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Addressing Sexual Intimacy Post-Spinal Cord Injury with Clients and their Significant Other

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's of Occupational Therapy

Grand Forks, North Dakota

May 2021

APPROVAL

This Scholarly Project Paper, submitted by Michelle Arnhalt & Taylor Beatty in partial fulfillment of the requirement for the Degree of Master of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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Title: Addressing Sexual Intimacy Post-Spinal Cord Injury with Clients and their Significant
Others

Department: Occupational Therapy

Degree: Master of Occupational Therapy

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ACKNOWLEDGEMENTS

The authors of this scholarly project would like to take the time to express gratitude and appreciation for the individuals whom made this project possible. First off, we would like to acknowledge the hard work that was contributed by our advisor, Dr. Julie Grabanski. Her continuous support, positivity, and feedback throughout the creation of this project is greatly appreciated and we could not have completed it without her guidance.

We would also like to extend a thank you to the University of North Dakota Occupational Therapy faculty for their dedication to our education during the last three years. A final thank you goes out to our friends and family for their continuous love and support throughout our time in the University of North Dakota Occupational Therapy Program.

ABSTRACT

Discussing sexual participation with a client who has experienced a spinal cord injury (SCI) can be a critical component to addressing their overall occupational needs during the rehabilitation process. Literature has shown that education on sexual intimacy following their injury is often neglected during therapy due to the sensitive nature of the topic (Federici, Artegianai, Pigliautile, Antonelli, Diotallevi, Ritacco, & Maschke, 2019; Hess & Hough, 2012; Walker, Otte, LeMond, Hess, Kaizer, Faulkner, & Christy, 2020). Overlooking the topic of sexual intimacy during the client's rehabilitation process can impact the client psychologically by decreasing their self-esteem and confidence, their desire to participate in sexual intimacy, as well as their relationship with their significant other.

Following an extensive literature review, it has been found that addressing and educating clients on sexual intimacy can help to address psychological factors relating to participation in sexual intimacy (Federici et al., 2019). Currently, no screening tools or assessments have been developed to facilitate discussion regarding sexual intimacy with clients who have experienced a SCI or the needs of their significant other. A screening tool to approach this topic would be beneficial for providers to gain a better understanding of each client's needs following a SCI, specifically sexual intimacy and the impact on their relationship.

The Let's Talk About Sex (LTAS) Screening Tool was created to meet the needs of clients and their significant other by facilitating conversation regarding sexual intimacy throughout the rehabilitation process. It is anticipated that this resource will assist occupational therapy practitioners to initiate discussion regarding sexual intimacy by providing them with a specific tool and guidance for meeting their clients' and significant others' unique needs. By utilizing the Person Environment Occupation (PEO) Model, the Intentional Relationship Model (IRM), and

the ALLOW Model the practitioner is able to address sexual intimacy, specifically the psychological aspect, and determine which component may be impacting successful participation. It is important that occupational therapy practitioners utilize this tool throughout all stages of the rehabilitation process and in collaboration with other disciplines to ensure the occupational needs of sexual intimacy are consistently addressed.

CHAPTER I

INTRODUCTION

Individuals who have experienced a spinal cord injury (SCI) often experience negligence in sexual rehabilitation when going through the therapy process (Hess & Hough, 2012). Unmet needs of these individuals have placed them at risk for a significant decrease in their quality of life. This issue can impact the psychological aspects of the individual, the individual's relationship, and their ability to participate in sexual relationships. Education on sexuality after a SCI is critical in improving individuals' confidence and self-esteem (Hess & Hough, 2012). Research has shown that the topic of sexual intimacy can be uncomfortable for both clients and healthcare professionals (Hess & Hough, 2012). Identifying how and when to address the clients' needs regarding sexuality throughout the therapy process can be critical and requires a certain level of trust within the therapeutic relationship. Being able to comfortably and confidently discuss sexuality needs with the client, when the client is ready, will help to address the unmet need of this population.

We have created a screening tool for clients following a SCI and their significant other to bridge the gap in addressing sexual intimacy. The purpose of this project was to provide a screening tool for professionals, guided by the models of ALLOW, Person-Environment-Occupation (PEO), and the Intentional Relationship Model (IRM), to use when addressing sexual intimacy with clients who have sustained a SCI. The screening tool is intended to provide professionals with an evidence-based tool to use when approaching the psychological aspects of sexual intimacy with individuals who have experienced a SCI. It will benefit clients and their significant others going through the rehabilitation process after a traumatic injury. The *Let's Talk About Sex (LTAS) Screening Tool* provides occupational therapy practitioners with a guide to

address the clients' perception of their occupational performance regarding the psychological aspects of sexual satisfaction, psychosocial impacts of the injury on the relationship, and communication with other healthcare professions to work as a collaborative team to meet each clients' specific needs. The overarching goal of the product is to provide more client-centered practice by increasing the comfort and trust in clients when initiating the discussion about sexual engagement and satisfaction following a SCI.

As mentioned above, the screening tool was created following the concepts from the PEO model, the IRM and the ALLOW model. PEO identifies various transactions between the three primary components of the model and how each impacts the individual's occupational performance. The screening tool utilizes these transactions to assist the administrator in narrowing down what specific aspect is preventing successful engagement in sexual intimacy (i.e. person, occupation, or environment). The second model that aided in the development of the LTAS Screening Tool is the IRM. The IRM recognizes that inevitable interpersonal events will likely occur throughout the rehabilitation process, especially when discussing the topic of sexual intimacy. This model highlights the importance of therapeutic use of self by the therapist to address these events and prevent them from negatively impacting the therapy process and therapeutic relationship. Lastly, the ALLOW model will help the therapist to understand when it is appropriate to address sexual participation with their client. This model encourages the topic of sexuality to be initiated by the healthcare worker rather than having the client be responsible. Oftentimes, sexuality is not brought up due to the clients' discomfort and worry of how their healthcare provider may react (Rodger, 2019). By requiring healthcare providers to address the topic, it opens the door for communication throughout the rehabilitation phase and ensures that all of the clients' needs will be met.

The following chapters will help the readers to gain a better understanding of the purpose of this screening tool. Chapter II includes a literature review that contains extensive research that helped to create this project. The literature review that was conducted includes findings from library databases, textbooks, and other educational materials to provide information on neglected education on sexual intimacy for individuals with a SCI, the psychological impact that a SCI has on an individual and their significant other, the occupational therapist's role in addressing this area, and information regarding the application of the PEO model, the IRM, and the ALLOW model. Chapter III then describes the methodology utilized in the creation of this product. Chapter IV contains the product of this research, the screening tool, which is intended for professionals to have an evidence-based tool to address sexual intimacy with clients and their significant other in order to enhance their overall quality of life and (re)engagement in sexual intimacy. Chapter V concludes this project with a brief summary, limitations and recommendations of the product, implications for future research, and information regarding implementation of this screening tool for future practice.

CHAPTER II

LITERATURE REVIEW

A spinal cord injury (SCI) is a traumatic, life-altering event that is typically associated with loss of motor and sensory function that impacts participation and engagement in sexual intimacy (Hess & Hough, 2012). According to the National Spinal Cord Injury Statistical Center (NSCISC) (2018), there are approximately 17,700 new SCI cases each year within the United States. The average age of onset is 43 years old, with 78% of cases occurring in males and the majority of injuries occuring between the ages of 16-30 years old, (NSCISC, 2018; Hattjar, 2012). The most common causes of injury involve motor vehicle accidents, work-related accidents, sporting/ recreation accidents, and falls (Hattjar, 2012). Injury to the spinal column can result in damage to the cervical, thoracic, lumbar, or sacral vertebrates, and can be considered either a complete or incomplete injury (Hattjar, 2012). Depending upon the level of severity, an individual may experience tetraplegia (impairment in motor or sensory function in the cervical area) or paraplegia (motor and sensory impairment at the thoracic, lumbar, or sacral areas of the spinal cord) (Hattjar, 2012).

After injury, individuals require skilled medical attention and therapy to regain and develop new skills that allow them to adapt to their new level of functioning. Throughout the rehabilitative process, sexuality is often overlooked until further down the road in recovery. Hess and Hough (2012) reported that grieving and working towards re-establishing one's life and self-meaning will take higher precedence during recovery, while the awareness and perception of sexuality often falls to a lower priority. Although addressing functional activities and regaining independence is a critical part of the rehabilitation process, placing more emphasis on sexuality with individuals post- SCI can also play a crucial role in promoting their overall quality of life

(Parker & Yau, 2012). Jörgensen, Hedgren, Sundelin, & Lexell (2019) reported that a majority of individuals with a SCI rated their sexual life with low satisfaction, whereas only 15% reported being satisfied.

Education on sexuality after a SCI is not adequately applied throughout the therapy process (Hess & Hough, 2012; Walker et al., 2020). Several other studies have shown that individuals that have experienced a SCI would like the topic of sexuality to be covered sooner in their rehabilitative experience so they would be better equipped to navigate the topic when they were emotionally ready (Alexander, Courtois, Elliott, & Tepper, 2017; New, Seddon, Redpath, Currie, & Warren, 2016; & Rodger, 2019). A person's sexual persona is a large part of their identity and must be rehabilitated along with their body (Hattjar, 2012; Walker et al., 2020). The ability to engage in sexual activities not only impacts their sexual intimacy, but also has an impact on the individual's psychological well-being and the relationship with their partner(s) (Walker et al., 2020).

Sexuality with a Spinal Cord Injury

Due to the trauma of a SCI, it is almost always a devastating event with various lifealtering implications and requires many adjustments throughout life post-injury. Sexual
adjustment to the SCI is an issue that is closely intertwined to body image, general psychological
health, self-esteem, and views of body attraction (Federici et al., 2019; Walker et al., 2020). The
intimate relationship between partners is more than having sex; it involves being able to express
feelings through open communication, touch, respect, and being psychologically turned on by
their partner (Hattjar, 2012). Individuals with a SCI and their partners will likely experience
anger, frustration, and lower sex drives which impact their relationships, both physically and
psychologically. Alexander et al. (2017) outlined various topics that should be addressed with

clients when discussing sexuality. Discussing communication styles/ approaches, sexual history, and education/ recommendations for exploration were all mentioned as being important to the client throughout their rehabilitation process (Alexander et al., 2017). Individuals with a SCI face many challenges physically which often results in sexuality and sexual health being overlooked during their rehabilitation process.

Psychological Impact

Psychosexual consequences following an injury may limit an individual's sexual engagement more than their physical disability (Thrussell, Coggrave, Graham, Gall, Donald, Kulshrestha, & Geddis, 2018). Zürcher, Tough, Fekete, and SwiSCI Study Group (2019), found that there is an increased risk for individuals with a SCI to develop a mental health disorder. A SCI requires an overall adjustment within the individual's context and impacts their ability to personalize life experiences (Hess & Hough, 2012). An individual who has sustained a SCI may experience depression and anxiety due to the impact of the injury on that individual's sense of identity, body image, self-esteem and sense of sexuality (Federici et al., 2019; Hess & Hough, 2012; Thrussell et al., 2018; Walker et al., 2020). The thoughts, feelings, and attitudes about disability will vary from person to person and may be influenced by certain personality features and aspects of their environment (Kim, M., Kim, S., & Choi, 2018). The person reaches acceptance through various stages after the disability and it is unique to each individual. Kim et al. (2018) found that individuals were able to improve their self-esteem and acceptance of their disability through efforts such as coping strategies, adaptations, and environmental changes.

Even after an injury occurs, individuals continue to identify themselves as sexual beings and consider sexual engagement as a critical component of their quality of life (Courtois, Alexander, & McLain, 2017; Thrussell et al., 2018). There is a significant impact on individuals'

sexuality due to the way they are now feeling about their bodies and the sexual capability of their new body (Salmani, Khoei, Aghajani, Bayat, 2019). Significant decrease in self-esteem and sense of value can lead to physical and emotional isolation, which will put the individuals' psychological well-being at risk (Hess & Hough, 2012). Individuals have to adapt to a different physical appearance, difficulties in social relationships, and the self-perception of negative social stigma (Parker & Yau, 2012). By addressing the specific psychological impacts on an individual's sexual adjustment post-injury, the ability to overcome these problems and engage in intimacy will be improved (Federici et al., 2019). However, the psychological impacts of a SCI not only directly affect the individual with the injury, but their significant other and should be taken into consideration as well.

Relationship Impact

More than half of individuals with a SCI are single/never married at the time of their injury (NSCISC, 2018). Despite this, the percentage of those married slightly increases over time, however, so do the divorce rates (NSCISC, 2018). Dating, developing new relationships, and maintaining relationships are meaningful life activities that become more challenging to individuals with a SCI (Hess & Hough, 2012). Parker and Yau (2012) found that participants with a SCI stated that it was more challenging to establish intimate relationships compared to before their injury.

Oftentimes spouses, as well as other family members, step up to take responsibility for the caregiving role (Jeyathevan, Cameron, Craven, Munce, & Jaglal, 2019). When spouses change their role from spouse to caregiver, there are challenges in the physical, psychological and social aspect of their relationship (Jeyathevan et al., 2019; Mohammed, 2017). This role change affects the dynamics of the relationship because providing constant care to individuals

can cause psychological distress for the partner (Jeyathevan et al., 2019). Intimacy can be affected by the spouse's role switching from sexual partner to caregiver and the amount of stress associated with caregiving (Hattjar, 2012). The constant provision of care also affects the ability for partners to connect intimately with the care recipient (Jeyathevan et al., 2019). "Several participants in romantic relationships mentioned they experienced loss of sex and intimacy postinjury" (Jeyathevan, et al., 2019, p. 6).

SCIs have many repercussions for aspects of a relationship regardless if it began pre- or post- injury. The individual with the SCI needs time to adjust to their abilities but so does the spouse, as they are also affected greatly by the injury (Kim et al., 2018). The spouses' characteristics can also facilitate moving beyond the negative aspects and help them to focus on positives aspects and coping strategies to move forward together. Both parties of the relationship must be willing to adjust their internal standards and values to accommodate for the realities of their lives after the injury occurs (Beaugard & Noreau, 2010). After a spouse experiences a SCI, there is often a lack of sexual engagement and intimacy that causes the separation between the couple (Parker & Yau, 2012). Individuals experience an internal battle with themselves when thinking about the longevity of their relationship with their partner, as well as being able to remain intimate (Salmani et al., 2019).

Communication in the relationship is essential and can foster both intimacy and closeness between partners (Hattjar, 2012). Being open and honest with willingness to express personal needs, wants, and desires will increase satisfaction not only with sex but also within the relationship as a whole. Engblom-Deglmann and Hamilton (2020) found that open communication around factors of the SCI and its impact, can play a role into greater emotional well-being and a higher sense of attachment, safety, and relationship health. If couples fail to

recognize the impact of the SCI, this can lead to feelings of shame and linked to behaviors that minimize emotional experiences and openness within the relationship (Engblom-Deglmann & Hamilton, 2020).

Role of Occupational Therapy

Current Interventions

The American Occupational Therapy Association has identified sexuality as an activity of daily living, which inherently establishes it as an important priority in rehabilitation medicine and adds to an individual's overall quality of life (Mohammed, 2017; Pieters, Kedde & Bender, 2018). Despite this, Mohammed (2017) reported that this area of practice is easily overlooked within the therapy process. Occupational therapists are fully equipped to assist their clients with SCIs to engage in sexual intimacy, as well as address both the physical and psychological effects of the injury. Individuals with a SCI experience many physical limitations, however, sexual intimacy does not always mean sexual intercourse but can encompass many variations of sexual expression (Walker et al., 2020). Intimacy refers to a trusting, accepting, emotional connection, whereas sexual intimacy refers to the couples' sexual connections (Engblom-Deglmann & Hamilton, 2020). Occupational therapists can provide useful information and education, psychotherapy, and the use of meaningful occupations and activities that promote socialization to address the sexual concerns that individuals with a SCI may have (Hess & Hough, 2012; Walker et al., 2020).

Therapeutic interventions will depend upon the age in which the injury occurs, developmental milestones and themes, an individual's culture, their sexual life experiences, and own personal perspectives (Hess & Hough, 2012). The severity and the level of SCI will also impact an individual's sexual response and guide which interventions are appropriate but does

not limit exploration of sexuality and intimacy (Hess & Hough, 2012; Mohammed, 2017). Individuals may be taught different strategies to help engage in sexual activity depending on which setting they are receiving services (i.e. acute, inpatient or outpatient rehabilitation). For example, in an acute rehabilitation setting, information is limited to compensatory strategies and does not fully address the needs of the population to engage in sexual activity (Hess & Hough, 2012). As the individual progresses in their rehabilitation, they may want to further address the challenges when engaging in sexual intimacy with their partners/ future partners.

There are many healthcare professionals within the rehabilitation team that play a key role in the education of a client post-SCI about changes to sexual health and/or intimacy, as well as strategies for adjusting to these changes (New et al., 2016). The multidisciplinary team involved often includes physicians, occupational therapists, physical therapists, psychologists, sexual therapists, nurses, social workers, and peer support workers (Pieters et al., 2018). Each discipline adds essential knowledge and perspective to the rehabilitation process and collaboration amongst the team is highly beneficial to meet the needs of clients post-SCI. Although the highlight of this project is in regard to the role of occupational therapists, it is important to recognize they will rarely be working alone when addressing sexual intimacy with their clients. Adequate education, psychological support, and partner involvement in discussions related to sexuality during the rehabilitative process are essential to facilitate successful participation in sexual activities after a SCI.

Psychosocial Impact on Relationships

There are many underlying issues that are closely intertwined with sexual intimacy that need to be addressed prior to successful engagement. As previously stated, SCIs can negatively impact individuals' self-confidence and self-esteem because of not knowing what their new body

is sexually capable of (Salmani et al., 2019; Thrussell et al., 2018). Low confidence can affect an individual's relationship with their partner because of a loss of intimacy and sex after they have been injured (Jeyathevan et al., 2019; Kim et al., 2018). Along with the lack of knowledge about sexual capabilities, there is also the possibility of depression and anxiety that the individual may experience (Hess & Hough, 2012).

Occupational therapists can address these psychological concerns that the individual is having to increase confidence in themselves, as well as enhance their quality of life by providing services to fit their needs. Occupational therapists who work in rehabilitation centers will support couples with SCI's to help to address the impact of the injury on the intimate aspect of their relationship and sexual functioning (Salmani et al., 2019). Therapy sessions can be modified first to provide educational groups and rehabilitative activities that are gender-specific (Thrussell et al., 2018). In these group sessions, occupational therapists can help individuals address social intimacy by working on communication and social skills to improve self-confidence and selfesteem when they are talking to friends and partners (Thrussell et al., 2018). As individuals become more comfortable discussing their sexuality, they may work with the therapist while including their partner to enhance their knowledge of their sexual capabilities (Thrussell et al., 2018). Inclusion of the sexual partner within the rehabilitation process has shown to increase sexual satisfaction and intimacy within relationships affected by a SCI (Beauregard & Noreau, 2010; Engblom-Deglmann & Hamilton, 2020; Federici et al., 2019; Kim et al., 2018; New et al., 2016; & Rodger, 2019).

Another aspect that occupational therapists are able to address with clients is the effect their injury has on relationship roles and routines within the home. Beauregard and Noreau (2010) explored couples' adaptive responses to housework, leisure activities, and the new role

demands/ expectations that are shaped by the injury. Accepting help and dividing up the homemaking tasks more evenly between each spouse (dependent upon the level of injury) can reduce the feelings of burden and allow more time for the couple to explore opportunities for intimacy to strengthen that aspect of their relationship. Acceptance of these new role demands and the couples' ability to adapt and communicate has a direct correlation with their relationship satisfaction and sexual engagement (Engblom-Deglmann & Hamilton, 2020). Occupational therapists may utilize Cognitive Behavioral Therapy (CBT) techniques to address the misconceptions and negative myths about sexuality and disability, sexual identity, and ideas of beauty and attractiveness of the body to identify how the negative thoughts are impacting the individuals' sexual behavior and involvement in intimacy. Identification of dysfunctional patterns plays a major role in overcoming the obstacles for intimacy and moving forward towards a healthier relationship with their partner(s) (Federici et al., 2019). Exploring the impact of injury on the couples' psychological well-being, in conjunction with the physical challenges they face, can help to promote a more positive sexual relationship for both partners.

Adaptive Equipment & Positioning

There are a variety of adaptive equipment and positioning options available for individuals with limited grasp, strength, and range of motion in their joints. Individuals with a SCI who have minimal function of their hands have the opportunity to be assessed for assistive devices (Hess & Hough, 2012). The equipment recommended for poor grasp and strength are often straps to hold sexual toys in place, as well as prescribed custom wrist splints (Hess & Hough, 2012). Individuals may also utilize Velcro straps to hold the sexual equipment on themselves in the absence of functional arm capability (Hess & Hough, 2012). Another adaptive strategy that may be useful to engage pelvic floor muscles for intimacy are perineal training

exercises. For men with some voluntary control of these muscles, these exercises can improve penile function and rigidity (Hess & Hough, 2012).

There are numerous positions and equipment that clients can explore to facilitate engagement in sexual activity. Individuals with a SCI experience limitations in hip extension, abduction, and external rotation, which can impact stimulation. Various positions that do not require these movements can facilitate greater pleasure and reduce other components that negatively affect intimacy such as muscle spasms, spasticity, contractures, and pain (Hess & Hough, 2012). Use of pillows, wedges, and/or bolsters under the individual's pelvis and legs can minimize the stretch of spastic muscles and allow for more comfortable positions (Hattjar, 2012; Hess & Hough, 2012). Utilization of the headboard to prop the client upright may also provide stabilization of core muscles for individuals with paraplegia and allow them and their partner to look at one another (Hattjar, 2012). Other positions may include "being on the bottom", sitting in a wheelchair, or side-lying (Hattjar, 2012). Pillows can be placed between the knees to prevent rubbing and skin breakdown in either the supine or side-lying position (Hess & Hough, 2012). Occupational therapists can encourage and educate clients to explore a variety of options that satisfy the sexual needs of both parties involved.

Model

Person-Environment-Occupation Model

The creation of this product was guided by the Person-Environment-Occupation (PEO) Model. PEO is an interdisciplinary model that focuses on the interactions of the person, environment and occupation (Law, Cooper, Strong, Stewart, Rigby, & Letts, 1996). PEO recognizes the impact that each component has on the individual's ability to engage in occupations, as well as their occupational performance (Law et al., 1996). In this case, the

occupational performance is referring to the individual's ability to engage in sexual intimacy, as well as the quality to which they are able to perform the occupation.

The Let's Talk About Sex (LTAS) Screening Tool was developed by categorizing statements in areas of Person x Environment, Person x Occupation, and Environment x Occupation. Through the lens of this model, the therapist can identify which components (person, environment, or occupation) are inhibiting the client from successfully engaging in sexual intimacy. More specifically, the therapist will look at the physical, cognitive, affective, and sensory aspects of each client (Law et al., 1996). Along with these specific aspects of the person, the model also assesses the physical, social, and cultural environments that may have an impact on the clients' performance (Law et al., 1996). According to Law et al. (1996), occupations consist of activities and tasks in which a person engages, in order to meet intrinsic needs for self-maintenance, expression and/or fulfillment. Through this model, an occupational therapist is able to analyze the transactions between the three components and understand the impact each transaction has on an individual's occupational performance, specifically engagement in sexual intimacy.

The Intentional Relationship Model

The Intentional Relationship Model (IRM) also influenced the development of the *LTAS Screening Tool*. This model was chosen because it recognizes and anticipates interpersonal events that occur throughout the therapeutic process between the therapist and client and assists therapists in appropriately addressing their clients' concerns. Literature has identified high rates of discomfort when discussing sexual intimacy due to the sensitive nature of the topic (Rodger, 2019). In order to build rapport and create a positive environment for the conversation, it is important for the therapist to utilize therapeutic use of self. Therapeutic use of self allows the

therapist to manage the therapeutic relationship with clients by using professional reasoning, empathy, and a client-centered, collaborative approach (AOTA, 2020).

The IRM also highlights that interpersonal events are naturally occurring events that have the potential to negatively impact the therapeutic relationship (Taylor, 2008). An occupational therapist may navigate these inevitable events through the use of their therapeutic use of self as well as by anticipating, identifying, and using different therapeutic modes when an incident occurs (Taylor, 2008). The therapist will use therapeutic use of self to decide when to initiate the conversation of sexual intimacy. Once the conversation regarding sexual intimacy has been initiated, the therapist can use the lens of the IRM and its components to guide them through the events that take place. The *LTAS Screening Tool* will also provide a framework for deciding the next steps of their clients' rehabilitation journey.

ALLOW Model

There are few existing models that directly address sexuality within the rehabilitation process, a few of which are the PLISSIT, the Ex-PLISSIT, and the ALLOW models. "PLISSIT stands for Permission to discuss sexuality, provision of Limited Information regarding sexuality, Specific Suggestions regarding the person's sexual issues, and Intensive Therapy with an expert when needed" (Dune, 2012, p. 249). The major difference between PLISSIT and Ex-PLISSIT is that the latter was created to be more cyclical in nature rather than the linear style of the original PLISSIT model (Mohammed, 2017). Both models generate the conversation regarding sexual intimacy, however it is unclear whether the approach be used in the rehabilitation process or upon the initiation of discussion from either the client or the healthcare worker (Dune, 2012). This generates confusion amongst all parties involved, which may impede the client's access to sexual health information. To limit this from continuing to occur within healthcare, key

components of the ALLOW model influenced the creation and design of the *LTAS Screening Tool*.

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</u> collectively in or to develop a treatment plan. (Dune, 2012, p. 251)

This model encourages the topic of sexuality to be initiated by the healthcare worker rather than placing the responsibility on the clients. Oftentimes, sexuality is not brought up due to the clients' discomfort and worry of how their healthcare provider may react (Rodger, 2019). By requiring healthcare providers to address the topic, it opens the door for communication throughout the rehabilitation phase and ensures that all of the clients' needs will be met. Another important aspect of the ALLOW model is the referral to a sexual health specialist (Dune, 2012). A multidisciplinary approach facilitates collaboration across professions to provide the best possible care for each client. The emphasis on collaboration between provider and client to develop a treatment plan that is individualized allows for a holistic and successful approach to the rehabilitation process. Utilizing the ALLOW model in conjunction with PEO and the IRM to develop a screening tool will ensure all aspects of the client and their needs are being met.

Summary and Conclusion

Overall, studies have shown a large gap in addressing sexual rehabilitation within healthcare and across the rehabilitation process (Hess & Hough, 2012). Individuals with SCIs are constantly evolving in their readiness to address sexual intimacy and functioning. Additionally, opportunities to discuss the ramifications of their injury should be provided throughout their

recovery and tailored to their particular needs (Hess & Hough, 2012). Previous research on intervention has primarily focused on the physical aspects of SCIs and engagement in sexual intimacy with less focus on the psychological impairments and impact on intimate relationships. Despite these limitations, there are studies showing the positive impact of incorporating the significant others of individuals with SCIs into the rehabilitation process (Rodger, 2019; Thrussell et al., 2018). There is also a need to increase healthcare provider comfort in the provision of education during screening, assessment and intervention (Hess & Hough, 2012). Addressing sexuality as a relationship with one's self and with others is a direction for best clinical practice and enhancement of rehabilitation outcomes (Hess & Hough, 2012). Occupational therapy is well-equipped to provide a holistic approach to this population in regard to sexuality, a specific area of occupation.

In order to address this issue through the occupational therapy perspective, a clinical screening tool has been created. Through the guidance of the ALLOW model, PEO model, and IRM, this screening tool consists of questions/ statements including how to initiate the conversation relating to sexual engagement, how to identify when clients would prefer to begin these discussions, the psychological aspects of a SCI towards sexual satisfaction, the psychological impacts of relationships, as well as resources for communicating with other healthcare professions to work as a collaborative team with clients who have a SCI. It is anticipated that, with this screening tool, occupational therapists will provide more client-centered practice by increasing the comfort and trust with their clients when initiating the discussion surrounding sexual engagement and satisfaction following a SCI. Through the information allowed, clients with a SCI will be able to enhance their overall quality of life and, in turn, improve their sexual satisfaction and intimacy with their significant others.

CHAPTER III

METHODOLOGY

An extensive literature review was conducted prior to creating the *Let's Talk About Sex* (*LTAS*) Screening Tool to gain a better understanding as to how sexuality is addressed throughout the rehabilitation process for individuals with a spinal cord injury (SCI). The authors of this project sought specifically to identify barriers that individuals and their significant others experience post-SCI including the psychological barriers, as well as the overall impact the injury has on the relationship. Research was conducted across various disciplines to gather information about previous and current interventions utilized with this population.

The literature review was completed on multiple databases on the University of North Dakota's School of Medicine and Health Sciences including CINAHL Complete, PubMed, ClinicalKey, AJOT, and Google Scholar. Key terms used within the research included partner, relationship, marriage, couple, dating, sexual intimacy, sexual health, sexuality, sexual activity, spinal cord injury, and occupational therapy. Articles were selected for review based on their relevance to the topic. The authors organized data within the literature review by first creating an outline and then adding pertinent information from each article under each of the headings and subheadings. Additional evidence was sought out from other literature sources, textbooks, and databases to further highlight the gap in research and support the need to address sexual intimacy with individuals post-SCI.

The literature revealed that although there are models in place (i.e. ALLOW, PLISSIT, Ex-PLISSIT), there are no specific screening or assessment tools utilized by occupational therapy (OT) practitioners to guide them when working with individuals with a SCI to address sexual intimacy. Many individuals with a SCI (and their significant others) either felt

uncomfortable to address the issue with their healthcare provider and/or reported that sexual intimacy was not discussed at a time when they felt ready (Rodger, 2019 & Thrussell et al., 2018). This gap in literature led the authors to create the product included in this manual, a screening tool for practitioners, to guide them in addressing sexual intimacy at various stages of rehabilitation to ensure the clients' needs are being met at a time they feel most comfortable. Utilizing a screening tool at each stage of recovery will increase the comfort and trust within the client-therapist relationship and allow individuals to engage in discussion and intervention regarding sexual engagement and satisfaction when they are ready. The screening tool was created through the guidance of concepts within the ALLOW model, Person-Environment Occupation (PEO), and the Intentional Relationship Model (IRM), and content based on the findings of the literature review.

The models previously listed were chosen to create a relevant and holistic approach to minimize the gap in literature for the identified population. PEO provided an occupation-based lens for the screening tool, while the ALLOW model and IRM offered guidance for incorporating sexual intimacy information relevant to both the client and their significant other through therapeutic use of self by the administrator. The main purpose in developing the screening tool was to provide healthcare workers, specifically occupational therapists, with an evidence-based resource to address sexual intimacy with clients post-SCI and their significant other at various stages of the rehabilitation process. Statements included on each screening tool focus on how to initiate the conversation regarding sexual engagement and satisfaction, client preference and timing to address sexuality, psychological impacts experienced since the SCI and the impact of injury on their sexual relationships. An anticipated benefit to utilizing the *LTAS Screening Tool* in practice, is the empowerment of clients to address the topic on their terms

throughout their rehabilitation and to address not only the physical limitations of their injury but also the psychological impact. Additionally, the tool highlights the importance of considering each individuals' circumstances, their readiness to discuss a sensitive topic, and ensure client-centered care is being implemented throughout all stages of the therapeutic process.

CHAPTER IV PRODUCT

Let's Talk About Sex Screening Tool User Manual

Overview

This screening tool was designed to address sexual intimacy throughout the rehabilitation process for individuals who have had a spinal cord injury (SCI). This tool acts as a guide and provides questions for occupational therapy practitioners to initiate the conversation regarding sexual participation within the rehabilitation process. Specifically, the psychological aspects will be addressed and the impact they have on engaging in sexual intimacy. Results of the screening tool can be utilized as a justification for referral to a specialized service, assist in creating goals/interventions for occupational therapy and/or notify clients of the various services available that can address their physical and psychological needs to successfully engage in sexual activity.

Development of Tool

This tool was developed by Michelle Arnhalt, MOTS and Taylor Beatty, MOTS as a product of their literature review concerning individuals impacted by a SCI. By conducting a literature review and discussing the needs of this population in comparison with resources and help provided by healthcare providers, the authors established a list of statements to include in the screening tool. A four-point Likert-type scale was chosen as a measure for administrators to ensure accurate representations are scored. The four-point scale also eliminates an odd number score in which individuals could depict as neutral. This could act as a default answer which would provide limited information.

Population

The screening tool was created for use with individuals who have experienced a SCI and are 16 years of age or older. These parameters were chosen as the majority of SCIs occur as early as the age of 16, and throughout middle-late adulthood (NSCISC, 2018; Hattjar, 2012). Although the focus of the screening tool was for individuals who have a SCI, the statements are not specific to this population. As a result, this tool could be used with any individual who has an injury that is impacting their ability to be sexually intimate.

Theory Implementation and Components of the Screening Tool

The creation of the *Let's Talk About Sex (LTAS) Screening Tool* was guided by the ALLOW Model, the occupation-based model Person-Environment-Occupation (PEO), and the Intentional Relationship Model (IRM). Each of these models bring a unique aspect to the tool and generate a holistic lens for the occupational therapist to approach the topic of sexuality with their clients.

The ALLOW Model

The ALLOW model encourages the topic of sexuality to be initiated by the healthcare worker, rather than the client (Dune, 2012). 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 or to develop a treatment plan (Dune, 2012, p 251).

The first section of the screening tool follows the ALLOW model in that it is a resource for healthcare professionals to use when addressing the topic. Providing a screening tool guided by ALLOW, will help to address sexual intimacy in each phase of the rehabilitation process more consistently. By having the conversation initiated by the healthcare professional, the pressure is taken off the client. This creates a more comfortable environment for the client to discuss their questions, comments, and/or concerns regarding sexual intimacy following their SCI.

Person-Environment-Occupation Model

The organization of statements included on the screening tool was influenced by the PEO model. The authors categorized statements based off of transactions that occur between the three main components. The tool recognizes that the interactions between the three main components of the model (person, environment and occupation) influence an individuals' ability to engage in sexual intimacy, as well as the quality to which they are able to perform this specific area of occupation. This allows the healthcare professional to narrow down which aspect is inhibiting the client from successful engagement in sexual intimacy.

Person: A person is a unique being who can assume many roles simultaneously and who can engage in activities and occupations that are needed and desired (Law et al., 1996).

- Physical: Relating to the movement, range of motion, strength, and tone of a person (Baptiste, 2017).
- Cognitive: Relating to the thought, memory, reasoning, and judgement components of a person (Baptiste, 2017).
- Sensory: Refers to an individual's touch, smell, sight, and hearing (Baptiste, 2017).
- Affective: An individual's emotion and mood (Baptiste, 2017).

Environment: The environment is considered the sum total of what surrounds a person and includes physical, social and cultural components (Law et al., 1996).

- Physical: Natural, living things that surround a person, including things that are built (Baptiste, 2017).
- Social: Primary and secondary groups such as family, teams, and intimate partners (Baptiste, 2017).
- Cultural: Rituals and rites, costumes, special food, and behavioral expectations (Baptiste, 2017).

<u>Occupation</u>: Occupations may provide a sense of fulfillment and social connectedness, bring joy and satisfaction, be purposeful, give meaning, and enable self-expression (Law et al., 1996). Specific areas of occupation are defined below as related to sexual intimacy.

- Activities of Daily Living (ADLs)
 - Sexual activity: "Engaging in the broad possibilities for sexual expression and experiences with self or others (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)" (AOTA, 2020).
- Health Management
 - "Procuring, using, cleaning, and maintaining personal care devices such as contraceptives and sexual devices" (AOTA, 2020).
- Social Participation
 - "Engaging in activities to initiate and maintain a close relationship, including giving and receiving affection and interacting in desired roles; intimate partners may or may not engage in sexual activity" (AOTA, 2020).

The Intentional Relationship Model

The IRM is also incorporated into the use of the LTAS Screening Tool. The intended incorporation of the IRM in the LTAS Screening Tool is to help guide the therapist into deciding when/if to include a significant other in the therapy process by utilizing therapeutic use of self. The IRM highlights that an interpersonal event is a naturally occurring communication, reaction, process, task, or general circumstance that occurs during therapy and has potential to negatively impact the therapeutic relationship (Taylor, 2008). It is important for the therapist to utilize therapeutic use of self to help manage the therapeutic relationship with clients by using professional reasoning, empathy, and a client-centered, collaborative approach (American Occupational Therapy Association [AOTA], 2020). Therapists can address these circumstances by anticipating inevitable events, identifying and coping, and then determining if a mode shift is required to be able to work with the client (Taylor, 2008). The interpersonal events that are most anticipated for this topic and population is the expression of strong emotion and intimate selfdisclosure. When, or if, this occurs, the therapist can redirect the client to the screening tool or ask if the client would wish to have their significant other involved in therapy. To include the significant other in the process, the therapist can provide them with the LTAS Significant Other (SO) Screening Tool, to identify their feelings on how the injury has impacted their relationship. Once the screening tools are completed, the therapist can identify the overall needs of the client and their significant other to choose the correct profession that would best address their needs.

Administration and Interpreting Results

Intended administrators of the *LTAS Screening Tool* are occupational therapists, occupational therapy assistants and occupational therapy students. Occupational therapy practitioners were chosen to administer the tool due to their holistic approach regarding the needs of the SCI population, as well as their enhanced clinical reasoning skills and areas of expertise that relate to the topic of sexual participation. The administrator is expected to understand the manual and the various levels of SCI and how it may impact participation in sexual intimacy, either physically or psychologically. Completing the *LTAS Screening Tool* is expected to take 5-10 minutes.

After completing the screen, the administrator will analyze the results to determine which component/transaction is inhibiting successful sexual participation. To analyze the results, the administrator will summarize the three sections of the screening tool separately (PxO, PxE, ExO). Based on each summary, the administrator will be able to identify what is currently inhibiting the client and their significant other from participating in successful sexual activities. The administrator is then expected to make appropriate referrals to other healthcare providers in order to address each clients' needs and assist in creating a specific plan of action.

Conclusion/Closure of Information

The purpose of the *LTAS Screening Tool* is to provide a tool for professionals to use when addressing sexual intimacy with clients who have sustained a SCI. It is meant to benefit clients and their significant others going through the rehabilitation process after a traumatic injury to address psychological aspects of sexual intimacy. Through the guidance of the ALLOW model, PEO model, and IRM, this screening tool consists of questions for how to initiate conversation relating to sexual engagement, how to identify when clients would prefer to begin discussions about sexual engagement, psychological aspects of a SCI towards sexual satisfaction,

psychological impacts of relationships, and communicating with other healthcare professions to work as a collaborative team with clients who have a SCI. It is anticipated that, with this screening tool, occupational therapists will provide more client-centered practice by increasing the comfort and trust in clients when initiating the discussion about sexual engagement and satisfaction with a SCI throughout all phases of the clients' rehabilitative process.

Let's Talk About Sex Screening Tool SECTION I - CLIENT BACKGROUND INFORMATION

AGE:	DATE:							
LEVEL OF INJU	URY:							
MONTHS/ YEARS SINCE INJURY:								
CURRENT PHYSICAL CONCERNS:								
CURRENT PSYCHOLOGICAL CONCERNS:								
SEXUAL PARTICIPATION STATUS:								
CURRENT/PREVIOUS SERVICES USED:								
I WOULD LIKE	TO ADDRESS S	SEXUAL PARTI	CIPATION AT	THIS TIME:				
	Yes		No					
IF NO, PLEASE ADDRESS SEXUAL PARTICIPATION AGAIN IN:								
1 Month	3 Months	6 Months	1 Year	Other:				
IF YES, PLEASE COMPLETE SECTION II.								

Let's Talk About Sex Screening Tool SECTION II - CLIENT FORM

Purpose

The purpose of this screening tool is to address sexual intimacy throughout all phases of the rehabilitation process for individuals who have had a spinal cord injury (SCI). Specifically, the psychological aspects will be addressed and the impact it has on engaging in sexual intimacy.

Occupational Therapy's Role

Occupational therapy (OT) services are provided for habilitative, rehabilitative, and the promotion of health and wellness for clients with and without disability-related needs (AOTA, 2020). When the client's wants, needs, and/or occupational identity is at risk, the occupational therapy practitioner gathers information and analyzes it from an occupational perspective. OT addresses various areas of occupation including activities of daily living, instrumental activities of daily living, sleep, work, education, leisure, play, and social participation. Sexual activity is one specific component within the occupation of activities of daily living. As stated by the Occupational Therapy Practice Framework- 4th Edition (2020), sexual activity is defined as "engaging in the broad possibilities for sexual expression and experiences with self or others (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)". OT can help to address not only the physical aspects, but also the psychological impacts that an injury or illness may have on participation in sexual activity. OT can assist with developing coping strategies, communication, role demands, etc. in order to facilitate and promote an individual's comfort to (re-)engage in sexual activities with their partner. As with all health care, addressing this topic will require the specialty services of other health care professionals such as physicians, sex therapists, counselors, physical therapists, urologists, etc., OT will work alongside many of these professionals to provide a holistic approach that further targets the specific needs of the client.

Instructions

Please fill out each area of the screening tool below to the best of your ability. You may leave a statement blank if it is not applicable.

Client Form	Strongly Disagree 1	Somewhat Disagree 2	Somewhat Agree 3	Strongly Agree 4				
Person x Occupation								
I am satisfied with my sexual participation.								
My self-esteem influences my sexual participation.								
I am confident in my ability to be intimate.								
I utilize coping strategies to manage stress/ frustrations that stem from my injury.								
I have explored different types of intimacy other than intercourse since my injury.								
I feel motivated to engage in sexual participation.								
Person x Environment								
My partner is my main caregiver.								
My injury impacts my relationship.								
My partner understands my current level of abilities.								
I am confident in my ability to develop new relationships.								
Environment x Occupation								
My physical surroundings impact my ability to be sexually intimate.								
My injury impacts my ability to be intimate with a partner.								
I utilize adaptive equipment to engage in sexual activities.								
My partner is supportive during intimacy.								

Let's Talk About Sex Screening Tool SECTION III - SIGNIFICANT OTHER FORM

Purpose

The purpose of this screening tool is to address sexual intimacy throughout all phases of the rehabilitation process for individuals who have had a spinal cord injury (SCI). Specifically, the psychosocial aspects will be addressed and the impact it has on engaging in sexual intimacy.

Occupational Therapy's Role

Occupational therapy (OT) services are provided for habilitative, rehabilitative, and the promotion of health and wellness for clients with and without disability-related needs (AOTA, 2020). When the client's wants, needs, and/or occupational identity is at risk, the occupational therapy practitioner gathers information and analyzes it from an occupational perspective. OT addresses various areas of occupation including activities of daily living, instrumental activities of daily living, sleep, work, education, leisure, play, and social participation. Sexual activity is one specific component within the occupation of activities of daily living. As stated by the Occupational Therapy Practice Framework- 4th Edition (2020), sexual activity is defined as "engaging in the broad possibilities for sexual expression and experiences with self or others (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)". OT can help to address not only the physical aspects, but also the psychological impacts that an injury or illness may have on participation in sexual activity. OT can assist with developing coping strategies, communication, role demands, etc. in order to facilitate and promote an individual's comfort to (re-)engage in sexual activities with their partner. As with all health care, addressing this topic will require the specialty services of other health care professionals such as physicians, sex therapists, counselors, physical therapists, urologists, etc., OT will work alongside many of these professionals to provide a holistic approach that further targets the specific needs of the client.

Instructions

Please fill out each area of the screening tool below to the best of your ability. You may leave a statement blank if it is not applicable.

Significant Other Form	Strongly Disagree 1	Somewhat Disagree 2	Somewhat Agree 3	Strongly Agree 4	
Person x Occupation					
I am satisfied with my sexual participation.					
I am motivated to educate myself regarding options for sexual intimacy with my partner.					
I am confident in my ability to be intimate with my partner.					
I utilize coping strategies to manage stress/ frustrations that stem from my partner's injury.					
I have explored different types of intimacy with my partner since their injury.					
Person x Environment					
I am the main caregiver for my partner.					
I have outside assistance to help care for my partner.					
I understand my partner's current level of abilities.					
My partner's injury impacts our relationship.					
Environment x Occupation					
My physical surroundings impact my ability to be sexually intimate.					
My partner's injury impacts their ability to be intimate with me.					
My partner and I utilize adaptive equipment to engage in sexual activities.					

Let's Talk About Sex Screening Tool SECTION IV - REFERRALS AND CONTINUATION OF SERVICES

Many healthcare disciplines are commonly involved in the rehabilitation process for an individual following an injury. Dependent upon the results of the *LTAS Screening Tool*, the occupational therapy practitioner may need to refer their client to a more specialized healthcare professional that can further address their needs regarding sexual intimacy. This section outlines the various disciplines that may be involved in the recovery process after a SCI and their specific role for promoting successful engagement in sexual activity.

Appendix A contains two case study examples that explain the application of the *LTAS* Screening Tool with a client and their significant other, as well as the referral process following completion of the screening tool. Step Four in each case study specifically highlights the component of the ALLOW model that incorporates making appropriate referrals to other professions (Open discussions about sexual issues for assessment and the provision of referrals to a specialist).

OCCUPATIONAL THERAPY:

OT services are provided for habilitative, rehabilitative, and the promotion of health and wellness for clients with and without disability-related needs (AOTA, 2020). When the client's wants, needs, and/or occupational identity is at risk, the occupational therapist gathers information and analyzes it from an occupational perspective. OT addresses various areas of occupation including activities of daily living, instrumental activities of daily living, sleep, work, education, leisure, play, and social participation (AOTA, 2020). OT's can help address physical and psychosocial aspects that an injury or illness may cause. Sexual activity is one specific component within the occupation of activities of daily living. More specifically, they can provide coping strategies, role demands, routine adjustments, environmental modification recommendations, and communication strategies to facilitate an individual's participation in sexual activities with their partner.

PHYSICAL MEDICINE AND REHABILITATION:

Physical Medicine and Rehabilitation (PM&R) physicians practice in a variety of clinical settings with a broad range of knowledge including musculoskeletal, neurological, rheumatological, and cardiovascular systems (American Academy of Physical Medicine and Rehabilitation [AAPM&R], 2020). They are trained using collaborative team skills and work with a variety of disciplines within their treatment facilities. SCI is one of the more common diagnoses and populations seen by PM&R physicians. PM&R physicians are skilled in managing conditions such as spine-related pain and dysfunction, neurogenic bowel/bladder, pressure sore management, spasticity management, and chronic pain (AAPM&R, 2020). Each of these are critical components that must be addressed and managed in clients with a SCI in order to safely and effectively engage in sexual activities. PM&R may also assist with family planning for their client and significant other.

NURSING:

Nursing care is critical, especially, in the early stages of recovery for a client following a SCI. Nursing can prevent further injury and promote the best possible client outcomes. Focus of care

may include, but is not limited to, maintaining stable blood pressures, monitoring cardiovascular function, ensuring adequate ventilation and lung function, and preventing and/or promptly addressing any infection or other complications (Bauman & Russo-McCourt, 2016). Nursing can provide education to both the client and their significant other regarding medications, physiological responses, bowel/ bladder management, and any other factors that may be impacting a client from participating in sexual activities (Bauman & Russo-McCourt, 2016).

UROLOGY:

Urologists specialize in treating conditions of the male and female urinary tract, which includes organs such as the bladder, kidneys, ureters, and urethra (MedicineNet, 2016). They will help to address pain during intercourse, trouble achieving or maintaining an erection, erectile dysfunction, or weak pelvic floor muscles (MedicineNet, 2016). The urologist will also assist in establishing an effective bowel/bladder program to minimize challenges during sexual intimacy.

PHYSICAL THERAPY:

Physical therapists treat a variety of problems related to a SCI including musculoskeletal, neurological, and orthopedic. They are trained in rehabilitation interventions to facilitate increased range of motion, strength, and stability following the client's injury (Physiopedia, 2020). Physical therapists can provide education regarding positioning, exercises, stretches, etc. that may assist their client to successfully engage in sexual intimacy (Physiopedia, 2020).

NEUROPSYCHOLOGY:

A neuropsychologist is a specialized psychologist who looks into the relationship between the physical brain and behavior (De Pietro, 2017). Neuropsychologists evaluate and treat individuals who have nervous system disorders that can affect the way a person feels, thinks, and/or behaves (De Pietro, 2017). They can help to determine what impairments a patient has, how severe they are, as well as determine a diagnosis. To determine a diagnosis, they can administer a neuropsychological evaluation to see if memory, cognitive ability, personality, problem-solving, reasoning, emotions, and personality have been affected due to the illness/injury (De Pietro, 2017). Following a SCI, an individual may experience a variety of feelings regarding their new level of abilities and the impact on their daily life, including sexual intimacy. A neuropsychology evaluation and treatment may benefit a client and/or their significant other to work through and understand their diagnosis.

SEX THERAPY:

Sex therapists address concerns about sexual function, sexual feelings and intimacy (Mayo Clinic, 2019). Sex therapy can help individuals work on issues such as: concerns about sexual desire or arousal, concerns about sexual interests, erectile functioning concerns, difficulty with sexual arousal, trouble reaching orgasm, painful intercourse, and intimacy issues related to a disability or condition (Mayo Clinic, 2019). This type of therapy will help clients learn how to express their concerns regarding sexual needs and activity, as well as their significant others' sexual needs (Mayo Clinic, 2019). The main type of therapy strategies used during these appointments is communication.

SOCIAL WORK:

Social workers provide services including both counseling and identification of available resources within the community. A social worker can assist their clients with a SCI with coping emotionally and adjusting to the effects of the injury, ensure proper supports are in place, exploring different ways of solving problems, dealing with changes in relationships, discuss concerns related to sexual health, and assist with future planning (Epstein, 2015).

Appendix A

CASE STUDY APPLICATION

Case study examples are provided below to guide the administrator of the *LTAS Screening Tool* through scenarios as to when/how to utilize the tool with clients. Each step of the process will be laid out step-by-step to foster a better understanding of how the tool can be implemented to facilitate a holistic approach to the rehabilitation journey.

CASE ONE: JESSIE

Jessie is a 30-year-old female who suffered a T6-7 fracture and was deemed an incomplete paraplegia. She has a spouse, Sophie, who she lives with. Jessie currently receives OT and PT 3 days a week to work on normal upper-body movement to participate in ADLs and walking in a standing frame. Jessie was asked about sexual interest/engagement during inpatient care but states she does not remember being asked. Documentation shows that she is to be asked again about sexual engagement when transitioning to an outpatient program for OT. Although the outpatient program focuses on increasing independence in ADL's by building strength, and using aides for independent function, the therapist noticed Jessie making statements regarding sexual intimacy.

STEP 1: Ask & Legitimize clients' concerns

Discuss the purpose of the *LTAS Screening Tool* with the client and **administer** Sections I-III. Acknowledge clients' concerns regarding sexual activity and function.

Application: The completed charts for Jessie and Sophie are provided below as reference for the remaining case application steps.

SECTION I - CLIENT BACKGROUND INFORMATION

NAME: Jessie K.

AGE: 30 DATE: 12/14/2020 LEVEL OF INJURY: T6-7 MONTHS/ YEARS SINCE INJURY: 1.5 years CURRENT PHYSICAL CONCERNS: Being strong enough to complete ADLs CURRENT PSYCHOLOGICAL CONCERNS: Having partner as primary caregiver, managing stress related to sexual intimacy SEXUAL PARTICIPATION STATUS: Lives with spouse, Sophie. CURRENT/PREVIOUS SERVICES USED: Acute therapy in the hospital following injury I WOULD LIKE TO ADDRESS SEXUAL PARTICIPATION AT THIS TIME: Yes No IF NO, PLEASE ADDRESS SEXUAL PARTICIPATION AGAIN IN: 1 Month 3 Months 6 Months 1 Year Other: IF YES, PLEASE COMPLETE SECTION II.

SECTION II - CLIENT FORM (JESSIE)

Client Form	Strongly Disagree 1	Somewhat Disagree 2	Somewhat Agree 3	Strongly Agree 4	
Person x Occupation					
I am satisfied with my sexual participation.	X				
My self-esteem influences my sexual participation.			X		
I am confident in my ability to be intimate.		X			
I utilize coping strategies to manage stress/ frustrations that stem from my injury.		X			
I have explored different types of intimacy other than intercourse since my injury.		X			
I feel motivated to engage in sexual participation.			X		
Pers	on x Environme	ent			
My partner is my main caregiver.				X	
My injury impacts my relationship.				X	
My partner understands my current level of abilities.			X		
I am confident in my ability to develop new relationships.	X				
Enviro	nment x Occup	ation			
My physical surroundings impact my ability to be sexually intimate.			X		
My injury impacts my ability to be intimate with a partner.				X	
I utilize adaptive equipment to engage in sexual activities.		X			
My partner is supportive during intimacy.			X		

SECTION III - SIGNIFICANT OTHER FORM (SOPHIE)

Significant Other Form	Strongly Disagree 1	Somewhat Disagree 2	Somewhat Agree 3	Strongly Agree	
Pers	son x Occupation	on			
I am satisfied with my sexual participation.		X			
I am motivated to educate myself regarding options for sexual intimacy with my partner.				X	
I am confident in my ability to be intimate with my partner.				X	
I utilize coping strategies to manage stress/ frustrations that stem from my partner's injury.			X		
I have explored different types of intimacy with my partner since their injury.		X			
Perso	on x Environme	ent			
I am the main caregiver for my partner.				X	
I have outside assistance to help care for my partner.	X				
I understand my partner's current level of abilities.			X		
My partner's injury impacts our relationship.			X		
Environment x Occupation					
My physical surroundings impact my ability to be sexually intimate.		X			
My partner's injury impacts their ability to be intimate with me.			X		
My partner and I utilize adaptive equipment to engage in sexual activities.		X			

STEP 2: Limitations in knowledge

After completing the form, the OT will **analyze the results to identify problem areas** that may be impacting the client's performance.

Application: To thoroughly analyze the results, the administrator will summarize barriers and strengths within each transaction.

CLIENT FORM INTERPRETATION

P x **O**: Client is highly motivated to be intimate with her partner, however, lacks confidence in abilities and has not explored other types of intimacy at this time. Not currently using coping strategies to manage stress/ frustrations.

P x E: Partner is primary caregiver which impacts their relationship. Client reports that she feels her partner has a basic understanding of the client's current abilities.

E x O: Client feels injury impacts ability to be intimate despite partner support during intimacy. No impact of physical surroundings on sexual intimacy. No report of AE usage.

SIGNIFICANT OTHER FORM INTERPRETATION

P x **O**: Client is not satisfied with sexual participation but is motivated to learn other options and confident in future ability to be intimate with their partner. Client uses minimal coping strategies to manage caregiver stress but has not yet explored other forms of intimacy.

P x E: Spouse reports she is the main caregiver for the client with no outside assistance, may impact amount of caregiver burden. Spouse feels there is a basic understanding of partner's current abilities, but the injury has impacted their relationship.

E x O: Spouse disagrees that the physical environment impacts ability to engage in sexual activity and has not utilized AE. Spouse somewhat agrees that their partner's injury impacts their ability to be intimate with them.

STEP 3: Open discussion about sexual issues

Discuss results of the *LTAS Screening Tool* with the client.

Application: Both client and spouse are motivated to learn about resources/options for being sexually intimate. Both would benefit from utilizing coping strategies to address stress related to injury, as well as exploring other forms of intimacy and AE options.

STEP 4: **O**pen discussion about referrals

Determine necessary referrals to other healthcare disciplines.

Application: Administrator may refer to Section V of the LTAS Screening Tool User Manual as reference regarding other healthcare professionals' role in sexual health/ intimacy. At this time, it is recommended the client continue to receive OT services to address coping strategies for stress management regarding the ability to be sexually intimate. The client would also benefit from seeing a social worker to discuss changes in the nature of the relationship, emotional adjustment following the impact of the injury, provide different ways to understand and solve problems within the relationship, as well as ensure proper supports are in place.

STEP 5: <u>W</u>ork collectively to develop a treatment plan If applicable, **identify client-specific goals** related to areas within the occupational therapy scope of practice.

Application: OT will collaborate with client (and spouse) to establish goals for further OT intervention.

Possible goal areas for Jessie may include but are not limited to exploration of AE to facilitate successful sexual activity, coping strategies for stress/ frustrations, communication strategies to foster open and honest discussion between client and spouse, etc.

CASE TWO: FRANK

Frank is a 48-year-old male status post a spinal fusion of the C6-C8 vertebrae, following a complete spinal cord injury. Frank had received initial PT and OT services while in the acute phase of recovery and was referred to an intensive inpatient rehabilitation program for therapy 5 days a week. He is currently working towards regaining independence with basic ADLs, including transfers. Frank has stated his primary goal is to reduce the amount of caregiver assistance needed to return home. Frank was living at home with his girlfriend of 5 years, Carol; she has been involved in all aspects of Frank's recovery thus far. During a recent OT session, Frank briefly mentioned some of his concerns for returning home. He stated he does not want to be a burden to his girlfriend and is worried about the impact that his injury has had and will continue to have on their relationship.

STEP 1: Ask & Legitimize clients' concerns

Discuss the purpose of the *LTAS Screening Tool* with the client **and administer** Sections I-III. Acknowledge clients' concerns regarding sexual activity and function.

Application: Frank's completed charts are provided below as reference for remaining case application steps.

SECTION I - CLIENT BACKGROUND INFORMATION

NAME: Frank **AGE: 48 DATE: 12/10/2020 LEVEL OF INJURY: C6-C8 MONTHS/ YEARS SINCE INJURY: 4 months** CURRENT PHYSICAL CONCERNS: Upper body strength, sitting in chairs without armrests, bowel/bladder management **CURRENT PSYCHOLOGICAL CONCERNS: Some brief episodes of depression** since injury **SEXUAL PARTICIPATION STATUS: Not yet attempted** CURRENT/PREVIOUS SERVICES USED: PT/OT in acute hospital, inpatient PT/OT I WOULD LIKE TO ADDRESS SEXUAL PARTICIPATION AT THIS TIME: Yes No IF NO, PLEASE ADDRESS SEXUAL PARTICIPATION AGAIN IN: Other: 1 Month 3 Months 6 Months 1 Year IF YES, PLEASE COMPLETE SECTION II.

SECTION II - CLIENT FORM (FRANK)

Client Form	Strongly Disagree 1	Somewhat Disagree 2	Somewhat Agree 3	Strongly Agree
Pers	on x Occupation	on		
I am satisfied with my sexual participation.	X			
My self-esteem influences my sexual participation.			X	
I am confident in my ability to be intimate.		X		
I utilize coping strategies to manage stress/ frustrations that stem from my injury.		X		
I have explored different types of intimacy other than intercourse since my injury.	X			
I feel motivated to engage in sexual participation.			X	
Perso	on x Environm	ent		
My partner is my main caregiver.			X	
My injury impacts my relationship.				X
My partner understands my current level of abilities.		X		
I am confident in my ability to develop new relationships.		X		
Enviror	ment x Occup	ation		
My physical surroundings impact my ability to be sexually intimate.				X
My injury impacts my ability to be intimate with a partner.				X
I utilize adaptive equipment to engage in sexual activities.		X		
My partner is supportive during intimacy. Not applicable				

SECTION III - SIGNIFICANT OTHER FORM (CAROL)

Significant Other Form	Strongly Disagree 1	Somewhat Disagree 2	Somewhat Agree 3	Strongly Agree	
Person x Occupation					
I am satisfied with my sexual participation.		X			
I am motivated to educate myself regarding options for sexual intimacy with my partner.				X	
I am confident in my ability to be intimate with my partner.	X				
I utilize coping strategies to manage stress/ frustrations that stem from my partner's injury.	X				
I have explored different types of intimacy with my partner since their injury.		X			
Person x Environment					
I am the main caregiver for my partner.				X	
I have outside assistance to help care for my partner.		X			
I understand my partner's current level of abilities.		X			
My partner's injury impacts our relationship.				X	
Environment x Occupation					
My physical surroundings impact my ability to be sexually intimate.			X		
My partner's injury impacts their ability to be intimate with me.				X	
My partner and I utilize adaptive equipment to engage in sexual activities.		X			

STEP 2: Limitations in knowledge

After completing the form, the OT will analyze the results to identify problem areas that may be impacting the client's performance.

Application:

CLIENT FORM INTERPRETATION

- **P x O:** Client is motivated to engage in sexual activity with his partner, however lacks self-esteem and confidence in abilities. Client reports that they are not using coping strategies while addressing stress and has not yet explored other types of intimacy at this time.
- **P** x E: Client feels injury greatly impacts his relationship with his partner. Client reports partner is primary caregiver. Client feels that partner does not have a basic understanding of the client's current abilities.
- **E x O:** Client reports injury and physical surroundings impact ability to be intimate with his partner. Client and partner have not utilized adaptive equipment to engage in sexual activities. Client is unsure about their partners' support during intimacy, as they have not yet attempted any sexual activities.

SIGNIFICANT OTHER FORM INTERPRETATION

- **P** x **O**: Partner reports that she is highly motivated to educate themselves with options for sexual intimacy due to her own lack of confidence and satisfaction with current sexual participation. Currently not utilizing coping strategies or other forms of intimacy at this time.
- **P** x E: Partner reports that she is the main caregiver with limited outside assistance to help care for her partner. She feels injury greatly impacts their relationship as well as her poor understanding of her partner's current level of abilities.
- **E** x O: Both the physical surroundings and her partner's injury impacts their ability to be sexually intimate. No AE has been explored at this time.

STEP 3: Open discussion about sexual issues

Discuss results of the *LTAS Screening Tool* with the client.

Application: Client and his significant other have both reported they are motivated to engage in sexual intimacy. The greatest barriers to engagement are lack of partner's education regarding client's current abilities, poor confidence in both parties, and client's low self-esteem following his injury. Both feel that the injury has greatly impacted their relationship, which has resulted in no attempts of engaging in sexual intimacy at this time. Client has concerns regarding how much assistance he may need upon returning home; he feels that if his partner needs to help too much it may impact her feelings of intimacy towards him.

STEP 4: Open discussion about referrals

Determine necessary referrals to other healthcare disciplines.

Application: Administrator may refer to Section V of LTAS Screening Tool as reference regarding other healthcare professionals' role in sexual health/intimacy.

At this time, it is recommended the client continue to receive OT services to address coping strategies for stress management regarding the ability to be sexually intimate. The client and his significant other would benefit from PM&R to get a better understanding of the injury. The client would also benefit from seeing a social worker to address changes in the nature of the relationship, emotional adjustment following the impact of the injury, provide different ways to understand and solve problems within the relationship, as well as find other caregiver supports so that the spouse is not the primary caregiver. Since the client reports episodes of depression, a neuropsychologist can evaluate him to get a better understanding of how the clients reasoning, emotions, problem-solving, cognitive abilities, and personality was affected by the injury. Urology would also enlighten the client and his significant other on what is occurring in the client's urinary tract, as well as identify an effective bowel/bladder program and educate on strategies for emptying before/after sexual intimacy occurs.

STEP 5: **W**ork collectively to develop a treatment plan If applicable, **identify client-specific goals** related to areas within the occupational therapy scope of practice.

Application: OT will collaborate with client (and significant other) to establish goals for further OT intervention.

Due to the client's primary concern of requiring too much assistance from his significant other, OT will continue with their current plan of care in the inpatient setting to address independence in ADLs such as dressing, toileting, bathing, transfers, etc. This will allow the client to be as independent as possible upon discharge home. OT will make appropriate referrals, as previously discussed, to address each of Frank and his partner's needs. Following discharge from this site, it is recommended the client continue skilled OT services in the outpatient setting to further address any concerns with higher level ADL and IADLs, including sexual participation.

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CHAPTER V

SUMMARY

The purpose of this project was to gain knowledge regarding the psychological impact a SCI may have on an individual and their significant other's engagement in sexual intimacy. A comprehensive literature review was conducted to gather the information presented in this project, using credible sources and databases. The majority of current literature discussed the physical impact of the injury but fails to address the psychological component. Other gaps found in literature included the inconsistency of addressing this topic across the rehabilitation process, if at all, as well as failure to acknowledge the importance of the client's significant other's perspective during therapy. According to the literature, occupational therapy practitioners are equipped to address physical and psychological factors of sexual intimacy with their clients, such as providing resources and education on the topic, psychotherapy, and utilization of meaningful activities and interventions to promote successful participation in sexual intimacy (Hess & Hough, 2012; Walker et al., 2020).

Upon completing an extensive literature review, the *Let's Talk About Sex (LTAS)*Screening Tool was created as a guide for addressing the topic of sexual intimacy across the rehabilitation continuum. After experiencing a SCI, individuals may have difficulty engaging in various sexual intimacy activities and is often overlooked by professionals throughout the rehabilitation process (Federici et al., 2019; Hess & Hough, 2012; Walker et al., 2020).

Administrators of the screening tool are intended to be occupational therapy practitioners due to their holistic approach to therapy and unique collaborative skills. Creation of this project was influenced by the Person-Environment-Occupation (PEO) Model, ALLOW Model, and the Intentional Relationship Model (IRM). The ALLOW model guided the product by highlighting

the healthcare professionals responsibility in initiating the conversation regarding sexual intimacy. Additionally, the ALLOW model was used to break down each step for implementing the screening tool in practice. PEO aided in developing the structure and organization of the screening tool (PxO, PxE, OxE), as well as to analyze and summarize the results of the tool. The IRM is embedded into the screening tool with the intent that the practitioner will utilize therapeutic use of self throughout the process, as well as, anticipate an interpersonal event may occur at any time due to the sensitivity of the topic. The focus of the IRM in this product is to help maintain a therapeutic relationship with the client by redirecting them to the screening tool. The purpose of the *LTAS Screening Tool* is to provide a resource for professionals to use at each rehabilitative stage so that sexual intimacy is being addressed more often, thus reducing both the client's and practitioners' discomfort when discussing this topic.

Implementation

The creators of this screening tool and manual intend that it be implemented at any stage of recovery following a client's SCI. It is important to highlight the initiation of the *LTAS Screening Tool* will depend on the trust and rapport between a therapist and the client. The occupational therapy practitioner must use therapeutic use of self to determine when/if the *LTAS Screening Tool* is appropriate for their client and their significant other. Once a need for the tool has been recognized, the practitioner will follow the User Manual to guide them through the process of implementing the brief screening tool and analyzing the results. Based upon the results, the administrator will collaborate with the client to determine an appropriate plan moving forward. Specifically, the *LTAS Screening Tool* includes a continuation of services section to ensure appropriate referrals are made to other healthcare disciplines to further meet each client's specific needs.

Implications for Occupational Therapy

The intent of creating a screening tool for addressing sexual intimacy across the rehabilitation process was to generate a certain level of ease for practitioners to implement at any stage. The feasibility of the LTAS Screening Tool allows the occupational therapy practitioner to approach this specific area of occupation and provide a more holistic approach to ensure the clients' needs are being met at a time that they are most comfortable. The creators were able to discuss the creation of the screening tool with current practitioners and identify certain aspects that are currently overlooked within the scope of occupational therapy practice. If this tool were to be implemented across each stage of recovery, it would allow for the profession to move forward into a new niche of practice. Future research and feedback of the tool would be greatly beneficial in further development to ensure its effectiveness. Although the tool is specific to the SCI population and individuals in a relationship, it could be adapted and expanded upon to meet the needs of a larger population including other diagnoses, age groups, and relationship statuses. If we were to do this project again, we would have utilized our fieldwork placements as opportunities to pilot the screening tool as well as hold focus groups with clients and/or practitioners. These experiences would help to generate a greater understanding of what the target population specifically needs. The creators hope future students are able to utilize this screening tool and expand upon it in efforts to continuously address sexual intimacy with clients as it is within our scope of practice as an activity of daily living.

Limitations and Recommendations

There are numerous limitations and recommendations of the *LTAS Screening Tool*. The first limitation acknowledged, is the specificity of the tool addresses one population in particular. This limitation excludes other illnesses/injuries that may also have a major impact on

psychological well-being and limiting their ability to be sexually intimate. A recommendation would be to generalize the screening tool so it can be used effectively with other diagnoses, age groups, and for individuals with varying relationship statuses. In doing so, the *LTAS Screening Tool* would be more inclusive to a wider range of populations and meet the needs of many individuals within the rehabilitation process. The tool could be adapted to screen other neurological disorders, orthopedic injuries, and musculoskeletal injuries/ disorders, etc. and provide guidance along the lifespan.

The authors would also like to acknowledge the concept of sexual intimacy is significantly larger than what this screening tool is able to cover, which may be considered another limitation of the product. The *LTAS Screening Tool* was intended to identify the psychological components that may be impacting participation in sexual intimacy; however, it is extremely difficult to narrow down all aspects, as each will vary greatly amongst clients.

Another limitation to the screening tool is that although a Likert scale is used to complete the tool, the data collected is not quantifiable. The summary and interpretation of the results are based on the qualitative analysis by the therapist utilizing the tool. Statements on the screening tool are separated by the various PEO transactions, which provide guidance for the occupational therapy practitioner. The administrator analyzes their clients' responses to each statement to determine which areas are either promoting or inhibiting successful participation in sexual intimacy. Although the tool was intended to have more qualitative results, one recommendation to improve the consistency and reliability of the tool would be to further develop the tool to allow for results that can be more objective.

A final limitation of this product is the assumption that each therapist administering the screening tool is comfortable addressing this topic with clients. Although therapists discuss many

sensitive issues with clients, sexual participation has remained unaddressed due to therapist and client discomfort. In order to address this limitation, it is highly recommended that therapists working with clients post-SCI participate in a continuing education course to further educate themselves in the possibilities for clients following their injury. This will promote the therapists confidence and comfortability when addressing this topic, thus making their clients feel more at ease as well.

Conclusions

Overall, *The LTAS Screening Tool* and User Manual were created with evidence-based research and through the lenses of the IRM, PEO, and ALLOW models. This tool facilitates the therapist's responsibility in initiating the topic of sexual intimacy to be addressed at any stage of the client's recovery process. The tool provides an overview with a holistic approach to therapy with the goal of meeting the unmet needs of the SCI population. Occupational therapy practitioners have a unique skill set which allows them to build strong therapeutic relationships with their clients and discuss all factors that may be impeding their clients' participation in sexual intimacy. Additionally, occupational therapy practitioners are well-equipped to provide further education and referrals that may instill confidence in both the client and their significant others' ability to be intimate with one other. Through the development of this screening tool, the creators hope the topic of sexual intimacy will be addressed and normalized throughout the rehabilitation process, just as any other important activity of daily living is approached.

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