



Addressing Sexuality in Practice: A Neuro-based Doctoral Capstone Experience

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# **A Capstone Project Entitled**

Addressing Sexuality in Practice: A Neuro-based Doctoral Capstone Experience

Submitted to the School of Occupational Therapy at University of Indianapolis in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree.

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### **Abstract**

Sexuality is one area of performance resulting in both direct and indirect deficits post brain injury; however, clinicians rarely address this topic during the rehabilitative process (Stocchetti & Zanier, 2016). The purpose of this doctoral capstone project was to determine the need for sexual health resources in an outpatient neurorehabilitation setting and address this need at Lutheran Outpatient Rehabilitation. Following a needs assessment, it was found that Lutheran Outpatient Rehabilitation had no sexual health resources available; however, 75% (6) of brain injury patients reported wishing they had received information regarding sexual health post ABI. To address this need a sexual health resource binder was created, and a supplemental in-service was held to assist outpatient clinicians in (a) recognizing the need to address sexual health with patients post ABI, (b) identifying available sexual health resources, and (c) developing appropriate strategies for addressing sexuality with patients post ABI. Many patients with brain injury want information about sexuality post ABI; however, therapists are hesitant to address this topic in practice. Outcomes from this doctoral capstone experience (DCE) indicate that more education and resources regarding sexuality post ABI could improve clinician competence and confidence incorporating this topic in the neurorehabilitative setting; therefore, improving holistic care and overall patient satisfaction. It is recommended that the facility further assess the outcomes of this project, ensure that comfort discussing the topic is routinely addressed with staff, and that resource files are updated as needed.

## **Chapter 1 Introduction**

As of 2013 acquired brain injury (ABI) is responsible for the disability of 12 million Americans (Brain Injury Association of America [BIAA], 2013). ABI can lead to physical, cognitive, and psychological deficits negatively impacting functional performance and quality of life (Stocchetti & Zanier, 2016). Sexuality is one area of performance resulting in both direct and indirect deficits post brain injury; however, clinicians rarely address this topic during the rehabilitative process (Stocchetti & Zanier, 2016). It is known that sexual health can influence the state of one's well-being and quality of life; therefore, clinicians need to address this topic in practice (McGrath & Sakellariou, 2016).

Throughout a 16-week doctoral capstone experience (DCE), an occupational therapy (OT) student demonstrated entry-level knowledge and skills of the OT process within the outpatient neurorehabilitative setting. The OT student performed holistic care through the production and implementation of a sexual health resource binder. The resource binder will be available for Lutheran Outpatient Rehabilitation therapists to utilize with patients needing and requesting information on sexual health post ABI.

## **Chapter 2 Literature Review**

### **Prevalence of Brain Injury**

Stroke and traumatic brain injury (TBI) are two of the most common adult disorders in the United States. Both diagnoses are neurological in origin and types of ABI (Rao, 2012). Acquired brain injury is defined as, "an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma...an acquired brain injury is an injury to the brain that has occurred after brain birth" (Brain Injury Association of America, n.d.). Acquired brain injuries are complex and can impact three general neurological systems: cognition, emotion

regulation, and motor function (Umphred, Lazaro, Roller, & Burton, 2013). The central location of these neurological systems can result in peripheral deficits. Therefore, treatment of ABI requires a dual approach focused on healing the brain through repetitive, challenging, and meaningful intervention; and increasing functional performance through restorative, adaptive, and/ or compensatory strategies (Umphred, Lazaro, Roller, & Burton, 2013).

### **Sexual Health Exposure in Clinical Programs**

The multidimensional impact of neurological diagnoses, like ABI, supports neurorehabilitation as a complex clinical subspecialty (Carey, 2010), requiring at minimum, entry-level clinical skills to perform high-quality patient-centered care (Umphred, Lazaro, Roller, & Burton, 2013). Although some students receive entry-level knowledge relative to neurological diagnoses and their prospective intervention approaches, there is limited potential for skill development within the confines of academic coursework. Sexuality is one area of neurorehabilitation with limited research and curricular exposure in programs for health professions (West et. al., 2012). The consequence of limited knowledge and exposure to sexual health deficits related to neurological disorders results in clinician incompetency addressing and treating sexuality post ABI.

### **Sexuality as an Occupation**

In the world of OT, the term “occupation” is considered anything an individual wants to do, needs to do, or is expected to do (AOTA, 2014). The Occupational Therapy Practice Framework (OTPF) considers sexuality an occupation, and more specifically, an activity of daily living (ADL) (AOTA, 2014). Sexuality is an important component to address in practice due to its influence on quality of life. A study by McClure (2012) addressed sexuality and the needs of mental health patients illustrating that patients have a higher quality of life when educated on

their diagnoses' impact on sexual function. Although the resources being collected for this project are not for mental health patients, the educational value is still relevant. Patients with neurological diagnoses have an increased likelihood of experiencing changes in sexual health (Umphred, Lazaro, Roller, & Burton, 2013); therefore, educational resources are beneficial to their rehabilitative experience.

### **Occupational Adaptation**

Gathering informative sexual health resources, for therapists to utilize with patients, is an objective following the construct of the occupational adaptation (OA) theory. This theory focuses on individuals who experience dysfunction within their environment and the adaptive strategies to improve occupational mastery (Cole & Tufano, 2008). For this project, patients who identify sexuality as a meaningful and purposeful occupation, and report deficits in sexual health, are considered to be experiencing occupational dysfunction. Through the creation and implementation of an informative sexual health resource binder, appropriate strategies and techniques can be incorporated in the rehabilitative process; therefore, increasing the quality of holistic patient centered care (Cole & Tufano, 2008).

### **PLISSIT Model**

Over the years, researchers have attempted to address the need for sexuality based services in healthcare. Unfortunately, sexual health needs are frequently given low prioritization or are disregarded altogether (Umphred, Lazaro, Roller, & Burton, 2013). McGrath and Sakellariou (2016) indicate several reasons why health professionals fail in attending to these needs including: (a) lack of knowledge; (b) client factors such as age, marital status, and gender; (c) concerns regarding the health professional's safety; (d) fear of causing offense or anger; (e) perceived lack of relevance and importance of sexuality for people with disability; (f)

institutional practices and policies that do not prioritize sexuality; (g) personal beliefs and attitudes; (h) and lack of clarity regarding professional roles and concerns regarding damage to professional reputation. Several models have been proposed as algorithmic answers to patients' sexual health needs, but there is little evidence supporting the impact on practice (Rutte et. al., 2015). Currently, the PLISSIT model is one of the only models created for addressing and treating sexual health problems with beneficial outcomes (Rutte et. al., 2015). The PLISSIT model was intended to assist therapists in structuring the order of sexuality related treatment, while being cognizant of therapist and patient comfort with the topic (Rutte et. al., 2015). The concept behind the PLISSIT model lies within the stages of its name. The PLISSIT stages include: (a) permission, (b) limited information, (c) specific suggestions, and (d) intensive therapy (Rutte et. al., 2015). Overall, the model is progressive in nature; meaning the stages transition from most to least conservative approaches to addressing sexuality with patients. The PLISSIT model has been successfully used across various populations including women with sexual problems (Fatemeh, Giti, Efat, Fatemeh, & H., 2012), patients with stomas (Ayaz & Kubilay, 2009), patients with gynecological cancers (Chun, 2011), and patients with diabetes (Rutte et. al., 2015).

Stages one and two of the PLISSIT model are the primary focus for this project. The creation of a sexual health resource binder will serve as an easily accessible toolbox to provide patients with *limited information* on relevant content. An in-service presentation focusing on the sexual health resource binder and its contents will also address the development of *permission* strategies to promote and improve clinician initiation of the topic. With the use of the PLISSIT models' conservative approach, it is hoped that therapists within this neurorehabilitative setting will have improved competence and confidence in their ability to address sexuality in practice.

**Sexual Assessment Framework**

To provide relevant and meaningful resources for therapists and patients at this setting, one must understand the components which make up sexuality. McBride and Rines (2000) organize the components of sexuality into a sexual assessment framework (SAF). These components include: (a) sexual knowledge, (b) sexual behavior, (c) sexual interest, (d) sexual response, (e) fertility and contraception, and (f) sexual activity (McBride & Rines, 2000). Sexual knowledge refers to the values and beliefs of one's sexuality, as well as the perceived changes in sexuality post injury (McBride & Rines, 2000). Sexual behavior acknowledges one's ability to initiate and/or maintain a social/sexual relationship, which can be impacted by communication skills, social constructs, and/or newly assumed caregiver roles (McBride & Rines, 2000). Sexual interest is both the physical and psychological drive for human closeness, while response refers to the naturally occurring physiological response to sexual stimulation (McBride & Rines, 2000). Fertility and contraception addresses issues related to family planning, safe sex, and contraception (McBride & Rines, 2000). Sexual activity, the last component of the framework, consists of motor abilities, hand function, strength, and management of bowel and bladder programs (McBride & Rines, 2000). The SAF will be used for better understanding patient needs, and for the organization and provision of a relevant resource binder.

**Chapter 3 Methodology/ Instrumentation**

In the best-case scenario, sexuality is the last issue to be addressed in the rehabilitative process (Umphred, Lazaro, Roller, & Burton, 2013). In the worst-case scenario, sexuality is not addressed at all (McGrath & Sakellariou, 2016). This evidence supports the need for further exploration of methods to implement sexuality in practice. The creation of a sexual health resource binder required consideration of current literature and the perspective of both treating



therapists and patients with ABI. A needs assessment was conducted to support evidence found in the literature and assist in the determination of needed resources with this site-specific population (Bonnel & Smith, 2018). Throughout the course of this 16-week DCE, the OT student completed a minimum of 32 clinical hours a week. Clinical hours consisted of evaluation, intervention planning, treatment, discharge, and documentation of patients with neurological diagnoses including: stroke, brain tumor, spinal cord injury (SCI), and traumatic brain injury (TBI). The OT student was instructed and supervised under a licensed occupational therapist and certified brain injury specialist trainer (CBIST) with relevant credentials supporting advanced knowledge in neurorehabilitation including: membership and leadership roles in the American Society for Neurorehabilitation, the American Congress of Rehabilitation Medicine, the Indiana Occupational Therapy Association (IOTA), and the American Occupational Therapy Association (AOTA). The occupational therapist has also played a role in designing and teaching a nationwide stroke certification course available through the National Stroke Association (RehabLab.org, n.d.). This 16-week exposure to neurorehabilitation facilitated increased understanding of neurological diagnoses and their accompanying deficits' impact on sexuality.

### **Participants**

Patients and therapists of Lutheran Outpatient Rehabilitation were invited to participate in a brief informal survey regarding personal experience related to sexuality and the rehabilitation process. All participants were recruited using convenience sampling. Inclusion criteria for convenience sampling of therapists included: current employment at Lutheran Outpatient Rehabilitation, and licensure as an occupational, physical, or speech therapist. Inclusion criteria for convenience sampling of patients included: being at least 18 years of age,

having sustained an ABI, and having received, or is currently receiving, services from Lutheran Outpatient Rehabilitation. Brain injury patients were included in the needs assessment to gain information on sexuality from the perspective of people with disabilities (Moreno, Gan, Zasler, & McKerral, 2015). Acquired brain injury was selected as the inclusive diagnosis because it encompasses the majority of patients being treated at this setting, and can result in decreased sexual function, sexual activity, and sexual satisfaction (Umphred, Lazaro, Roller, & Burton, 2013). A total of 31 patients and 26 therapists were recruited. Of the 31 patients on caseload 53.6% had a primary diagnosis of stroke, 21.4% had a primary diagnosis of TBI, 3.6% had a primary diagnosis of brain tumor, and 21.4% had a primary diagnosis unrelated to ABI.

### **Assessment of Need**

The surveys were implemented to identify therapist and patient perceptions of sexual health deficits post ABI, and the site-specific needs related to components of the SAF. Survey content was guided by evidence regarding the under recognition of sexual health concerns in a therapeutic context (McGrath & Sakellariou, 2016). All survey questions were organized from least invasive to most invasive to simulate the progressive nature of the PLISSIT model (Rutte et. al., 2015). Both therapists and patients were informed that anonymity would be ensured in support of ethical guidelines. First draft survey content was reviewed and edited by a licensed occupational therapist working in the neurorehabilitative setting. Suggestions made by the licensed occupational therapist were accepted, and all edits were made prior to implementation.

Twenty-six outpatient therapists, including physical, occupational, and speech, received a brief, informal, pre-post survey consisting of three Likert scale questions. Survey content was targeted at identifying awareness of sexual health deficits post ABI and perceived competence and confidence in addressing sexual health needs. Therapists were asked to identify their level of

awareness of changes in sexuality post ABI, as well as their perceived levels of competence and confidence in addressing sexuality (Rutte et. al., 2015). Surveys were distributed to therapists' mailboxes with instruction to return to a designated location post completion. A brief paragraph explaining the survey purpose was included, as well as a statement ensuring there would be no consequence if choosing not to participate. Twenty of the twenty-six pretest surveys were completed and returned to the OT student. Survey responses were transferred to electronic copies so that data analysis could be completed via google surveys.

Thirty-one patients with ABI diagnoses received a brief, informal, six question survey consisting of four Likert scale, one yes or no, and one multiple choice question. Survey content was targeted at identifying site specific needs in relation to concepts described in the six domains of the SAF. Prior to receiving a survey, patients were informed of the survey content and asked whether they would like to participate in survey completion. A brief paragraph explaining the purpose of the survey was included. Patients were asked to identify their level of satisfaction regarding their outpatient experiences, whether they received information and/or resources about changes in sexual health post ABI (Umphred, Lazaro, Roller, & Burton, 2013); what disciplines provided this information (McGrath and Sakellariou (2016), and whether they experienced changes in sexual health post ABI (Umphred, Lazaro, Roller, & Burton, 2013). Patients were also asked whether they would have liked to receive information about changes in sexual health post ABI, and identified specific sexuality concerns relative to the SAF (McBride & Rines, 2000). Ten of the 15 patient surveys were completed and returned to the OT student. Survey responses were transferred to electronic copies so that data analysis could be completed via google surveys.

**Therapist Perceptions**

Seventy-five percent of therapists agreed or strongly agreed that sexuality can be affected by neurological diagnoses like ABI. Of the 20 responding outpatient therapists, only 10% (2) reported feeling competent in providing sexual health resources for patients and only 15% (3) reported feeling confident in providing sexual health resources.

**Patient Experience**

Eighty percent (8) of patients reported not being informed about potential changes regarding sexual health post ABI. Of this 80% (8), 60% reported wishing they had received information or resources regarding sexual health post ABI. Patients reported wanting information in all six domains of the SAF; however, the most relevant areas of sexual health needs were in the domains of sexual behavior, sexual activity, and sexual interest. The information collected in this survey will be used to guide the collection of resources for the sexual health resource binder.

**Chapter 4 Methodology/ Intervention**

A relevant sexual health resource binder was created following the needs assessment. Based on survey responses, there is a clear need for education on mechanisms to address sexuality within the scope of OT practice. The PLISSIT model suggests the first steps to approaching sexuality in practice are gaining permission and providing limited information (Rutte et. al., 2015). The sexual health resource binder intended to propose the invitation of a sexual health conversation, and normalize the sexual problem for individuals post ABI (Rutte et. al., 2015). Resources included (a) information on specific brain structures and their relation to sexual function and sexual deficits; (b) information on ABI diagnoses and expected sexual deficits; (c) information on adaptive equipment for sexual dysfunction; (d) positioning strategies;

(e) lists of books, blogs, podcasts, and websites with more information about sexual dysfunction post brain injury; (f) referral sources and contact information of local specialists including urologists, sexual educators, sexual counselors, and sexual therapists; and (g) tools for screening and assessing sexual health. All resources were organized based on the six components outlined in the SAF to easily locate resources and maximize appropriate usability by outpatient therapists (McBride & Rines, 2000). The resource binder is located in the outpatient office in a designated area where all specialty resource binders are housed. An electronic copy of the resource binder was also made available. The electronic version is accessible from all outpatient computers under the g-drive and is titled and organized identical to the hard copy binder.

### **Staff Development**

The OT student communicated the project purpose to all outpatient staff via written and verbal communication. Outpatient staff shared personal experiences regarding patient sexuality post ABI and expressed support for the creation of a sexual health resource binder. To maximize use of the resource binder, the OT student conducted a one hour in-service dedicated to education on the need to address sexual health, the available resources provided in the sexual health resource binder, and the development of strategies for addressing sexuality with patients post brain injury. Staff were also educated on the components of the SAF to promote ongoing organization of future resource collection.

### **Leadership Development**

Leadership skills were demonstrated by the OT student throughout all phases of the DCE. Self-directed learning and professional behavior were utilized with both clinicians and patients. These skills were necessary to facilitate completion of project goals and objectives. The self-directed process led to professional development of time management, organization, and intrinsic

motivation to acquire responsibility of all project duties. The OT student also demonstrated improved leadership skills through the demonstration of consistent dependability in attendance and assignment completion, and maximized participation in educational opportunities.

Advocacy skills were demonstrated through active communication with other disciplines regarding patient care and the relevance of sexuality in OT's scope of practice.

### **Chapter 5 Results**

Throughout the 16-week experience, the occupational therapy student created and implemented a sexual health resource binder to address clinician competence and confidence with addressing sexuality in neurorehabilitative practice. The education piece of this project advocated for the relevance of sexuality in outpatient neurorehabilitation. Dissemination of this project resulted in clinicians of multiple disciplines being able to confidently identify sexuality as an ADL within the OT scope of practice (AOTA, 2014). Outpatient clinicians were educated why and how to address sexuality in practice with the use of a PowerPoint presentation. The OT student verbally and visually articulated the theoretical base supporting the organizational format including explanation of both the PLISSIT model and SAF. By the end of the in-service presentation, outpatient staff could identify the purpose of each resource being provided and discussed ways in which these resources could be used to educate their patients.

### **Chapter 6 Conclusion/ Discussion**

The implementation of this DCE facilitated learning and professional development beneficial for future practice. The OT student improved clinical reasoning skills during 32 hours of weekly patient care and was exposed to a variety of complex neurological diagnoses including stroke, TBI, SCI, brain tumors, and some undiagnosed conditions. Exposure to these diagnoses facilitated improved problem solving, clinical reasoning, and overall competency in the

neurorehabilitative setting. Exposure to these clinical skills allowed the OT student opportunity to address sexuality with brain injury patients. The student frequently informed patients that sexuality was an appropriate topic of discussion for occupational therapy. Most patients were receptive to this information and, as a result, self-initiated conversations with the OT student about their own sexual health on multiple occasions. These interactions lead to three key experiential takeaways: (a) sexuality is a meaningful and purposeful occupation for some ABI patients, (b) when patients are aware of sexuality's occupational relevance they are more likely to seek help from an occupational therapist, and (c) educational resources on sexual health are beneficial to patients with ABI as they demonstrate the potential for improved occupational engagement.

Staff at this site played a significant role in the OT students learning and development of leadership skills. Teamwork amongst outpatient therapists was consistently demonstrated throughout all therapeutic processes. Therapists frequently engaged in interprofessional decision making and goal setting regarding patient care supporting the decision to include all outpatient staff in the evaluation and implementation of this project. Several speech therapists expressed gratitude for knowing that sexuality is in OT's scope of practice, because they now know their responsibility in referring these issues to the appropriate rehabilitative profession. Although, not all therapists were receptive to this topic, interprofessional discussions consistently demonstrated respect for others' opinions.

Although project implementation increases potential for improved quality of care, it is the responsibility of each clinician to utilize the tools provided and implement change. It was recommended that the outpatient rehabilitation team further assess the outcomes of this project at monthly meetings, ensure comfort discussing the topic is routinely addressed with staff by using

the therapist survey post future sexual health in-services, and update resources as needed. The facility plans to schedule an in-service to be presented by one of the local specialists provided in the resource binder to discuss more rehabilitative strategies for sexuality related deficits with relevance to neurological diagnoses. Through the provision of education and resources, outpatient therapists are better equipped to address sexual health needs with brain injury patients.



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