and three women with acute spinal cord injuries participated in same-gender focus groups 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. A fourth researcher reviewed the final coding scheme for erroneous assumptions. Following an independent analysis of the men's and women's focus group results, the notable similarities and differences were highlighted.

RESULTS. The general outcome concerning when to initiate sexual education services post-SCI was highly varied. Participants identified an array of factors that may impact one's readiness for sexual education including one's relationship/dating/marital status, age, sexual drive and previous enjoyment of sexual activity, imminent health concerns, level of acceptance, and one's level of function in terms of the establishment of routines and development of skills. As a result of all these variables, the importance of acknowledging and respecting individual differences and preferences became the prominent, overarching outcome regarding patient readiness and the timing of sexual education services.

CONCLUSIONS. Occupational therapists must be attuned to the highly individualistic nature of human sexuality post-spinal cord injury. Professionals must educate themselves and be prepared to answer a wide variety of questions without passing judgment. Interventions should reflect patient preferences. Future research should explore a structured method to evaluate patient priorities and preferences for sexual rehabilitation post-SCI, such as a standardized pretest.

An Investigation of Patient Readiness: Helping OTs Initiate a Sexual Discussion Post-SCI

Sexuality is a legitimate and fundamental need in human beings; however, its significance and the ways in which it is expressed are highly individualized (Elliot, 2006). Sexuality is more than intercourse. It encompasses the biological, psychological, sociological, spiritual, and cultural aspects of life (Woods, 1984). It impacts our feelings of femininity and masculinity, our self-concept and desirability, and our relationships with others (Medlar, 1998). Human sexuality is a highly complex phenomenon and is a central component of our identity.

The majority of individuals with a spinal cord injury (SCI) will experience a complex array of complications post-injury. Unfortunately, the topic of human sexuality is often overlooked as part of holistic care. Therefore, this paper will first explain the impact and importance of sexuality to individuals with SCI. Second, the role, attitude, and support for sexuality within the profession of OT will be explored. Finally, a need for information regarding a client's readiness for sexuality information following SCI by an occupational therapist (OT) will be investigated.

Sexuality and SCI

The estimated annual incidence of SCI in the U.S., not including those who die at the scene of the accident, is 11,000 new cases per year. In 2000, the average age of injury was 38 years; furthermore, 78% of the SCI population were male and 52% were single when injured (National Spinal Cord Injury Statistical Center, 2006). As portrayed by these figures, SCI impacts individuals during a prime period of sexual maturation, expression, and procreation.

While sexual expression should be a fundamental right of every individual, unfortunately, the topic of sexuality has become inundated with many perverse myths which inhibits the healthy sexual expression of many disabled populations. Althof and Levine (1993) outlined three major

cultural misconceptions regarding the sexuality of individuals with SCI: 1) sex is only for the young, beautiful, and able-bodied; 2) men and women with spinal cord injury are asexual; and 3) one cannot be sexual without having intercourse. Regrettably, these myths can become self-fulfilling prophecies for those individuals with impaired sexual capabilities. In fact, it has been suggested that denial of an individual's sexuality constitutes an occupational injustice (Sakellariou & Simo Algado, 2006). Due to the fact that SCI has the potential to impact every facet of an individual's life within a matter of seconds, it is important to understand the significance of client sexuality following a spinal cord injury.

In order to understand the impact of a spinal cord injury on sexual function, the level and degree of injury must be known. The level of injury is the last normal neurological level which includes both motor and sensory function (Sipski, 1997). The degree of injury is classified as complete or incomplete: this determination is based upon whether there is voluntary contraction of the external anal sphincter as well as sensation around the rectum (Sipski, 1997). A determination concerning whether the damage is an upper or lower motor neuron injury is also of key importance in determining an individual's future level of sexual abilities. In respect to genitourinary function, upper motor neuron lesions refer to injuries above the sacral reflex arc whereas as lower motor neuron lesions result from direct injury to the sacral reflex arc (Smith & Bodner, 1993). Often upper motor neuron lesions produce spasticity below the level of the lesion, reflexive contractions of the bladder, short-lived reflex-based erections in males, and vaginal secretions are preserved in females (Smith & Bodner, 1993). Contrastingly, with lower motor neuron lesions the bladder is flaccid, reflexive erections and vaginal secretions are absent, and psychogenic erections are rare. Again, these predictions vary as physicians evaluate and determine the level and completeness of one's injury over a period of time.

The physical impact of SCIs on males and females must be considered in order to fully understand sexuality post-injury. SCIs in men can alter erectile function, ejaculation, orgasm, and fertility. Often, men with UMN injury lose the ability for voluntary, psychogenic erections, but possess the potential for reflex erections. Conversely, men with LMN injury rarely have reflexogenic erections, but often maintain control over psychogenic erections (Hodge, 1995). Male infertility is often the result of poor semen quality and ejaculatory dysfunction; nevertheless, techniques are available to help facilitate erections and ejaculation in men with SCIs (Hodge, 1995).

Despite the growing research, there is still a misconception that the sexuality of women with SCIs is irrelevant in today's society because women experience relatively less impaired genital function post-injury. While women with SCIs often experience amenorrhea for several months, vaginal lubrication dysfunction, and orgasmic issues, typically, a SCI has minimal impact on a woman's ability to conceive, carry a child full-term, and delivery vaginally (Hodge, 1995). Nevertheless, complications with pregnancy and delivery may arise; however, a mother's ability to breast feed is typically not impaired (Goddard, 1988).

While the physical impact of SCI on men and women is different, there are additional limitations following SCI that may influence both sexes ability for physical expression. For example, sexual partners must learn how to address bowel and bladder issues, muscle spasms, range of motion difficulties, sexual positions, abnormal or lack of sensations, and other sexual performance difficulties (Alexander, 1991). It is important to note that each SCI case is unique and all capabilities depend on the level, degree, and classification of the injury.

While the physical implications of SCI on sexuality are important, a complete understanding of psychosocial factors is also necessary. According to Miller (1984), it is

imperative that sexual functioning following SCI be considered within the complete picture of total function, rather than in isolation. Common emotional and psychological factors overlooked following SCI include decreased self-esteem, poor body image, depression, and anxiety (Alexander, 1991). While often short lived, patients or partners occasionally become hypersexual or obsessive in their thoughts or behaviors (Althof & Levine, 1993). It is imperative that psychosocial issues are not ignored following SCI. Therefore, rehabilitation professionals who integrate psychological factors into their treatment planning will provide better care to their clients with SCI (Mona, Krause, Norris, Camerson, Kalichman, & Lesondak, 2000).

Relationships are also impacted by SCI. For instance, an able-bodied partner may feel resentful, confused, or scared by their new role; thus, new dependency issues, worry, and fear are not uncommon (Alexander, 1991). According to 8 able-bodied women who made post-injury marital commitments to men with SCI, the major disability-related challenges involved caregiving, financial and health concerns, restriction of activities and physical limitations, and sexuality/conception issues (Milligan & Neufeldt, 1998). Furthermore, quite a few women reported intrusive warnings, suspicion, and/or disapproval from friends and family regarding their commitment to a man with SCI. Therefore, it is important that a partner's needs and concerns are not neglected during rehabilitation. Finally, in order to create a safe and judgment-free environment, where clients feel comfortable discussing any issues regarding their sexuality, it is also important to weave a client's lesbian, gay, or bisexual identity into daily occupations during the rehabilitative process (Jackson, 1995).

Importance of Sexuality to Individuals with SCI

While society may asexualize individuals with disabilities, research indicates that sexual expression does not cease to exist post-injury. Anderson (2004) conducted a survey asking

individuals with SCI to rank order seven functions in order of importance to quality of life. She received 681 useable responses, with 51% of the subjects having quadriplegia and the remaining 49% paraplegia. The results indicated that recovery of sexual function would provide the most benefit to the quality of life for an individual with paraplegia. Similarly, individuals with quadriplegia indicated that a restoration of arm/hand function would provide the greatest improvement to their quality of life, while sexual function was the second most important priority. The implications of this study are two-fold. First, due to the fact that sexual function has been identified as an important element for individuals living with SCI, a successful sexual adjustment could profoundly improve their quality of life rating. Second, sexual counseling following SCI can not be dismissed or considered a luxury—it must be addressed with every client.

Kreuter, Sullivan, and Siosteen (1996) conducted a controlled survey to identify determinants of sexual adjustment and the quality of relationships with 75 persons with SCI as compared to an age and sex-matched control group in the general population. An 80-item questionnaire was administered, but then broken down by the authors into three separate scales: three items from the questionnaire made up the Sexual Activity and Satisfaction scale (SAS), seven items composed the Sexual Behavior scale (SB), and seven additional items were compiled to construct the Emotional Quality of the Relationship scale (EQR). The latter two scales were previously constructed by all three authors and published in two studies in 1994. Furthermore, quality of life (QL) was recorded on a 0-100 visual analogue scale developed by Carlsson. Finally, 6 items reflecting depression were taken from Zigmond and Sainth's Hospital Anxiety and Depression (HAD) scale which Lundqvist, Siosteen, Blomstrand, Lind, and Sullivan had previously proven as a valid measure of quality of life. Individuals with SCI scored

significantly lower on the SAS scale, SB scale, and QL rating. They reported factors such as fewer orgasms, a greater decline in the frequency of sexual activity, and less intercourse at the culmination of sexual contact than the control group. The group with SCIs also scored higher on the depression scale compared to the control group. Nevertheless, results from the EQR scale showed no significant differences. While there were significant differences in the ways individuals with SCI assess their sexuality as compared to non-injured peers, an overwhelming majority of SCI respondents, 97%, considered sex an important part of their lives as compared to 100% of the control group. This study demonstrated that sexual expression is still an integral part of life for individuals with SCI; therefore, it should be addressed by professionals aiming to provide holistic care.

In order to examine the sexual issues of 40 women with SCI, Singh and Sharma (2005) developed a standardized questionnaire based upon their clinical experience and review of relevant literature. The questions focused on sexual activity (interest, importance, satisfaction, frequency, partner perceptions), medical issues influencing sexuality (menstruation, bowel/bladder), pregnancy, child bearing, and partner relationships. While many factors were studied, the results demonstrated that 73% of women had an interest in sex and 88% understood the importance of sex in their everyday lives. Sipski and Alexander (1993) utilized a verbally administered questionnaire with 25 females with SCI. They found that while sexual satisfaction significantly decreased post-injury, sexual desire did not diminish. Therefore, their results confirmed that women are interested in expressing themselves sexually following SCI. Richards, Tepper, Whipple, and Komisaruk (1997) conducted semi-structured interviews with 15 women with SCI in order to examine their sexually-related experiences post-injury. One woman's quote sums up the majority opinion concerning the essence and importance of female sexuality:

It is a tremendous core of who I am. Everything else comes out of that. How I think and feel about my body, my physical body. How I would define myself as a woman. How I am in all my relationships, whether they are sexual or otherwise. How I decorate my house. It's everything that I am. I may not have another way...another component that is so strong that I could say sums up everything that I am. (p. 275).

As demonstrated by these examples, it is clear that sexuality is of utmost importance to women following SCI.

According to the literature, men with SCI also find their sexuality to be of profound significance post-injury. Sakellariou and Sawada (2006) conducted in-depth, unstructured interviews with 6 men living in Greece with SCI and found that sexuality was a central, initial concern after injury. Furthermore, none of the participants reported a reduced desire for sexual relationships or acts. Their results also confirm the impact one's cultural identity can have on sexual adjustment following SCI. Thus, health professionals not only need to acknowledge the importance of sexuality to men post-SCI, clinicians must also be cognizant of a client's culture and the impact it can have on a positive sexual adjustment.

Alexander, Sipski, and Findley (1993) verbally administered a questionnaire to 38 men with SCI. They found that while 97% of pre-injury men reported an appropriate or high sexual desire, only 78% had a similar desire post-SCI. As professionals, we need to recognize the inherent sexual nature of all humans because, as this study demonstrates, the majority of men still have a high interest in sexuality following SCI, however, changes are notable.

Finally, Hart, Rintala, and Fuhrer (1996) conducted a survey of 590 adults with SCI living in the community in order to identify educational topics of interest. They discovered that nearly 40% of participants indicated great interest in sexuality issues. Thus, research supports the

proposition that while individuals with SCI face limitations, a person is not asexual because of their disability; in fact, it is of prime importance. Thus, in order to offer effective, holistic rehabilitation to an individual with SCI, health professionals must not only understand the impact a SCI has on sexuality, it is also important to recognize that individuals with SCI identify a strong desire and educational interest in sexuality post-injury.

Sexuality and Occupational Therapy

As OTs, one of our fundamental areas of expertise includes occupational analysis. In essence, we are trained to explore the nature and causes of dysfunction in occupational performance and to select appropriate adaptations or compensations to benefit our clients. Nelson and Thomas (2003) asserted that as OTs, we are able to synthesize occupational forms compatible with the abilities in a person's developmental structure which allows him or her the opportunity to engage in occupations that have meaning and purpose. Therefore, as a member of the interdisciplinary SCI rehabilitation team, OTs are able to help individuals identify ways to express their sexuality within the realm of their capabilities.

While there are many philosophical arguments in favor of the inclusion of sexuality within the domain of occupational therapy, there are also practical considerations. For example, OTs are often involved in performing assessments that involve bodily exposure and intimate touch (Jones, Weerakoon, & Pynor, 2005). Furthermore, we are involved in many other intimate occupations such as dressing, bathing, and toileting. In fact, our very own Practice Framework declares sexual activity as an occupation of daily living (American Occupational Therapy Association, 2006). Burton (2006) echoes this assertion and reinforces the importance of the issue by describing the direct impact sexuality can have on one's quality of life. In addition, OTs often possess the best understanding of a client's motor and functional abilities, home

environment, and emotional and relationship status (Miller, 1984). Consequently, therapists possess not only the knowledge to initiate the discussion of a client's sexual health following a SCI, therapists are obliged to breach this discussion due to our fundamental philosophy of holism.

Attitudes and Beliefs of OTs regarding Sexuality

Conine, Christie, Hammond, and Smith (1979) administered two questionnaires to 26 practicing adult-rehabilitation OTs. The first questionnaire listed six major sexual rehabilitation tasks and asked the therapists to indicate whether they performed the task, believed it to be important to OT, and their level of preparation. The second questionnaire was used to ascertain therapists' attitudes toward sexual rehabilitation by having them agree or disagree with 14 statements. The researchers discovered unanimous agreement among the therapists in the four following areas: 1) sexuality is an important dimension of health care; 2) information on sexuality should be made available to patients; 3) sexuality should be included in OT curricula; and 4) rehabilitation teams should routinely discuss sexuality. Despite the consensus, Conine et al. found that 62% of OTs do not participate in sexual aspects of rehabilitation. Furthermore, over two-thirds of OTRs felt inadequately prepared to deal with tasks related to a patient's sexuality due to insufficient preparation and poor role determination. This was later confirmed by Novak and Mitchell (1988).

Novak and Mitchell (1988) surveyed 100 OTs and 100 rehabilitation nurses working with patients with SCI across the nation. Seventy-five percent of the questionnaires were returned: 58 from the profession of OT and 72 from nursing were appropriate for analysis. Among OTs who work within the SCI population, they found that 48% had no formal education regarding sexual counseling; however, respondents from both professions indicated that sexual counseling was a

vital component to the overall rehabilitative process. Unfortunately, less than half (48%) of OTs reported approaching patients with SCI concerning their sexuality post-injury. Of the OTs who reported engaging in routine sexual counseling, only 29% reported conducting follow-up interviews on the topic. The current study is intended to offer knowledge to OTs concerning the most suitable time to initiate the discussion of sexuality post-SCI, which will alleviate a major gap in knowledge.

Couldrick (1998b) performed 10 semi-structured interviews with OT practitioners in England, who represented the breadth of OT practice. Nine of the 10 participants not only reported that a client's sexual expression was a legitimate domain of concern; they also believed sexuality was compatible with the holistic and humanitarian values of the profession. In practice however, only half of the OTs discussed sexual expression with their clients, thus, a major theme was the large disparity between ideology and practice. Four major factors that discouraged their inclusion of sexuality in practice included: 1) the comfort, attitudes, and competence of the therapist; 2) client factors, including respect for individual privacy, age, and gender; 3) a high pressure or unsupportive context; and 4) societal factors, such as cultural taboos, language, and legal and ethical boundaries. Assessing readiness can help increase comfort, provide an opportunity for patient input, create a supportive forum, and offer permission for clients to discuss the topic in the face of cultural restrictions.

Rehabilitation begins at admission when an interdisciplinary team including physicians, nurses, OTs, physical therapists, speech and language pathologists, social workers, and other specialists develop a comprehensive, personalized program. Sexual counseling should be a key element of the treatment plan, which is defined as providing the patient with the information he or she needs to make a personal choice about sexual activity (Novak & Mitchell, 1988).

Occupational therapists should be as prepared as other rehabilitation professionals to provide limited sexual counseling in their clinical settings (Neistadt, 1986); however, it is often difficult to conclude where an OT's role in client sexuality begins and ends because of client readiness concerns.

Role of Occupational Therapists in the Provision of Sexual Education Post-SCI

Couldrick (2005) examined the two opposing opinions regarding sexuality as a topic of concern in occupational therapy and concluded that OTs are prime candidates to promote the sexual health of their clients where illness, treatment, or disability has impacted sexual expression. Furthermore, she identified one of the cornerstones of our profession: holism, which supports OT involvement in client sexuality (Couldrick, 1998a). Therefore, if we are to remain true to our philosophy, we cannot treat a client with a SCI without addressing the multi-faceted issue of sexuality within the context of everyday life.

Miller (1984) believes that a background in OT makes us a well suited profession (with additional training requirements) to address the sexual issues that precipitate following a spinal cord injury for several reasons. First, we see sexuality within the context of total functioning: we are able to assess capabilities and maximize function. Second, we have specialized interviewing skills to explore a client's sexual history and values. Third, we possess a strong neuroanatomy and physiology background; as a result, we can translate medical reports and help our clients understand how their injury will effect their sexual functioning depending on its classification. Fourth, we have excellent problem solving abilities. For example, SCI presents many sexual health issues that require unique and varied solutions such as dealing with birth control methods or assessing effective sexual positions. Finally, we have a deep appreciation for the psychosocial factors that influence one's adaptation to different disabilities. Thus, we are equipped to help a

patient manage the issues associated with sexual experiences and practices post-injury.

Unfortunately, because of the social stigma associated with visiting a sexual health specialist, an OT provides individuals with SCI another available avenue for support and education.

Both individuals with SCI and OTs believe that sexuality is an important aspect of rehabilitation; however, there is minimal conclusive research on the appropriate time to initiate this topic. While many researchers stress the need for professional initiation of the topic (Neistadt, 1986; Herson, Hart, Gordon, & Rintala, 1999; McAlonon, 1996), many are not fulfilling this role. It cannot be assumed that patients nor their partners are not interested in sexuality information simply because they do not ask for it; it is possible they are too embarrassed or too fearful to self-initiate the discussion.

Due to the fact that many aspects of sexual expression such as the integrity of bodily functions, capacity to perform social roles, relationship changes, and an array of other physical and psychosocial concerns are often of central importance following an SCI, timing of sexual education services is of prime importance. For instance, the issue of viable sperm production in males following SCI is important to consider in the topic of timing. According to Brown, Hill, and Baker (2006) sperm quality deteriorates 6-12 days post-injury; therefore, the collection of sperm samples through processes such as electroejaculation or vibratory stimulation need to be made available during this critical period in order to obtain a near-normal sample. Furthermore, a lack of information can lead to prejudice, misconceptions, potentially dangerous sexual behavior, unplanned pregnancies, and/or unrealistic expectations (Sakellariou, 2006). Thus, is it ethical to wait for a patient to signal his/her readiness? Should a patient be discharged without any discussion of their sexuality post-SCI?

The research reflects a considerable array of suggestions and speculation concerning patient readiness and the timing of sexual rehabilitation following a SCI; unfortunately, the research to support these propositions is scarce. For example, Herson, Hart, Gordon, and Rintala (1999) believed that an assessment of patient readiness is important to determine the amount and kind of information a patient wants at a given time; however, neither a method nor a time frame were proposed. Goddard (1988) reported that when faced with a reluctant patient, a discussion of sexuality must be initiated after the patient's condition has stabilized. However, the definition of stability and a method to make this determination were ambiguous. Elliot (2006) believed sexual knowledge should be given to patients as soon as they are ready; however, the pattern continues with no documentation of supporting research for this assertion. Smith and Bodner (1993) asserted that sexual education should be initiated once patients recognize the permanent reality of their injury and are comfortable with their self-image, whereas Althof and Levine (1993) recommended that sexual counseling be initiated within the first 3 to 6 months after the trauma. While the aforementioned assertions demonstrate the importance of the topic, the empirical support and medium through which all of these ideas are to come to fruition is left up to the discretion of the audience.

While the research is lacking, several studies have addressed the topic within their research designs. For example, White (1986) utilized 31 rehabilitation nurses with a minimum of 6 months of experience with patients with SCI in an attempt to determine verbal and nonverbal behaviors thought to convey readiness for sexuality information. A behavior checklist was developed and participants were asked to report the ways patients signaled their readiness. The most common verbal behaviors observed that were thought to signify readiness included declarative statements (77%), single word phrases (71%), posing questions (61%) and joking

about the topic (58%). The nonverbal indicators most often identified by nursing staff included facial expressions (74%) and whistling and patting, both reported by 71% of participants. The results of this study demonstrate the need to measure behavioral indicators of patient readiness for altered sexual information post-injury in a formal manner.

McAlonan (1995) interviewed 12 persons with SCI to gain patient perspectives in order to improve sexual rehabilitation services. In terms of the timing of services, her findings illustrate the depth of factors that must be considered before initiation of the topic. For example, many reported needing to deal with denial, anger, and acceptance of their injury; whereas other respondents were more concerned with vital ODLs and secondary health complications. Still, one gentleman reported readiness for "...any and all information as soon as possible" (p. 831). While the timing of sexual rehabilitation varied amongst participants, McAlonan reported that participants did indicate a desire to know what their options were regarding sexual education services so they could make timely and intelligent choices. As a result, the need to evaluate an individual's readiness and preferences becomes of crucial importance. In fact, one participant suggested the development of a "pretest" to evaluate a patient's priorities, concerns, and preferences regarding future sexual rehabilitation. Thus, a need for a structured method to evaluate patient readiness was established, which was further explored in the current study.

Northcott and Chard (2000) sought to gain the perspective of 7 clients with different sexually-impacted disabilities through the use of in-depth interviews. Only 2 participants received sexual information and both had to personally initiate the discussion. In terms of the timing of the discussion, both participants indicated a lack of interest initially, with their desire increasing later in the rehabilitation phase and upon returning home. Nevertheless, this data was only based upon the preferences of two individuals; thus, generalization is limited.

In a study conducted by Westgren and Levi (1999), 8 women with SCI were interviewed to illuminate their sexual experiences post-injury. While respondents wanted a support contact introduced during the early stages, many wanted continued support throughout their transition to home-life. Furthermore, the subjects indicated a need for both psychological support and practical advice. In essence, the women wanted to talk about sexuality post-SCI, but suggested allowing time for reorientation to life post-injury.

Leibowitz (2005) used semi-structured interviews with 24 women with SCI in order to explore their experiences and concerns with inpatient sexual rehabilitation services (SRS). While multiple themes emerged, the strongest theme stressed the importance of honoring individual differences when it came to a variety of SRS aspects including the issue of timing. In essence, readiness for SRS is an unfolding process rather than an all-or-none interest. Several women emphasized the importance of communication from professionals that hinted toward sexual changes, in fact one woman reported:

So if it had been...brought to my attention, I could have started dealing with it differently, maybe, or they could have given me better directives to give me a more positive outlook about the fact that I couldn't feel it instead of just DISCOVERING it on my own and DEALING with it one my own. (p. 91)

Furthermore, it is important to be aware that all participants agreed that SRS should at least be introduced during the inpatient stay, regardless of a patient's readiness. Those professionals, who fear infringing on personal territory should note: "None of the women, including those least interested in SRS during their inpatient experiences, expressed offense at the topic being raised by health professionals" (p. 92).

The major study conducted to identify appropriate timing of sexual health interventions following SCI was performed by Fisher, Laud, Byfield, Brown, Hayat, and Fiedler (2002). They examined four intervals between initial inpatient rehabilitation and 18 months post-discharge using surveys with 40 individuals with SCIs. Using a longitudinal logistic regression model, they discovered that respondents were significantly more interested in sexual information and counseling at 6 months than during their inpatient stay, but no different in their interest from 6 to 12 months or from 12 to 18 months. Thus, the first 6 months following discharge were reported to be a critical period for sexual counseling. Nevertheless, they found that the inpatient period remains an important time during which the impact of one's spinal cord injury is realized and one's interest in sexual health is initially noted. Therefore, human sexuality is alive and present throughout the post-injury period.

As the results of the aforementioned studies indicated, the topic of patient readiness is complex. One must consider the severity and time since injury, mood, independence in personal goals, pain, relationship status, medical complications, cultural and religious values, fatigue, etc. Nevertheless, it is an important concern of both patients and OT practitioners. Therefore, the purposes of this study are: 1) to identify when the topic of sexuality should be addressed following SCI, and 2) to facilitate the role of an OT in a patient's sexual adjustment by establishing the most appropriate time to begin sexual health services post-SCI.

Current Study

Yallop and Fitzgerald (1997) explored both OT students and practicing therapists' comfort with client sexuality issues through the use of a focus group, clinical observations, informal interviews, and a scenario instrument. An increase in knowledge was the major factor identified to improve comfort with client sexuality issues. Therefore, the current study seeks to

provide therapists with research-based knowledge concerning the most appropriate time to initiate the topic of sexuality with individuals following a SCI. According to Achterberg (1988) health professionals can better decide what and how to educate clients by first assessing a client's readiness to learn. Discovery of the most suitable moment to initiate sexual education services may provide the patient with a sense of control regarding the exploration and discussion of their sexuality post-SCI. Forcing a client to learn when they are not receptive is a waste of time for both the learner and educator (Achterberg, 1988). Furthermore, with growing health care changes, OTs need to be efficient as well as sensitive to our clients' needs. Thus, investigating factors that impact readiness for sexual information following SCI is important for OTs who assume this role, but may be more important in drawing OT professionals to fill this void when sexuality is overlooked in their settings. In addition, educating therapists will ensure that our philosophy of holistic, client-centered practice remains a primary focus in OT practice. What a client may "hear" may be different from what is "said"; therefore, it is our hope that through the assessment of readiness, communication mishaps between OTs and their clients will be minimized. Thus, through the medium of the current study, the role of an OT in initiating a sexual discussion will be facilitated by investigating the most appropriate time to begin sexual education services post-SCI.

Method

Participants

According to Krueger (1994) the ideal size of a focus group is 6 to 9 participants and anything over 12 limits individual contributions. Thus, the original subject recruitment goal was ten male and ten female participants, however, the location and recruitment of a special population, such as individuals with spinal cord injuries willing to discuss their experiences

regarding sexual education post-injury, limited the available pool. Participants were recruited from current SCI support groups, personal contacts and referrals, e-mailings, flyers, and throughout the community by “word of mouth.” Due to the inherent sensitive nature of sexuality, same-gender groups were chosen to alleviate additional awkwardness and create a safe, comfortable, and judgment-free atmosphere for the focus group discussions.

One week prior to the focus group session, participants were contacted by phone and/or email to remind and confirm their participation. In order to participate, subjects had to meet the following inclusion criteria: (a) have experienced a traumatic or sudden SCI; (b) be 18-years of age or older; (c) exhibit no significant cognitive impairments, as evidenced by the participant’s ability to attend support group meetings and/or engage in a coherent conversation with the researchers; (d) possess a willingness to discuss the topic of sexuality post-injury; and (e) give informed consent prior to enrollment in the study (McAlonan, 1996; Leibowitz, 2005). These 5 inclusionary criteria reflect the importance of protecting vulnerable participants by ensuring they possess the cognition and maturity necessary to understand the nature and sensitivity involved in the study of sexuality post-SCI.

Rationale for Method

Focus groups were selected as the main method of data collection for a variety of reasons. First, they offer a socially-oriented approach to research. Subjects are able to interact with others in a natural, real-life setting in hopes of increasing open, honest, and candid responses (Krueger, 1994). Furthermore, participants are able to listen to the accounts of others, build upon their responses, and develop their own viewpoints in the company of others with similar conditions (Morgan & Krueger, 1998). Second, focus groups permit an element of flexibility. Moderators can explore unanticipated issues, probe deeper into areas of concern, instantly clarify responses,

and gain additional insight through appropriate follow-up questions. Third, the responses obtained have a high face validity; thus, the discussion allows researchers to accurately capture individual and group opinions and attitudes that may have been overlooked on structured surveys. Fourth, focus groups permit the researcher to obtain large and rich amounts of data from a group of respondents, in a quick, relatively low cost manner as compared to the time and resources needed to conduct individual interviews (Krueger, 1994).

According to Krueger (1994) focus groups are an effective medium through which to gather data when the research goal is to uncover factors related to complex, multi-faceted behavior. In addition, focus groups provide insight into dynamic topics, such as human sexuality, where beliefs and practices are conditional. Thus, when a researcher wants ideas to emerge through a discussion, focus groups foster an environment where open-ended comments are valued. Hence, they can be a helpful method to attain opinions regarding areas needing improvement, as well as aid in the establishment of general guidelines for future interventions and/or programming. As a result, they were the method of choice selected for completing this study.

Procedure

Using the focus group interview method, insights and suggestions regarding the initiation of a sexual discussion post-injury were explored. The questions for this protocol were developed based upon Krueger's (1994) guidelines for question development. The questions were formulated to reflect our primary purposes: when the topic of sexuality should be addressed following SCI and the role of OT in this process. A complete focus group protocol with questions can be found in Appendix A.

Arrangements were made with The University of Toledo Health Science Campus to reserve a wheelchair accessible conference room for the two meetings. The women's group was conducted on Monday, October 29, 2007 and the men's on Monday, November 26, 2007. In order to maintain attention, both sessions were approximately 2 hours in duration and were scheduled from six to eight PM. Prior to each focus group session, the tables were arranged in a U-shape (Morgan, 1997) and the temperature, lighting, and background noise were evaluated to create a comfortable environment for all participants (Krueger, 1994). Furthermore, chairs were arranged for the primary and assistant moderators and the remainder were stacked in a corner to allow participants easy access to the tabletops. An assistant moderator was present to record hand written notes, assist with logistics, and seek clarification and elaboration from participants when necessary.

Upon arrival, participants were greeted and asked to complete an informed consent agreement. Once securing consent, participants were given a first-name-only name tent (Krueger, 1994) and a demographic questionnaire (Appendix B). The questions solicited information regarding each participant's gender, age, race, marital and familial status, level of injury, years since injury, employment, education, and other relevant details. After completing the document and waiting for all group members to arrive, light refreshments were served to promote friendly conversation and ease any tension (Stewart & Shamdasani, 1990; Krueger, 1994). Once the entire group was present, members were asked to find a place around the tables and sent up their name-tents. Following the collection of all paperwork, introductions were made, a brief overview of the study was given, and a few ground rules were established.

Due to the fact that an audiocassette recorder is an essential component of data collection in focus groups, it was introduced at the beginning of the study as a tool to help capture

everyone's comments. Therefore, participants were encouraged to speak one at a time (Krueger, 1994). While first names were used throughout the focus group discussion, participants were assigned a number during the transcription process, which was utilized throughout the entire analysis. In addition, the significance of maintaining confidentiality was stressed to all participants during the introduction given by the primary researcher prior to the commencement of the official discussion. Finally, the notes taken by the assistant moderator captured seating arrangements and noteworthy quotes, as well as provided insight into elements the tape recorder could not capture, such as nonverbal body language (Morgan & Krueger, 1998).

Data Analysis

A vertical analysis was completed due to the purpose and design of the study, which means each focus group discussion was analyzed separately with commonalities and differences addressed at the conclusion of the study (Morgan & Krueger, 1998). Furthermore, based upon the suggestions of Krueger (1994) and Morgan and Krueger (1998) for data analysis and report writing, the following plan of action was devised prior to data collection.

1) In order to analyze the data, a tape-based procedure was utilized. In essence, the primary researcher listened to the tapes and prepared two unabridged transcripts while simultaneously consulting the field notes taken by the assistant moderator, the debriefing discussion, and the summary comments made following each focus group. Two transcripts were prepared reflecting the responses of each group organized generally by question.

2) After making the transcriptions, three researchers read through the women's and then the men's transcripts independently. The researchers considered the words, context, internal consistency (flow of opinion changes and possible triggers), frequency (how often comments were made), extensiveness (how many participants discussed a topic), intensity (strength or

depth of viewpoint), specificity (responses based on specific experiences made with a greater degree of detail), as well as reflected upon the overall purpose of the study in order to capture the big ideas (Krueger, 1994). The identification of primary themes was facilitated by each of the three researchers through the process of reading and highlighting key findings and quotes as well as note-making on the transcripts.

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

4) Using the preliminary coding scheme, each researcher then independently coded the data. The researchers noted both statements and passages that appeared un-categorizable or categorizable into multiple thematic categories to be discussed at the next collaborative meeting.

5) After individually coding the data using the preliminary coding scheme, the researchers met a second time to review their results and negotiate modifications. A final coding system was then developed to reflect the pertinent themes.

6) Each researcher used the revised themes to re-code the data. Discrepancies in the coding of specific statements or passages was resolved through further negotiation until arriving at a consensus.

7) After finalizing the themes and coding process, a fourth outside researcher blind to the aforementioned meetings and discussions reviewed the unabridged transcripts and final coding results. This step was utilized to reduce the possibility of erroneous assumptions or faulty reasoning. The three original analysts reviewed the suggestions and negotiated the final coding outcomes.

In order to complete a scientifically robust qualitative research study, several critical principles were exercised. First, a systematic, disciplined process was defined prior to data

collection. Second, the results of focus group interviews must be verifiable; therefore, quotes were selected verbatim with a systematic trail of evidence documented to allow for replication (Krueger, 1994). Third, credibility was established through use of a code-recode procedure called thematic analysis. Finally, the utilization of three researchers fostered healthy debate as well as the triangulation of sources. Finally, peer-checking by a fourth, outside researcher offered an additional defense against faulty outcomes, which have the potential to impact the results of a qualitative study. Thus, mechanisms were in place to protect the integrity of the participants' responses in order to contribute high quality results to the profession of occupational therapy.

Results

Participant Demographics

The current study included a total of eight participants, five males and three females, which reflects the current statistics indicating that spinal cord injuries are more prevalent among males than females. The women ranged in age from 42 to 55 years ($M = 50$, $SD = 7.00$). All three women identified themselves as Caucasian on the demographic questionnaire and two of the three women completed high school, whereas the third had attained her bachelor's degree. In terms of marital status, one woman was single, one was married, and one was divorced. Two of the women had children prior to their injury and none birthed any children post-injury. The third woman did not bear any children prior to or following her injury. Two of the women reported not having the potential to have children post-injury, whereas one indicated the potential still remained. In terms of their current employment status, two women classified themselves as unemployed and one as retired. One woman reported living alone, while the other two women reside with their families. Furthermore, none of the three women have a paid personal attendant. The etiology of these women's injuries varied from a vehicular accident to a sports/recreation

accident. The third woman selected the Other category to classify the cause of her injury. All three women identified their injury as incomplete paraplegia. The women classified their injury levels as T6, T7, and the third woman reported multiple injuries including T4-T5 and S1-S2. The average age of injury onset was 42.3 years ($SD = 11.24$, *Range* 30-52). The years that have elapsed since their injuries ranged from 4 to 12 years ($M = 8$, $SD = 4.00$). All three women reported being sexually active both before and after their injuries. Furthermore, all three women reported participating in occupational therapy services; however, only one reported that her sexuality was discussed post-injury by an OT professional. Nevertheless, during the actual focus group discussion the same participant reported nursing was responsible for the content she received; thus, a minor discrepancy exists regarding the specific discipline involved in her sexual education experience.

The male focus group consisted of five men ranging in age from 29 to 64 years ($M = 44.6$, $SD = 13.50$). Four of the five men identified themselves as Caucasian and one reported to be African-American. Educational levels varied with one participant reporting less than a high school diploma, one reporting a high school diploma, one an associate's degree, and two participants had achieved a bachelor's degree. Three of the participants were single, one was divorced, and one indicated being both married and in a stable non-cohabiting partnership. Two of the men had children prior to their injuries and the other three had not. None of the men have had any children since their injuries; however, three of the men reported having the potential, one reported no potential, and the fifth man wrote in, "I hope." In terms of their current employment status, two of the men reported being employed, one unemployed, one a student, and the other retired. Four of the five men reported living with their families, while one reported living alone. Three of the men have a paid personal attendant and the other two do not employ

paid assistants. The men varied in terms of their injury etiologies with three reporting vehicular accidents, one a sports/recreation incident, and one was due to a fall. Neurologically, three of the men classified their injury as incomplete quadriplegia and the other two reported complete paraplegia. The injury levels reported from highest to lowest included: C5; C5, 6, and 7; C6; T6; and T8. The average age at injury onset was 26.8 years ($SD = 8.01$, *Range* 21-39) and a collective mean of 17.4 years had elapsed amongst the participants regarding the duration of time that had passed between injury onset and data collection ($SD = 7.92$, *Range* 8-26). Four of the men had been sexually active before their injuries; however, the fifth was not. Nevertheless, all five men reported being sexually active following their accidents. Only one of the men reported that he had not participated in occupational therapy services; therefore, the other four had experiences with an occupational therapist post-injury. Finally, four of the five men reported that their sexuality was not discussed during occupational therapy, whereas the one gentleman who had not received occupational therapy wrote in “NA.”

Women's Focus Group Themes

Thirteen themes were created during the analysis of the women's focus group transcripts. Each of the 13 themes identified will be discussed followed by an outline of the men's group results. Noteworthy quotes have been selected for inclusion under each theme to illustrate both the significance and context from which each theme was developed. Furthermore, some information has been added for clarification which will appear in brackets [text], while the omission of non-essential words or passages have been denoted through the use of ellipses (...).

Lowered status. All three women identified sentiments associated with feelings of inferiority. They explained how other people perceive them to be of a minority and treat them differently than before their injuries. In fact, when asked if their injuries had impacted their

feelings of femininity from pre to post injury, all women gave affirmative responses. However, their change in status appeared to be perceptions imposed by society, not self-inflicted as the following quotations exhibit.

One woman stated her feelings this way,

“...You feel like, like you’re not as good as you were walking, but that’s definitely not true.”

She went on to state,

“I found out that now I know what minorities feel like. Cause that’s us, we’re in a minority.”

Another woman shared,

“Yeah, yeah I feel the same way, I feel like people see me differently and they think that I don’t have the same kind of feelings as I did before my injury.”

The third woman made the comment,

“...you know and for some reason people are afraid of you. I mean, that’s the way I feel.”

One of the women responded by saying,

“They’re [people in general are] uncomfortable...just because you’re in a chair.”

She also later added,

“Like we’re, like we’re the plague and I’m going to change that. And that is my mission in life. You’ll see changes in the next few years, if I’ve got anything to do with it.”

Vulnerability. Due to the fact that a spinal cord injury happens within the context of everyday life stressors and circumstances, the women discussed many feelings that reflected the

tenets of vulnerability. The discussion focused on the financial, emotional, and functional implications of their injuries that left them susceptible to an array of negative outcomes.

One woman stressed being prepared for deceitful suitors who are looking for a woman to take advantage of during this major life transition,

“Oh yeah, they [future women with SCIs] need to get prepared for that. And they need to get prepared for users too, they think you’ve got money... you’ve gotta learn not to be naïve, cause all those guys are after is what you’ve got, they could care less about you, but they’ll treat you like, ‘Oh I’ve been there, done that’...big time and they’ll take you and rob you blind.”

Another woman expressed her vulnerability in terms of an emotional overload,

“...I think a lot of my problem right now is I’m still hurting a lot, um there was too many things that came together all at the same time. Plus I’m dealing with things that my kids are doing, and I don’t know, at this point of my life I would like to get in a vehicle and run away. Okay, but if I did find somebody I would be really happy. So, you know it’s just right now.”

Elements of vulnerability were also present when the women discussed their rehabilitation experiences and functional capabilities. For example, one woman said,

“It’s hard to explain. It’s just something you deal with when you first get injured and they tell you, you gotta do something, mentally it really messes your head up, don’t it kind of? For me it did cause I felt like I had to do it, or it wasn’t gonna, or I wasn’t gonna ever get better.”

Nevertheless, when questioned about the consequences of not getting sexual education services post-injury, the women responded with a variety of answers that created images of

vulnerability such as being hurt, embarrassed, afraid, bitter, hating men, or losing sexual interest all together.

The theme of vulnerability also surfaced when the women spoke of physical intimacy. For example, one woman stated,

“...just go to sleep with somebody and you have a bowel movement and you never want to be with them again.”

Body image. Following their injuries, the women experienced both physical and mental changes regarding their bodies. While two of the women reported gaining weight, one took the opposite approach and lost a considerable amount of weight. Nevertheless, all three reported that they had experienced changes in how they viewed themselves as sexual beings.

One woman explained her weight gain this way,

“I gained weight big time cause you didn’t care...”

She went on to explain,

“You know what made me feel down and out is because of law. I was a waitress, always on my legs, my legs got me to work walking. I was very active that way, and I weighed like 130 something, size 7, cause I was solid...but when I lost all my legs...I was like...80 some pounds, you know, but then you start eating that, you gotta do your pills. I couldn’t drink, so I had to always use pudding instead of the good stuff so I blew up like a balloon. You know, because you weigh that 130, but that’s a lot of weight when you don’t have no legs. You know, so I was weighing back up to where I was, but it didn’t, I just went here [indicating additional weight gain].”

The other woman shared,

“I weighed 140 pounds when I got in my chair. I’ve gained about 100 pounds since then. That’s really not good. That didn’t make me, that makes me feel even worse.”

She also added the following comment regarding how other’s have noticed her changing body image,

“And my son says and here’s your granny flap.”

Need to be understood. While the women spoke about feelings of inferiority and vulnerability, they also had a strong desire to be understood in the most sincere fashion. They want people to see past their disability and realize that they are still unique human beings with real thoughts and feelings. Furthermore, the women also expressed their preferences regarding how to break the barrier between the cultures of the able-bodied world and life with a disability.

One woman said,

“I get angry...that bothers me when somebody says I know what you’re going through. No you don’t. ... You may say I, I have a feeling of maybe what you are going through, but don’t sit there and tell me and argue with me that you know.”

Another woman responded by saying,

“I agree, don’t ever go up to someone and say, I know how you are feeling or I know what you are going through, cause you don’t.”

In order to get better acquainted with individuals with spinal cord injuries and begin to understand their lived experiences, one woman suggested that therapists should,

“Hang out with us for a day.”

Another participant commented on the primary researcher’s approach by saying,

“I think you did it correct by you know, joining a group that has spinal cord injuries and getting to know us a little bit, so that we are more comfortable talking to you.”

One woman expressed her need to be understood quite fervently when she said explained her plan for the future,

“I learned from somebody else in a wheelchair. That’s why my social hours are so, going to be so crucial. Cause I’m going to start coming to the hospital and talking to you guys and I’m going to hit all the rural areas because that’s how you learn. What we know are not taught in books. They’re not on video, they’re not on the internet, and there’s no movies and nobody talks about us.”

Characteristics of clinician. As a result of their injuries and the subsequent health concerns that arise following a spinal cord injury, the women had several primary suggestions regarding the skills and personality characteristics they would like to see in their treating therapists. More specifically, they discussed several issues concerning the topic of sex and potential techniques or approaches that may complicate or alleviate their anxieties.

For instance, all three women expressed the need for therapists and doctors to be well educated on the subject of sexuality post-SCI. In fact, one woman explained her wants this way,

“For therapists and doctors that are on the ball.”

Another said outright,

“I think the biggest part though is the therapists themselves need to be educated, I really do. Because, like I had to ask my urologist why certain parts of my vagina didn’t [work], or why it felt like this, why it hurt here and I couldn’t feel anything there.”

Still the third added,

“I would not want somebody coming to me and telling me about sex ed when they have no clue. No way.”

In terms of demographic characteristics, two of the women did not have a personal preference regarding the gender of the health care professional to initiate the initial discussion with them; however, one had a strong preference.

“...I loved my rehab doctor to death, and I still do. I think he’s a wonderful, you cannot meet a better, um physical medicine doctor, I mean he cares 100% for his um patients, but I think I would have been a little embarrassed discussing sexuality with him.”

She later responded affirmatively to a follow up question, which was coded under the Delivery Method theme. The quote indicated that she could have handled a conversation with her male doctor with her husband present, but still would have preferred a same gender health care provider,

“...I probably would have been able to handle a discussion with the doc with my husband. Rather than just me with a, a, the opposite sex.”

Finally, the women discussed several additional characteristics or behaviors, which included:

“And you can’t act surprised. You have to just kind of sit there....”

One of the subjects added,

“Yeah, don’t ever be judgmental.”

Patient lack of knowledge. Many of the issues associated with sexuality post-injury are derived from the fact that patients lack a profound array of knowledge. Spinal cord injuries are

complex and there are many issues that require immediate attention following an injury. As a result, patient sexuality is often overlooked by clinicians, which directly impacts the level of knowledge patient's possess. As the women pointed out, not knowing or understanding their limitations and capabilities is often worse than the reality of what their injuries impose on their occupations of daily living.

To this point, one participant said,

“Um, I think one of the things I thought about was would I be able to feel the same things as I did as before my injury... Cause I didn't know, nobody said well when you have sex you may feel this, or you may not, you know no one said that to me.”

Another participant commented on a similar experience,

“I didn't know if I was able. I didn't know if it was going to hurt me. I didn't know, you know. Nobody told me, you know, what I could and couldn't do. Is there anything inside of me that's going to get screwed up. I don't know, cause nobody told me...Nobody told me what my injuries were and what I could and couldn't do.”

One participant's lack of knowledge even influenced her desire for sex altogether, which was compounded by the fact that she did not know who to turn to for advice regarding her injury,

“And then I started thinking, well what if we're having sex and I have an accident or something, you know, those kind of things were running through my head. And you know...like maybe I shouldn't have sex. And then it's like you know, I don't even know who to talk to about this, you know. Where do I go, what do I say? And um, it was kind of hard for me, you know. And at that, at that time, you know that

was the factor, I had met someone, um you know and then I started thinking and I had no clue. Am I going to be able to feel anything? Am I going to be able to have the same reactions that I had before or you know, I didn't know."

Delivery method. This theme highlighted several poignant aspects of post-SCI sexual education. For example, the women in this focus group experienced a diverse range of delivery methods in terms of how their sexuality was actually approached post-injury. Furthermore, the participants also expressed their preferences regarding ideal methods for delivering sexual education in the future of SCI rehabilitation.

One participant explained the way her sexuality was initially approach this way,

"My, my rehab doctor talked to my husband.

Researcher: But not you?

No, but not me. He, he was more comfortable with talking with my husband...so then [my husband] talked to me, you know."

In response to this experience, the woman further explained,

"But he could have had one of the PT people, most of the PT people I worked with were women, the OT people were women and that wasn't given to me as an option, that wasn't an option made to me."

She also stated,

"...I probably would have been able to handle a discussion with the doc with my husband. Rather than just me with a, a, the opposite sex."

Another participant had to watch an educational video regarding sexuality post-injury, which she classified this way,

“Well it was more like a handicapped disability porn tape. It was! I mean to be totally honest.”

She, along with the others, offered alternative options regarding the delivery of sexual education materials and information with the following advice:

“Well, you might just be open and say...have you thought about...what it’s going to be like having intercourse...”

Additional delivery method ideas included,

“I would say if there’s any websites you can go to where they discuss, if there’s a contact number, a therapist or somebody at the hospital. When you’re ready to talk about sex, you whatever, something like that or a brochure, make a little tiny brochure where they can...they’ll read it, they’ll read it in the bathroom. You know, not this big thing that says ‘I want sex!’ You know what I’m saying...Just something little where they can stash it somewhere and read it in their own time.”

Furthermore, another woman emphasized the importance of offering options,

“Okay, I would say um, we have some options you know, would, would you like to talk about sex now or would you prefer to wait until another time. You know like say maybe after you go home or you wanna come in or you know, give them options.”

One woman stressed the importance of peer to peer relationships as another valid delivery method, which was affirmed by a second participant,

“I’d be more comfortable talking to [participant’s name] about it, about my sex life when I first got injured.”

When the topic of timing arose regarding the dissemination of information, one woman offered this comment, which was positively confirmed by a second participant:

“...I think it should be given to you before you’re discharged...That way everything’s there.”

As previously mentioned in the Characteristics of the Clinician section, two of the three women did not have a preference regarding same gender group composition, however, one woman did. In response to the dissent, one woman offered the following comment,

“...you should give them options.”

Furthermore, all women agreed that the initial discussion should be conducted in a private setting.

Delayed readiness. The content of this theme reflects the delay the women in this focus group experienced following their injury in regards to a desire or receptiveness for sexual information. Based upon their aforementioned remarks, they want the information early, but may not always be completely receptive due to the other issues that arise following a spinal cord injury. The issue of importance appeared as an underlying theme that contributed toward the period of delay the women described regarding their interest in sexuality post-injury.

One woman recalled that she did not begin to think about how her sexuality had been impacted until returning home, which was echoed by another participant,

“I think for me it was like a about a month or so after I go home. Because I was so involved in, what, while I was in the hospital to begin with I didn’t even know I was paralyzed. I mean until I got here...they transferred me here from another hospital. I didn’t even realize that I didn’t have control of my bowel and bladder, I didn’t realize that I didn’t have control of my legs... I knew absolutely nothing.”

The second woman responded,

“Because of everything else that’s going, you hit it right on the nail, you wasn’t, your mind wasn’t even there, your mind wasn’t...but then when I got home and actually that’s a different story.”

The third woman said this about her readiness for sexual education,

“...it wasn’t important to me at that time. I mean I was still dealing with so much of trying just to be able to do a pressure relief and um and you know trying to get some type of a bowel routine going....I don’t think I was really ready to hear about it...”

When questioned further, she stated her interest peaked during outpatient rehabilitation,

“I think for me, it was like after by the time I was going to outpatient rehab is when that would have been the, the best time, because before that I was dealing with so much.”

Opportunity. This theme indirectly relates to the aforementioned category of delayed readiness. Fundamentally, the theme reflects the fact that all three women mentioned an opportunity or occasion that influenced the re-emergence of their sexual selves. In essence, it was the availability of an opportunity that appeared to pull them away from their delayed readiness.

One woman explained how her interest peaked in this manner,

“When you lay next to your man...”

Similarly, a second participant commented,

“Um, I think for me I had met someone and I thought, um, that he felt the same way about me that I felt about him.”

Still a third participant said,

“You know maybe the fact that we were going to go on vacation, so we would have some time alone and you know with the privacy factor.”

Acceptance. All of the female participants used the terminology, accept and/or acceptance, to describe one of the factors that was necessary for them to progress in their thoughts and feelings regarding sexuality. It is important to recognize that the women also mentioned other life events that either aided or hindered their progress toward achieving acceptance of their injuries.

One woman described her journey in the following manner,

“See I think I started um thinking about it [her sexuality] maybe about 2 or 3 months after I was home and I got myself together, you know and I had to process this whole thing first. What happened to me, um, what my futures going to be like. I had to process all that stuff first. But then when I started to feel more comfortable with myself and I started going out more, um, then I starting thinking a little more about well, it would be nice if you know I had somebody to put an arm around me or something like that, you know just you know just to have somebody with me.”

Another woman summarized this theme with simple brevity,

“Yeah, if your not ready to deal with what happened to you, you’re not ready to do anything.”

She also added this poignant statement, regarding a recent change in her mood and behavior,

“And I closed up and I think because I never, like you guys are talking, when I woke up I was like this, I don’t think I ever really mourned the loss of my legs.”

Still, one woman mentioned the importance of spirituality in terms of her acceptance,

“Mine was just, almost, like in the emergency room. My pastor came and said, um, ‘Just remember God’s in control.’ And I never, you know...well, I’ve always had God in my life and I kind of, I kind of forgot that. That he’s in control and I mean we can make all the plans that we want and that’s who’s in control. It was like instantaneous for me.”

Relationships. The status of one’s relationships and the level of intimacy shared between partners prior to an injury appeared to determine the level of anxiety these women experienced in regards to their post-injury sexual experiences. The participants also expressed concerns regarding how their partners would react to or had reacted to the issues that a spinal cord injury imposes during intimate relations.

One woman said,

“So, I still really don’t know, you know, what’s gonna happen if I do find somebody, how are they going to react if I do have a bowel movement while we’re having sex or something, or you know or what’s gonna happen, you know, what are they gonna do, are they gonna say, oh I can’t handle this and leave. You know what’s gonna happen. But you have to maybe say to the person this may be a consequence.”

Another woman gave this advice,

“If they love you, and they’re making love to you, it’s just like that one guy did. I wiped him off, and said go into the other room. I wouldn’t want to tell nobody that

cause they won't, they'd be thinking of that the whole time they're having sex with ya. My opinion."

All three women agreed that marriage would impact how one's readiness for sexual education may progress. This was reinforced by the one married participant,

"Well for me... I had been married for 20 years, well almost 20 years when the accident happened and you know I have to admit we were in a lull, but um, you know, you have peak periods and that and so, I think [that] would have something to do with whether or not you're going to be willing, to be ready to discuss it is if you know have someone that you know, you know well okay, we're married, does this automatically just stop now because I'm in a chair and I can't feel."

Humor. All three participants mentioned the importance of humor in coping with the awkwardness associated with sexual situations as well as the general issues an individual with a spinal cord injury faces on a daily basis. Humor was present during many aspects of the entire focus group, however, it was specifically mentioned by participants as a mechanism for managing stress in the following quotes.

One participant said this of her experience with the sexuality tape she viewed,

"You always joke you know cause you had to have humor in it because it was so devastating to even think to have to do what that tape was telling us we might have to do. Ha ha. I mean the shower, I mean they got, there was nothing blocked out of this tape at all. I'm serious."

Another woman later added,

"I think, I think I use humor to keep...myself from getting, trying not to get to the point where I'm so depressed I can't handle it."

To which another participant responded and the third affirmed,

“Right. Humor is for those bad days.”

Autonomy/control/independence. This theme summarizes the negative cycle that can ensue following a spinal cord injury. In essence, the participants lost an aspect of their independence in many occupations of daily living including control over various aspects of their sexual experiences. As a result, they value options and relationships that offer control and respect their autonomy as a unique individual.

For example, one woman explained her struggle for independence this way,

“So now, I’m in a wheelchair, I’ve lost some of my independence, and my kids were just overwhelming me cause they thought they had to be there all the time. So, I had no privacy and when they finally did settle down and I had a chance to think about it, you know I’m thinking oh what do I do now. How am I gonna, you know, who is gonna want me like this and because no one talked to me, I didn’t know what was gonna happen if I did. You know, you know what happens next. So I had like four years of whoa.”

Another participant added this comment regarding her desire for autonomy in terms of disability etiquette,

“You’ve gotta be very careful with injured people because they already done lost somethin’ and when you start talking to their significant other, other than you, you’re going to make that person feel twice as worse.”

The issue of control also came up when the participants were questioned about the creation and dissemination of a standard questionnaire to evaluate patient readiness and

preferences for sexual education. While all participants endorsed the idea, one woman voiced her thoughts in the following manner,

“Give them the options, let them be in control, because if you give them control they’ll more than likely respond to you better. If you tell them that, you’re already here and you gotta do this and you’re going to be in that chair, and you ain’t never probably ever gonna get out of it. They already hear all that, just give them that paper and give them the option, the more options you give them the more comfortable they’re gonna feel...”

Men’s Focus Group Themes

Twelve themes emerged during the analysis of the men’s focus group transcript, which included data from five male participants. For more information regarding the demographic profile of this population please refer to the previous section entitled, Participant Demographics.

Reactions. The men described a broad range of reactions regarding the subject of human sexuality. While society often categorizes male sexuality as one dimensional, the men in this group expressed complex, multi-faceted thoughts and feelings regarding the topic. Furthermore, two of the subjects expressed how their reactions to sexuality were directly influenced by their familial backgrounds and experiences. Thus, this theme was erected to capture the eclectic array of reactions the men discussed concerning the matter of human sexuality.

For instance, when questioned about what comes to mind when the topic of sexuality is mentioned, one subject responded,

“Well, embarrassment at first...it’s just...I guess maybe it’s that Catholic thing.”

Conversely, another subject discussed his indifference to the topic due to the fact that his family bred livestock when he was growing up; thus, making the topic a normal aspect of

everyday life. Additional reactions that were mentioned when discussing one's receptiveness to sexual information post-injury included one's "shyness" as well as being "ashamed." While the reactions varied from participant to participant, the primary goal of this theme was to capture the essence of the individualized, unique reactions that the men expressed regarding the subject matter.

Reproduction. The issue of reproduction surfaced several times throughout the duration of the focus group. The men had contrasting experiences and insights regarding their reproductive capabilities as well as the way in which the topic of sexual reproduction was addressed by a professional or lay person.

One man described his first encounter with the topic of reproduction as follows,

"...the thing that blew my mind was two days after I was in the hospital, as soon as I was stable, they asked me if they wanted, if I wanted to have kids down the road and if I did they were going to collect my semen and freeze it for a few [years] and use it then. It totally caught me off guard."

Another subject expressed his desire for the aforementioned opportunity by saying,

"I wish someone would have come up to me, like they did to you, and tell you about the freezing the semen and all that kind of stuff..."

To which the first subject responded,

"They wanted to get it done as soon as possible because the body changes so much, with heat and you know the quality of the semen goes down and then two years down the road it's not so hot, so but it was one of those deals, where I could care less right now. I, um, what am I going to move my arms and that again."

Later in the course of the discussion, one participant added another dimension to this theme by bringing up a daughter he had prior to his injury,

“I was just thankful I had, at the time of my injury when I got hurt, I had one of my own and I’m still enjoying that, she’s here now.”

It is important to mention that one participant also highlighted the curiosity of others regarding his reproductive capacities by telling this anecdote,

“It was only, it was actually this Thanksgiving, my one nephew asked me, he says: ‘Can you have kids?’ I says, ‘Yeah, but I’m getting too old for that!’”

The level of injury was also discussed by several participants throughout the focus group discussion as it directly impacts the reproductive abilities and limitations that may be experienced post-SCI. For instance, one gentleman stated this consideration simply,

“It may take some a little bit longer than others depending on how, what, could even be the level of injury.”

Perceptions of sex. Several poignant issues were categorized under this theme, including each subject’s own perception of his sexuality both pre- and post-injury and what new sexual perceptions were acquired as a result of expanding experiences and opportunities. In addition, the men discussed how an understanding of their capabilities and limitations may influence their perception of sexual relationships in the future.

When questioned if their pre-injury perceptions of sexuality had changed as a result of their injuries, four of the five men responded that their perceptions were the “same.”

Nevertheless, one gentleman responded to the question as follows,

“Totally different...Before, before it meant just sexuality— I think girls or something, I don’t know. Now, what I’m going to do with ‘em.”

This same participant elaborated upon his initial concerns, his experience with an injured peer in the hospital, and his emerging perception of sexuality by sharing,

“Me and that quadriplegic, we was talking and he was like ‘It ain’t going to be that bad man,’ and I was like ‘Yup, it’s over for me.’ And I was like for one I couldn’t control my bowels or whatever and I was like what am I going to look like riding down the street with my girl, ‘damn, baby what’s wrong?’ ‘I just number two and I couldn’t see it.’ I thought it was over, but I got out and learned it’s, it’s like they’re somebody for everybody and girls are still attracted to people in wheelchairs.”

Another participant had a significantly different perception of sex post-injury,

“I looked at it this way, it’s one of those things, I hadn’t had the chance before my injury happened and um, how can you miss something that you never had, so it wasn’t a big deal, until of course I got older.”

Later in life, his perception was dramatically different, which he explained this way,

“Well obviously as I got older and my brothers and sisters started getting married and that kind of thing and you see how happy they are and then they starting having their kids and how happy and then you wish, geez, and then you miss that kind of thing, that type of thing. I mean my family loves me to death, but there’s a difference, you know it’s a different type of love.”

Another participant highlighted how his perception of intimate relationships had changed post-SCI, which now had to include an extensive explanation with the start of every new sexual partnership,

“...the fact that when you start a relationship with someone after you’re in a wheelchair there is a lot of explaining if there not up on spinal cord stuff: What’s this do? What’s this do? What can you do?”

Still another man added the impact modern pharmaceuticals have on one’s sexual perceptions and experiences by sharing,

“When I first learned about the pills say, ‘eh, they don’t work,’ until another paraplegic told me, put a bug in my ear, told me that um, ‘try not to eat before you take the pill’ and that’s, that was one of the things I ran into.”

In addition, one gentleman explained the importance of knowledge and education on one’s future sexual perceptions, indicating dire consequences without sufficient information,

“There’s a, there’d be a big learning curve and I think that might uh, keep you away from a relationship without knowing what you’re capable of, you know, what kind of options are available.”

Finally, it is important to note that while most of the men experienced a delay regarding their sexual futures, one man had a different perception. In fact, when questioned about how long post-injury they considered their sexuality, he responded:

“When I was revived. I thought, they revived me and that’s one of the first things that went through my mind when they told me I was paralyzed. I mean you know, what happens then.”

Acceptance. Acceptance involves the acknowledgement, reception, and comprehension of the terms and conditions associated with one’s situation. With a spinal cord injury, there are many issues and concerns that may obstruct or facilitate acceptance of the new roles and

occupations one assumed in his or her pre-injury state. Several of the men directly mentioned the role acceptance played in their ability to address their sexuality post-SCI.

For instance, when questioned about what factors contribute toward one's readiness to discuss his or her sexuality, one participant shared,

"I think it's where you are in acceptance of your injury."

He further elaborated on the fact that he had caused his injury as a direct result of his own behavior, thus, he was not hurt by someone else nor had he hurt anyone else. Consequently, his acceptance came with greater ease.

Another premise regarding the issue of acceptance surfaced regarding when to initiate and disseminate sexual education information. Several of the participants acknowledged the importance of accepting their rehabilitation regime. In the following quote, acceptance included achieving a level of comfortability with one's routine and gaining confidence in one's skills necessary for completing occupations of daily living.

"You know I think...once someone's getting comfortable with rehab and the routine and you can almost...look at them and say 'Wow, he's getting a little confidence back, maybe it's time to bring this subject up or something.'"

New opportunity. This theme evolved to capture how several of the men expanded their horizons post-injury and embraced each new opportunity they were afforded as it arose. For example one gentleman said,

"There were a lot of things that I wanted to do physically and that I never had the time to do before I was injured and after I was injured it freed that time up to go ahead and do things I wanted to do. I became a certified scuba diver...and I've

been involved in a lot of sports and I speak a lot to different groups. I'm not afraid to be in public, I'm not afraid of how people look at me."

This openness to new opportunities and challenges may relate to one's willingness for altered sexual strategies and information; however, none of the participants made this assertion directly. Instead, it was implied when the men were questioned about whether or not their injuries had impacted their feelings of masculinity. In fact, for all participants who responded, no changes were reported from pre- to post-injury, in fact, one participant added,

"Not for me. In fact I probably do things more wild than I did before I got hurt."

Thus, he indicated that not only was his masculinity un-altered, but he was embracing new opportunities. It is important to note that new opportunities may not always be safe opportunities, which is difficult to draw from this simple statement; thus, therapists must use clinical judgment when assessing one's willingness to try new things and the implications associated with this new found openness.

Other's perceptions. Due to the fact that a spinal cord injury is typically a visible disability, if the use of a wheelchair is necessary, observations are common among able-bodied individuals. The perceptions of others were duly noted throughout the focus group discussion on several different fronts including masculinity, online dating, and harmlessness.

In fact, one participant provided this insight regarding the issue of masculinity introduced above with the following quote,

"I don't think my uh, perception of masculinity has changed, but I think other people's perception of my masculinity has changed. ...they think you're in a wheelchair and they might talk to whoever's with you or above you or around you, not to you. But, I'm fairly assertive so I kind of take the bull by the horns."

Another participant explained his experience with online dating and how other's perceive his disability this way,

“When you fill out the bio, you’re putting things about yourself and you’re writing about yourself; they don’t see the wheelchair right away. Although, I’ve, I’ve found that if I right away you know say, bring up the fact that I am disabled and they always ask for a picture, I make sure my chair shows up then. And ... the older women it does not bother them; they’re not looking, you know they’re done having kids and they’re looking at the inside, they’re not looking at the outside. And they’ll actually flat out tell you they don’t want sex all the time, they just want to go hold hands and snuggle watching a movie, having popcorn. You know, the simple, the simple type of things, it doesn’t have to lead to sex.”

The theme of harmlessness also appeared to be a strong theme concerning how others perceive a male with a spinal cord injury amongst two of the participants. In fact, one man shared his thoughts this way,

“...it would be the perception of harmlessness...the perception of they’re safer with me. Does that make sense? ... I’m not a physical threat to a girl...In the same way that if they’re in a car with me in the same way that another guy would be...alone, at two in the morning.”

Infantilism. The majority of the men expressed feelings of being treated like a baby or young child by different people they encounter in their daily lives. Due to the fact that infants and children are not typically viewed as players in the sexual world, treating grown men as such may impair their sexual opportunities and self-esteem. Furthermore, these perceptions of helplessness by others contributed toward the participants’ feelings of inferiority, anger, and

disrespect. This oversimplified behavior on the part of others is not warranted or desired by these male participants. Being infantilized implies that one is of a lesser status or has impaired cognition, which is both insulting and demeaning.

One gentleman said,

“...they look down at you. I’ve had people pat me on the head, I’ve had people be overly helpful.”

Another participant described his experience by sharing,

“...like where I’m from they, people that’s understanding that over play their part: ‘Oh come here, let me,’ you know, they want to baby you to the T, but then again, sometimes it’s disrespectin’ you like its cool, its alright, you gonna go for it. I’m not a, I’m not a, I’m not a angry person or a mean person, but there’s been times I’m hiding my anger in this wheelchair.”

Finally, one participant spoke directly about his experience during his hospital stay,

“But it is one of those things, I felt how a baby felt: helpless. It is one of those things, you get an itch on your nose and you hate like heck for something stupid like that to hit the buzzer, the nurse comes in and they said don’t worry about it, it’s our job, we’re supposed to, you hit the bell if you want something to drink, said well okay, but I never did that kind of stuff.”

As this anecdote points out, even when the behavior is warranted, the participant still refused the services offered because it made him feel helpless like a baby.

Delayed readiness. This theme was developed to illustrate the delay most participants experienced concerning their sexuality post-injury. Nevertheless, as previously mentioned under the perceptions of sex theme, one man did not experience this delay; rather, he had an immediate

interest in and concern for his sexuality. Issues such as the importance of sex, the status of one's relationships, one's functional capacity, one's progress in the establishment of routines, as well as one's life plans were also discussed regarding the delay in readiness experienced by most participants. This theme also captured the factors the men discussed that may expedite or further delay one's desire for sexual information. Acknowledging and respecting individual differences and preferences regarding the commencement of sexual education services was emphasized as key to success.

One participant explained his delay in this manner,

"I thought a lot about my own mortality at that time, but I didn't really think much about sexuality...my biggest concern was how I was going to do my bowel and bladder and I didn't really think about sex, or women, or my girlfriend, or anything at that point."

Another man told the following anecdote to express his experience,

"It wasn't me thinking about it, it was others bringing it up as a reason for hope. So someone would come in my hospital room like two days after my injury and be like, 'You can still have kids!' And I'd be like, 'Yeah, freaking rah!' Cause basically I was a head in a bed on a vent. So, it was like I don't give a damn. This machine is breathing for me, let's worry about that first."

Still another contributed this insight,

"All I was concerned about was how much am I, what kind of function am I going to get back. It was, I never even thought about sex until six months later when um I was in a class...that the therapist had set up where she went over pressure sores

and the whole nine yards and that's when it was first brought up. That's when it woke me up again I guess."

He also added,

"I was more concerned with my career as a farmer. I was trying to get myself financially set before I decided to settle down."

When questioned about what factors they believe contribute toward an individual's readiness to discuss their sexuality post-injury, the men gave varied responses.

One participant said,

"How old you are, if you're married or not...if you're dating someone seriously, like I wasn't so I'm assuming it would be a higher priority for someone who was dating someone really seriously."

Another added,

"Their own sexual drive I believe. Um, whether or not they were enjoying sex prior to, um and if they had an adequate amount."

Still two others spoke of other pending health concerns, as well as where they were in terms of their acceptance.

Finally, the men discussed the importance of respecting individual differences in regards to timing sexual education services. For example, one participant said,

"Every individual's different. It could be one day, it may be 6 months, it may be a year and longer."

Another participant expanded upon this same idea,

"The time, the time frame, there are so many different things that you're getting, that are being thrown at you in such a short time. You just can't, you just can't

assimilate it all. It just kind of goes, you know you're in a daze from the injury in the first place and you haven't, some, some adjust quickly and some don't. And it just kind of goes... in one ear and out the other, and then a couple years down the road they might, can somebody talk to me about that? Who do I, who do I go talk to about it?"

Delivery method. This theme covered a broad array of issues related to the delivery of sexual education. For example, some men shared the methods they experienced while in rehabilitation, while others expressed their preferences for how they would have liked the information delivered ideally. The possibility of a standardized questionnaire used to gather their preferences was also discussed; in addition to some specific content that needs to be covered by a health care provider. Factors necessary for improvement were also highlighted.

One man said this of his experience,

"In rehab, um, actually it wasn't the OTs it was the psychiatrists. Um, the psychiatrist there, it was kind of a running joke around the hospital because he was like the quadriplegic sex guru. Except he wasn't paralyzed. I mean, but that was his thing, you know. My PT was like, "He's got tapes of paras with paras, and paras with people that walk, and quads with quads, and he's got quad porn and he's got'...And you know, he'd pop in and 'Anytime you want to know about sex, let me know.' You know, so he was, it was like that was his big project would be the way to put it."

However, he added that the man lacked discreteness and neglected any element of privacy regarding the matter by sharing,

"He'd blurt it out with eight people in your room. It's like thanks dude."

Another participant shared,

“...like 3 months or so after I got into rehab. I think there was a small class and they were discussing the sexual changes for men and women, it wasn't just one-on-one.... Kind of an informative class, it wasn't like question and answers, it was just detailing what, what options were.”

However, he had the following opinion about his experience in this class,

“There was a female quadriplegic on a vent and I can't remember if she was pregnant or she wanted to be pregnant and everything was pretty much built around what she wanted to hear...”

While the methods in which each participant's sexuality was addressed were different, what may be more important to current practitioners is how they wished things would have happened. For example, one man suggested the following idea,

“...I kind of wish a, there was something like a syllabus when you go into rehab, have a doctor or a nurse come in and say, the structure of our typical rehab and you know, we could talk about sexuality, we could talk about your OT, your PT, your psychiatry and ... just kind of give you an overview that way and if you're ready to talk about something you can bring it up at that point.”

When asked about a standardized questionnaire to solicit personal preferences and concerns, the participants had profound insight. For example, one man endorsed the idea completely saying,

“That would be great. You know a questionnaire that said you know um, what are your child you know creation options, what are forms of uh you know like Viagra and that kind of stuff whatever, aids for intercourse, um just the whole you know

how to get comfortable in a sexual relationship with you know a new person, how to a break the ice and uh say this is how things work and just A-Z.”

Nevertheless he added,

“...of course I couldn’t write at the time, I was learning how to write, if they came up to me, would you like a man to fill this out for you or a woman, now to me it really wouldn’t matter cause by then all the privacy stuff [was gone].”

Another participant said this of the questionnaire,

“...it wouldn’t bother me a bit.”

However, another man added some provisional thoughts on the questionnaire by saying,

“Seems like I would um, just wouldn’t want anybody to dump it off on me like, hum, I’m just still so surprised, you know, I want to be ready and know what’s coming so I’ll be ready and I’ll know what to expect and what not to expect. And you know, I want to, that’s basically just assessing yourself, giving you a chance to think about it before this actual questionnaire, video tape, whatever...As long as I’m asked, as long as I’m asked and I know when it’s coming.”

Still another expressed his concern regarding the lack of privacy he experienced post-injury while still in the hospital and how a therapist would need to exercise caution when approaching the matter.

“See that’s the other thing is, at least at my level at that time people are grabby with your stuff, so if something is sitting in your room...Every person, every person that come in your room is gonna grab this...there’s no such thing as private, so its, its degrees of privacy.”

The men also provided a quick list of content they think should be delivered to men with spinal cord injuries which included the following suggestions,

“Techniques, positioning, everything we could know.”

“Examples, options”

“Possibly even video.”

“Yeah, pictures.”

“Porn.”

“To see if your libido is still working or not.”

“Probably. actually um, uh, maybe a quad or a para to talk about their own things.”

In order for the aforementioned suggestions to become a reality, one man explained a major issue in today’s health care arena,

“I can tell you right now, it’s time. Now when I was injured, like I said, I had rehab for almost an entire year. Now they’re lucky if they’re in the hospital for four weeks and they’re out of there; they’re in outpatient therapy and that’s a whirlwind too.”

Change in relationships. While many aspects of life are altered following a spinal cord injury, relationship changes appeared to be a prominent theme amongst the men in this focus group. While there was not a universal response among any involved party, change was undeniable.

For example, one man discussed how potential female partners turned away from him following his injury or the difficulties he faced in meeting women post-injury.

“I just didn’t see my old girlfriends, you know they all just kind of, because Green Springs is an hour and a half away from here and all those relationships tend, they tend to just drift away you know and a lot of the people, they didn’t know, they felt uncomfortable around me.”

Another participant reported a distinctly different scenario, detailing the increased occurrence of affectionate acts from female acquaintances following his injury.

“So I never had anyone really snub me because I was in the chair, it...worked the opposite. Now, now, they might of snubbed me without me knowing it. The group I was with immediately, well not immediately when I got back home, but once I started going out back home we’re all kind of cool and the girls that hung around in that group of course alcohol was involved not with me, but with them, but they were much more, much more agreeable to come up and give me a big kiss on the forehead or the lips or whatever than they would be with any guy on his feet, which I didn’t even care.”

Still two others described the readiness of their partners for sexual activity as compared to their own willingness. One gentleman said,

“I was more ready than my wife was.”

However, another participant shared his experience, which was slightly different,

“Well, my girlfriend was a lot more ready than I was. I was pretty nervous... Afterwards, you’re kind of ready and then you’re trying to educate the girl. It’s reversed.”

Awareness of women/sexual self. While there appears to be a delay in readiness for sexual information post-injury for the majority of participants, the men also revealed that they

experimented a bit by flirting with opposite gendered health care professionals to explore their new sexual identities. In addition, the men simply explained that they started to notice women again, which sparked their interest in what the future may hold. In fact, one participant described his experience in the following fashion,

“...I did a lot of flirting with the aides and that down at the rehab hospital and you know they got a kick out of it just as much as I did, but that was as far as it went.”

Another gentleman explained that flirting may be a way some individuals signal their readiness,

“When you start flirting, there’s got to be something on you mind.”

To which another participant added,

“You see a nice lady and you, you just say ‘Doctor, are you married?’”

Characteristics of clinician. This theme serves to capture the ideal set of characteristics that a professional must try to embody to connect with a client regarding his or her sexuality. Furthermore, the men discussed some specifics regarding disciplines and gender considerations.

For example, one man preferred,

“[A clinician with] a non-embarrassed demeanor.”

In addition, he said,

“I think, you know, a competent demeanor is always better than someone mousey.”

Another participant contributed,

“...a sense of humor...that could laugh about it.”

Exhibiting a sense of humor was also echoed by another participant later in the conversation with a gentle warning for clinicians who assume the role of sexual education coordinator on the rehabilitation team,

“Be prepared for off the wall questions. Be blunt with the answers and truthful with the answers. And maybe a little humor thrown in there too.”

Still another added,

“Yeah, and a communicative skill.”

The relationship between the occupational therapist, primary nurse, and patient was also emphasized,

“I think there ought to be a good communication skill between the OT and the primary nurse and the third party being the patient.”

Several of the men also discussed the fact that they do not have a strong preference for which health care discipline addresses their sexuality, but rather who they are most comfortable with during their rehabilitation is a better indicator for receptiveness to information.

For example, one gentleman said,

“Um, just like he said that, that recognition that every person’s different so I, I mean like for my case, I mean my physiatrist was a jack ass, so from him I wouldn’t have been receptive of any information and would have been somewhat dubious of any information given. Um, but, but, for him to ask me, ‘Who are you comfortable getting this information from?’ And me saying, ‘Oh, the PT or this particular nurse or that particular you know therapist,’ that, that would have been, that would have been a workable way to do it is someone asking me, ‘Hey who do you want to hear this from?’ And then like I said, I like the science of the

thing, so somebody who knows all the terms and exactly why things do what they do.”

For another participant, his professional of choice happened to be is occupational therapist,

“My OT, I mean she, she was great and professional and um, I probably would have felt most comfortable with her. I mean she taught me how to put on an external catheter, I was putting it on and got an erection and it didn’t phase her. She just kept on going.”

A final issue that was discussed regarding a clinician’s characteristics surfaced concerning gender preferences. All five men expressed their preference for female caregivers during some aspect of the focus group discussion. For instance, one man explained his feelings this way,

“I guess, like he was saying, a male, I had like one or two here or there in the hospital and, and he seemed to heighten the nervousness is what I’m trying to say.”

Another gentleman offered a similar explanation,

“Now my issue with aides, my issue with the men is not a gender thing, it’s the men, the male nurses I have had tend to have hero syndrome, does that make sense? ...It’s, it’s like they’re there to rescue me; and it’s kind of like dude chill...the males I’ve had taking care of me need more reinforcement and it’s kind of annoying.”

Another participant offered a divergent explanation regarding his preference,

“You know I think that um, uh, the men prefer the women because touch is love. And uh, most men don’t like to be touched by another man and uh, just a woman touch[ing] you is, is, can be quite sensual.”

Discussion

While the original purposes of this study were to determine when sexual education services should be initiated post-SCI in order to facilitate the role of occupational therapy in this process—the general outcome was highly varied. As the current study ascertained, there is an eclectic array of factors that may impact one’s readiness for sexual education. For example, several factors discussed in the focus groups included: relationship/dating/marital status, age, one’s own sexual drive and previous enjoyment of sexual activity, imminent health concerns, level of acceptance, and one’s level of function in terms of the establishment of routines. As a result of all these variables, the importance of acknowledging and respecting individual differences and preferences became the prominent, overarching outcome regarding patient readiness and the timing of sexual education services. In fact, of the eight total participants, only one implied a general satisfaction with the methods utilized to address his sexuality post-injury. Sentiments of dissatisfaction with sexual rehabilitation post-SCI were echoed by participants in other studies as well. For example, 6 of the 12 participants interviewed in McAlonon’s study (1996) rated their experiences as dissatisfactory in nature and over half of the 251 participants surveyed in Tepper’s (1992) study reported that the sexual rehabilitation services they received did not meet their needs. Thus, there is considerable room for improvement in the future of SCI rehabilitation. Hence, the current study demonstrated the complex, multi-faceted nature of human sexuality and the importance of recognizing, respecting, and incorporating individual preferences and varied options into sexual education services post-injury.

While the outcome of this study highlighted the need for holistic, client-centered programming, there were several general trends in terms of timing the initiation of services. It appeared that offering the opportunity to discuss the topic early was important; however, therapists must realize that many clients may not be completely ready or receptive. Tepper (1992) found similar findings in his survey of 251 persons with spinal cord injuries regarding their experience with and preferences for sexual education services post-injury. In terms of when participants thought the initiation of sexual services should have occurred, 17% reported immediately, 30% reported within 1-5 weeks post-injury, 19% reported 6-10 weeks, 8% reported 11-15 weeks, and another 8% believed the topic of sexuality should not be brought up until more than 15 weeks had passed since acquiring a spinal cord injury. Byfield, Brown, La Favor, Murphy, Laud, and Fiedler (1999) surveyed 42 newly injured individuals with spinal cord injuries just prior to their inpatient discharge. Their results revealed that inpatients underestimate the impact an injury has on future sexual functioning and relationships. Furthermore, only half of the participants wanted more sexual information despite the fact that their discharge was nearing; however, only half expressed competence in their ability to locate additional information in the future. Thus, there is a disconnect between the knowledge individuals with SCI currently possess, want, and will be able to locate in the future. In 2002, Fisher, Laud, Byfield, Brown, Hayat, and Fiedler surveyed 40 individuals with SCI four times over an 18-month period. They discovered that respondents were significantly more interested in sexual information and counseling at 6 months post-SCI than during their inpatient stay. However, their interest was no different from 6 to 12 months or from 12 to 18 months post-injury. A study by Leibowitz (2005) with 24 women with spinal cord injuries summarized the process of sexual interest perfectly by stating: it is an unfolding process rather than an all-or-none phenomenon. The current study, as

well as the ones outlined above, all illustrate the highly individualistic nature of timing sexual education services to meet each client's unique needs and preferences. Participants in the current study suggested providing varying options at different points both during and post-rehabilitation such as pamphlets, opportunities for peer to peer counseling, websites, and contact information for someone to answer questions and concerns throughout one's continuum of care from hospitalization to months and years post-discharge. In fact, despite one man's shock when questioned about sperm collection within the appropriate time frame (approximately 6-12 days post-injury; Brown, Hill, & Baker, 2006), another gentleman expressed considerable disappointment that this option was not made available to him during this critical period post-injury. Thus, there are issues, such as future reproduction, that demand certain aspects of one's sexuality be addressed within due time. Failure to discuss one's sexuality may lead to some of the consequences discussed both in the Introduction and by the participants in this study. For example, the current group of participants divulged potential consequences such as losing sexual interest all together, not entering intimate relationships, hating the opposite sex, or being hurt, used, embarrassed, afraid, and/or bitter.

In order to better understand patient readiness, the participants in the current study were receptive to the idea of a standardized questionnaire to gather their preferences concerning sexuality post-injury. The idea of a "pretest" to evaluate a patient's priorities, concerns, and preferences regarding future sexual education services post-injury was first suggested by a participant in McAlonan's (1995) qualitative, interview-based study as a possible method for gathering personal data and opinions. Nevertheless, the participants in the current study outlined several important considerations that must be respected in the development and implementation of such an instrument. For instance, the current participants discussed the importance of pre-

warning patients prior to the introduction of such a tool, as well as maintaining their privacy during data collection. In addition, they mentioned the importance of assessing hand dexterity in order to write in their preferences. Finally, they cautioned that the questionnaire could not serve as a substitute for personalized, face-to-face communication regarding the subject matter. In fact, it was through the establishment of professional rapport that it was recommended a therapist time the introduction of the questionnaire all together.

To further understand the complexity of the topic, the notable similarities and differences between the two groups will be highlighted in the following section. Moreover, a discussion of the implications for occupational therapy will highlight the secondary purpose of this study, which included how to facilitate the role of an OT in a patient's sexual adjustment post-injury. In addition, the limitations of this study as well as suggestions for future research will be provided.

Notable Similarities and Differences

It is important to note that while there were general trends between the women and men, the sample size was small. Therefore, generalization of the following discussion to the population at large would be premature. Nonetheless, some of the findings were quite profound. Thus, it was deemed necessary to share them the audience in order to better understand the complex nature of human sexuality post-SCI.

The themes for each analysis were created independently of one another; thus, the similarities and differences between the two groups may provide insight into the thoughts, needs, and interests of men and women with spinal cord injuries regarding their sexual health and abilities. For example, the following four themes were created to code material in both focus groups: 1) acceptance, 2) delayed readiness, 3) delivery method, and 4) characteristics of

clinician. Both groups had themes related to relationships and opportunity as well; however, the themes exhibited slightly different content and were named to reflect these differences. The themes can be compared side by side in Appendix C in order to note the primary differences. However, a more specific comparison of the groups will now ensue.

One of the major differences between the two groups arose concerning the whole idea of sexual relations post-SCI. The men never appeared to question “if” they would have sexual relations post-injury; rather, their concern was more focused on “when” this occupation would occur. Contrastingly, the women did not exhibit the same confidence regarding their sexual futures; instead, they were more focused on “if” sexual partners and relationships would re-emerge. An issue to highlight regarding this finding is in respect to how each group’s sexuality was addressed post-injury. Tepper (1992) found in his survey of 251 individuals with spinal cord injuries that a woman’s odds of not receiving sexual education post-injury were approximately double when compared to males. Similar results were reflected in the current study. All of the men received some element of sexual education post-injury from a health care professional; however, only one of the women received any services which were ill received at best. Thus, does having a health care professional introduce the topic provide clients with a level of control and autonomy and reduce their feelings of vulnerability post-injury? The current study appears to support this idea. Four themes extrapolated from the analysis of the women’s transcript indirectly relate to this idea: vulnerability, need to be understood, patient lack of knowledge, and autonomy/control/independence.

Related to the aforementioned idea is the fact that the men experimented with their sexuality by flirting; however, the women did not mention using any sort of strategy to self-address the issue of sexuality. Instead, they mentioned working through issues of acceptance and

working on the establishment of relationships and routines as key to their future sexuality. These sentiments were reinforced by Leibowitz (2005) during the semi-structured interviews she conducted with 24 women post-SCI. Participants from her study reported that their lack of receptivity to sexual rehabilitation services was delayed because they were focusing on other priorities such as gaining function, learning occupations of daily living, reuniting and caring for their children, and learning to cope with the emotional and physical changes that resulted from their injuries. It is also important to note that all of the women in this study, even those least interested in sexual education services, agreed that the topic should at least be *introduced* during one's inpatient stay by a health care professional. Simply because a woman does initiate the discussion, does not mean that she is not interested in her sexual options and future.

Another major comparison that emerged following data analysis reflects both the similarities and differences the men and women suggested regarding their preferences for the delivery methods and content to be used in the provision of sexual education. For example, the only woman to receive any official information was shown a tape, which she classified as pornography and horrible. Nevertheless, the men specifically asked for pictures and videos, including porn. While this was a vast difference, both groups emphasized the significance of respecting and accommodating the unique individualism regarding the methods and content to be included in one's sexual rehabilitation program. Preferences regarding the health professional's gender were highly variable as well. For instance, all three women suggested same-gender was best; however, two of the women personally did not have a strong opinion if they were selecting an educator for themselves. Nevertheless, all five men expressed a relatively strong preference for female caregivers. However, it was difficult to ascertain if this preference simply applied to general health care professionals such as nurses and aides, or whether is applied to sexual

educators as well. Follow-up research studies would be necessary to clarify this point. The other characteristics the participants desired in a sexual health clinician did not differ from group to group, instead general similarities were noted such as being knowledgeable and prepared for questions; refraining judgment; being honest; using humor appropriately, and exhibiting good overall communication skills. In addition, members in both groups reported not knowing who to turn to regarding sexual questions and concerns. With these recommendations, therapists should be well-prepared to address sexuality post-SCI across the life-span.

The final difference that was noted post-analysis was the difference in the emphasis humor was given by each group. The only mention of humor by the men was in regards to the clinician's characteristics. Contrastingly, the women repeatedly expressed the need for humor as a coping mechanism necessary in the context of everyday life. All three female participants described the importance of humor in regards to bad, devastating or depressive situations that they have encountered as a result of their injuries.

Finally, it was interesting to note that one of the unmarried male participants asked what the women reported, in terms of preferences and insights, during their focus group discussion. Inquiry of such a sort reinforced a common theme in both groups: where to find potential partners post-injury. Similarly, participants in both groups mentioned using the internet as commonplace, which should also be explored more thoroughly in future studies.

Implications for Occupational Therapy

Facilitation of the role of occupational therapy in client sexuality post-SCI was a further aim of this study. While there was no exact time that suited all participants regarding the initiation of sexual education services, the results of this study are still pertinent to the practice of occupational therapy. As previously discussed in the literature review, occupational therapists

are experts in facilitating one's highest level of independence in occupations of daily living, which includes sexual activity according to our Practice Framework (American Occupational Therapy Association, 2006). Based upon the theory and principles of occupational therapy, clinicians are to assess and collaborate with clients to provide holistic, client-centered services, which includes the physical, psychosocial, and cognitive aspects of sexuality. As Miller (1984) emphasized, occupational therapists view sexual function not in isolation, but rather within the context of total function. This includes integrating all aspects of life including one's motor, sensory, and cognitive function, home environment, socioemotional control, relationship status, and family support into all tenets of therapy, which includes human sexuality. A therapist's ability to conduct an occupational analysis and divide a complex occupation, such as sexual expression, into manageable sub-occupations is the heart of occupational therapy. This skill may not only be used to develop a repertoire of potential sexual positions or achieve effective birth control methods within the limits of one's hand and body function (Miller, 1984), but locating community resources to help clients meet potential partners, plan dates, or attend a support group may also help with the process of sexual adjustment post-injury.

Due to the fact that no two clients are the same, therapists should be prepared to develop sexually-based intervention plans with the same sensitivity to personal goals and meaningful occupations that are used in developing all occupational therapy services. Therapists may need to schedule social outings to aid in community reintegration; develop occupation-based exercise programs or hobbies that will address body image concerns; arrange peer to peer counseling; and/or develop graded educational materials to meet each person's unique needs and abilities. These occupations all need to be planned to address the personal goals of each patient within a time frame he or she sets forth. In essence, the results of the current study provide considerable

insight into the importance of tailoring sexual rehabilitation services to meet the individual needs and characteristics that each client possesses.

While an exact time was not prescribed by participants to initiate a sexual health discussion, suggestions were given to initiate the subject early, often, and over the long term. Simply because a client does not appear interested in his or her sexual function at first does not mean an evolution may not occur over time. In fact, participants expressed that this is often the case—indicating that they may want information when they get home or when other aspects of life are more established such as career plans. Thus, therapists have been challenged to assess one's readiness by noting confidence levels and success with other areas of rehabilitation such as gaining success with bowel and bladder routines. For men, observations of flirtatious behavior may also be a signal of growing readiness. Furthermore, maintaining a contact person for individuals to reach post-discharge or someone assigned to make follow-up phone calls months later were also valid methods for addressing client sexuality that were desired by several participants. As a result of this study, therapists are challenged to continuously stay abreast on current advancements and growing knowledge, work on their general interpersonal communication skills, and increase their comfortability with the subject. In essence, OTs should be well prepared to initiate the topic of sexuality post-injury in order to alleviate the anxiety that is often experienced by patients due to the taboo nature associated with the subject of sexuality. This assertion is echoed by Boyles (2007) in the opening of her chapter concerning sexuality post-injury: "Sexuality/sex after a spinal cord injury is something that everybody wants to know about, but nobody want to talk about." Due to the fact that participants mentioned they are overloaded with various other issues post-injury, asking subjects for their preferences and opinions regarding their sexuality is both valued and recommended. In fact, if they don't want to

talk to you, several participants warned they may tell you; however, several mentioned that they simply comply to the requests of medical professionals. Therefore, clinical judgment is highly important when breaching this subject. Furthermore, it is important to note that the men and women in this study have had many years to process their injuries; thus, newly injured individuals may feel differently.

Limitations

While the researchers designed and utilized several techniques to enhance the overall quality of the current study, limitations were inevitable. First, the use of focus groups as a data collection mechanism have several limitations. For example, there were both dominant and passive participants in both groups; thus a full range of each participant's personal thoughts and opinions may have been hindered. Furthermore, the primary researcher's inexperience with focus group moderation may have occluded the process of gathering accurate, in-depth information equally from each participant.

Second, the analysis of the qualitative data gathered from the focus groups may also contribute to study error. For instance, while a fourth person was recruited to review the final coding results, which were collaboratively made amongst three analysts to reduce the possibility of erroneous reasoning or assumptions, the results were still subject to human interpretation. Thus, the possibility of biasness and alternate interpretations may exist.

The small sample size of this study serves as an additional limitation. A larger population would have provided better evidence to support the assertions and opinions made by the subjects in this study. Furthermore, the lack of diversity amongst participants and the fact that they all resided within the Midwest may have impacted their responses. In fact, the primary researcher was contacted by several out-of-state participants as a result of advertising on the

National Spinal Cord Injury Association website, however, the accommodations requested by the potential subjects were not within the budget of this study.

A fourth limitation existed as a result of the fact that some of the participants knew each other and/or the primary researcher prior to the focus group sessions. While it appeared to enhance participation, some participants may have refrained from sharing ideas as a result that they would have future interactions with others following the discussions.

Finally, the study was retrospective and participants varied in terms of their level of injury, time since injury, and other demographic factors which could impact their thoughts, opinions, and suggestions regarding sexuality post-SCI. Controlling for some of these factors and running several focus groups with a more homogenous population may help to provide a more accurate portrait of what individuals are truly ready for post-injury.

Future Research

In order to better understand the timing of sexual education services post-SCI and the role of occupational therapy in this matter, several recommendations have evolved from this study. First, exploring the topic with a larger sample size and a more experienced focus group moderator may provide greater insight into issues that were poorly understood such as whether the men's preference for female caregivers was as a whole or only in specific situations. Second, a pilot study exploring the development of a readiness/preferences questionnaire could be useful in helping therapists assess a patient's desire for sexual information and of what nature. Third, further exploring the factors influencing readiness, such as acceptance or body image, may help clinicians enhance the rehabilitation process and develop interventions more integral with the typical life experiences of individuals with spinal cord injuries. Finally, a study exploring

partner readiness, desire, and preferences for sexual information may offer additional insight into the multi-faceted topic of sexuality post-SCI.

Conclusion

The findings of this study regarding the timing of sexual education services post-SCI should help fill the gap occupational therapists reported concerning a lack of knowledge as a barrier to addressing client sexuality post-injury. While an exact time was not pinpointed, participants reported many factors and strategies that should aid therapists in the initiation and development of holistic, client-centered intervention plans of a sexual nature. Occupational therapists possess unique training in occupational analysis, as well as an appreciation for the physical, psychosocial, and cognitive impact a disability such as a spinal cord injury can have on functional outcomes. These skills coupled with the results of this study should help therapists address client sexuality post-SCI with more confidence. Respecting individual differences and providing continuous, varied options both during and beyond rehabilitation may afford clients an element of control during a period of dramatic change.

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Appendix A

Focus Group Protocol

An Investigation of Patient Readiness: Helping OTs Initiate a Sexual Discussion Post-SCI

Introduction Outline

- Upon arrival, the participants will be greeted, checked-in, asked to complete an informed consent agreement, and given a first-name-only name tent.
- After securing consent, participants will be given a demographic questionnaire to fill out.
- After gathering the questionnaires, the participants will be encouraged to have a snack and mingle until everyone arrives.
- Once the entire group arrives, participants will be asked to find a place around the table.
 - Welcome (Morgan & Krueger, 1998):
 - Thank participants
 - Introduce moderator and assistant moderator
 - I am only here to guide the discussion; the assistant moderator will be taking some notes and seeking clarification of your responses.
 - Overview of the topic
 - You were selected because we believe you possess valuable insight into the lived experience of sexuality post-SCI.
 - The results will be used in fulfillment of my scholarly research project requirement for completion of my doctorate degree in occupational therapy from The University of Toledo Health Science Campus.
 - Establishment of guidelines and ground rules
 - No right or wrong answers

- We're tape recording, please speak one at a time
- We're on a first name basis: Emphasis confidentially
- If you feel uncomfortable at anytime, feel free to stop or excuse yourself from the group, there will be no penalties or loss of benefits for discontinued participation at any time
- You don't have to agree with others, but please listen respectfully as others share their viewpoints
- We ask that you turn off your cell phones and pagers. If you cannot and you must respond, please do so quietly and rejoin us as quickly as you can.
- Opening question: The first question is designed to break the ice and engage all participants one at a time. It is risky to ask participants for questions during the introduction. Thus, a formal invitation for questions will not be solicited, however, if questions are posed they will be addressed (Krueger, 1994).
- **Introduction Script** (Krueger, 1994)
 - "Good evening and welcome to our session tonight. Thank you for taking the time to join our discussion of sexuality following spinal cord injury. My name is Kristen Lohrer and I am an occupational therapy student at The University of Toledo Health Science Campus. Assisting me is Dr. Barbara Kopp Miller, a professor in our program. I am only here to guide the discussion; Dr. Kopp Miller will be taking some notes and seeking clarification of your responses when needed.
 - We want to find out more about when the topic of sexuality should be initiated post-injury in order to help OTs in addressing this topic. We have invited people

with SCI to share their perceptions and insights. We are particularly interested in your views because they will benefit the future of SCI rehabilitation and education.

- You were selected because we believe you possess valuable insight into the lived experience of sexuality post-SCI. There are no right or wrong answers, but rather differing points of view. Please feel free to share your opinions and ideas even if it differs from what others have said. The results will be used in fulfillment of my scholarly research project requirement for completion of my doctorate degree in OT.
- Before we begin, let me share some ground rules with you. This is strictly a research project. Please speak up and only one person should speak at a time. We are tape recording the session because we don't want to miss any of your comments. If several are talking at once, the tape will get garbled and we'll miss your comments. We will be on a first name basis tonight; however, in our later reports no names will be attached to comments. We want to assure you that every effort will be made to preserve your confidentiality. We understand that you are sharing information with us as well as with the individuals present; thus, we ask that you respect the privacy of your peers. You don't have to agree with others, but please listen respectfully as others share their viewpoints. Please keep in mind that we're just as interested in negative comments as well as positive ones. In fact, sometimes the negative comments are most helpful in making changes in the future. Finally, we ask that you turn off your cell phones and pagers. If you cannot and you must respond, please do so quietly and rejoin us as quickly as you can.

- Our session will last about 2 hours. Let's begin. We'd like to start by going around the room and asking each of you to tell us your first name, where you received your rehabilitation post-SCI, and if you have ever received occupational therapy services.”
- Potential Probes (Krueger, 1994)
 - Does anyone see it differently?
 - Are there any other points of view?
 - Would you explain further?
 - Would you give me an example of what you mean?
 - Would you say a little more?
 - Is there anything else?
 - Please describe what you mean.
 - I do not understand, would you clarify?

Purpose

- The purposes of this study are: 1) to identify when the topic of sexuality should be addressed following SCI, and 2) to facilitate the role of an OT in a patient's sexual adjustment by establishing the most appropriate time to begin sexual health services post-SCI.

Introduction Questions

1. We'd like to start by going around the room and asking each of you to tell us your first name, where you participated in rehabilitation post-SCI, and if you have ever participated in OT services.
2. When you hear the topic of sexuality 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/femininity?
- Probe: intimacy, physical performance, fertility

Readiness Questions

3. How long after your injury did you start to think about how your sexuality had been affected?
 - Initially, what were your greatest sexual concerns post-injury?
 - Probe: physical functioning, fertility, relationships/dating, sociocultural issues
4. How long after your injury until your sexuality was discussed?
 - Describe the first time sexuality was discussed with you post-SCI?
 - Probe: Who initiated the discussion? Who was present? Where were you?
5. What factors do you think contribute to an individual's readiness to discuss sexuality post-injury?
 - What factors might get in the way of a person's readiness to talk or be receptive to sexual information post-injury?
 - Probe: relationship status, psychosocial issues, body image
6. What are some ways you think people signal their readiness to discuss sexuality?
 - Probe: jokes, behaviors
7. How do you feel about a standardized questionnaire to evaluate patient readiness to discuss sexuality?
 - Probe: who should administer, what kinds of information should it gather, how to approach those who do not fill it out

8. Looking back on your experience, when do you think individuals would be most receptive to sexuality information?
 - What information does a patient need before returning to the community?
 - What are the potential consequences if sexuality is not discussed before discharge?
9. How should spousal/partner readiness be addressed?
 - Do you think there is a major difference in readiness between an individual with SCI and their partner?

OT Involvement Questions

10. What kinds of skills do you think an occupational therapist needs to initiate the topic of sexuality post-SCI?
 - Probe: education, gender
11. Suppose you were planning a seminar to educate occupational therapists on how to initiate the topic of sexuality post-SCI, what advice would you give?
 - Probe: Terminology (technical vs. lay), approaching partners
12. What changes are necessary for you to get the information you want from an occupational therapist post-injury?
 - Probe: Insurance funding, private rooms

Closing Questions

13. If we lived in an ideal world, how would you envision your first sexual discussion following SCI?
 - When would it have occurred: timing
 - Who would have initiated the experience: profession, male vs. female

- Who would be involved: other patients, partners, how many professionals
- Where would it occur: group setting, individual sessions
- What kind of materials would be desired: films, pamphlets, discussion
- How long would it last?

14. Give summary, is this an adequate summary?

15. Give overview, have we missed anything?

Appendix B

Focus Group Demographic Questionnaire

An Investigation of Patient Readiness: Helping OTs Initiate a Sexual Discussion Post-SCI.

Please answer the following questions:

1. What is your gender? Female Male
2. What is your age? _____ years
3. What is your race?

<input type="checkbox"/> Hispanic	<input type="checkbox"/> Caucasian
<input type="checkbox"/> African-American	<input type="checkbox"/> Asian-American
<input type="checkbox"/> American Indian	<input type="checkbox"/> Other (please specify)
4. What is the highest level of education you have completed?

<input type="checkbox"/> Under 12 th grade	<input type="checkbox"/> Master's Degree
<input type="checkbox"/> High School Diploma	<input type="checkbox"/> Doctoral Degree
<input type="checkbox"/> Bachelor's Degree	
5. What is your marital status?

<input type="checkbox"/> Single	<input type="checkbox"/> Stable partnership non-cohabiting
<input type="checkbox"/> Married	<input type="checkbox"/> Stable partnership cohabiting
<input type="checkbox"/> Separated	<input type="checkbox"/> Widowed
<input type="checkbox"/> Divorced	<input type="checkbox"/> Other
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

13. What is your neurological classification?

- Paraplegia-Incomplete Paraplegia-Complete
 Quadriplegia-Incomplete Quadriplegia-Complete

14. What level is your spinal cord injury (i.e. 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 your sexuality post-SCI with you? Yes No

Appendix C

Coding Themes

Themes for Coding Women's Transcript

1. Lowered status
2. Vulnerability
3. Body Image
4. Need to be understood
5. Characteristics of Clinician
6. Patient Lack of Knowledge
7. Delivery Method
8. Delayed Readiness
9. Opportunity
10. Acceptance
11. Relationships
12. Humor
13. Autonomy/Control/Independence

Themes for Coding Men's Transcript

1. Reactions
2. Reproduction
3. Perceptions of Sex
4. Acceptance
5. New Opportunity
6. Other's Perceptions
 - a. Masculinity
 - b. Harmlessness
7. Infantilism
8. Delayed Readiness
9. Delivery Method
10. Change in Relationships
11. Awareness of Women/Sexual Self
12. Characteristics of Clinician