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# Sexuality and Spinal Cord Injury: A Manual for Occupational Therapists in the Inpatient Rehabilitation Setting

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# SEXUALITY AND SPINAL CORD INJURY: A MANUAL FOR OCCUPATIONAL THERAPISTS IN THE INPATIENT REHABILITATION SETTING

By

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A Scholarly Project

Submitted to the Occupational Therapy Department

of the

University of North Dakota In partial fulfillment of the requirements

for the degree of

Master of Occupational Therapy

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# APPROVAL PAGE

This Scholarly Project Paper, submitted by Courtney Jacobson and Esada Mujcic in partial fulfillment of the requirements for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under who the work has been done and I hereby approved.

Cherry Shamb Faculty Advisor

3/22/17 Date

# PERMISSION

Title Sexuality and Spinal Cord Injury: A Manual for Occupational Therapists

in the Inpatient Rehabilitation Setting

Department: Occupational Therapy

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Courtney Jacobson, MOTS

Esada Mujcic, MOTS

(Made Man) | Date: 1/15/17

# TABLE OF CONTENTS

LIST OF	FIGURES AND TABLES	vi
ACKNOV	WLEDGEMENTS	vii
ABSTRA	CT	viii
CHAPTE	R	
I.	INTRODUCTION	1
	Definition of Terms.	3
II.	LITERATURE REVIEW	6
III.	METHODOLOGY	18
IV.	PRODUCT	21
V.	SUMMARY	23
REFERE	NCES	25
APPEND	ICES	31

# LIST OF FIGURES AND TABLES

Figure or T	Page	
Table 1.	Innervations and Movements	42
Figure 1.	ASIA Impairment Scale (AIS)	44
Table 2.	Interventions	59
Table 3.	Interdisciplinary Roles	66

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### ABSTRACT

The topic of sexuality has not been addressed in its entirety within the profession of occupational therapy and has been identified by patients as a need in order to receive comprehensive and holistic care (New, Seddon, Redpath, Currie, and Warren, 2016). More specifically, with 12,500 new cases of spinal cord injury (SCI) that occur each year, in addition to the significant impact on body functions that result from SCI, the topic of sexuality needs particular attention with this population (National Spinal Cord Injury Statistical Center, 2015). The purpose of this scholarly project was to create a manual supported by literature that can be used by occupational therapists working with patients with SCI in the inpatient rehabilitation setting to address sexuality. The authors conducted an in-depth literature review regarding the topic of sexuality in the healthcare setting as well as sexuality with the SCI population. The authors created a manual, guided by the Ecology of Human Performance (EHP) model and the ALLOW model. These models provide structure to the occupational therapy treatment process, from the evaluation to the outcomes. The manual is to be used as a reference, a resource, and a guide for occupational therapists to use when addressing sexuality with patients with SCI in the inpatient rehabilitation setting.

### **CHAPTER I**

### INTRODUCTION

The problem addressed in this scholarly project is the need for the occupational therapy profession to address sexuality\* with all patients, specifically patients who have a spinal cord injury (SCI). The problem is significant because it has not been addressed in its entirety within the profession and has been identified by patients as a need in order to receive comprehensive and holistic care (New, Seddon, Redpath, Currie, and Warren, 2016). The population of interest is occupational therapists working in the inpatient rehabilitation setting who work with patients who have sustained a SCI.

The authors are proposing for the use of a manual to aide occupational therapists with addressing sexuality through evaluation, intervention, and outcome measurement of patients who have sustained a SCI. When using the manual, the occupational therapists will evaluate and provide treatment interventions that address the patient's client factors and performance skills that are inhibiting the patient's occupational performance. The contexts and environments of the patient is also assessed during evaluation and considered during intervention.

The manual consists of an overview of physical, physiological, and psychosocial complications as it relates to sexuality that result from sustaining a SCI. The manual includes a comprehensive list of resources for patients as well. The manual also lays out an overall

1

<sup>\*</sup>Terms are defined at the end of this section

interdisciplinary rehabilitation team approach in order to best meet the needs of the patient within the topic of sexuality.

The manual is intended to be used by occupational therapists working in inpatient rehabilitation settings, who are motivated to address all areas of occupation. These areas include activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, work, education, leisure, and social participation\* (AOTA, 2014). The occupation of sexuality is considered an ADL and will be addressed as such when working with patients with SCI during inpatient rehabilitation.

Throughout the literature search, although the topic of sexuality within occupational therapy was addressed, limited evidence was found regarding the specific therapy process when addressing the area of sexuality with patients with SCI. While conducting the search, the authors noted the use of the PLISSIT model when addressing the topic of sexuality with patients. However, through further research, the authors concluded that an alternative tool, the ALLOW model, was more appropriate for the present day health care context, and therefore is reflected throughout the created manual.

The authors did not find a specific occupational therapy model that has been shown to be used when addressing the topic of sexuality however, the Ecology of Human Performance (EHP) model was chosen to guide the manual. This model is suited for the use with patients in the inpatient rehabilitation setting due to its interdisciplinary nature as well as the population that is being addressed.

The literature review and findings, the methodology used to create the manual, the product, and a summary of the process are described in the following chapters.

<sup>\*</sup>Terms are defined at the end of this section

## **Definition of terms**

**ADLs:** "Activities oriented toward taking care of one's own body (adapted from Rogers & Holm, 1994). ADLs also are referred to as basic activities of daily living (BADLs) and personal activities of daily living (PADLs). These activities are "fundamental to living in a social world; they enable basic survival and well-being" (Christiansen & Hammecker, 2001, p. 156).

Client factors: "Client factors include (1) values, beliefs, and spirituality; (2) body functions; and (3) body structures that reside within the client that influence the client's performance in occupations" (American Occupational Therapy Association [AOTA], 2014, p. S22).

**Context:** "[R]efer to a variety of interrelated conditions that are within and surrounding the client" (AOTA, 2014, p. S28) and "include cultural, personal, temporal, and virtual contexts" (AOTA, 2014, p. S28).

**Cultural context:** "Customs, beliefs, activity patterns, behavioral standards, and expectations accepted by the society of which a client is a member. The cultural context influences the client's identity and activity choices" (AOTA, 2014, p. S28).

**Education:** "Activities needed for learning and participating in the education environment" (AOTA, 2014, p. S20).

**Environment:** "The term environment refers to the external physical and social conditions that surround the client and in which the client's daily life occupations occur" (AOTA, 2014, p. S28).

**IADLs:** "Activities to support daily life within the home and community that often require more complex interactions that those used in ADLs" (AOTA, 2014, p. S19).

**Leisure:** "Nonobligatory activity that is intrinsically motivated and engaged in during discretionary time, that is, time not committed to obligatory occupations such as work, self-care, or sleep" (Parham & Fazio, 1997, p. 250).

**Performance skills:** "Observable elements of action that have an implicit functional purpose; skills are considered a classification of actions, encompassing multiple capacities (body functions and body structures) and, when combined, underlie the ability to participate in desired occupations and activities" (AOTA, 2014, p. S 25).

**Personal context:** "Features of the individual that are not part of a health condition or health status" (World Health Organization [WHO], 2001, p. 17). The personal context includes age, gender, socioeconomic status, and educational status and can also include group membership (e.g., volunteers, employees) and population membership (e.g., members of society)" (AOTA, 2014, p. S28).

**Physical environment:** "Natural and built nonhuman surroundings and the objects in them. The natural environment includes geographic terrain, plants, and animals, as well as the sensory qualities of the surroundings. The built environment includes buildings, furniture, tools, and devices" (AOTA, 2014, p. S28).

**Play:** "Any spontaneous or organized activity that provides enjoyment, entertainment, amusement, or diversion" (Parham & Fazio, 1997, p. 252).

**Sexuality:** "A central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction" (WHO,

2002, ¶7).

**Social environment:** "Presence of, relationships with, and expectations of persons, groups, or populations with whom clients have contact. The social environment includes availability and expectations of significant individuals, such as spouse, friends, and caregivers; relationships with individuals, groups, or populations; and relationships with systems (e.g., political, legal, economic, institutional) that influence norms, role expectations, and social routines" (AOTA, 2014, p. S28).

**Social Participation:** "The interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends" (Gillen & Boyt Schell, 2014, p. 607); involvement in a subset of activities that involve social situations with others (Bedell, 2012) and that support social interdependence (Magasi & Hammel, 2004). Social participation can occur in person or through remote technologies such as telephone calls, computer interaction, and video conferencing" (AOTA, 2014, p. S21).

**Temporal context:** "The experience of time as shaped by engagement in occupations; the temporal aspects of occupation that "contribute to the patterns of daily occupations" include "rhythm tempo synchronization duration and sequence" (Larson & Zemke, 2003, p. 82; Zemke, 2004, p. 610). The temporal context includes stage of life, time of day or year, duration and rhythm of activity, and history" (AOTA, 2014, p. S28).

**Virtual context:** "Environment in which communication occurs by means of airwaves or computers and in the absence of physical contact. The virtual context includes simulated, real-time, or near-time environments such as chat rooms, email, video conferencing, or radio transmissions; remote monitoring via wireless sensors; or computer-based data collection"

(AOTA, 2014, p. S28).

**Work:** "Labor or exertion; to make, construct, manufacture, form, fashion, or shape objects; to organize, plan, or evaluate services or processes of living or governing; committed occupations that are performed with or without financial reward" (Christiansen & Townsend, 2010, p. 423).

### **CHAPTER II**

# LITERATURE REVIEW

## Introduction

When a person experiences an unexpected life event or trauma such as a spinal cord injury (SCI), he or she looks to healthcare professionals to educate them on the nature of their injury and how their areas of occupation such as activities of daily living (ADLs), instrumental activities of daily living (IADLs), work and education, leisure, and social participation may be affected. In general, discussion about these topics are often open and informative; however, the topic of sexuality is often found to be neglected during the discussions (Fritz, Dillaway, & Lysack, 2015; Haboubi & Lincoln, 2003).

Sexuality, as defined by the World Health Organization (2002) is "a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction" (¶7). Northcott and Chard (2000) identify sexuality as "a basic fundamental aspect of human development, personality, and behavior" and "is a natural and healthy part of living and includes physical, spiritual, emotional, psychological, and ethical dimensions" (p. 412). A disability may affect a person's sexuality; however, the person's desire and ability to give and receive love and affection remains (Northcott & Chard, 2000). With 12,500 new cases of SCI that occur each year, in addition to the significant impact on body functions that result from SCI, the topic of sexuality needs particular attention with this population (National Spinal Cord Injury Statistical Center, 2015).

The topic of sexuality with the SCI population is best approached from an interdisciplinary perspective rather than a discipline specific perspective. Utilizing an interdisciplinary team, the likelihood of addressing all concerns the person may have (Booth, Kendall, Fronek, Miller & Geraghty, 2003; Fronek, Booth, Kendall, Miller & Geraghty, 2005; Post, Gianotten, Heijen, Lambers, & Willems, 2008). Occupational therapy is an integral part of this team by using a client-centered and holistic approach to sexuality (Fritz et al., 2015). This literature review will cover the physical, physiological, and psychosocial aspects of a SCI as it pertains to sexuality, the need to include sexuality in discussions, an interdisciplinary approach to providing sexual education, and the role of occupational therapy in sexuality with the SCI population.

# **Sexuality with Spinal Cord Injury**

Individuals with a SCI experience physical, physiological, and psychosocial changes after their accident (Courtois & Charvier, 2015; Ducharme, 2011; McCabe & Taleporos, 2003; Whalley Hammel, 2007). These changes have an effect on a person's sexuality and it is crucial to address all changes in order to treat the person in a holistic way.

# Physical and Physiological

Depending on the level of injury and whether the injury is complete or incomplete, both men and women may experience bowel and bladder dysfunction, pain, pressure ulcers, sensory loss, weakness, fatigue, decreased muscle tone, and muscle spasms when engaging in sexual intimacy (Courtois & Charvier, 2015; Ducharme, 2011). Specifically, men may experience erectile dysfunction, difficulty with ejaculation, and achieving orgasm (Courtois & Charvier, 2015; Ducharme, 2011). Women may experience problems with vaginal lubrication, vaginal

infections, achieving orgasms, and pregnancy (Courtois & Charvier, 2015; Ducharme, 2011; Fritz et al., 2015).

# **Psychosocial**

While physical changes are often the focus after a SCI, psychosocial changes cannot be neglected. Psychosocial factors can either inhibit or facilitate sexual adjustment following a SCI (New, Seddon, Redpath, Currie, & Warren, 2016). Studies have shown that individuals with a SCI feel less sexually desired than their able-bodied counterparts due to their physical disability having limitations on their sexual life (Esmail, Darry, Walter, & Knupp, 2010; McCabe & Taleporos, 2003). According to Ricciardi, Szabo, and Poullos (2007), individuals with a SCI must "redefine their ideas about who they are as sexual beings" (p. 678) and must physically and psychosocially adapt to their changed body.

Research has shown that depressive disorders are more prevalent in the SCI population than the general medical population due to the immediate and chronic nature of the injury (Williams & Murray, 2015). In addition, depressive disorders can have an effect on a person's sexuality such as communication with their partner, self-expression, and self-esteem within intimate relationships (McCabe & Taleporos, 2003; Whalley Hammel, 2007). Another significant psychosocial factor that affects individuals with SCI is the feeling of fear when attempting to re-engage in sexual intimacy (Fritz et al., 2015). Specifically, patients are concerned with how their limitations and health issues will affect their physical functioning during sexual intimacy (MacRae, 2013). It is important that healthcare providers address a patient's physical, physiological, and psychosocial needs in order for the person to maintain his/her overall well-being, as well as participation and expression of sexuality; which in turn may

enhance his/her quality of life after injury (Dune & Shuttlesworth, 2009; Fritz et al., 2015; Northcott & Chard, 2000).

# **Inclusion of Sexuality in Rehabilitation**

New, Seddon, Redpath, Currie, and Warren (2016) conducted a mixed methods study to provide recommendations for professionals in spinal rehabilitation settings regarding sex education. Researchers found that inpatient rehabilitation, while often underutilized for this, was a particularly important setting in which the rehabilitation team can broach the topic of sexuality with patients. Furthermore, it is suggested that sexuality rehabilitation services should be addressed routinely with patients as part of the rehabilitation process just as other regular rehabilitation services are provided (New et al., 2016). Individuals with SCI still see sexuality as an important aspect of their lives despite their impairment and look to healthcare professionals for information about their injury in relation to sexuality (New et al., 2016). Patients also express the need for their clinicians to be comfortable in addressing the topic of sexuality in a professional and sincere manner if the subject were raised (Northcott & Chard, 2000).

Fritz, Dillaway, and Lysack (2015) found that individuals who had a SCI received little or no information during rehabilitation regarding sexual intimacy or how to deal with SCI-related conditions during sexual activity. In addition, Northcott and Chard (2000) conducted semi-structured interviews with patients who had various physical disabilities, some of which included SCI. Those who participated in the interviews emphasized that it would have been beneficial to receive information about sexuality and how their disability had affected this occupation (Northcott & Chard, 2000). Specifically, one participant in particular stated that if sexuality rehabilitation information was provided by his/her healthcare team, his/her relationship may have improved with his/her significant other (Northcott & Chard, 2000). A recent study

asked patients with SCI what modes they would have liked to have sexuality information be delivered in (New et al., 2016). Most participants stated that sexual rehabilitation services should be brought up by health professionals and not reliant on patients to request it.

Haboubi and Lincoln (2003) studied the views of nurses, doctors, physiotherapists and occupational therapists about discussing sexual issues with their patients. The researchers found that 90% of respondents of their survey stated that sexual issues should be addressed as part of holistic care although research has shown that healthcare professionals are still not addressing sexuality for various reasons (Haboubi & Lincoln, 2003; New et al., 2016). Specifically, "the majority of respondents (68%) never initiated discussion about sexual issues with patients, while 26% initiated discussion a few times and only 6% initiated discussion on a frequent basis" (p. 293). Reasons identified by respondents in the study for not discussing sexuality included lack of knowledge/training, embarrassment, and lack of time. New et al. (2016) also discussed discomfort, perception of expertise elsewhere, and readiness of the patient to receive information as barriers for not addressing sexuality.

Fronek, Booth, Kendall, Miller, and Geraghty (2005) conducted a study that focused on the use of a sexuality training program for the interdisciplinary SCI rehabilitation team and its effectiveness on improving knowledge, comfort, and attitudes with addressing sexuality. The participants showed an increase in their knowledge, comfort, approach, and attitude toward addressing sexuality with patients who have sustained a SCI after completing the implemented sexuality training program (Fronek et al., 2005). This study showed that healthcare providers can be better prepared for addressing sexuality concerns with patients when they are provided with the appropriate resources to do so.

# **Interprofessional Healthcare Team**

To ensure inclusion of all aspects of sexuality during the rehabilitation process, discussion about the topic should come from an interdisciplinary approach (Esmail, Knox, & Scott, 2010; Evans, Halar, DeFreece, & Larsen, 1976). Due to the complex nature of sexuality rehabilitation, it is most appropriate to involve multiple disciplines in order to cover all the various topics of sexuality and to allow the patient to have all of his/her questions about sexuality addressed from multiple professional perspectives (Booth et al., 2003; Evans et al., 1976). Patients also expressed that sexuality within the rehabilitation stage should be addressed directly by members of the rehabilitation team who have knowledge of the topic and have an appropriate attitude in order for patients to speak openly about their concerns regarding their sexuality (New et al., 2016).

Literature has supported the inclusion of physicians, nurses, physical therapists, occupational therapists, psychologists, and social workers as part of a SCI rehabilitation team (Fronek et al., 2005; Post, Gianotten, Heijen, Lambers, & Willems, 2007). These professionals can use their clinical expertise to address sexuality with patients and discuss any concerns that the patients and their significant others may have. Physicians can take on the responsibility of evaluating the physiological aspects of sexual dysfunction (Evans et al., 1976) and "may ask about family planning and sexual activity, or discuss when it is safe to resume sexual activity, and risks for sexually transmitted infections" (Esmail et al., 2010, p. 3). Physicians may also provide medications to address erectile dysfunction and orgasm for both men and women (McDonald & Sadowsky, 2002).

Nurses may discuss self-care of perineal area, bowel and bladder programs, educate patients on skin care and the risk of pressure ulcers, and inform and educate patients about

medication options (Evans et al., 1976; Ricciardi, Szabo, & Poullos, 2007). Nurses also use open communication in order to provide comfort and assist patients in promoting a positive and realistic self-concept as it relates to their sexuality rehabilitation (Evans et al., 1976; Ricciardi et al., 2007).

Due to the lack of research in physical therapy's role in sexuality, the American Physical Therapy Association's (APTA, 2014) scope of practice was reviewed. The role of a physical therapist may include educating a patient regarding autonomic dysreflexia and how to manage signs and systems (Ellexson, 1996). According to the APTA (2014), physical therapists are well suited in assessing and providing therapy on assistive and adaptive devices for functional mobility, peripheral nerve integrity, body mechanics, balance, joint integrity, and pain. From this information, it may suggest that physical therapists can integrate their knowledge when addressing sexuality with patients with SCI.

A psychologist and social worker can obtain a patient's psychosocial history related to sexual behavior, attitudes, sexual functioning, and also include a patient's sexual partner (if applicable) to discuss areas of concern within the sexual relationship (Evans et al., 1976). Miller and Byers (2009) also noted that psychologists should use evaluations that include "some assessment of sexual well-being, such as sexual orientation, past sexual trauma, sexual concerns/problems, or sexual symptoms specific to a disorder or medication" (p. 216).

Although the aforementioned disciplines have specific knowledge about sexuality within their scope of practice, all healthcare professionals on the rehabilitation team should have the knowledge to answer most questions at a basic level (Booth et al., 2003). When the topic expands out of the provider's scope of practice or area of competence, he/she should refer to the

most appropriate practitioner (Booth et al., 2003). Further research is needed on the specific roles of various healthcare professionals when addressing sexuality with SCI.

# **Role of Occupational Therapy in Addressing Sexuality**

The occupational therapy (OT) profession views sexuality as an aspect within one's self-care that is important to address in the rehabilitation setting (Northcott & Chard, 2000). The topic of sexuality is within the OT scope of practice as it is defined as a basic activity of daily living (MacRae, 2013). Occupational therapists look at all relevant contexts and environments of the person and how a person's client factors are affected due to an injury, in contexts across the lifespan (American Occupational Therapy Association [AOTA], 2014). Therefore, in order for occupational therapists to treat patients in a client-centered manner, sexuality must be included (Pollard & Sakellariou, 2007). For those with SCI, occupational therapists must look at the person as a whole, not the disability and limitations due to his/her injury. Occupational therapists can use their knowledge to educate and train patients and significant others on the use of adaptive equipment, positioning, transfers, self-cares, and relationship skills as they relate to the patient's sexuality (AOTA, 2004; AOTA, 2014).

Hyland and McGrath (2013) focused on the attitudes of occupational therapists with addressing sexuality with patients and suggested that occupational therapists would benefit from further education and training in order to increase their readiness to educate patients on sexuality rehabilitation. To aide therapists in addressing sexual concerns with those with SCI, Fritz et al., (2015) suggested that occupational therapists develop a client-centered sexual education program to use with their patients to address sexual desires and goals, incorporate strategies to improve confidence regarding sexuality as well as ways to improve relationship building skills, and

advocate for their patients in seeking out information for unique sexual concerns. Based on this suggestion, a manual was created guided by the Ecology of Human Performance Model.

#### Models

# **Ecology of Human Performance Model**

The Ecology of Human Performance (EHP), developed by Dunn, Brown, and McGuigan (1994) examines the interaction between the person and the environment and how this interaction affects behavior and performance of tasks. When looking at a patient with a SCI, the context in which sexuality occurs cannot be overlooked. The physical context of a patient with a SCI as it relates to sexuality may include the bedroom set up and how the features of the bedroom either enhance or inhibit performance. The social context may include an individual's support system, significant other, and/or partner of the patient. Cultural considerations, such as values and beliefs about sexuality, must also be examined (Dunn, Brown, & McGuigan, 1994). If a patient places high value on his/her ability to perform in the area of sexuality, this must be included as part of the rehabilitation.

According to the EHP model, a person's context may be limited, which would then hinder performance and decrease their performance range despite the person's ability to perform a task (Dunn et al., 1994). A person with a SCI is still able to perform in the area of sexuality; however, his/her context may not be facilitating performance; which would then lead to intervention. The EHP model includes specific intervention strategies (establish/restore, alter, adapt/modify, prevent, and create) to guide treatment (Turpin & Iwama, 2011).

This model can also be used in interdisciplinary settings as the term "task" is used in place of "occupation" for the use of common language across disciplines (Turpin & Iwama, 2011). This is especially important with this manual when referring to other

professionals. When there is common language among professionals, there is mutual understanding about how the task of sexuality is being hindered. In addition, other disciplines can create their own guide for addressing sexuality in the same concepts as this manual due to the interdisciplinary usage of the EHP model.

### PLISSIT Model

Literature has identified the PLISSIT model as an accepted model in sexuality rehabilitation for clients with SCI (Booth et al., 2003). The PLISSIT model, developed by Annon in 1976, stands for Permission, Limited Information, Specific Suggestions, and Intensive Therapy and uses these components in order to talk about sexuality with clients (Booth et al., 2003). Since the development of the PLISSIT model in 1976, new paradigms have emerged about the treatment and discussion of sexuality and SCI within rehabilitation. Sexuality in today's society is less taboo and therefore healthcare providers are often more open to addressing patient's needs in regards to sexuality and physical disability (Northcott & Chard, 2000). Although this model has been recognized as a researched method in sexuality rehabilitation, the ALLOW model of sexuality is more suited for the present day healthcare context.

### ALLOW Model

ALLOW stands for <u>A</u>sk the patient about sexual activity and function, <u>L</u>egitimize the patient's concerns by acknowledging them as relevant within their rehabilitative program, addressing <u>L</u>imitations presented by lack of knowledge and comfort, <u>O</u>pen discussions about sexual issues for assessment and the provision of referrals to a specialist, and <u>W</u>ork collectively in order to develop a treatment plan (Dune, 2012, p. 251).

This model directs the topic of sexuality to be initiated by healthcare providers rather than the patient as in the PLISSIT model. This strategy of healthcare provider initiation was supported by Northcott and Chard (2000) who found that participants who had received information about sexuality during their rehabilitation felt it would have been better if the topic of sexuality was initiated by the healthcare provider rather than the patient. This illustrates the need for healthcare providers to initiate open discussion about sexuality with patients.

The ALLOW models focuses on the collaborative approach between the healthcare provider and the patient to create a client-centered treatment plan. This model also emphasizes referrals to specialists when sexual concerns are outside the area of expertise of the healthcare provider, which can create open discussions about sexuality in a comfortable and professional manner (Dune, 2012). Referrals to other healthcare disciplines will create a team approach to addressing sexuality with patients with SCI and all concerns the patient may have can be addressed which aligns well with our desire for the inclusion of an interdisciplinary team focus in our product.

# Clinical Manual for Addressing Sexuality with Patients with SCI

Sexuality is an essential human need as well as a desired behavior (Northcott & Chard, 2000). Individuals with SCI continue to have these desires despite physical limitations (Northcott & Chard, 2000). Sexuality appears to be a continued topic of neglect for healthcare professionals due to lack of knowledge, lack of training, and level of comfort in addressing the topic with patients (Fritz et al., 2015; Haboubi & Lincoln, 2003). Occupational therapists can address the topic through looking at the whole person, his/her specific sexual concerns, physical and psychosocial changes, and finally, specific contexts, environments, and client factors that have been affected due to their injury (AOTA, 2014; Courtois & Charvier, 2015; Ducharme,

2011; Fritz et al., 2015; McCabe & Taleporos, 2003; Whalley Hammell, 2007; Williams & Murray, 2015).

In order to address this topic in depth through the occupational therapy lens, a clinical manual will be created. Through the guidance of the EHP and the ALLOW models, this manual will consist of information regarding physical aspects of sexual intercourse and intimacy, psychosocial aspects of relationship building, how to manage symptoms as they relate to sexuality, how to approach the topic of sexuality with patients with SCI, and when to refer to other healthcare professionals. With this manual, it is anticipated that occupational therapists will increase their knowledge and level of comfort when initiating discussion about sexuality with patients with SCI. Through the information given, overall quality of life for patients who have sustained a SCI, may improve in the area of sexuality.

### **CHAPTER III**

### METHODOLOGY

The authors conducted an in-depth literature review regarding the topic of sexuality in the healthcare setting as well as sexuality with the SCI population. Access to journal articles used in the literature review was gained through the University of North Dakota's Health Sciences

Library. Many journal articles were also accessed through an interlibrary loan. The authors searched journals from various healthcare professions including occupational therapy, physical therapy, medicine, nursing, social work, and psychology. Pertinent information was obtained from various articles in order to construct the literature review and ultimately guide the development of the product. Information about the models and theories was obtained from course textbooks and journal articles.

After the literature review was conducted, the authors used the third edition of the Occupational Therapy Framework: Domain and Process (AOTA, 2014) to create the layout of the manual. The Ecology of Human Performance (EHP) model was also used to guide the specific content of the manual. After review of various occupational therapy models, this specific model was chosen based on numerous reasons. The EHP model looks at the person and the context and how the relationship between these factors affects one's performance in their chosen tasks (Dunn, Brown, & McGuigan, 1994). Within the manual, the aspects of the person (sensorimotor skills, cognitive skills, psychosocial skills, past experiences, and values/interests) are reflected in the evaluation and intervention sections (Dunn, Brown, & Youngstrom, 2003). The context refers to the temporal context and the environment of the patient (Dunn, Brown, &

Youngstrom, 2003). The context factors are also reflected in the evaluation and intervention sections of the manual. The authors determined that objective performance will not be assessed in the manual due to the context of the inpatient rehabilitation setting. However, with the information given throughout the manual as well as interventions provided, the patient's performance and confidence with sexuality may increase after treatment.

The evaluation section of the manual addresses components of the EHP model, including aspects of the person and the patient's contexts. The ALLOW model was also used in the evaluation section due to its emphasis on initiation of the topic of sexuality by the healthcare provider (Dune, 2012). To assist occupational therapists in initiating the discussion of sexuality, questions were adapted from Paralyzed Veterans of America (2010) in order to gain information about the patient's interest, values, and past experiences regarding his/her sexuality.

The interventions provided in the manual were created using the specific intervention approaches identified in the EHP model and are as follows: establish/restore, alter, adapt, prevent, and create (Turpin & Iwama, 2011). The authors categorized interventions specific to sexuality into the intervention approaches mentioned and created a chart for organizational purposes. From the literature review, the authors noted the general occupational therapy interventions addressed in an inpatient rehabilitation setting and geared them toward the topic of sexuality and sexual intimacy.

Due to the complexity of sexuality, specifically with patients with SCI, the authors emphasized the use of an interdisciplinary team approach. From the literature search, it was found that the inpatient rehabilitation team who work with individuals with SCI, often includes: physician, nursing, psychologist, social work, physical therapy, and occupational therapy (Esmail et al., 2010; Evans et al., 1976; Fronek et al., 2005; McDonald & Sadowsky, 2002;

Miller & Byers, 2009; Paralyzed Veterans of America, 2010; Post et al., 2007; Ricciardi et al., 2007). Included in the manual is a table that outlines each profession's role in addressing sexuality with patients with SCI in an inpatient rehabilitation setting.

The final section of the manual outlines treatment outcomes. The authors generated questions that may be used prior to discharge in order to assess the patient's level of understanding and the need for further resources about sexuality. A satisfaction survey is also included for the patient to rate his/her satisfaction with the way the topic of sexuality was addressed. Resources were compiled through an online search of relevant and credible sources that are easily accessible to the general public. These resources include information on SCI in general, changes in sexual function after a SCI, and support groups for individuals with SCI.

### **CHAPTER IV**

#### **PRODUCT**

The topic of sexuality has been found to be neglected by healthcare professionals, including occupational therapists (Fritz, Dillaway, & Lysack, 2015; Haboubi & Lincoln, 2003; New, Seddon, Redpath, Currie, & Warren, 2016). In order to treat patients holistically, this topic cannot be ignored and occupational therapists must be educated on how to address the topic of sexuality with their patients. This manual was created to be used by occupational therapists working in the inpatient rehabilitation setting to assist in the evaluation, treatment, and outcome measurement regarding sexuality with individuals with spinal cord injury (SCI). With 12,500 new cases of SCI that occur each year, in addition to the significant impact on body functions that result from SCI, the topic of sexuality needs particular attention with this population (National Spinal Cord Injury Statistical Center, 2015) and is therefore the focus of this manual. This manual is intended to be used with individuals with SCI who are 18 years and older.

To guide the creation of this manual, The Ecology of Human Performance (EHP) model as well as the ALLOW (Ask patient about sexual activity and function, Legitimize patient's concerns, address Limitations presented by lack of knowledge, Open discussions about sexual issues and further referrals, Work collaboratively with patient [Dune, 2012]) model were used. The EHP model is an occupation-based model, which focuses on the interaction between the person, his/her context, the task, and how these factors affect performance (Dunn, Brown, & McGuigan, 1994). The evaluation and intervention sections of this manual are laid out using EHP concepts. A strength of this model is its use in an interdisciplinary setting (Turpin &

Iwama, 2011), which is highlighted in this manual to include working with others on the rehabilitation team. The ALLOW model is also used throughout this manual as it fosters collaboration between the patient and the healthcare provider when planning and implementing treatment (Dune, 2012). Similar to the EHP model, the ALLOW model may also be used in interdisciplinary settings as it emphasizes the referral to specialists when necessary (Dune, 2012).

The title of the product is "Sexuality and Spinal Cord Injury: A Manual for Occupational Therapists in the Inpatient Rehabilitation Setting". The manual is laid out from the beginning of evaluation through discharge and can be used at any time throughout the inpatient rehabilitation process. The manual consists of an overview of the aforementioned models, physiological and psychosocial complications following a SCI, occupational therapy evaluation, occupational therapy intervention, interdisciplinary care and team referral, and outcome measurement. An occupational therapist can use this manual when a patient with a SCI is placed on the rehabilitation caseload.

From the use of this manual, it is the hope that occupational therapists are more knowledgeable and more confident to address sexuality with patients with SCI. The full manual is available in appendix A of this project.

### **CHAPTER V**

#### **SUMMARY**

The topic of sexuality has been found to be a neglected area within healthcare and the realm of occupational therapy. Reasons identified for not addressing the topic include lack of knowledge, lack of time, and lack of comfort (Haboubi & Lincoln, 2003; New et al., 2016). These reasons guided the creation of "Sexuality and Spinal Cord Injury: A Manual for Occupational Therapists in the Inpatient Rehabilitation Setting". This manual, guided by the EHP model, is intended to be used by occupational therapists to address the occupation of sexuality with patients who have sustained a SCI. The manual lays out the evaluation process, specific interventions that may be used in the inpatient rehabilitation setting, and how to measure outcomes.

The manual may be implemented by occupational therapists practicing within an inpatient rehabilitation setting. Therapists can use the manual to gain knowledge, gain confidence, and become familiar with a possible structure to address sexuality during inpatient rehabilitation. The manual can also be used as a building block to creating continuing education and further training on the topic of sexuality.

This manual is to be used as a reference as it lays out the spinal cord injury levels, implications of the injury levels on functioning, and the physical, physiological, and psychosocial outcomes of SCI with sexuality. This manual is also to be used as a resource when working with other team members as it provides an overview of the various roles of other healthcare professionals. Additional resources are also provided for patient and occupational

therapists. Finally, this manual can be used to guide the therapeutic process of addressing sexuality throughout the occupational therapy process, including evaluation, intervention, and outcomes.

The manual does have its limitations such as its limited use, limited research available, and limited experience of the authors. The manual was specifically created for use in the inpatient rehabilitation setting and may not have the same use in an alternative setting. An additional limitation of the project is the lack of research that is available regarding the specifics of addressing the topic of sexuality. Lastly, the authors of this project have limited experience in working with patients who have a SCI or addressing sexuality with patients.

Future recommendations for the project include research on the effectiveness of the manual in the inpatient rehabilitation setting and creating modifications to the manual to make it useful in other practice settings. This project will be presented at Frank Low Research Day at the University of North Dakota School of Medicine and Health Sciences in Spring of 2017 and plans may be made to also present this project at state or national conferences in future.

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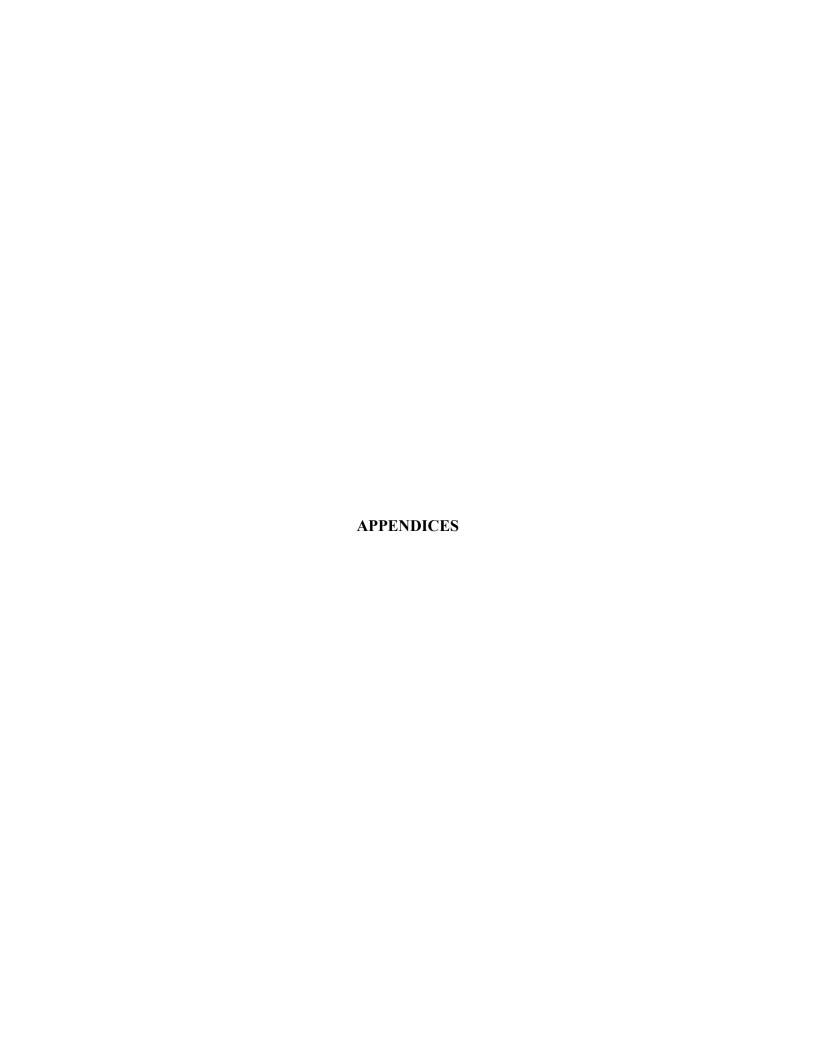
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# Appendix A Sexuality and Spinal Cord Injury: A Manual for Occupational Therapists in the Inpatient Rehabilitation Setting

# Sexuality and Spinal Cord Injury: A Manual for Occupational Therapists in the Inpatient Rehabilitation Setting

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# TABLE OF CONTENTS

INTRODUCTION	36
OVERVIEW OF MODELS	38
ECOLOGY OF HUMAN PERFORMANCE MODEL	39
ALLOW MODEL	
PHYSICAL, PHYSIOLOGICAL, AND PSYCHOSOCIAL CHAN	GES OF A SCI.42
PHYSICAL CHANGES	43
MALE & FEMALE PHYSIOLOGICAL CHANGES	46
MALE SEXUAL RESPONSE SYSTEM CHANGES	
FEMALE SEXUAL RESPONSE SYSTEM CHANGES	
PSYCHOSOCIAL CHANGES	50
OCCUPATIONAL THERAPY EVALUATION	51
EVALUATION OF THE PERSON	53
EVALUATION OF THE CONTEXT	56
OCCUPATIONAL THERAPY INTERVENTION	58
INTERDISCIPLINARY HEALTHCARE TEAM	64
TEAM REFERRAL	64
OCCUPATIONAL THERAPY OUTCOMES	71
APPENDIX B PRE-TREATMENT & POST-TREATMENT QUE	STIONNAIRE 73
APPENDIX C PATIENT SATISFACTION SURVEY	74
APPENDIX D PATIENT RESOURCES	75
APPENDIX E CASE STUDY	76

#### Introduction

The topic of sexuality has been found to be neglected by healthcare professionals, including occupational therapists (Fritz, Dillaway, & Lysack, 2015; Haboubi & Lincoln, 2003; New, Seddon, Redpath, Currie, & Warren, 2016). In order to treat patients holistically, this topic cannot be ignored. Occupational therapists and other healthcare professionals must be educated on how to address the topic of sexuality with their patients. This manual was created to be used by occupational therapists working in the inpatient rehabilitation setting to assist in the evaluation, treatment, and outcome measurement regarding sexuality with individuals with spinal cord injury (SCI).

With 12,500 new cases of SCI that occur each year, in addition to the significant impact on body functions that result from SCI, the topic of sexuality needs particular attention with this population (National Spinal Cord Injury Statistical Center, 2015) and is therefore the focus of this manual. This manual is intended to be used with individuals with SCI who are 18 years and older.

To guide the creation of this manual, The Ecology of Human Performance (EHP) model as well as the ALLOW (Ask patient about sexual activity and function, Legitimize patient's concerns, address Limitations presented by lack of knowledge, Open discussions about sexual issues and further referrals, Work collaboratively with patient [Dune, 2012]) model were used. The EHP model is an occupation-based model which focuses on the interaction between the person, his/her context, and the task and how these factors affect performance (Dunn, Brown, & McGuigan, 1994). The evaluation and intervention sections of this manual are organized using EHP concepts. A strength of this model is its use in an interdisciplinary team setting (Turpin & Iwama, 2011), which is highlighted in this manual to include working with others on the

rehabilitation team. The ALLOW model is also used throughout this manual as it fosters collaboration between the patient and the healthcare provider when planning and implementing treatment (Dune, 2012). Similar to the EHP model, the ALLOW model may also be used in interdisciplinary team settings as it emphasizes the referral to specialists when necessary (Dune, 2012).

The layout of this manual consists of an overview of the aforementioned models, physiological and psychosocial complications following a SCI, occupational therapy evaluation, occupational therapy intervention, interdisciplinary care and team referral, and outcome measurements. A case study is also included that outlines the use of this manual with a potential patient. From the use of this manual, it is hoped that occupational therapists are more knowledgeable and more confident to address sexuality with patients with SCI.

# Overview of Models

#### **Ecology of Human Performance Model**

The Ecology of Human Performance (EHP) model is reflected throughout this manual. The main concepts of this model includes person, task, context, and performance (Turpin & Iwama, 2011). The EHP model examines the interaction between the person and the context and how this interaction affects behavior and performance in tasks (Dunn, Brown, & McGuigan, 1994). This model can also be used in interdisciplinary team settings as the term "task" is used in place of "occupation" for the use of common language across disciplines (Turpin & Iwama, 2011). The interdisciplinary versatility of this model works well for the manual, which includes various rehabilitation professions and their roles in addressing sexuality with individuals who have sustained a SCI.

The first concept of EHP reflected in this manual is the person. The person is comprised of person variables which include sensorimotor skills, cognitive skills, psychosocial skills, past experiences, and values/interests (Dunn, Brown, & Youngstrom, 2003). These person variables should be assessed during the initial evaluation and addressed throughout intervention planning as these person variables "influence the tasks that are chosen" (Dunn, Brown, & Youngstrom, 2003, p. 225). Examples of person variables for the SCI population include functional level, sensory level, cognitive abilities, self-confidence and self-concept, past sexual experiences, and level of interest in the area of sexuality.

The second concept of the EHP model is task. Tasks are defined as "objective representations of all possible activities available in the universe" (Brown, 2014, p. 496) and "are the building blocks of occupations and roles" (Cole & Tuffano, 2008, p. 118). The relationship between the person and his/her context will determine the set of tasks that a person engages in

(Turpin & Iwama, 2011). The task that is being addressed within this manual is sexuality and the various aspects of sexuality experienced by individuals with a SCI.

The third concept is context, which includes the temporal context and the environment of the patient (Dunn, Brown, & Youngstrom, 2003). The temporal context consists of chronological age, developmental stage, life cycle, and health status (Dunn, Brown, & Youngstrom, 2003). This manual will focus on the health status component of the temporal context related to the acuteness of injury as well as chronicity of the disability. The occupational therapist can use his/her own judgement to assess appropriateness of discussion of sexuality based on the patient's health status. The environment includes the physical, social, and cultural dimensions of the patient's environment (Dunn, Brown, & Youngstrom, 2003). The patient's physical, social, and cultural environment needs to be assessed during evaluation and considered for intervention and discharge planning as factors that can promote or inhibit occupational performance.

The last concept of the EHP model reflected throughout this manual is performance. The term performance is defined by the "result of the person interacting with [the] context to engage in tasks" (Dunn, Brown, & Youngstrom, 2003, p. 226). Objective performance related to sexuality will not be assessed during inpatient rehabilitation, nor be an expected outcome. However, the occupational therapist will give the patients resources and skills to evaluate their performance and consider possible barriers and supports to empower patients to participate in sexuality as desired.

Lastly, the EHP model has specific intervention strategies including: establish/restore, alter, adapt, prevent, and create (Turpin & Iwama, 2011). These strategies were used in this manual to create interventions specific to sexuality and they were tailored to the inpatient

rehabilitation setting. The intervention strategies will be further explained in the intervention section of this manual (page 25, Table 1).

#### **ALLOW Model**

ALLOW stands for <u>Ask</u> the patient about sexual activity and function, <u>Legitimize</u> the patient's concerns by acknowledging them as relevant within their rehabilitative program, addressing <u>Limitations</u> presented by lack of knowledge and comfort, <u>Open discussions</u> about sexual issues for assessment and the provision of referrals to a specialist, and <u>Work collectively</u> in order to develop a treatment plan (Dune, 2012, p. 251).

This model directs the topic of sexuality to be initiated by healthcare providers rather than the patient. The ALLOW model also focuses on the collaborative approach between the healthcare provider and the patient to create a client-centered treatment plan. This model emphasizes referrals to specialists when sexual concerns are outside the area of expertise of the healthcare provider, which can create open discussions about sexuality in a comfortable and professional manner (Dune, 2012). Referrals to other healthcare disciplines will create a team approach to addressing sexuality with patients with SCI. Concepts of this model are reflected throughout this manual. Throughout the guide, the <u>A</u> and <u>L</u> are incorporated on page 18, the <u>L</u> and <u>O</u> are reflected on page 31 and the <u>W</u> is reflected on page 24.

# Physical, Physiological, and Psychosocial Changes of a SCI

# **Physical Changes**

Table 1. Innervations and Movements

Spinal Level Key muscles innervated		Movement possible	
C1-3	<ul><li>Sternocleidomastoid</li><li>Neck accessories</li><li>Cervical paraspinal muscles</li></ul>	<ul><li>Neck flexion</li><li>Neck extension</li><li>Neck rotation</li></ul>	
C4	<ul><li> Upper trapezius</li><li> Diaphragm</li><li> Cervical paraspinal muscles</li></ul>	<ul> <li>Neck flexion</li> <li>Neck extension</li> <li>Neck rotation</li> <li>Scapular elevation</li> <li>Inspiration</li> </ul>	
C5	<ul> <li>Elbow flexors:         <ul> <li>Biceps brachii</li> <li>Brachialis</li> <li>Brachioradialis</li> </ul> </li> <li>Deltoid</li> <li>Rhomboids</li> <li>Serratus anterior (partially innervated)</li> </ul>	<ul> <li>Shoulder flexion</li> <li>Shoulder abduction</li> <li>Shoulder extension</li> <li>Elbow flexion</li> <li>Elbow supination</li> <li>Scapular adduction</li> <li>Scapular abduction</li> </ul>	
C6	<ul> <li>Wrist extensors:         <ul> <li>Extensor carpi radialis longus</li> <li>Extensor carpi radialis brevis</li> <li>Extensor carpi ulnaris</li> </ul> </li> <li>Clavicular portion of pectoralis major</li> <li>Supinator</li> <li>Serratus anterior</li> <li>Latissimus dorsi</li> </ul>	<ul> <li>Scapular protraction</li> <li>Some horizontal adduction</li> <li>Forearm supination</li> <li>Radial wrist extension</li> </ul>	
C7-C8	<ul> <li>Triceps brachii</li> <li>Latissimus dorsi</li> <li>Sternal portion of pectoralis major</li> <li>Pronator quadratus</li> <li>Extensor carpi ulnaris</li> <li>Flexor carpi radialis</li> <li>Flexor digitorum profundus</li> <li>Flexor digitorum superficialis</li> </ul>	<ul> <li>Elbow extension</li> <li>Wrist extension</li> <li>Wrist flexion</li> <li>Finger flexion</li> <li>Finger extension</li> <li>Thumb flexion</li> <li>Thumb extension</li> <li>Thumb abduction</li> </ul>	

	<ul> <li>Extensor digitorum communis</li> <li>Flexor pollicis</li> <li>Extensor pollicis</li> <li>Abductor pollicis</li> <li>Lumbricals</li> </ul>	
Т1-Т9	<ul> <li>Intrinsics of the hand</li> <li>Internal intercostals</li> <li>External intercostals</li> <li>Erector spinae</li> <li>Lumbricals</li> <li>Flexor pollicis</li> <li>Extensor pollicis</li> <li>Abductor pollicis</li> </ul>	<ul> <li>Full upper extremity movement</li> <li>Limited upper trunk stability</li> <li>Increased endurance from innervation of intercostals</li> </ul>
T10-L1	<ul> <li>Internal intercostals</li> <li>External intercostals</li> <li>External obliques</li> <li>Rectus abdominis</li> </ul>	Good trunk stability
L2	<ul> <li>Iliopsoas</li> </ul>	Hip flexion
L3	• Quadriceps	Knee extension
L4	Tibialis anterior	Ankle dorsiflexion
L5	Extensor hallucis longus	Long toe extension
S1	<ul><li>Gastrocnemius</li><li>Soleus</li></ul>	Ankle plantar flexion

### **ASIA Impairment Scale (AIS)**

- **A** = **Complete.** No sensory or motor function is preserved in the sacral segments S4-5.
- **B** = **Sensory Incomplete.** Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-5 (light touch or pin prick at S4-5 or deep anal pressure) AND no motor function is preserved more than three levels below the motor level on either side of the body.
- C = Motor Incomplete. Motor function is preserved at the most caudal sacral segments for voluntary anal contraction (VAC) OR the patient meets the criteria for sensory incomplete status (sensory function preserved at the most cauda sacral segments (S4-S5) by LT, PP or DAP), and has some sparing of motor function more than three levels below the ipsilateral motor level on either side of the body.

(This includes key or non-key muscle functions to determine motor incomplete status) For ASIS C- less than half of key muscle functions below the single NLI have a muscle grade  $\geq 3$ .

- **D** = Motor Incomplete. Motor incomplete status is defined above, with at least half (half or more) of key muscle functions below the single NLI having a muscle grade  $\geq 3$ .
- **E** = **Normal.** If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without an initial SCI does not receive and AIS grade.

**Using ND:** To document the sensory, motor and NLI levels, the ASIA Impairment Scale grade, and/or zone of partial preservation (ZPP) when they are unable to be determined based on the examination results.

(American Spinal Injury Association, 2015)

# Male & Female Physiological Changes

- Autonomic dysreflexia (Consortium for Spinal Cord Medicine, 1997, as cited in Atkins, 2008)
  - Spontaneous rise in blood pressure
  - May occur during sexual activity
  - Occurs in those with lesions at or above T6
  - Educate patient on:
    - Signs and symptoms
      - Pounding headache
      - Heavy sweating
      - Flushed skin
      - Goose bumps
      - Blurry vision
      - Stuffy nose
      - Anxiety
      - Difficulty breathing
      - Chest tightness
    - Stopping any ongoing activity to reduce rise in blood pressure
    - Check blood pressure
    - If blood pressure is high, sit up with head elevated
    - Loosen clothing and abdominal binder
    - Seek medical assistance
- Orthostatic Hypotension (Rehabilitation Institute of Chicago-Spinal Cord Injury Team, 2016)
  - Sudden fall in blood pressure due to loss of nervous system control and decreased muscle tone to assist with returning blood to the heart
  - Caused by going from lying down to a sitting or standing position
  - Most common in lesions that occur in the cervical and high thoracic regions, T1 T6
  - Educate patient on: (Consortium for Spinal Cord Medicine, 1997, as cited in Atkins, 2008)
    - Signs and symptoms
      - Light-headedness
      - Pale skin
      - Visual changes
    - Check blood pressure
    - Lower the head of bed

- Lift legs if sitting up in chair
- Recline wheelchair to place head at or below level of the heart
- Spasticity (Mayo Clinic, 2009)
  - o Increased muscle tone resulting in a tightening or shortening of the muscles
  - Can make positioning difficult
- Pain (Mayo Clinic, 2009)
- Involuntary bowel movements and bladder leakage (Mayo Clinic, 2009)
- Orgasm may still be possible (Mayo Clinic, 2009)

# Male Sexual Response System Changes

# Erection and Ejaculation

**Reflexogenic erection**: Erection controlled by a reflex arc between the genital area and the cord as a result from direct stimulation of the genital area (University of Miami/Jackson Memorial Medical Center, 2009).

→ Induced by stimulation below injury level (Biering-Sørensen & Sønksen, 2001)

**Psychogenic erection:** Results when messages are passed down the spinal cord from the brain to the sacral area (University of Miami/Jackson Memorial Medical Center, 2009).

→ Caused by visual, auditory, olfactory stimuli, fantasies and memories (Biering-Sørensen & Sønksen, 2001)

**Spontaneous erection:** Induced by internal stimulation such as a full bladder (Craig Hospital, 2015)

# Patient with a lesion above T10 of the spinal cord (Courtois & Charvier, 2015)

- → Can maintain reflexogenic erections with genital stimulation, and can experience ejaculation
- → Will not have psychogenic erections

# Patient with a lesion to thoracolumbar (T10-L5) segments of the spinal cord (Courtois & Charvier, 2015)

- → Can maintain reflexogenic erections with genital stimulation
- → Will not have psychogenic erections
- → Will commonly not experience ejaculation

# Patient with a lesion to the sacral segments of the spinal cord or cauda equina (Courtois & Charvier, 2015)

- → Can maintain psychogenic erections
- → Will not have reflexogenic erections
- → Possible premature ejaculation

# **Female Sexual Response System Changes**

- Possible decrease in lubrication and more time needed for lubrication to occur (Craig Hospital, 2015; Courtois & Charvier, 2015)
- Fertility is not affected (Craig Hospital, 2015)
  - Still possible to become pregnant through intercourse
  - Can carry a baby to term
- Clitoris is capable of erection, and stimulation can lead to orgasm (Craig Hospital, 2015)

# Patients with lesions to cervical or thoracic segments (above T10) of the spinal cord (Courtois & Charvier, 2015)

→ Can maintain erection of the clitoris, have vaginal congestion, and vaginal lubrication to direct genital stimulation, but not psychogenic responses

# **Patients with incomplete lesions to cervical or thoracic levels** (Courtois & Charvier, 2015).

→ Can maintain vaginal responses as a function of preserved pinprick sensations in the T11–L2 dermatomes

#### Patients with lesions to sacral segments of the spinal cord (Courtois & Charvier, 2015)

→ Can maintain genital responses (erection of the clitoris, vaginal congestion and lubrication) through psychogenic stimulation but not through genital stimulation

# **Psychosocial Changes**

While physical changes are often the focus after a SCI, psychosocial changes cannot be neglected. Psychosocial factors can either inhibit or facilitate sexual adjustment following a SCI (New et al., 2016). Psychosocial complications after a SCI may include the following:

- Feeling less sexually desired (Esmail, Darry, Walter, & Knupp, 2010; McCabe & Taleporos, 2003).
- Depressive disorders (Whalley Hammel, 2007).
- Difficulty with communication, self-expression, and self-esteem within intimate relationships (McCabe & Taleporos, 2003; Whalley Hammel, 2007).
- Feelings of fear when attempting to re-engage in sexual intimacy (Fritz, Dillaway, & Lysack, 2015).
- Concerns regarding physical functioning during sexual intimacy (MacRae, 2013).

# Occupational Therapy Evaluation

Through our research, we were unable to find an occupational therapy assessment specific to sexuality. Therefore, we recommend tailoring the evaluation your facility currently uses to address sexuality. An occupational therapist may add questions to the existing evaluation, such as asking the patient what questions he/she may have regarding their sexuality and sexual activity and inquiring about past experiences with the occupation of sexuality. More detailed questions are described on pages 18 and 19.

Evaluation of sexuality should be towards the end of the initial evaluation to ensure baseline rapport has been established with the patient. To be congruent with the EHP model, the assessment should address person variables and context and identify how these variables may affect the patient's sexuality.

#### **Evaluation of the Person**

#### 1. Interests/values

Make sure that the patient is comfortable.
Determine if the patient values his/her sexuality.
Determine if it is of interest for patient to discuss his/her sexuality.
Examples of questions that may be asked include:

- 1. "After a spinal cord injury, many people have questions related to sexuality and sexual activity; what questions do you have? This may include how you see yourself as a sexual being, potential relationships, or completing self-cares to make you feel good before meeting someone new."
- 2. "Would you like me to provide you with some information?"

  (Consortium for Spinal Cord Medicine [CSCM], 2010)

By asking the patient these questions, the occupational therapist is initiating the discussion and legitimizing the patient's concerns regarding sexuality, which are the first two concepts (" $\underline{A}$ " and " $\underline{L}$ ") of the ALLOW Model, as stated at the beginning of this manual.

- ☐ Inform/remind the patient that sexuality encompasses sexual activity, pleasure, dating, and intimate relationships.
- ☐ If the patient chooses to discuss the occupation of sexuality in further treatment, an outcome measure will be administered in the form of a pre-treatment questionnaire. This questionnaire is located in Appendix B.

# 2. Experiences

- □ Evaluate the patient's experiences with sexuality prior to his/her injury
- □ Examples of questions the therapist may ask include:

- 1. "Can you tell me about your sexual activity prior to your injury?"
- 2. "Did you have any sexual difficulties prior to being injured?"
- 3. "Can we talk a little about what was going on at the time?"
- **4.** "Were you sexually active before your injury, and if not, do you have specific questions at this time?"

(CSCM, 2010)

# 3. Sensorimotor Components

- ☐ Another component of the person that should be assessed during the evaluation is the sensorimotor function of the patient. This includes the level of injury and effects on the patient's sexuality as well as how he/she may perform during sexual activity.
- □ Refer to Table 1 on page 25 and Figure 1 on page 10 of this manual to review spinal levels and ASIA Impairment Scale.

#### 4. Psychosocial Components

When conducting the evaluation, psychosocial factors of the person cannot be ignored. Psychosocial concerns that may emerge after a SCI related to sexuality must be considered during evaluation to ensure a holistic evaluation of the patient.

- □ Refer to patient's chart for review of mental health history.
- ☐ Questions to ask to evaluate the patient's psychosocial status:
  - 1. "How do you feel you are coping with your injury?"
  - 2. "Do you feel like your self-esteem has been affected? How so?"
- ☐ Refer to page 15 of this manual to review psychosocial changes of a SCI.

# 5. Cognitive Components

- □ Cognition is not affected as a result of a SCI unless the patient sustained a head injury during the accident or he/she had a previous cognitive impairment.
- ☐ For the purpose of this manual, cognition will not be explicitly addressed, but the patient's cognitive status should be considered when addressing sexuality.

# **Evaluation of the Context**

# 1. Temporal Context

9	Health	ı etatne

	☐ Using clinical judgment, consider the following:				
			Symptoms		
			Stage of healing		
			Acuteness of injury		
			Health status prior to injury		
			Prior normal activity level		
2.	Environment	t			
	a. Physic	cal Envi	ironment		
	Evalua	ation of	the patient's physical environment, specifically where sexual		
	activity may o	occur by	asking the patient about his/her home setup.		
		Things	s to consider:		
			Bed placement		
			Type of bed		
			Surface height with regards to transferring from wheelchair (if		
			applicable)		
			Space in room		
		This w	rill be further assessed if/when a home evaluation is conducted.		
	b. Social	Enviro	nment		
		Consid	der the following:		
			Social supports		

	Partners	
☐ If the patient is dating or not dating		
☐ If patient would like to start dating		
	How he/she goes about dating or meeting new partners	
	If the patient has an established relationship	
	If the patient is married or has recently gotten married	
Spouses may be used	as strong social supports. If appropriate, including the spouse in	
the discussion of sexuality m	ay help the patient feel more comfortable during the evaluation.	
c. Cultural Env Cultural consi	iderations should be noted throughout the evaluation process as well	
	s to consider with culture:	
_		
_	Age	
	Gender roles and expectations (Bhavsar & Bhugra, 2013)	
	Explanations of sexual behavior (Bhavsar & Bhugra, 2013)	
☐ Explanations for sexual dysfunction (Bhavsar & Bhugra, 2013)		
☐ Personal and cultural beliefs regarding healing (Bhavsar & Bhugi		
	2013)	
	The culture's view about disability	
	Cultural norms such as type of apparel worn and self-expression	

# Occupational Therapy Intervention

Throughout the intervention process, the occupational therapist should work collaboratively with the patient in order to be client-centered, which is the final concept ("<u>W</u>") of the ALLOW Model. It is also recommended to have the patient's partner present (if applicable and if patient agrees) when discussing adaptations to sexual activity and for increased support for the patient.

Intervention regarding sexuality can be incorporated into other interventions that the patient will be working on during inpatient rehabilitation. Some examples include: working on transfers, positioning, use of adaptive equipment, education on pressure relief, and managing bowel and bladder cares. The EHP model includes various intervention strategies that are described below, including how they can be specifically applied to address sexuality with patients with SCI.

Table 2. Interventions

Intervention	Description	General Intervention	Intervention Regarding Sexuality
Strategy	_		
Establish/Restore	"[E]stablishing skills that people haven't had previously or restoring skills and abilities that have been lost" (Turpin & Iwama, 2011, p. 110).	The occupational therapist (as well as the physical therapist) will need to teach the patient proper transferring techniques from his/her wheelchair (if applicable).	Establish transferring skills from wheelchair to bed/surface in order to engage in sexual activity.
		Establish new positions.	Establish new sexual positions
		Establish medication management routine.	Establish medication management routine around sexual activity (Ex. Taking pain medications prior to engaging in sexual activity).
		Establish pressure relieving techniques and routine.	Establish pressure relieving strategies during sexual activity.
		Establish bowel and bladder routine.	Establish bowel and bladder routine prior to engaging in sexual activity.
Alter	"[S]electing a different environment in which the person is able to perform the task" (Turpin & Iwama, 2011, p.111).	Patient may need to move to a more accessible bedroom inside the home.  Patient may need to move to a more accessible home.	If the patient is considering moving to a new, more adaptable room or home, considerations for sexual activity such as space, bed placement, and width of doorways.

Adapt/Modify	"[A]dapt the contextual features and/or task demands"	Positioning	Adapted positions to decrease spasticity
	(Turpin & Iwama, 2011, p.111).	Adaptive equipment	Use of adaptive equipment to enhance performance in sexual activity.  *A resource for sexual devices is located in Appendix D (Naphtali & MacHattie, 2009).
		Adapting the home environment after a home evaluation	Adapting the patient's current home environment to enhance performance in sexual intimacy after conducting a home evaluation.  Examples include:  Rearranging bed position Removing door frame for wider entryway Adjusting bed height
		Adapting dressing techniques.	Adapting dressing/undressing techniques for preparation for going on a date, sexual intimacy, and/or sexual activity.
		Adapting grooming/hygiene techniques.	Adapting grooming and hygiene techniques for preparation for going on a date, sexual intimacy, and/or sexual activity as well as for self-expression.

Prevent	"[T]o preclude the development of performance problems" (Dunn et al., 2003, p. 232).	Prevent pressure sores through pressure relief, positioning.	Positioning to prevent pressure sores, shearing, and pain during sexual activity
		Preventing involuntary bowel movement and/or bladder leak throughout the day.	Prevent an involuntary bowel movement and/or bladder leak during sexual activity, maintain a regular bowel and bladder program or try to have a bowel movement before any sexual activity and prior to going on a date (Mayo Clinic, 2009).
		Preventing spasticity during activities with stretching exercises.	Preventing spasticity during sexual activity.  • Warm bath before sexual activity  • Massage  • Warm room temperature  • Stretching before sexual activity
		Preventing occupational deprivation.	Preventing deprivation within the occupation of sexuality by addressing the topic.

Create	"[C]reat[e]	Recommending a more comfortable bed	Recommending a more comfortable
	circumstances that	such as a self-adjusting bed.	bed to enhance sexual performance.
	support optimal		
	performance for all		
	persons and	Creating a comfortable physical	Adjusting the temperature and
	populations" and	environment such as adjusting the	lighting in the room to set the mood
	"does not assume that	lighting in the room and maintaining a	for sexual activity to occur.
	a disability problem	comfortable temperature.	
	exists or is likely to		
	occur" (Dunn et al.,		
	2003, p. 232).		

# Interdisciplinary Healthcare Team

### **Team Referral**

To ensure inclusion of all aspects of sexuality during the rehabilitation process, discussion about the topic should come from an interdisciplinary team approach (Esmail, Knox, & Scott, 2010; Evans, Halar, DeFreece, & Larsen, 1976). Due to the complex nature of sexuality rehabilitation, it is most appropriate to involve multiple disciplines in order to cover all the various topics of sexuality and to allow the patient to have all of his/her questions about sexuality addressed from multiple professional perspectives (Booth, Kendall, Fronek, Miller, & Geraghty, 2003; Evans et al., 1976).

Based on available literature, we have chosen the inclusion of physicians, nurses, physical therapists, psychologists, and social workers as part of a SCI rehabilitation team within this manual, in addition to occupational therapists (CSCM, 2010; Esmail, Knox, & Scott, 2010; Evans et al., 1976; Fronek, Booth, Kendall, Miller & Geraghty, 2005; McDonald & Sadowsky, 2002; Miller & Byers, 2009; Post, Gianotten, Heijen, Lambers, & Willems, 2007; Ricciardi, Szabo, & Poullos, 2007). The specific areas addressed by these professionals were created based on review of the literature and is not all inclusive. These professionals can use their clinical expertise to address sexuality with patients and discuss any concerns that the patients and their significant others may have.

The included disciplines have specific knowledge about sexuality within their scope of practice and all should have knowledge to answer most questions at a basic level. When the topic expands out of a professional's scope of practice or clinical expertise, he/she should refer to the most appropriate practitioner. There may also be overlap amongst the various healthcare providers' roles regarding sexuality. Open discussions with the rehabilitation team will be imperative to determine each profession's role on the team as well as recognizing areas of

expertise may cross disciplinary lines. Special attention will need to be placed on billing for services that may be covered by multiple disciplines. For example, positioning may be covered by the occupational therapist as well as the physical therapist.

The team approach reflects the "L" and the "O" components of the ALLOW model which are: "addressing Limitations presented by lack of knowledge and comfort, Open discussions about sexual issues for assessment and the provision of referrals to a specialist" (Dune, 2012, p. 251).

Table 3 Interdisciplinary Roles

Healthcare Profession	Roles
Physician	• Evaluate the physiological aspects of sexual dysfunction (Evans et al., 1976; CSCM, 2010)
	• Evaluate the reproductive system (Evans et al., 1976; PVA, 2010)
	Conduct assessment of sensory and motor preservation (Evans et al., 1976; CSCM, 2010)
	Predict remaining sexual responses (Evans et al., 1976; CSCM, 2010)
	Ask about family planning and sexual activity (Esmail et al., 2010)
	Discuss when it is safe to resume sexual activity (Esmail et al., 2010)
	Discuss risks for sexually transmitted infections (Esmail et al., 2010)
	Provide medications to address erectile dysfunction and orgasm for both men and women
	(McDonald & Sadowsky, 2002)
	Discuss possible side-effects with medications as well as other medications the patient may
	be
	taking (CSCM, 2010)
	There may be multiple physicians with various specialties on the patient's team. These physicians should be consulted as appropriate and may include, but are not limited to:
	<ul> <li>Physiatrist</li> <li>Urologist</li> <li>Neurologist</li> <li>Gynecologist</li> <li>Orthopedist</li> </ul>
	Same pounds

Nursing	• Discuss self-care of perineal area (Evans et al., 1976; Ricciardi, Szabo, & Poullos, 2007)
	<ul> <li>Educate patients on skin care and the risk of pressure ulcers (Evans et al., 1976; Ricciardi, Szabo, &amp; Poullos, 2007)</li> </ul>
	<ul> <li>Inform and educate patients about medication options (Evans et al., 1976; Ricciardi, Szabo, &amp; Poullos, 2007)</li> </ul>
	<ul> <li>Encourage patients to think about bowel and bladder care before engaging in sexual activity (CSCM, 2010)</li> </ul>
	<ul> <li>Explore alternative plans if incontinence should occur during sexual activity (CSCM, 2010)</li> </ul>
	<ul> <li>Provide comfort and assist patients in promoting a positive and realistic self-concept as it relates to their sexuality rehabilitation (Evans et al., 1976; Ricciardi et al., 2007)</li> </ul>
Psychology and Social Work	Obtain a patient's psychosocial history related to sexual behavior, attitudes, sexual functioning (Evans et al., 1976)
	• Include a patient's sexual partner (if applicable) to discuss areas of concern within the sexual relationship (Evans et al., 1976)
	<ul> <li>Provide sexual counseling while considering the patient's cultural, physical, spiritual, and social contexts (CSCM, 2010)</li> </ul>
	<ul> <li>Conduct assessments of sexual well-being, "sexual orientation, past sexual trauma, sexual concerns/problems, or sexual symptoms specific to a disorder or medication" (Miller &amp; Byers, 2009, p. 216)</li> </ul>
Physical Therapy	Due to the lack of research in physical therapy's role in sexuality, the American Physical Therapy Association's (APTA, 2014) scope of practice was reviewed. According to the APTA (2014), physical therapists are well-suited to:
	Educate patient regarding autonomic dysreflexia and how to manage signs and symptoms

	(Ellexson, 1996; CSCM, 2010)
	<ul> <li>Assess for and provide assistive and adaptive devices for functional mobility (APTA, 2014)</li> </ul>
	<ul> <li>Assess for peripheral nerve integrity (APTA, 2014)</li> </ul>
	<ul> <li>Discuss and assess proper body mechanics (APTA, 2014)</li> </ul>
	<ul> <li>Address balance as it relates to sexuality (APTA, 2014)</li> </ul>
	• Joint integrity (APTA, 2014)
	<ul> <li>Address pain as it relates to sexual activity (APTA, 2014)</li> </ul>
	Address bed mobility (APTA, 2014)
	<ul> <li>Positioning in bed and wheelchair (APTA, 2014)</li> </ul>
	• Educate patient on transfer techniques (APTA, 2014)
	<ul> <li>Consider spine precautions specific to the level of injury of the patient to ensure safe sexual activity (CSCM, 2010)</li> </ul>
	<ul> <li>Perform home evaluations while considering sexuality (APTA, 2014)</li> </ul>
Occupational Therapy	<ul> <li>Address dressing and undressing techniques in preparation for sexual activity and intimacy.</li> </ul>
	Address hygiene and grooming as related to sexuality
	Educate patient on transfer techniques
	Address bed mobility and positioning

- Educate individuals about optimal positioning during sexual activity
- Educate patient on obtaining assistance from partners or spouses in preparation for sexual activity (if applicable)
- Consider spine precautions specific to the level of injury of the patient to ensure safe sexual activity (CSCM, 2010)
- Making environmental modifications to enhance the quality of the sexual experience
- Educate patient on pressure relieve strategies to prevent shearing during sexual activity and intimacy
- Educate patient regarding autonomic dysreflexia and how to manage signs and symptoms

# Occupational Therapy Outcomes

There are two outcomes that will be measured in this manual. The first is measuring the patient's level of understanding of his/her sexuality after their injury. This is measured by the pre and post-treatment questionnaire. The pre-treatment questionnaire is given during the evaluation and the post-treatment questionnaire is given at discharge from the inpatient rehabilitation unit. As mentioned, this questionnaire is found in Appendix B of this manual.

Another outcome of this manual is the patient's satisfaction with programming, specific to the occupation of sexuality and how it was addressed by occupational therapy at discharge.

The satisfaction survey is found in Appendix C of this manual.

### APPENDIX B

### **Pre-treatment & Post-treatment Questionnaire**

On a scale of 0-5 (0= not at all/not at all comfortable; 5= fully understand/very comfortable), please rate the following questions:

- 1. How well do you understand how your body has changed with regards to sexuality after your injury?
- 2. How comfortable do you feel about your sexuality after your injury?
- **3.** What other questions or concerns do you have?

# APPENDIX C

# **Patient Satisfaction Survey**

On a scale of 0 to 5 (0 not at all satisfied, 5 very satisfied), how satisfied are you with the way the topic of sexuality was addressed?

### APPENDIX D

### **Patient Resources**

- Craig Hospital
  - o www.craighospital.org
- United Spinal Association
  - o www.unitedspinal.org
  - o www.spinalcord.org
  - Peer support groups by state:
    - http://www.spinalcord.org/spinal-network/support-groups/
- Paralyzed Veterans of America
  - o www.pva.org
- Rehabilitation Institution of Chicago
  - http://www.ric.org/conditions/spinal-cord/
- Christopher & Dana Reeve Foundation
  - o https://www.christopherreeve.org/
- PleasureAble: Sexual Device Manual for Persons with Disabilities
  - o http://www.dhrn.ca/files/sexualhealthmanual lowres 2010 0208.pdf

### APPENDIX E

### Case Study

John is a 32 year old male who sustained a T1 complete spinal cord injury due to being in a car accident. He was admitted to inpatient rehabilitation after 10 days on the inpatient acute unit. John's tentative discharge date is within five weeks. John is receiving treatment from occupational therapy (OT), physical therapy (PT), nursing, a physiatrist, psychology, and social work. Based upon chart review, it is noted that he is recently engaged and lives with his fiancé. John is a high school football coach and finds his job to be very enjoyable and important for him. He also lives in a two story house. At this time John is medically stable and it is an appropriate time to begin discussing the topic of sexuality.

Using the layout of this manual, evaluation and intervention would appear as follows:

**Evaluation:** In addition to using the standard evaluation provided by the facility, such as the Barthel Index of Activities of Daily Living, assessment of sexuality was evaluated using concepts from the EHP model.

### Person:

At the end of the standard evaluation, the occupational therapist wanted to know John's level of interest regarding his sexuality and therefore asked, "After a spinal cord injury, many people have questions related to sexuality and sexual activity; what questions do you have?" After thinking for a minute, John expressed, "I want to be intimate with my fiance, but I am nervous about how that will work. My fiancé and I also want to have kids one day. Will I be able to?"

The occupational therapist validated John's concerns by reassuring John that being sexually intimate is still possible as well as having kids. John is also assured by the occupational therapist that his questions will be addressed throughout his rehabilitation stay. The occupational therapist also wanted to know about John's experience with sexuality prior to his injury and asked, "Did you have any sexual difficulties prior to your injury?" John reported that he has had no prior difficulties with sexuality and that he was sexually active with his fiance before the injury.

To evaluate John's functional ability, the occupational therapist assessed his level of injury. Since John sustained a complete SCI at the level of T1, he will have full upper extremity movement, limited upper trunk stability, and increased endurance from innervation of intercostals. The occupational therapist will also conduct manual muscle and range of motion testing to assess John's functional ability.

To assess John's psychosocial status, the occupational therapist referred to the psychologist's initial evaluation conducted while John was on the inpatient acute unit. It was noted that John displayed depressive symptoms. It was observed that John was withdrawn during evaluation and appeared to have decreased motivation to fully participate in treatment. From the cognitive screen conducted by OT on the inpatient acute unit, it was noted that John has no cognitive deficits.

### **Environment**

The occupational therapist inquired about John's physical home environment. John gave a description of the layout of his 2 story home. He stated that his current bedroom is on the second floor but, he and fiance have talked and that they are planning on moving to the bedroom on the main floor where there is more room for John to navigate his wheelchair although, he

states that his bed is tall. The occupational therapist brought up doing a possible home evaluation closer to John's discharge date in order to evaluate John's home and make recommendations that would allow John to engage in sexuality comfortably. John appeared to be very interested in a home evaluation. The occupational therapist also asked about John's social environment. John shared that his fiance is supportive and is planning on coming to some therapy sessions with him. From what the occupational therapist observed, John viewed his sexuality as a topic of interest and acceptable to be brought up within his culture. The occupational therapist administered the pre-treatment questionnaire with the following questions in order to measure John's level of understanding regarding sexuality

Based on the evaluation with John, the occupational therapist has created various interventions to address John's areas of concern within the occupation of sexuality.

### **Intervention:**

Area of concern	Strategies used & intervention
Intimacy with fiancé	<b>Establish/Restore:</b> Teach (establish) transferring skills such as transferring from wheelchair to bed/surface in order to engage in sexual activity with his fiancé.
	Adapt/Modify: Teach John adapted sexual positions that he and his fiancé could try to increase performance in the task of sexual intimacy. Also educate John on the use of pillows or wedges for increased comfort and performance. The therapist can teach John adaptive dressing/undressing and grooming/hygiene techniques for preparation for going on a date with his fiancé, sexual intimacy, and/or sexual activity.
	<b>Prevent:</b> Use pillows or wedges to prevent pain during sexual activity. Discuss positioning to prevent pressure sores, shearing, and pain during sexual activity. To prevent an involuntary bowel movement and bladder leak during sexual activity, teach John how to maintain a regular bowel and bladder program or

	try to have a bowel movement and empty his catheter before any sexual activity.
Home environment	Adapt/Modify: Suggest adaptations to John's home after conducting a home evaluation such as adjustable lighting, temperature, and adding music or having the television on to set the mood in preparation for sexual activity to occur.  Alter: Consider aspects of the new bedroom that John will move to such as, space in the room, location of the bed, width of doorway, if there is a bathroom in the room.
Future family planning	<b>Team Referral:</b> The occupational therapist can give John general information about fertility, however, this topic should be referred to a specialist such as John's primary physician.
Depressive symptoms	<b>Team Referral:</b> The occupational therapist should actively listen to John's concerns during treatment. The therapist should also refer John to his psychologist for further treatment.

### **Outcomes:**

Prior to discharge, the occupational therapist will ask John to complete the post-treatment questionnaire in order to measure John's level of understanding regarding sexuality.

The occupational therapist will also give John the satisfaction questionnaire to evaluate his satisfaction with programming specific to the occupation of sexuality and how it was addressed by occupational therapy. Resources will also be given to John for future reference. John will also be instructed to contact the occupational therapist or other team members if questions should arise.

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