

2024

Comfort: an application to address sexual health and intimacy for patients with brain injuries receiving occupational therapy

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BOSTON UNIVERSITY
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

COMFORT:
AN APPLICATION TO ADDRESS SEXUAL HEALTH AND
INTIMACY FOR PATIENTS WITH BRAIN INJURIES
RECEIVING OCCUPATIONAL THERAPY

by

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Submitted in partial fulfillment of the
requirements for the degree of
Doctor of Occupational Therapy

2024

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ACKNOWLEDGMENTS

I would like to express my deepest appreciation and thanks to Nicole Villegas, my academic mentor, without whom this project would not have been possible. Thank you for your support and assistance during this process. I would also like to thank Karen Jacobs for providing edits and support throughout this project. Thank you to the Boston University occupational therapy community for making this project possible. Thank you to my husband and family who have provided background support and encouragement to continue with my education and research.

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ABSTRACT

Patients with brain injuries can encounter several neurological symptoms that affect physical and psychological functioning. This change in function can impact sexual health and intimacy. Patients with brain injuries who are referred to acute rehabilitation hospitals spend three hours a day in therapy. These patients develop rapport with their occupational therapy practitioners (OTPs) who are in a unique position to address sexual health and intimacy concerns. There is limited research on occupational therapy (OT) interventions for sexual health and intimacy with adults after brain injury. This paper proposes an application program that addresses sexual health and intimacy education for patients with brain injuries receiving occupational therapy. The smartphone application, *Comfort*, will assist occupational therapists to overcome barriers to include sexual health and intimacy in client-centered and occupation-based care.

PREFACE

This project to address sexual health and intimacy for adult's post brain injury was inspired by my experiences working in the acute rehabilitation hospital setting. My patients who experienced brain injuries struggled to return to their prior level of independence. Most of my patients were unaware that occupational therapists can address sexual health and intimacy. Discussing these topics with patients and learning about their concerns and questions helped me to identify the lack of information on these topics as a gap in practice.

It is my hope that this work inspires other therapists to begin addressing sexual health and intimacy with patients, specifically those post brain injury. Occupational therapy practitioners have a crucial role to play in addressing these topics and ensuring that patients feel comfortable returning home to all their valued meaningful occupations.

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LIST OF ABBREVIATIONS

ADL	Activity of Daily Living
AOTA	American Occupational Therapy Association
App.....	Application
BIANJ	Brain Injury Alliance of New Jersey
BU	Boston University
OT	Occupational Therapy
OTP.....	Occupational Therapy Practitioner
OTPF-4	Occupational Therapy Practice Framework
SDT	Self-Determination Theory
WCAG	Web Content Accessibility Guideline

CHAPTER ONE – Introduction

Sexual health plays a large role in quality of life (Flynn et al., 2016). Flynn et al. (2016) stated that 62.2% of men and 42.8% of women reported that sexual health was of high importance to quality of life. Occupational therapy practitioners (OTPs) are distinctly positioned to address the psychosocial and biological aspects involved in sexual health. Occupational therapy practitioners (OTPs) address activities of daily living (ADLs) which includes sexual activity (American Occupational Therapy Association, [AOTA], 2020). While sexual activity is listed as within the scope of practice for OTPs many therapists do not address this topic in practice (Young et al., 2020). This project proposes to address this gap in practice through an application (app) that will address sexual health and intimacy for adults with brain injuries in the inpatient setting. The application, called *Comfort*, will increase patient knowledge on sexual health and intimacy, increase quality-of-life scores, and decrease depression scores. While this topic is broader than a specific diagnosis, *Comfort*, will specifically address brain injuries in design and practice. Information covered in the app will include healthy relationships, consent, positioning, and the effect of symptoms on sexual health and intimacy through a holistic and occupation-based lens.

The problem of addressing sexual health in occupational therapy reaches far beyond the inpatient setting. Research has shown that occupational therapy (OT) students do not feel confident addressing sexual activity as an activity of daily living (ADLs) (AOTA, 2020; Young et al., 2020). Addressing sexual health and activity as an ADL starts with knowledge at the academic level. Clinicians must be prepared to address this

topic with patients starting as young as puberty and continue throughout a patient's life. While the Occupational Therapy Practice Framework (2020) lays out scope of practice, many practitioners and schools do not delve deeper into interventions for sexual health and intimacy. All other ADLs are reviewed, discussed, analyzed, and addressed with patients during OT sessions to determine levels of independence or the need for modification or adaptation. OTPs are aware that sexual activity should be addressed but many practitioners do not feel confident in their knowledge to approach the topic (Jones et al., 2005; Areskoug-Josefsson & Fristedt 2019). The recently updated Occupational Therapy Practice Framework (OTPF-4) also provides an ambiguous definition of sexual activity: "Engaging in the broad possibilities of sexual expression and experiences with self or others (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)" (AOTA, 2020).

The taboo nature of sexual health and intimacy impacts how healthcare professionals approach the subject with patients. Education on sexual health in the United States ranges state to state with 20 states providing information on contraception, 19 states requiring that instruction should include engaging in sexual activity only when married, and 35 states allow parents to remove their child from instruction on sexual health (*Sex and HIV Education*. 2023). The idea that sexual health and intimacy are topics to avoid begins with school aged children and leads to adults who struggle to communicate about these topics. Occupational therapy practitioners (OTPs) can provide inclusive and comprehensive education on the topics of sexual health and intimacy that are specific to individuals using *Comfort*.

OTPs may struggle with addressing sexual health and intimacy because there is limited research on interventions and no available quantitative assessments specific to these topics. Occupational therapy encourages evidence-based practice and with limited research specifically targeted to OT on sexual health and intimacy, practitioners may avoid these topics. This is a barrier to therapists who wish to address topics with their patients as they have no set guidelines for interventions. Objective measures can assist practitioners in treatment planning by identifying areas that should be addressed. When objective measures are present, they provide can provide structure for topics to be covered. *Comfort* will utilize the Quality-of-Life Scale, Hospital Anxiety and Depression Scale, Sexual Health Indicators, and knowledge-based quiz to determine if the impact of the app is statistically significant.

Comfort is an app that will address the lack of OT interventions focused on sexual health and intimacy for patients with brain injury. This app will provide accessible and specifically designed educational modules to patients on consent, positioning, and safety. It will also include resources to ensure that patients receive vital information that they may not have thought to search for or ask about. This will help patients gain the knowledge to advocate for themselves regarding this meaningful occupation. *Comfort* will support the holistic practices of occupational therapy and help patients with brain injury improve their health related to sexual health and intimacy.

CHAPTER TWO – Project Theoretical and Evidence Base

Introduction

Sexual health and intimacy are considered activities of daily living (ADLs), a core concept that occupational therapy practitioners (OTPs) can address with patients. Sexual health is a broad term and, in this paper, will refer to the World Health Organization's 2002 definition:

“Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled.”

This definition includes all aspects of an individual and considers outside factors that may impact sexual health. For the purposes of this paper, intimacy will be defined as “a close, familiar, and usually affectionate or loving personal relationship with another person or group” (*Intimacy*. 2022). Occupational therapy practitioners are in a unique position to address sexual health and intimacy with patients but the research regarding interventions in OT are limited.

While OTPs address ADLs in inpatient rehabilitation hospitals, sexual health is often overlooked or forgotten. There is very little research on sexual health through the holistic lens of OT. Most research surrounding sexual health is focused on psychological disorders, pelvic health, or focused on the medical model. This lack of research affects how practitioners approach the topics of sexual health and intimacy and means that few resources are available to patients who are seeking answers. Patients with brain injuries who are unable to access information regarding sexual health and intimacy may feel

stigmatized. When patients feel stigmatized, they may experience decreased quality of life, decreased medical adherence, decreased self-esteem, and social isolation (Connell et al., 2013; Burgener et al., 2015; Hammer and Toland, 2017; Sehlo & Bahlas, 2012; Weiss et al., 2006). Without a standard of care or communication regarding sexual health and intimacy, patients are not provided the resources and information to develop their competence, autonomy, and relatedness on this topic, key ingredients in the development of self-motivation (Gagné & Deci, 2005).

Throughout this chapter sexual health and intimacy will be examined through research on standards of care, patient concerns, stigmatization and isolation, and patient education. This topic is provided with limited funding and attention, as evident by the lack of research.

Brief Description of the Visual Model

Figure 1A demonstrates the model of the problem. Sexual health and intimacy is not addressed as an ADL for patients with a brain injury receiving inpatient rehab occupational therapy. This gap in care is moderated by insurance companies' willingness to reimburse treatment and stigma surrounding sexual health and intimacy. Without proactively addressing sexual health as an ADL patients look for help online to address sexual health and intimacy. Patients do not find evidence-based resources on sexual health and intimacy that are specific to brain injury. When no resources are available, patients feel lost, confused, isolated, stigmatized. These feelings lead to increased anxiety and depression, decreased quality of life, and low relationship satisfaction.

Theoretical Framework

Sexual health and intimacy are taboo topics in the United States, this is especially the case for individuals with disabilities. The problem that this paper will address is multifaceted and includes examining the consequences that occur when sexual health and intimacy is not addressed by OTPs in a healthcare setting. Research has shown that patient education impacts proper use of the healthcare system as well as allowing for self-management of chronic diseases (Shoemaker et al., 2014; Nossum et al., 2013). It is possible that individuals seeking information on sexual health while in a healthcare setting feel isolated, stigmatized, and marginalized when these topics are not addressed. These feelings negatively impact quality of life and health outcomes of patients (Burgener et al., 2015; Connell et al., 2013; Courtin & Knapp, 2017; Holt-Lunstad et al., 2015; Manemann et al., 2018; Sehlo & Bahlas, 2012; Valtorta et al., 2016; Weiss et al., 2006). Self-determination theory (SDT) and the Sexual Health Model will be the frameworks for understanding and addressing these topics.

Self-determination theory (SDT) guides the understanding of patient motivation when it comes to sexual health and brain injuries. Through the lens of SDT, the internal motivation of patients can be examined to properly address these topics in a way that is comfortable and appropriate for them. The three main concepts of SDT include competence, autonomy, and relatedness (Gagné & Deci, 2005). Examining research through the lens of SDT will provide insight into patient's choices and motivations regarding sexual health and intimacy (Gagné & Deci, 2005).

The Sexual Health Model will be utilized to create the educational materials that

Comfort will present to patients. The Sexual Health Model was originally created to fill a gap in theories that could address HIV prevention (Robinson et al., 2002). The model is focused on a sex positive and comprehensive approach to sexual education (Robinson et al., 2002). The 10 major components of the sexual health model are: talking about sex, culture and sexual identity, sexual anatomy functioning, sexual health care and safer sex, challenges, body image, masturbation and fantasy, positive sexuality, intimacy and relationships, and spirituality (Robinson et al., 2002). *Comfort* utilizes this theory to address potential barriers to sexual health and intimacy that patients with brain injuries may face.

Sexual Health and ADLs

There is no research on a standard of care to address sexual health with patients. Throughout this paper, ADLs will refer to activities that are “fundamental to living in a social world; they enable basic survival and well-being” (Christiansen & Hammecker, 2001 p. 156)” (American Occupational Therapy Association, [AOTA], 2020). This definition is used in the American Occupational Therapy Association’s (AOTA) Occupational Therapy Practice Framework (OTPF-4) which outlines the scope of practice for OTPs. Sexual health is included in the OTPF-4 as an ADL and therefore should be addressed during therapy sessions (AOTA, 2020).

Education for OTPs surrounding sexual health and intimacy is limited which leads to the current gap in practice. Much of the research surrounding OT and sexual activity are survey based and focused on education of OTPs on these topics (Areskoug-Josefsson et al., 2016; Helland et al., 2013; Jones et al., 2005). Occupational therapy

practitioners (OTPs) who have not been educated on sexual health may not know how to bill for sessions involving sexual health and intimacy. According to McGrath and Sakellariou (2016) research continues to suggest that OTPs do not feel prepared to address sexuality during sessions. Without an understanding of how to address sexual activity and intimacy, OTPs will not include these topics in their practice. Self-determination theory (SDT) suggests that practitioners will not feel motivated or comfortable addressing topics that they do not feel competent with.

The Commission on Accreditation of Rehabilitation Facilities (CARF) has standards for inpatient rehabilitation hospitals that include addressing sexual health and intimacy (Commission on Accreditation of Rehabilitation Facilities, [CARF], 2023). CARF requirements include addressing sexual health with patients diagnosed with a stroke, limb loss, and spinal cord injury but does not include brain injuries in general (CARF, 2023). The standards state that individual therapy plans must address intimacy and sexual health issues as desired by the patient (CARF, 2023). Examples are provided such as referrals to other professionals and education without specific guidance on what information or referrals to provide (CARF, 2021). Vikan et al. (2019) examined sexual health policies in nine rehabilitation centers across seven countries. The study found that healthcare workers in centers without policies regarding sexual health felt less confident addressing these topics (Vikan et al., 2019). A lack of specific support was found to be a barrier to healthcare workers including this topic in care (Vikan et al., 2019). In a New Zealand qualitative study performed by Freeman et al. (2017) five heterosexual couples at the Burwood Spinal Unit engaged in semi-structured interviews with a nurse regarding

sexual activity and intimacy. In New Zealand the average spinal cord injury stay is up to 26 weeks which impacts privacy, negatively impacting couple intimacy (Freeman et al., 2017). The study found that a common theme the couples discussed was a lack of privacy, whether from staff or other patients, while in rehabilitation (Freemen et al., 2017). An example of the change in sexual health was noted by one couple:

“Before Barry’s injury, Brenda said she loved “hopping into bed and being intimate” but now there were “cushions everywhere and catheter bags”, and it had become much more difficult. Not being able to connect sexually, as they had done previously, emphasized the losses associated with the spinal injury because of the interruption to the “close bonding you enjoy with sex and being intimate” (Barry)”. (Freeman et al., 2017, p. 440)

Policies regarding sexual health in rehabilitation hospitals impact how and if these topics are addressed with patients.

Insurance companies may be a limiting factor in how and when sexual health is addressed. According to Hoffman and Paradise (2008) there is a strong correlation between health insurance coverage and medical management of chronic conditions. When health insurance companies do not require OTPs to address sexual health as an ADL for reimbursement, these topics are left behind. Sexual health and intimacy are considered ADLs and within OT scope of practice (AOTA, 2020). Occupational therapy practitioners (OTPs) feel that there is a lack of education regarding sexual health which results in not addressing these topics in practice (Young et al., 2020). This lack of

education combined with a lack of requirements from insurance companies contribute to the cycle of leaving sexual health and intimacy unaddressed.

Patient Searching for Information

Evidence on patients' attitudes and questions regarding sexual health are limited, but research demonstrates the importance of addressing patient questions and concerns. One of the key components of the sexual health model is talking about sex (Robinson et al., 2002). The ability to communicate the topics of sexual health and intimacy comfortably will provide patients with support and assistance in identified areas (Robinson et al., 2002). The concept of relatedness plays a large role in patient questions about sexual health. In a culture where “clinicians may assume patients will initiate discussions about sexual health” patients are left without answers to questions (Flynn et al., 2016, p.2). According to SDT, people absorb and internalize the values and beliefs around them (Gagne & Deci, 2014). When patients have internalized the beliefs that sexual health is not something to be discussed with healthcare practitioners, they do not ask questions or receive answers.

Lintz et al. (2003) found that half of the participants in their study on prostate cancer patients had some concerns about sexuality that were not being met. This gap in patient care can only be addressed when patients' concerns are communicated. Walker et al. (2016), who cited the Lintz study, found that there was an increase in relationship satisfaction for patients and partners who engaged in workshops focused on sexual activity post prostate surgery. This study highlights the importance of discussing and addressing sexual health and the positive outcomes for couples when sexual difficulties

occurred (Walker et al., 2016).

Ellis et al., (2021) found that sexual activity was linked to quality of life and meaningful community reintegration for the veterans who were interviewed. Individuals in this study expected providers to broach the topic of sexual activity and initiate appropriate therapies (Ellis et al., 2021). These findings indicate that patients have concerns and questions regarding sexual health and sexual activity and expect practitioners to initiate conversations and discuss potential barriers. The outcomes also demonstrate the importance of sexual health for quality of life.

Stigmatization, Isolation, Confusion

Patients with brain injuries seeking answers regarding sexual health and intimacy may feel lost, confused, stigmatized, or isolated when information is not readily available. For the purpose of this paper, the definitions are as follows:

- Lost will be defined as not knowing where to look to access information.
- Confusion will be defined as feeling unsure or in doubt regarding topics of sexual health and intimacy.
- Stigmatization is defined as “the act of treating someone or something unfairly by publicly disapproving of him, her, or it” (Cambridge University Press, 2022).
- Isolation is defined as “detachment from others often involuntarily” (Merriam-Webster, n.d.).

While researching the effects of stigma and isolation on patients struggling with sexual health and intimacy, no study encompassing all key terms were found in CINAHL, the Boston University library, or PubMed. Hammer and Toland (2017) state

that self-stigma impacts overall patient outcomes for those with mental illness. According to Sehlo and Bahlas (2013) a significant relationship was found between perceived stigma and depression in women with systemic lupus erythematosus. Corrigan et al. (2014) identified two sets of barriers related to stigma that may influence why patients seeking mental health services do not participate in care, they include personal-level barriers and system-level barriers. Person level barriers referred to stigma that leads to avoiding treatment, lack of support, and cultural contexts (Corrigan et al., 2014). The system level barriers included insurance companies and staff cultural competence (Corrigan et al., 2014). Individuals seeking care and assistance with sexual health and intimacy face similar barriers to individuals searching for mental health services. The Internalized Stigma Mental Illness Inventory-29 (ISMI-29) is a measure of four main types of self-stigma including: alienation, stereotype endorsement, discrimination experience, and social withdrawal (Hammer and Toland, 2017). This measure was created because self-stigma has been linked with lower treatment adherence, impaired self-esteem, and impaired self-efficacy in those with mental illness (Hammer and Toland, 2017). When healthcare workers, the support system for many patients experiencing an acute health change, avoid discussions about sexual health and intimacy patients will feel alienated.

Isolation is defined by the Cambridge Dictionary as “the condition of being alone, especially when this makes you feel unhappy” (2022). Social isolation has a strong social impact on health (Courtin & Knapp, 2017). Burgener et al. (2015) found that isolation was associated with depression, anxiety, health, and many other factors such as activity

participation. Feeling alone or isolated can happen by omission of information which is often the case with topics of sexual health and intimacy. According to Evans and Fisher (2021) individuals with strong social support have better mental and physical health outcomes than socially isolated peoples. Scores among the socially isolated were significantly higher for depression and anxiety (Evans & Fisher, 2021). Valtorta et al. (2016) examined the effects of social relationships on cardiovascular health; outcomes indicated that social isolation results in higher rates of coronary heart disease. These studies demonstrate the impact that social connections have on both mental and physical health (Evans & Fisher, 2021; Valtorta et al, 2016). A behavioral study performed by Kouchaki & Wareham (2015) examined how social connections impact choices an individual makes. The results reveal that those who were ostracized were more likely to exhibit unethical behaviors (Kouchaki & Wareham, 2015). These findings align with SDT and the idea that relatedness impacts an individual's motivation. The studies examined here span multiple countries and diagnoses. The conclusion for all of these studies demonstrates that isolation and social support impact health outcomes.

Patient Education Impacting Care

Patient education has wide ranging benefits including financial and physiological. For this paper, the American Family Physician definition of patient education will be utilized “the process of influencing patient behavior and producing the changes in knowledge, attitudes and skills necessary to maintain or improve health” (*Patient Education*, 2000). This change in knowledge, attitudes, and skills will affect communities of interest including hospitals and health organizations, patients with brain injuries, and

OTPs.

Research on patient education is a growing field that demonstrates the importance of involving patients in their own care and treatment plans. A scoping review by Stenberg et al. (2019) examined 69 studies on the topic of patient education for peoples living with chronic illness or impairment/loss. This review found that education has a positive impact on physical activities and physiologic outcomes (Stenberg et al., 2019). Participants reported medical adherence and improved knowledge (Stenberg et al., 2019). This benefits both patients and the medical institutions that provide education as increased adherence and knowledge impacts future care. Inpatient education may be related to decreased length of stay for patients and reduced hospital costs (Hosseini et al., 2019). Occupational therapy practitioners (OTPs) must advocate for the importance of patient education by emphasizing the impact on cost and length of stay to gain the support of administration.

Conclusion

Sexual health and intimacy impact patient outcomes and quality of life. Without a standard of care to address sexual health, patients have questions and feel isolated when they cannot access answers. While sexual health and intimacy are within the scope of practice of OT, there are many other factors that impact whether or not these topics are addressed. Communities of interest such as hospitals and rehabilitation centers, OTPs, and patients with brain injuries, also influence whether topics of sexual health and intimacy are addressed during rehabilitation. Occupational therapy practitioners (OTPs) can fill this gap and address sexual health to improve patient psychological and

physiological outcomes.

CHAPTER THREE – Overview of Current Approaches and Methods

Introduction

Sexual health and intimacy for patients with brain injuries is an under addressed area of concern. The Journal of Head Trauma Rehabilitation has a special issue on sexual functioning after traumatic brain injury from 2013. In this issue Stowyk et al. (2013) examined the reliability and validity of the Brain Injury Questionnaire of Sexuality (BIQS). The study consisted of 865 participants whose severity of injury ranged from mild to severe (Stowyk et al., 2013). Participants answered a 25 question self-report and the study determined that the BIQS is a reliable and valid measure. Stowyk et al. (2013) states that the BIQS can be used to determine changes in sexual function with treatment interventions. Occupational therapy practitioners (OTPs) can utilize this measure to create and implement holistic, occupation-based approaches for sexual health and intimacy.

Sexual health and intimacy are included in the occupational therapy (OT) scope of practice under the OTPF-4 (American Occupational Therapy Association, [AOTA], 2020). Most of the research on OT and sexual health are surveys based on the education and knowledge of practitioners (Young et al., 2020). Research on sexual health and intimacy interventions in OT is limited. Sexual health and intimacy are primarily addressed by pelvic therapists, neurology and urology doctors, and psychologists. The following chapter will outline common themes that these practitioners encounter when addressing sexual health and intimacy and will demonstrate the need for a holistic occupation-based approach to the topics.

Physical Health

Cardiology/Neurology

While doctors in many fields can address sexual health and intimacy, research in the fields of cardiology and neurology focuses more on these topics in the context of anxiety, depression, and long-term outcomes (Terrill et al., 2022; Palmer & Herbert 2016; Kazemi et al., 2020; Maresca et al., 2020; Noye, 1954; Rathore et al., 2019; Tulloch et al., 2021). These studies approach diagnoses under the cardiology and neurology umbrella in terms of how their relationships or sexual health influences psychological outcomes. According to Tulloch et al. (2021), “couple distress is associated with cardiovascular disease (CVD) risk factors” (p. 909). This research argues that interpersonal factors play a large role in survival rates for individuals with CVD (Tulloch et al., 2021).

Palmer and Herbert (2016) state that brain injuries can place stress and challenges on relationships which impact general functioning. This study states that relationship satisfaction and general function are correlated (Palmer & Herbert, 2016). Kazemi et al. (2020) examined the effect of sexual activity on quality of life through counseling using the PLISSIT model for young women with multiple sclerosis, which includes Permission (P), Limited Information (LI), Specific Suggestions (SS), and Intensive Therapy (IT). The study found that the group that received treatment reported a significantly better level of sexual quality of life in the long term (Kazemi et al., 2019). Maresca et al. (2020) examine the impact of body image on outcomes during neurorehabilitation. This study found that psychological and nutritional approaches to body image may assist patients

with acquired brain injuries in their overall outcomes (Maresca et al., 2020). Rathore et al. (2019) demonstrate the need to address sexual health for persons with epilepsy. The study states, “the prevalence and nature of sexual dysfunctions in people with epilepsy, its causes, and optimal management strategies are poorly understood” (Rathore et al., 2019 p. 1525). Sexual health and intimacy in the context of those with disabilities continues to be under researched.

Pelvic Health

Pelvic therapy has long addressed sexual health and intimacy through various methods. The Physical Therapy Journal (PTJ) had a special issue in 2017 specifically targeting pelvic floor dysfunction (Ohtake & Borello-France, 2017). Physical therapy is most often associated with pelvic therapy, although OTPs also practice in this specialty area. Occupational therapy practitioners provide a holistic approach to pelvic health with a focus on occupation. Viewing patients and their goals through an occupation-based lens leads to new perspectives on pelvic health as demonstrated in the OT section of this chapter. Pelvic therapy focuses on pelvic pain and associated sexual dysfunction (Rosenbaum & Owens, 2008). According to Rosenbaum and Owens (2008) the main forms of pelvic health treatment are manual therapy, exercise, pelvic floor biofeedback, electrical stimulation and other modalities, and the facilitation of multidisciplinary collaborative care. Pelvic therapy has a large musculoskeletal approach with specific muscular techniques to improve urinary incontinence that has mixed results (de Andrade et al., 2018). While this is true, pelvic rehabilitation has proven effective in treating pelvic and sexual disorders (Stein et al., 2019). When it comes to access to care, many

pelvic floor therapists do not accept insurance and the cost of therapy can range widely (Sukenick, 2021). The cost and labor of seeking out a pelvic floor therapist is only accessible to some individuals. Occupational therapy practitioners (OTPs) are in a position to train on pelvic therapy and apply an occupation-based approach that examines the whole person.

Cancer

Gynecological cancer, breast cancer, and prostate cancer can all impact the sexual health and intimacy of individuals during and after treatment. Walker et al. (2016) examined the impact of a couple's intimacy workshop for individuals post-prostate cancer treatment. This study took place over a two-year period and showed an increase in relationship satisfaction after attending a couple's intimacy workshop (Walker et al., 2016). This study states the importance of a randomized control study to further the research. Other studies regarding prostate cancer examined the psychological impacts of the diagnosis and treatment (Qan'ir & Song, 2019; Lintz et al., 2003). Quality of life scores were negatively impacted in those who had decreased sleep, increased pain, and decreased social supports (Lintz et al., 2003). The importance of occupational therapy's role in addressing sexual health and intimacy for patients with prostate cancer has not been explored in research.

Sexual health and breast cancer have been explored through various studies. Huber et al. (2006) completed an analysis of current research on breast cancer and sexual health and the key findings include that strong partners resulted in good sexual functioning, postoperative expectation for breast reconstruction should be address prior to

surgery, and long-term issues from treatment of breast cancer should be assessed and addressed. The literature review that was conducted demonstrates that sexual health and intimacy are important topics to discuss with patients who have or have had breast cancer, but interventions are not suggested or reviewed (Huber et al., 2006). According to Reese et al. (2019), less than half of women with breast cancer receive information on sexual health and intimacy. Reese et al. (2019) examined the impact of an intervention called iSHARE, which includes education about the topics of sexual health for breast cancer patients, to breast cancer clinicians. The study found that discussions about sexual health did not significantly add to clinic visit times, which is a barrier many clinicians cite as to why these topics are not addressed (Reese et al., 2019).

For gynecological cancer, Suvaal et al. (2021) examined a sexual rehabilitation program after radiotherapy (SPARC). This intervention involved face-to-face sessions from 1–12 months post-treatment and examined sexual health from a physical perspective with emphasis on pain during intercourse, vaginal dryness and health, and pelvic floor exercises (Suvaal et al., 2021). The interventions explored in this study were beneficial but did not provide a holistic approach to sexual health and intimacy. Another study by Armbruster et al. (2016) examined sexual dysfunction in endometrial cancer survivors. The intervention was 30 minutes of moderate exercise at home for five days a week with telephone counseling and printed materials (Armbruster et al., 2016). This study found that there was no statistically significant change in sexual function with physical activity (Armbruster et al., 2016). While sexual health and intimacy have been explored in the population of cancer patients with oncology doctors and nurses, there is

no current occupational approach to addressing these topics.

Special Topics

Use of Applications on Lifestyle/Health

As technology continues to advance more studies examine how they can be utilized to improve health and function. Driver et al. (2019) created a lifestyle change program with a focus on weight loss and weight management that includes a phone application to engage traumatic brain injury patients. This program is a proposed study, and the application was created with HIPAA compliance and provides information to patients on lifestyle change and attention control support groups (Driver et al., 2019). The pilot study provided positive results in use with the phone application (Driver et al., 2019).

Feroz et al. (2021) looked at how mobile phones can be utilized to improve sexual and reproductive health for young people in low- and middle-income countries. Studies utilizing mobile health applications were reviewed primarily in East and West Africa and show significant changes in education and behavior change (Feroz et al., 2021). Barriers identified to the use of phone applications in low- and middle-income countries included poor technology literacy, low network coverage, low literacy levels, high cost of service, and cultural beliefs and expectations (Feroz et al., 2021). Use of mobile phones in managing health is becoming more popular and continued research on the impact of sexual health and intimacy would be beneficial.

An emerging area of interest is the impact of artificial intelligence (AI) on health and healthcare management. Nadarzynski et al. examined barriers and facilitators to

using AI-based chatbots for the topics of sexual and reproductive health (2021).

Participants expressed that the chatbot is useful for topics seen as embarrassing to discuss in face-to-face interactions with healthcare providers (Nadarzynski et al., 2021).

Participants were concerned with the privacy of utilizing online chatbots to discuss sensitive information (Nadarzynski et al., 2021).

Psychological Health

Impact of Relationships on Health

Many factors influence and impact an individual's psychological health. For this paper relationships will refer to emotionally or physically intimate connections with other individuals. A meta-analysis performed in 2015 showed that “individuals with adequate social relationships have a 50% greater likelihood of survival compared to those with poor or insufficient social relationships” (Holt-Lunstad et al., 2015, p. 14). This demonstrates that relationships have the same impact as other risks for mortality including obesity, smoking, and physical inactivity (Holt-Lunstad et al., 2015). While this study demonstrates the impact of relationships on mortality, another meta-analysis in 2004 found that relationships impact medical adherence (DiMatteo, 2004). Research on people with diabetes suggests that there are improved outcomes for partnered individuals (Wooldridge & Ranby, 2023). Woolridge and Ranby (2023) found that relationship factors impact a patient's self-efficacy with diabetes management.

Women and Mental Health

Sexual issues can impact women's well-being and are associated with symptoms of depression (Merwin et al., 2017). Lack of communication on the topic of sexual health and intimacy in a relationship can also lead to decreased relationship satisfaction and an increase in depression symptoms (Merwin et al., 2017). Providing strategies to assist women in discussions about sexual health can assist not only with relationships, but with overall well-being. A literature review examined sexuality and intimacy for women post diagnosis and treatment of breast cancer (Huber et al., 2006). According to Huber, Ramnarace, and McCaffrey (2006) patients lack knowledge on how cancer can affect sexual health. While breast cancer survival rates have continued to increase, sexual health changes can persist after treatment for cancer has ended (Huber et al., 2006). This study reflects the importance of a holistic approach to care with healthcare practitioners who address the needs of their patients throughout their lifespan.

Sansone, Chu, and Wiederman (2011) examined borderline personality disorder (BPD) and its correlation with sexuality. The study found that women who scored positive for BPD had a higher number of sexual partners as well as a higher rate of rape (Sanson et al., 2011). The study framed its conclusion that women with BPD are more impulsive and prone to victimization (Sansone et al., 2011). The examination of a specific psychological diagnosis and its impact on sexual health is important. It is also crucial to provide holistic care aimed at addressing behaviors associated with specific diagnoses while acknowledging that an increase in sexual partners does not necessarily mean a decrease in sexual health.

While researching sexual health and intimacy in psychology, many of the studies focused on women. Tasca et al. (2012) examined the lengthy history of women and hysteria, a diagnosis that was given to women who lived outside of the cultural norms of the time. The history of mental health diagnoses specific to women dates to 1900 BC and describes spontaneous uterus movements (Tasca et al., 2012). This long history of women and mental health may help to explain why psychological research focuses on women and their relationship with sexual health and intimacy and often does not address men.

Occupational Therapy

Current Interventions

Research has shown that OTPs understand that sexual health and intimacy are ADLs but do not address these topics during therapy (Young et al., 2020). Ellis et al. (2021) created a study examining sexual health and intimacy with the military population. This study used a qualitative research approach to examine the experiences of three clients with the Occupational Therapy Sexuality and Intimacy Program at a Military Treatment Facility (Ellis et al., 2021). The study emphasizes the importance of OTPs role in addressing these topics as they are specifically trained for holistic care and working with individuals' daily routines (Ellis et al., 2021). The OTPF-4 (2020) lists sexual activity as an ADL and 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)” (p. 30). While OTPs agree that sexual health is an important topic and within their scope of practice, most acknowledge that they do not

address the topic in practice secondary to lack of education or lack of confidence in knowledge (Young et al., 2020).

Education for Practitioners

A lack of knowledge on how to address sexual health in practice has been identified as a barrier by OTPs (Young et al., 2020). To assist with this barrier the Institute for Sex, Intimacy, and Occupational Therapy was created by Dr. Kathryn Ellis. The website provides virtual continuing education courses (CEU) for OTPs on topics such as inclusive practice, sexuality and breast cancer, assistive devices for sexual activity, and more (Ellis, 2022). Courses through the site are approved through the AOTA for CEU.

While formal continuing education credits on the topics of sexual health are growing there are more informal avenues of learning available. Occupational Therapy After Dark is a podcast that addresses topics of sexual health and intimacy through an inclusive lens (K & JJ, 2019–present). The podcast is targeted toward OTPs with an emphasis on models, interventions, and approaches for sexual health that can be used in practice (K & JJ, 2019–present). This less formal education on the topic of sexual health is accessible to practitioners and can be utilized to further knowledge and comfort with the topic.

Advocates with Lived Experience

The disabled community are the driving force behind new practice areas, with members leading the way by discussing topics and sharing personal stories. The Disabled After Dark Podcast is run by Andrew Gurza and is a resource to learn more about

disability and sexual health (Gurza, 2016–present). The target audience is members of the disability community with guests discussing personal experiences with sexual health and relationships (Gurza, 2016–present). Disabilities featured on the podcast include down syndrome, chronic pain, hearing loss, cerebral palsy and more (Gurza, 2016–present). This podcast also discusses sex care workers and how sex workers can assist those with disabilities (Gurza, 2016–present).

Melissa Crisp-Cooper authored *Our Sexuality, Our Health: A Disabled Advocates Guide to Relationships, Romance, Sexuality, and Sexual Health* (Crisp-Cooper, 2018). This is a guide that addresses power imbalances, medical appointments, sexual violence, dating, marriage, pregnancy, and more (Crisp-Cooper, 2018). This guide is targeted toward both individuals with disabilities and anyone who would like to learn more about disabilities and sexual health. Melissa Crisp-Cooper acknowledges that as a cisgender, white, heterosexual woman, and wheelchair user, she brings her own biases and experiences into the guide (Crisp-Cooper, 2018). Occupational therapy practitioners (OTPs) can learn from the information provided and apply it to practice by beginning conversations about sexual health with discussions on power and respect.

The National Partnership for Women & Families and the Autistic Self Advocacy Network created a pamphlet titled “Access, Autonomy, and Dignity: Comprehensive Sexuality Education for People with Disabilities” (Mhatre, 2021). This pamphlet provides information on the importance of sexual education, specifically for those with disabilities (Mhatre, 2021). The pamphlet recommends training educators about specific concerns of people with disabilities, building trust between educators and the disability community,

enacting laws to support sexual education access, and more in order to ensure access to sexual health education for those with disabilities (Mhatre, 2021). These proposals emphasize the importance of discussing and learning about sexual health to improve mental health, decrease risk of STIs and HIV, and empower individuals to have healthy sexual relationships (Mhater, 2021).

Conclusion

Research on sexual health and intimacy are currently focused on physical health with specific conditions and psychological health. While pelvic therapists address sexual health, their focus is musculoskeletal based and does not have the occupation and holistic lens that OTPs can provide. Research demonstrates that there is a gap in practice regarding sexual health and intimacy education and practice. The BIQS is a proven measure for sexuality in those with traumatic brain injuries but has yet to be fully utilized by OTPs in practice settings. Through advocates' lived experiences, OTPs can learn about sexual health education and effective approaches to treatment. As demonstrated in this chapter, OTPs require more education on the topic of sexual health and intimacy, and it can be provided by increased lectures from advocates and incorporating sexual health topics into discussions about specific disease states including brain injuries.

CHAPTER FOUR – Description of the Proposed Program

Proposed Project

Comfort is an app that will provide educational materials to patients currently receiving therapy for brain injuries in inpatient rehabilitation settings. Hospitals and organizations will purchase the app for use by their patients and therapists to assist with addressing sexual health and intimacy. This educational material will include tip sheets, videos on positioning and safety, lectures on healthy relationships, and virtual worksheets. The app will also have an area for anonymous questions that can be asked to clinical OTPs who can provide the answer to the community at large or may refer the questions to another healthcare worker. Occupational therapy practitioners (OTPs) will assist patients with downloading and setting up the app to allow patients the privacy of exploring the app individually or exploring the app in a supported environment. *Comfort* aims to address problems and barriers that patients experience regarding sexual health and intimacy through an occupational, holistic, and patient centered lens.

Sexual health and intimacy are rarely addressed with patients who have an acquired brain injury during their hospitalization and rehabilitation. Although many healthcare workers have the potential to address this topic, sexual activity is considered an ADL and should be addressed by an OTPs. Hospitals and organizations lack a standard of care regarding this topic and would benefit from a comprehensive app that provides some of the education and information that patients require.

Exploratory Model and Theory

Self-Determination Theory

Theory drives OT practice, self-determination theory (SDT) is used to support the claims of this program. Self-determination theory has three core concepts: autonomy, competence, and relatedness. Autonomy is focused less on independence and more on the ability to choose and follow an individual's own interests (Gagne & Deci, 2005). *Comfort* will provide autonomy to individuals as they are able to explore topics and make choices to find answers that satisfy their needs. With knowledge gained from the app, patients will feel a sense of competency on topics that are often taboo in the medical setting. The app will allow patients to gain an understanding of sexual health and intimacy without having to ask questions to a healthcare worker. *Comfort* will provide a network of healthcare information and resources so that patients can feel a larger sense of community and relatedness. Self-determination theory supports the use of an app to communicate information on sexual health and intimacy.

Sexual Health Model

The sexual health model was created to fill a gap in theories that could address HIV prevention and is focused on a sex positive and comprehensive approach to sexual education (Robinson et al., 2002). This model provides relevant information for education on sexual health and intimacy. The 10 major components of the sexual health model are as follows: talking about sex, culture and sexual identity, sexual anatomy functioning, sexual health care and safer sex, challenges, body image, masturbation and

fantasy, positive sexuality, intimacy and relationships, and spirituality (Robinson et al., 2002). *Comfort* will address each component of the sexual health model through online modules that patients will access through their smartphones. The sexual health model will be used to develop relevant educational materials for *Comfort*.

Communities of Interest

Hospitals and organizations who are interested in preventative care and are implementing cost saving techniques are candidates for *Comfort*. These organizations will be key players in the implementation of the app by providing referrals to patients. The hospitals and organizations will provide logistics on rolling the app out to their current therapists in an effective manner that will best benefit their patients and staff. Referrals to specialists within each organization will be made through the app to assist with patient retention. As data returns about the app, hospitals and organizations will aid with analyzing the information ensuring that their interests are being met. Hospitals and organizations will provide funding for *Comfort* and their interests will be addressed via pre and post data analysis.

Occupational therapy practitioners who provide education on *Comfort* to patients will be involved in all parts of the program. Occupational therapy practitioners working in inpatient acute facilities have a unique view on the needs of their patients, and they can assist with developing the design of the app to ensure that it is user friendly and provides information that patients may be interested in. Occupational therapy practitioners are critical to the implementation of *Comfort* as well. They will introduce the app to patients and instruct patients on use and benefits of the app. Occupational therapy practitioners

are in a unique position to provide feedback on educational materials provided in *Comfort*. They can provide a holistic approach to topics and assist with ensuring that patients feel comfortable using *Comfort*. They will be helpful in the reflection process of the program to analyze the results of data that emerge as well as providing feedback on patient satisfaction with *Comfort*.

Patients with acquired brain injuries are a key community of interest in the success of *Comfort* as the app will be created with a vision targeted toward improving their quality of life and satisfaction. Patients will provide information regarding topics that they would like to learn more about, types of learning styles, and current data regarding relationships and anxiety/depression. The information gathered during the surveys will be utilized in the planning phase to ensure that *Comfort* is filling a need. Patients will engage in sessions with *Comfort* during their inpatient stay with the assistance of occupational therapists. This will ensure that any problems using the application can be addressed immediately and patients will feel more comfortable using the application on their own. After discharge, patients will use the app at home and will be prompted to reflect on their experience with *Comfort* and the impact that new information on sexual health and intimacy has had on their life. The target demographic for patients who utilize *Comfort* will be adults over the age of 18, in the inpatient rehabilitation setting, of any gender, who can read English, have access to a smartphone, and are in the United States. Figure 2 demonstrates an example of a patient utilizing *Comfort* with success.

Figure 2*Case Scenario*

Jennifer is a 31-year-old female admitted to the hospital post traumatic brain injury. She has been experiencing decreased safety and cognition as well as poor balance, decreased endurance, decreased fine motor skills, and vertigo. Jennifer is referred to an inpatient rehabilitation hospital where she receives OT services. When discussing goals with the OTPs Jennifer discusses her relationship with her significant other. She asks questions about when she can resume participating in sexual activity and trying for a child. The OTPs addresses Jennifer's questions and refers to *Comfort*. After demonstrating how to utilize the app Jennifer can explore the resources available. During her next OT session Jennifer expresses her satisfaction with the application and her hospital stay. She feels reassured that her relationship and sexual health can continue and states that her stress levels have decreased since her exploration of *Comfort*.

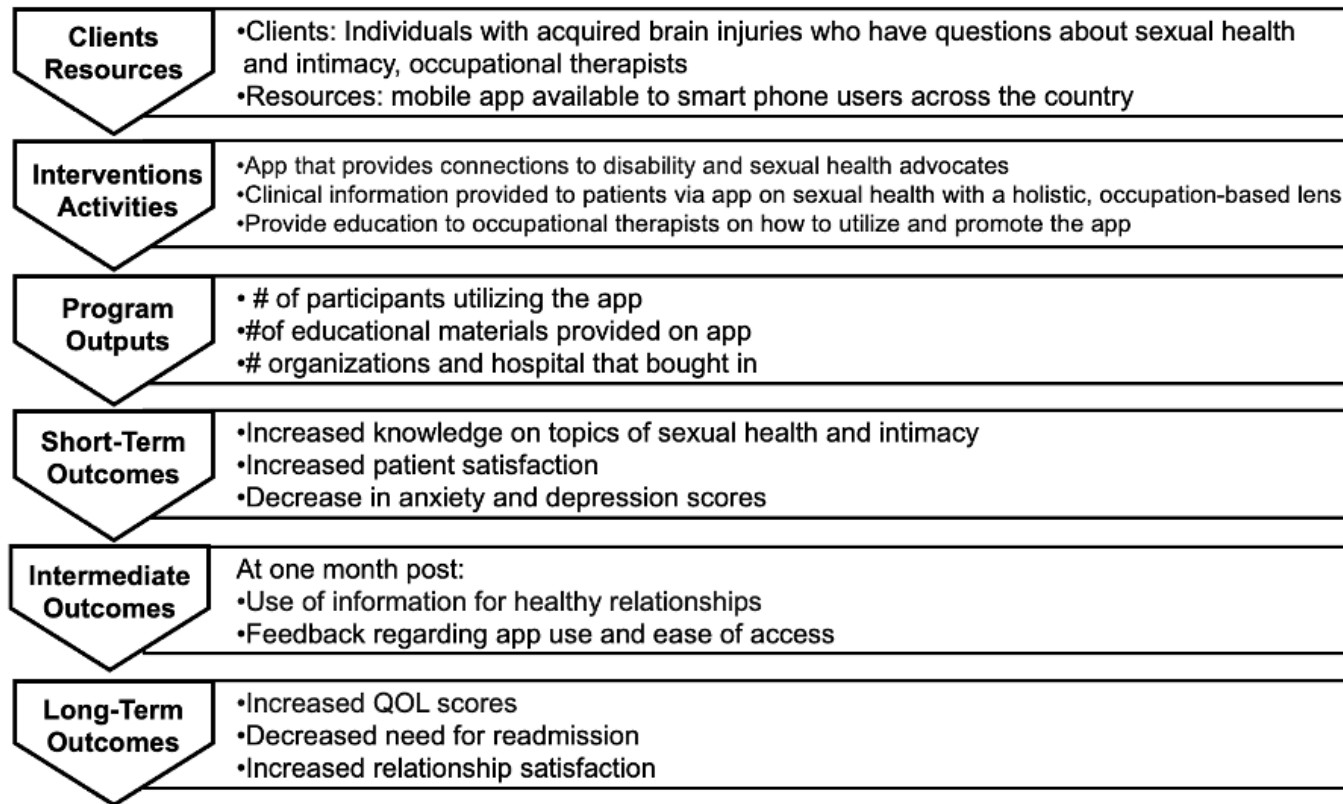
Aims and Objectives

Comfort is designed to create a safe and judgment free environment for individuals with brain injuries to learn more about sexual health and intimacy. The main aims and objectives of *Comfort* are to increase patients' knowledge and quality of life. Through the application, patients will increase knowledge and understanding of sexual health and intimacy topics post brain injury. Patients will report an increase in comfort addressing topics of sexual health with doctors and health care workers. Patients will report a decrease in feelings of isolation and loneliness after utilizing *Comfort*. Other aims of *Comfort* include increasing patients' understanding of specialists who can address the topics of sexual health and intimacy and expanding the role of occupational therapists

in addressing sexual health and intimacy. A logic model demonstrating how these aims and objectives will be reached is in Figure 3. As demonstrated in this figure, an increase in knowledge on the topics of sexual health and intimacy, patient satisfaction, and a decrease in anxiety and depression scores will result in an increase in quality of life and decrease readmissions.

Figure 3

Simplified Logic Model of the Proposed Program and Evaluation



Program clients and resources

Comfort will be an online app that patients can access from their smartphones. To gain access to the app patients will be provided with a pin code for the hospital or organization they are receiving care from. *Comfort* will provide modules on sexual health and intimacy with topics ranging from consent, safe positioning, types of intimacy, and healthy relationships. While the information will be provided to patients via an online format, OTPs will provide one on one sessions that address utilizing *Comfort*, the information that *Comfort* provides, and how the information can be applied to individuals' lives.

The American Occupational Therapy Association (AOTA) will be vital in spreading information and the importance of *Comfort* to hospitals and organizations. Occupational therapy practitioners will be prepared to provide sexual health and intimacy education to patients across diagnoses and settings. Specialists who can address specific parts of sexual health and intimacy such as urologists, neurologists, pelvic therapists, and cardiologists will be contacted to refer patients to *Comfort* as well. These specialists will benefit from the use of the app because patients will know the assistance that each specialist can provide and whom to reach out to. Local advocacy groups for brain injuries will also assist in spreading the use of *Comfort*. Local brain injury groups will be contacted and provided with hospitals and organizations that have partnered with *Comfort*. Practitioners within each hospital and organization will be provided with continuing education courses on the importance of addressing sexual health and how referring patients to *Comfort* can impact outcomes and quality of life.

Interventions and Activities

Theory Driving Interventions

Comfort will utilize SDT to unite the modules and information and ensure that participants are motivated to continue learning and using the app. *Comfort* will provide six modules that will present information on relationships, sexual health, and intimacy. The content for these modules will be developed using the sexual health model. This model has 10 pillars which are: talking about sex, culture and sexual identity, sexual anatomy functioning, sexual health care and safer sex, challenges, body image, masturbation and fantasy, positive sexuality, intimacy and relationships, and spirituality (Robinson et al., 2002). The modules will each have questions that relate to the overall topics. The content of the module will be non-sequential so that individuals have the autonomy to choose which topics and questions that they would like to explore during a session. After choosing a question to explore patients can choose to flip through slides with information and visual examples, or they can listen to a video describing the answer. The ability to choose which questions to answer and how the information is presented will build autonomy for patients. Patients will also choose when they use the app and for how long.

As patients move through the modules, they will gain knowledge about sexual health and intimacy. The content in the app covers anatomy and brain injuries, facts about how the United States approaches sexual health education, definitions of consent and situations in which consent is given, and more in compliance with the sexual health model. Patients who utilize *Comfort* will gain competency in the development of healthy

relationships, how brain injuries can affect sexual health, how anatomy is relevant to sexual activity, and how society views and addresses sexual health. Patients will also be able to contact OTPs for further information or questions. This ability to continue problem solving outside of the app will contribute to overall competency and participants will feel motivated to continue using *Comfort* according to SDT (Gagne & Deci, 2005).

For individuals to develop internal motivation they must feel connected to their community and this is called relatedness (Gagne & Deci, 2005). *Comfort's* first module is an introduction to sexual health and tackles the barriers to addressing these topics in the United States. Sexual health and intimacy are taboo topics in the United States with restrictions on how information is taught in public schools (*Sex and HIV Education*. 2023). The restrictions and public debate about how, when, and if sexual health is addressed in schools reflects overall culture in the United States that sexual health is to be dealt with privately. *Comfort* will provide reassurance to patients that they are not the only ones with questions and concerns about sexual health that are not being addressed elsewhere. The app will provide resources to connect patients with healthcare workers who can answer questions in person, and provide podcasts, news articles, and more to create a community of individuals who wish to know more about these topics. Patients will be motivated to continue learning and advocating for themselves on the topic of sexual health and intimacy because *Comfort* is designed with SDT and the sexual health model.

Accessibility and User Experience

Comfort will be designed using the Web Content Accessibility Guidelines (WCAG) and will go another step to ensure that it is specifically accessible to those with brain injuries (Díaz & Del Cano, 2021). The main principles of WCAG are perceivable, operable, understandable, and robust (Díaz & Del Cano, 2021). *Comfort* will provide audio, video, and text information that provides the same content so that individuals can access knowledge however they choose. All videos will have captions and videos will have audio descriptions. The modules will be nonlinear, and patients will be prompted to choose which questions they would like to explore and what media they would like to use to explore them. *Comfort* will ensure that there are no time limits on how long media is presented for, patients will be able to swipe through media at their own pace and return to prior information with ease. Visual accessibility will be important, and *Comfort* will utilize contrast ratios of 4:5:1, have limited background media, and arial typeface as demonstrated in Figure 4B. Colors featured in *Comfort* will be subdued and faded without bright blue light to avoid headaches or eye strain and fatigue.

The modules of *Comfort* will be designed to last 10–15 minutes so that participants can attend to the information provided. Participants will have the ability to navigate through the application at their own pace. Rest breaks will be provided halfway through each module and then for every 5 minutes spent on the application. These rest breaks will be pop ups that consist of an auditory and visual break with less blue light and auditory and visual cues to participate in deep breathing and a stretch, with different stretches for each module. An example of the content for modules can be found in

Appendix C. These modules will receive a 70 or higher on the Flesch-Kincaid readability score to ensure that the general public is able to understand the content provided (Scott, 2023).

Modules and Continued Use

During the first two years of existence, *Comfort* will launch in three phases (Figure 5D). The first phase includes the original six modules outlined in Table 1E. Each of these phases will provide patients with knowledge and resources on a specific topic. Occupational therapists will provide *Comfort* to patients and assist with navigating the application. This phase will last six months to continue editing information and formatting. Phase 2 will include four new modules as well as an interactive section to ask questions to occupational therapists. This expansion will allow patients to ask specific questions in a safe and virtual setting. This phase will also include a calendar to track symptoms associated with brain injuries to assist with planning intimacy which can be used indefinitely. Phase 2 will be introduced after six months. Phase 3 will introduce four more modules and a peer support section to create a deeper community and provide lived experiences. The peer section will be monitored by an OTPs to ensure that misinformation or harmful rhetoric is not present. The peer section and symptom calendar will allow patients to continue using the application after they have finished the modules.

Program Outputs and Outcomes

Comfort has multiple goals that apply to organizations, practitioners, and patients. Each of these communities of interest are addressed in the program's outputs and

outcomes. Outputs will examine the number of patients who utilize the app and how long these patients are active. This information will provide information on the effectiveness of the app and provide data for realistic module running times. The educational modules that are produced for *Comfort* will also be an output from the program that can be used in other formats as needed. Patient data that is gathered from *Comfort* on quality-of-life surveys will be considered an output from the app.

Formative and summative outcomes will be gathered for *Comfort*. Formative data will examine the effectiveness of the app at imparting desired information on relevant topics. Surveys and questionnaires will be used in the app to ensure that patients have gained knowledge and feel that their needs are being met. Information gathered at this stage will contribute to education that is provided in *Comfort* and the effectiveness of media that is used in the app.

Summative data will include knowledge questions, quality-of-life questionnaires, anxiety and depression scales, and satisfaction in relationships. These surveys will be provided by an OTPs prior to using *Comfort*. Patients will take the scales and quiz again six months after access to *Comfort* begins. This data will allow researchers and communities of interest to note if there are changes in identified areas. The amount of time and frequency that patients utilize *Comfort* will also be tracked and reported to communities of interest.

Anticipated Barriers and Challenges

Taboo

Sexual health and intimacy are taboo topics in the United States, this is evidenced by restrictions and limits on how and when sexual health is addressed in schools (*Sex and HIV Education*. 2023). When sexual health is addressed in schools it is focused on abstinence and topics do not surround pleasure or sexual health for disabled peoples (National Conference of State Legislatures, 2020). These conversations do not often occur at home, and since they are not addressed in schools many individuals turn to alternative outlets for education. Porn and television are often substitutes for education surrounding sexual health and intimacy which can be problematic when attempting to address these topics in healthcare. Religion has historically played a role in conversations about sexual health and intimacy, contributing to the taboo nature of these topics. Religions have lobbied for sexual education in schools to focus on abstinence and many religions focus on no sexual intercourse before marriage (Boonstra, 2008). Healthcare practitioners have reported that they do not bring up sexual health and intimacy because they do not want to offend patients (Young et al., 2020).

Tackling societal and religious taboos can be difficult as many of these ideals have been ingrained since childhood. *Comfort* will utilize a culturally sensitive approach to addressing the topics of sexual health and intimacy that will put users at ease and allow for understanding across cultures. Information that is provided will be medically relevant and focused on an occupational, holistic approach. Providing information in multiple formats will also ensure that patients are comfortable accessing educational materials.

Comfort will be an app on smartphones and outside individuals will not know what the app is for, preserving privacy for participants.

Practitioner Education

Occupational therapy practitioners have reported that they do not feel comfortable addressing sexual health and intimacy because they do not feel they have enough knowledge on the topic (Young et al., 2020). Lack of knowledge on the topic of sexual health is a common reason why healthcare practitioners avoid discussions on these topics. When healthcare providers are hesitant to answer questions on sexual health and intimacy patients may feel that these discussions are not allowed to occur. Avoiding discussions about sexual health and intimacy in medicine reinforces the idea that these topics are stigmatized and not to be talked about.

Continuing education credits are required for healthcare providers in the United States. While these requirements vary from state to state it would be beneficial for requirements to include one credit on the topic of sexual health and intimacy regardless of specialty or position. This education will focus on how to approach the topics of sexual health and intimacy and which specialists to refer to if patients have further questions. Creating an environment where patients feel comfortable asking questions to practitioners is critical to preventing feelings of stigmatization and depression.

Literacy

Comfort is an online app that can be accessed through smartphones. Patients will need to be able to access the app and navigate through the modules. This requires access to a

smartphone and the internet, and a level of computer literacy that some individuals may not have. As patients navigate through the app they will encounter educational materials that are written as well as videos and audio content. Providing content in various formats will be beneficial to some patients who learn better through alternative means, but the app can be more difficult to manage with links to PDFs and videos.

Occupational therapy practitioners will be able to provide initial assistance with using *Comfort* to ensure that participants can navigate through the app. Patients will also be able to reach out to their OTPs while using *Comfort* with questions or concerns. For those with lower technology literacy, the app may be intimidating and may affect the amount of time that they spend using it.

Conclusion

Comfort is a crucial tool that helps to bridge a gap in practice that is not being addressed in a holistic manner by any one healthcare provider. Sexual health and intimacy are taboo topics that are avoided by both patients and healthcare providers. While these topics may be uncomfortable, it is important for patients to have their questions and concerns answered in a supportive environment. Occupational therapy practitioners are in a unique position to facilitate the use of *Comfort* by individuals with brain injuries receiving therapy. These therapists have a unique view on how brain injuries can affect overall patient outcomes and how these outcomes may impact sexual health and intimacy. Hospitals and organizations can set themselves apart by providing *Comfort* to ease patient concerns about sexual health and intimacy after a brain injury.

CHAPTER FIVE – Program Evaluation Research Plan

Introduction

Comfort is an app that will provide needed information to patients while also contributing to the pool of research that occupational therapy practitioners (OTPs) are creating on the topic of sexual health and intimacy. To accurately determine the impact of *Comfort* on all communities of interest multiple outcome measures will be analyzed. Formative and summative outcomes will be measured through a mixture of qualitative and quantitative measures. The mixed methods approach to outcome measurements will provide depth to the study and will contribute to research.

Program Scenario and Identified Communities of Interest

Sexual health and intimacy are rarely addressed with patients who have a brain injury during their hospitalization and rehabilitation. Although many healthcare workers have the potential to address this topic, sexual activity is considered an ADL and should be addressed by an OTPs. Hospitals and organizations lack a standard of care regarding this topic and would benefit from a comprehensive app that provides some of the education and information that patients require. The app will provide educational materials, link users with leaders in the disability community, and connect users to other providers in the hospital or organization.

Comfort will provide educational materials that include tip sheets, videos on positioning and safety, lectures on healthy relationships, and virtual worksheets. The app will also have an area for anonymous questions that can be asked to clinical OTPs who may refer the questions to another healthcare worker or can provide the answer to the

community at large. Occupational therapy practitioners (OTPs) will assist patients with downloading and setting up the app to allow patients the privacy of exploring the app individually or exploring the app in a supported environment. Hospitals and organizations will purchase the app for use by their patients and therapists to assist with addressing sexual health and intimacy.

Theory drives occupational therapy practice and self-determination theory (SDT) and the sexual health model will be utilized to support the claims of this program. Self-determination theory has three core concepts: autonomy, competence, and relatedness (Gagne & Deci, 2014). *Comfort* will provide autonomy to individuals utilizing it as they are able to explore topics and make choices to find answers that satisfy their needs. With gained knowledge from the app patients will feel a sense of competency. The existence of *Comfort* will provide patients with reassurance that they are not alone in their concerns and questions about sexual health which contribute to a sense of relatedness. The app will allow patients to gain an understanding of sexual health and intimacy without having to ask questions to a healthcare worker that they may feel uncomfortable discussing these topics with. The sexual health model will provide structure for the education materials that *Comfort* provides. The sexual health model has 10 components that guide patient education and each of the 10 topics will be addressed in the educational materials (Robinson et al., 2002).

Comfort will be provided to patients during their hospitalization. Occupational therapy practitioners will provide patients with the information on *Comfort* and teach patients how to utilize the app. Patients will be given the opportunity to explore the app

on their own while still in the hospital and presented with the chance to ask questions about information and use of the program. Patients will have access to *Comfort* upon discharge and can explore it for information at any time. Although the app will be on a smartphone, the context of learning about, and exploring the app, will begin in the hospital or inpatient treatment center where it is introduced to the patient. The OTPs introducing *Comfort* should be prepared for questions regarding sexual health and intimacy.

Hospitals and organizations that have purchased *Comfort* can grant any patient access to the program. While many of these patients may have a diagnosis other than brain injury, they may still benefit from the information provided on sexual health and intimacy. Patients with a variety of diagnoses can access information and referrals to other healthcare workers through the app. Occupational therapy practitioners are communities of interest in the creation of *Comfort* as the app will expand their practice in the hospital and inpatient setting. Occupational therapy associations will be communities of interest at a larger level to encourage education of sexual health and intimacy for OTPs to better prepare them for addressing these topics. Occupational therapy practitioners will answer questions on sexual health and provide referrals to other healthcare workers within the system. Hospitals and organizations will gain referrals to other practitioners that patients may not have sought out without use of the app and OTPs.

Vision for the Program Evaluation Research

The vision for *Comfort* will include changes in the way that sexual health and intimacy are addressed in healthcare systems for patients with acquired brain injuries. In

the immediate future *Comfort* will increase knowledge on sexual health and intimacy for patients with acquired brain injury. Patients will utilize the app to view tip sheets and resources to better understand the topics of sexual health and intimacy. This increase in knowledge will result in increased patient satisfaction as patients will feel that their questions and concerns are being addressed. The formative and summative assessments will demonstrate that utilization of *Comfort* will decrease depression and anxiety in patients. As results come in from users, the app will be adjusted to ensure that patients' areas of concern are being addressed. The short-term vision for *Comfort* focuses on patient satisfaction and use which allows communities of interest such as hospitals and organizations to analyze data and promote their unique approach to addressing an underserved area of healthcare.

As *Comfort* continues to develop and improve, the long-term vision will include increased quality of life scores and increased relationship satisfaction. Providing patients with the education and resources that they require regarding sexual health and intimacy will ensure that problems in this area are resolved prior to leaving the healthcare facility. Patients will utilize the information that they have gained from *Comfort* to engage in healthy and satisfying relationships. This increase in satisfaction of relationships and the increase in knowledge will lead to increased quality-of-life scores. Hospitals and organizations will benefit from this data as they can demonstrate increased patient satisfaction scores.

On a larger scale the vision for *Comfort* includes reducing the gap in care regarding sexual health and intimacy, placing OTPs as the primary healthcare

professional to address these topics. Occupational therapy practitioners working in acute care will need further education on sexual health and intimacy to feel comfortable answering questions and utilizing *Comfort* with their patients. Increasing awareness of the role that occupational therapists play in addressing sexual health and intimacy will impact funding from agencies such as NJOTA and AOTA. These agencies will benefit from the data collected and will impact care of patients on a national level.

Simplified Logic Model of the Program and Evaluation Plan to Share with Communities of Interest

Creating a logic model of the program and evaluation plan will assist communities of interest with visualizing what the app will provide and how it will benefit the clients involved. Figure 3 lays out which clients *Comfort* will be targeted toward as well as the resources required to access the program. Figure 3 describes the interventions that the app will provide to patients as well as outcomes at different stages of the program's development. Figure 3 also outlines the program outputs.

Engagement of Communities of Interest in the Program and Evaluation Research

Communities of interest engagement is critical to create a successful app that will be utilized to address sexual health and intimacy in hospitals. The communities of interest involved include OTPs, patients with brain injuries, hospital and organizations that have bought in, the AOTA and NJOTA, and myself as the researcher. Occupational therapy practitioners who provide the app to patients will be involved in all parts of the program. Occupational therapy practitioners working in inpatient acute facilities have a unique view on the needs of their patients, they can assist with building the app to ensure that it

is user friendly and can provide perspective on information that patients may be interested in. These therapists are critical to the implementation of *Comfort* as they will be introducing it to patients and instructing patients on use and benefits of utilizing the program. Occupational therapy practitioners will be helpful in the reflection process of the program as they analyze the results that emerge as well as providing feedback on patient satisfaction with *Comfort*.

Patients with brain injuries are a key community of interest as *Comfort* will be created with a vision targeted toward improving their quality of life and satisfaction. Patients will provide information regarding topics that they would like covered in the app, types of learning styles, and current data regarding relationships and anxiety and depression. The information gathered during the surveys will be utilized in the planning phase to ensure that *Comfort* is filling a need. Patients will engage in sessions with *Comfort* and utilize the app at home to gather information. During this engagement they will be prompted to reflect on their experience with the app.

Hospitals and organizations who have purchased *Comfort* will be key players in the implementation of the program. Occupational therapy practitioners will introduce the program to the patients while they are in the hospital. The hospitals and organizations will provide logistics on rolling the app out to their current therapists in an effective manner. As data comes in, this community of interest will aid with analyzing the information ensuring that their interests are being met.

Comfort will expand the role of OTPs in inpatient hospitals and acute care to include addressing sexual health and intimacy. This expansion will garner attention from

the NJOTA and AOTA. These organizations will assist with funding for *Comfort* and will assist with reflection on the data and research quality. NJOTA and AOTA will utilize the high quality of research performed on *Comfort* to allow for changes in policy regarding OTPs as the primary healthcare professionals to address sexual health and intimacy. Both organizations will provide insights and advice on dissemination of the research to reach the largest audience and to encourage others to utilize *Comfort*. Table 2F outlines the communities of interest that *Comfort* will target. This table examines possible roles of each community of interest and the specific interests that *Comfort* will address for them.

Eliciting Communities of Interest Involvement and Ensuring that Evaluation

Results will be Used

Community of interest involvement will ensure the success of *Comfort*. To ensure that communities of interest are involved and excited about results, meetings will take place prior to the soft launch of the app. Meetings will involve OTPs who will introduce the app to patients, hospital staff who have an interest in sexual health and intimacy, and hospital administration. Each of these communities of interest will participate in a quarterly meeting to discuss current outcomes and ensure that the app is meeting the needs of the organization. The meetings will take place in the hospital where the soft launch will occur. Communities of interest will have the option to attend in person or virtually via Zoom. To ensure that the meetings are collaborative and participatory, each community of interest will have a representative who will contribute to the meetings by providing their perspective on the app and the process of creation.

Meetings with communities of interest will begin prior to the initial survey that

patients will receive regarding qualitative information. The initial meeting will outline the logic model provided in Figure 3 and review the goals of *Comfort* to improve patient health and quality of life by addressing sexual health and intimacy during their hospital stay. Communities of interest will have the opportunity to provide their perspectives on questions for the survey that patients will take to assist with formation of the app. A literature review of the current research on sexual health and intimacy impacting quality of life and patient satisfaction will be provided to the group. Research on this topic is limited and will demonstrate to communities of interest the importance of the app and further research in this area.

Communities of interest involvement will assist with the success of *Comfort* and it is important that these communities of interest are active participants in evaluating results as well as the creation of the app. Hospitals and organizations will play an important role in disseminating the results of any research conducted. Their perspective and goals must be included and accounted for. An online network such as Microsoft Teams will be used outside of set meeting times to allow communities of interest to provide insights on the research and results.

To ensure that evaluation results will be utilized by communities of interest, a mixed methods approach will be used for research. Formative information will be gathered utilizing a survey that includes a Likert scale and open-ended questions. The qualitative data will help organizations and hospitals to ensure that their values and needs are being met by the research. The summative data will consist of quality-of-life scale, the hospital anxiety and depression scale, the sexual health indicators inventory, and a

knowledge-based quiz. The scales will be completed before and after utilizing *Comfort*. Changes from the pre and post survey will be recorded and presented to hospitals and organizations with emphasis on patient satisfaction and references to healthcare workers in the same system.

Program Evaluation Research Questions by Communities of Interest Group

Table 3G outlines research questions that the primary communities of interest will examine. The primary communities of interest will include myself as the researcher, patients with brain injuries, hospitals and organizations that have bought into *Comfort*, and the AOTA and NJOTA. Each of these communities of interest has a unique view on the app and on the research questions that should be examined which is reflected in the following table. The formative questions in Table 3G will assist with app development and will ensure that the program is reaching the intended audience in the manner predicted. The summative questions will examine whether the app is effective in its goals.

Research Design

Formative Research Design

The impact of sexual health and intimacy on individuals with brain injuries has not been highly researched through the lens of OT. Without a large basis of research to pull from the qualitative and quantitative information gathered will be crucial to creation of the app and formation of the program. Patients will participate in a mixed methods study before their first session utilizing the app to find out what patients want to learn about and how they learn best. This survey will utilize a Likert scale for questions

regarding how important the materials were to them as well as interest levels of different topics of sexual health and intimacy. These areas may include consent, sexually transmitted infection prevention, positioning and safety, energy conservation during sexual activity, and pleasure and health. There will be a section for short answers regarding topics of interest and values that patients can fill out to provide a broader image for the study. The results of these surveys will impact the information that is included in the app and the way that this information is presented.

Once patients begin utilizing *Comfort* they will be presented with surveys in the app regarding their experience. Patients will be prompted to answer Likert scale questions on the presentation of information and quality of app. This information will impact how *Comfort* is updated and changed to better reflect the needs of patients. This survey will also have a section for short answers where patients can describe their experience with the app and with their relationships while utilizing it. These surveys will be provided on a quarterly basis to assist with updates and to allow communities of interest to have up to date information on patients' experiences.

Summative Research Design

Outcomes focused research design will utilize a quasi-experimental design. Pre and post program data will be the most informative at this stage as sexual health and intimacy are personal topics and may not translate from person to person. Examining the same individual before and after their use of *Comfort* will provide valuable information to all communities of interest involved. Patients will take a Quality-of-Life Scale, Hospital Anxiety and Depression Scale, Sexual Health Indicators, and knowledge-based

quiz before utilizing *Comfort* and at the three-month, six-month, and one year mark of utilizing the application. Recording changes in results from pre and post program use will provide insights into the way that *Comfort* impacts patients' lives and relationships.

Methods

The methods for data collection will be approved by the Institutional Review Board (IRB) prior to any data collection. Informed consent for patients will ensure that they fully understand what will be involved in the research that they are a part of and their involvement in the study. Any risks or benefits from taking part in the program will be described to patients and patients will be informed that there are no penalties for not participating (*Informed Consent FAQs*). Informed consent also requires that individuals voluntarily participate in the program. Informed consent details what personal information will be gathered and how that information will be used and stored.

Any research study requires strict participant confidentiality to ensure safety and compliance. Confidentiality will be upheld by encoding software that contains the codes for patient names. Original copies will be changed to codes within two business days of receiving them. Access to original files will be limited to the head researcher and all data, even coded data, will be restricted to password protected computers and laptops. All research staff will be trained on confidentiality.

Formative Data Collection

To collect qualitative and quantitative data from the mixed methods study design, a survey will be provided to patients while they are staying in the hospital. Patients who are currently hospitalized for an acquired brain injury, are 18–75 years old, score 13 or

higher on the Glasgow coma scale, score mild to moderate for cognitive deficits, are currently receiving OT services, speak and write in English, have access to a smartphone, and have access to the internet will be provided with the survey. The proposed number of patients to participate is 150. The survey will be provided by an OTPs and will be online via survey monkey, patients will have the option to utilize a paper survey. The information from this survey will be collected after the patients first session utilizing the app. Patients will also receive survey questions on the app once they begin use, this information will be used to improve *Comfort*. Most of the surveys will be completed electronically, paper surveys will be put into the electronic system by one of the researchers. The questions utilized for the short answer portion of the survey will be checked by peers and mentors to minimize bias and ensure reliability and validity.

Methods for Formative Data Management and Analysis

Survey questions utilizing the Likert scale will be entered into an analysis software such as NVivo to better understand the patterns that emerge. The analysis will include percentages of patients with the same attitudes toward different questions. Open-ended questions will be placed into NVivo to analyze themes that emerge from the questions. Questions will also be examined manually to determine if the identified themes match up with those identified by the computer program.

Summative Data Collection

Analyzing data from the quasi-experimental design will provide quantitative feedback to researchers and communities of interest involved in rolling out *Comfort*. The

independent variables in the study will be the amount of time and the level of engagement with the app. Dependent variables identified in this study include knowledge on the topics of sexual health and intimacy, quality-of-life, satisfaction in sexual relationships, anxiety, and depression.

The data collection will take place online, each of the scales and measures will be provided through an online survey software. Participants will include patients who are currently hospitalized for a brain injury, are 18–75 years old, score 13 or higher on the Glasgow coma scale, score mild to moderate for cognitive deficits, speak and write in English, have access to a smartphone, and have access to the internet. These participants will be recruited by OTPs who identify them as appropriate candidates for the study.

Participants will take the Quality of Life Scale, the hospital anxiety and depression scale, the sexual health indicators inventory, knowledge-based quiz, and number of referrals. These scales will address the dependent variable of the patient's mood, patients' sexual health, and information gained from *Comfort*. The Quality of Life Scale and the Hospital Anxiety and Depression Scale have been utilized many times and have been proven valid and reliable tools for research (Burckhardt & Anderson, 2003; Bjelland et al., 2002). Sexual health indicators are a more recent survey developed to measure sexual health (Smylie et al, 2013). The sexual health indicators were proved valid for Canadians aged 16–24 and utilizing these indicators with a larger age range will lead to more data on the indicators and contribute to the current research on this topic (Smylie et al., 2013).

Data collection will begin with the participants first session with OT prior to

introduction to *Comfort*. Patients will take the scales and quiz again six months after access to *Comfort* begins. This data will allow researchers and communities of interest to note if there are changes in identified areas. To coordinate follow up at the six-month mark a follow up appointment will be made before discharge for patients to come in and fill out the scales and quizzes for the second time. This will encourage follow through to ensure the most results from participants.

Methods for Summative Data Management and Analysis

Results from participants will be entered into NVivo so that all information on each patient can be found in one area. The information will also be entered into Excel to easily browse the available information. Hospitals and organizations that participate in research on *Comfort* may have staff to assist with statistical analysis and interpretation of the results. The quasi-experimental research design means that data will be examined for significant changes from the pre and post program scales. This research design will also mean that the findings will be inferential in nature as there is no control group to compare data to. As stated earlier the pre and post testing will be utilized so a t-test analysis can be used to determine statistically significant changes (Module 6, 2022).

Strengths and Limitations

This research study has a strong quasi-experimental research design. The study will look at multiple outcomes and will use a large group of participants. *Comfort* presents the opportunity for a cost-effective research study with therapists who are employed by the organization being trained on the app. This researcher has no affiliations

with hospitals or organizations that will be involved in the study.

This study will not have a control group which is a limitation. There are no current research studies examining the effects of an application focused on sexual health for brain injury patients. This limits the contribution of the study as it is the first of its kind, it also opens a new conversation on ways to address sexual health in medical settings. *Comfort* is aimed at a very specific population which limits the versatility of this study.

Conclusion

Comfort is designed to provide positive outcomes for patients and hospital organizations. These outcomes will be measured using knowledge-based questions, quality-of-life scale, sexual health indicators, and hospital anxiety and depression scale. Current literature and studies do not examine the effects of brain injuries on sexual health and intimacy, each of these measures from *Comfort* will help OTPs to address these topics with more accuracy and effectiveness to improve patient outcomes. This app will allow patients to explore the topic of sexual health and intimacy online on their own time. Patients will be able to develop questions and learn how to initiate conversations with healthcare providers.

CHAPTER SIX – Dissemination Plan

Summary

Sexual health and intimacy are under addressed in healthcare settings. *Comfort* is an app which will help to bridge this gap. *Comfort* is an app for smartphones that will be purchased by hospitals and organizations for patients with brain injuries to learn about sexual health and intimacy. This app will provide a holistic and patient-centered approach to education and resources on sexual health and intimacy in a safe and anonymous environment. The app's user interface will be designed for patients with brain injuries, utilizing muted color choices, rest breaks, and simple navigation, for example. *Comfort* will initially launch with six modules containing nonlinear sections that can be chosen by the patient. In the second year, *Comfort* will release modules seven through ten along with an anonymous question and answer section for occupational therapy practitioners (OTPs) to respond to specific questions and concerns as outlined in Figure 5D.

Dissemination of *Comfort* will be targeted toward rehabilitation hospitals and OTPs and is critical to the success of the app.

Dissemination Goals

Discussions about sexual health and intimacy must be brought up by healthcare workers during a patient's stay. Research has shown that many OTPs are not addressing this critical topic (Young et al., 2020). *Comfort* aims to address this gap in practice for patients in a comfortable and safe environment that can be accessed on their smartphones.

Short-term goal: Two rehabilitation hospitals will purchase and utilize *Comfort* for inpatient adults.

Short-term goal: OTPs will introduce *Comfort* to 100% of eligible adults with brain injuries that are treated in the department.

Short-term goal: OTPs will report feeling more comfortable addressing sexual health and intimacy with use of *Comfort* application.

Long-term goal: Rehabilitation hospitals who have purchased *Comfort* will report an increase in patient satisfaction after one year of purchase.

Long-term goal: The dissemination of *Comfort* will lead to an increase in OTPs including sexual health and intimacy in practice with adults with brain injuries.

Target Audiences

Hospitals and organizations are the main target audience for *Comfort* as they will purchase the app for use by OTPs and patients. Initial dissemination of *Comfort* will target the northern New Jersey region which includes multiple rehabilitation hospitals. Larger hospital systems such as Atlantic Health Systems and Robert Wood Johnson Barnabas Health will be targeted next to ensure a larger presence once the prototype has been utilized successfully. These larger systems will allow *Comfort* to be used in rehabilitation hospitals and centers in Northern New Jersey and will set the precedent that sexual health and intimacy must be addressed in the inpatient setting for adults with brain

injuries.

Occupational therapy practitioners are another target audience as they will be the healthcare professionals introducing the topic of sexual health to patients and teaching the use of *Comfort*. Occupational therapy practitioners are in a distinct position to address sexual health and intimacy as they practice through a holistic lens. Sexual health is in the scope of practice for OTPs and is considered an ADL (American Occupational Therapy Association, [AOTA], 2020). Occupational therapy practitioners report that they do not feel comfortable addressing sexual health and intimacy as they do not learn about these topics in school and they do not want to offend patients (Young et al., 2020). *Comfort* will assist therapists in introducing the topics of sexual health and intimacy to adults with brain injuries in a less intimidating setting.

Key Messages

Including *Comfort* in patient care will result in increased sexual health indicators, increased safety with positioning, and decreased anxiety and depression scores. The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) will see improvement as patients who have their questions about sexual health and intimacy answered will be more satisfied with their overall care. Patients who have subdural hematomas or increased symptoms with different positions will learn how to engage in sexual activity without pain or increased risk of injury. This information will be provided proactively via *Comfort*. Hospitals and organizations provide the Patient Health Questionnaire (PHQ-9) to patients during inpatient rehabilitation stays to measure

depression. A decrease in anxiety and depression on the PHQ-9 from patients utilizing *Comfort* will benefit these organizations.

Occupational therapy practitioners will be leaders in introducing sexual health and intimacy to patients in the inpatient rehabilitation setting. *Comfort* will assist in addressing topics that patients may feel uncomfortable asking healthcare professionals. *Comfort* allows OTPs to work in their full scope of practice addressing all ADLs. Practitioners will be encouraged to include sexual health in their “elevator pitch” of what OTPs can address during sessions. This change will open the door for questions on sexual health that the app, *Comfort*, can be used to address. Practicing to the full extent of their training as OTPs allows them to bill for different activities and can provide holistic treatment.

Sources/Messengers

Trusted messengers will assist with disseminating information about *Comfort* to rehabilitation hospitals and OTPs. These messengers will lend their credibility and trust as professionals to impart the benefits of utilizing *Comfort*. Rehabilitation hospitals and OTPs who hear about *Comfort* from a trusted messenger will be more likely to purchase and utilize the app.

Kathryn Ellis OTD, OT/L, certified sexuality counselor is the founder of the Institute for Sex, Intimacy, and Occupational Therapy. Dr. Ellis has published a textbook on sexuality and intimacy for OTPs to learn from and collaborates with different

healthcare professionals to ensure best practice. Dr. Ellis would be an ideal messenger for OTPs as she has conducted multiple studies on OT and sexual health. As an OTPs, she has experience implementing sexual health and intimacy into practice and knows first-hand the benefits of including these topics.

“Ease” is an educational program run by Arlene Lechner M.Ed. and Melissa Hochberg M.Ed. Arlene Lechner works in the Inclusion and Disability Department at the Pozez Jewish Community Center (JCC) of Northern Virginia. She has a BA in Human Development from Hofstra University and a Master in Special Education from George Mason University. Melissa Hochberg is the Research Specialist at the Pozez JCC of Northern Virginia working in the Inclusion and Disability Services Department. She has a BS in Speech Communications and Linguistics from SUNY Oneonta and a Master in Special Education from the University of Virginia (Lechner & Hochberg, n.d.). Their business called “Ease” provides education on sexual health and intimacy for adults with intellectual and developmental disabilities. Arlene and Melissa will be able to meet with rehabilitation hospitals to discuss the benefits of education on sexual health and intimacy. They will be able to speak to the gap in practice and the monetary benefits of addressing this gap.

Dissemination Activities

Hospitals and organizations will learn about *Comfort* through local hospital conferences. *Comfort* will be marketed at a stand at local hospital conferences to ensure that the benefits of *Comfort* are provided to relevant parties. When *Comfort* can connect

with rehabilitation hospitals, in person education sessions will be arranged with a presentation to pitch the benefits and feasibility of *Comfort* for patients and organizations. Direct outreach to hospitals will be targeted toward rehabilitation directors with contact to directors interested in best practice and improving patient care.

Occupational therapy practitioners will be provided with in-services on the benefits of *Comfort* and the importance of educating patients with brain injuries on sexual health and intimacy. These in-person courses will teach OTPs how to approach sexual health and intimacy with patients and will encourage OTPs to incorporate these techniques into practice. *Comfort* will also be featured on OT focused podcasts such as “OT After Dark” and “Spill the OT”. Podcasts are an inexpensive way to spread information about *Comfort* and allow OTPs to learn more about discussing sexual health and intimacy with patients with brain injuries.

Budget

A preliminary budget for dissemination projects and activities is listed in Table 4H. These activities will be used to access both primary and secondary audiences for *Comfort*.

Evaluation

Hospitals and organizations: To evaluate the effectiveness of the dissemination efforts, *Comfort* developers will keep track of the number of connections made during each conference that they attend. This list will be used so that representatives from

Comfort can follow up with hospitals and organizations and track the number of successful sales. In-person presentations pitches will be considered effective if hospitals and organizations purchase the app for use.

Occupational therapy practitioners: The effectiveness of disseminating information via in-services will be determined using a brief questionnaire after the presentation is finished. Occupational therapy practitioners will be asked about their likelihood of utilizing *Comfort* in practice, likelihood of discussing *Comfort* with patients, and likelihood of them discussing sexual health and intimacy with/without *Comfort*. The effectiveness of podcast appearances will be tracked by the number of views that each podcast receives.

Conclusion

The target audience for *Comfort* will be the hospitals and organizations that utilize the app and the OTPs who will educate on sexual health and intimacy. Although patients with brain injuries stand to gain the most from *Comfort*, hospitals and organizations will be purchasing the app. In-services, conferences, and podcasts will all be utilized to spread information about *Comfort*. All these activities provide an opportunity for marketing *Comfort* and sharing information on sexual health and intimacy for patients with brain injuries.

CHAPTER SEVEN – Funding Plan

Introduction

Comfort is an app for inpatient adults with brain injuries to target the existing knowledge gap about sexual health and intimacy. The app will be purchased by hospitals and organizations and will be distributed during therapy sessions by OTPs. The app will focus on patient education through a holistic and occupation-based lens. Patients and providers will be able to access *Comfort* on their smartphones to continue learning, or to use the app as a reference. *Comfort* will roll out in two phases with updates occurring as needed to avoid bugs and improve performance as outlined in Figure 5D. The first phase of *Comfort* will include modules 1–6 and the second phase will include modules 7–10 and a question-and-answer section for OTPs. This app will be developed by OTPs with assistance from software developers and computer engineers to ensure all accessibility features are functional. Funding will be provided from hospitals and organizations who purchase services and will also come from research grants.

Local Resources

The launch of *Comfort* will be strengthened by the author's collaborative relationships with multiple entities in the New Jersey community. Local universities, support groups, and volunteers will assist in creating the app to ensure that *Comfort* is relevant to all participants. New Jersey Institute of Technology (NJIT) has many student run groups and organizations. These organizations are a potential source of volunteers to assist with creation and testing of *Comfort*. The Advocates for Sexual Health Awareness Club and the International Game Developers Association will be approached to assist

with *Comfort*. The Advocates for Sexual Health Awareness Club is a source of potential assistance for marketing of the app and can spread awareness of how brain injuries can impact sexual health. The International Game Developers Association can assist with development of the modules quizzes section to make them interactive and attention grabbing. These students will be able to earn volunteer hours and contribute to the development of *Comfort*.

Rutgers University is another potential source of in-kind student support. Rutgers University has a Doctor of Occupational Therapy (OTD) program and a Software Engineering program. Students in the OTD program must complete three level 1 fieldwork rotations. These students can work with *Comfort* to ensure that modules are at an appropriate reading level, analyze different positions to ensure safety after brain injury, and assist with social media creation/management to expand awareness of the application and its uses. OTD students would receive class credit for their participation with *Comfort* and gain specialized knowledge on alternative OT careers. The students studying software engineering can assist with creating a website for *Comfort* and can provide insight into changes in code that would make the app easier to navigate. These students can receive volunteer hours for their work on *Comfort* and will gain experience working with healthcare professionals to develop effective software for brain injury clients.

The Brain Injury Alliance of New Jersey (BIANJ) is a source of advocacy, support, and education for people with brain injuries and their families (Brain Injury Alliance of New Jersey, 2021). The BIANJ provides resources and hosts events for

people with brain injuries, caregivers, and families. Additional funding is available to assist individuals with traumatic brain injuries to access services and supports. The BIANJ is another potential source of in-kind support. Members can potentially assist with the creation of *Comfort* by ensuring that modules are accessible for the clients they work with daily. They can also assist with marketing by listing *Comfort* as a resource on their website.

Budget

In addition to the vast opportunities for in kind support, the launch of *Comfort* will also require additional funding support. Creating an app will require experts with app and software as well as designers who can ensure that the vision put forth by occupational therapists are achievable. Table 5I outlines the salary and pay of consultants for the first two years of the launch of *Comfort*. App developers will create the back end of the app including software and code that will be the basis of *Comfort*. *Comfort* will be an involved app with multiple modules, quizzes, and various types of media including audio and video. Two app developers will be required to complete the work and maintain the app over the course of the first two years. An OTPs will also provide consultation services as needed for content development, specifically in sexual health and intimacy post brain injury. An app designer will be employed for the first two years to maintain the front end of the application and ensure accessibility. app development requires only minimal physical resources. Table 6J outlines the resources that are needed to develop and implement *Comfort*.

Potential Funding Sources

Potential funding sources include grants as well as subscription fees for use of the app. *Comfort* will ultimately be paid for by hospitals and organizations who will utilize it with their patients. Development of the app will be funded by grants for sexual health and brain injuries. The Brain Injury Association of America (BIAA) is offering a grant for projects that revolve around the chronic nature of brain injuries (Brain Injury Association of America, 2023). The small business innovative research (SBIR) provides funding to small businesses who assist the federal government with research and development, innovate technology, and increase commercialization from said technology (America's Seed Fund, 2023). *Comfort* will apply for a grant through the International Society for the Study of Women's Sexual Health (ISSWSH, 2023). This organization aligns with the educational goals that *Comfort* sets forth. Table 7K outlines the funding sources that *Comfort* will utilize to develop the app.

Angel capital will also be utilized to create *Comfort*. Anonymous individuals will be able to contribute to the startup costs of *Comfort*. This capital will come from family and friends of those involved in creating *Comfort* but will not be relied upon as a yearly or set amount. Angel investors will not have a decision-making stake in the business. These extra funds will be utilized to purchase extra storage or design assistance as needed.

Conclusion

The primary source of *Comfort* startup costs will be from grants and angel investors, whereas upkeep costs will primarily be funded by hospitals and organizations

paying to utilize the app. For applications, startup costs are the most expensive with the first two years requiring the largest budget (Dogtiev, 2023). *Comfort* will utilize local resources, grants, and angel investors for startup funding and maintenance for the first two years. Utilizing technology to improve healthcare education on sexual health and intimacy is a new avenue for occupational therapists to explore and pave the way.

CHAPTER EIGHT – Conclusion

Comfort is an innovative application that aims to address sexual health and intimacy for patients with brain injuries receiving occupational therapy services. This application will center occupational therapy practitioners (OTPs) as the leaders in healthcare who can address the topic of sexual health and intimacy through a holistic lens. *Comfort* will empower individuals to learn more about sexual health and intimacy on their own and will refer them to appropriate resources outside of the application. This proposed program aims to address the gap that patients with brain injuries encounter when searching for information on sexual health and intimacy.

Occupational therapy practitioners are in a unique position to address sexual health and intimacy through a holistic and patient centered lens. Sexual activity is listed in the OTPF-4 as an activity of daily living (American Occupational Therapy Association, [AOTA], 2020). This is an under-accused topic for patients with brain injuries. Introducing the topic of sexual activity to patients encourages individuals to think about goals and concerns for intimacy. Examining sexual health and intimacy through activity analysis allows practitioners to break down potential barriers for patients and allows them to reach their goals. This proposed program centers OTPs as the experts on sexual health and intimacy.

Sexual health education curriculum in the United States varies state to state on topics such as anatomy, consent, and safe sex practices (*Sex and HIV Education. 2023*). When patients do not have the terminology to form questions to healthcare workers about sexual health and intimacy, they may avoid these topics. Healthcare practitioners who

address these topics using only medical terminology will discourage patients from seeking more information. Using an online application for patients with brain injuries to learn more about sexual health and intimacy encourages individuals to learn independently about terminology and potential barriers to safety. *Comfort* will bridge the current gap in care for patients with brain injuries to find answers to critical questions that they may not know can be addressed by various practitioners.

Patient education is critical to positive long-term outcomes for patients (Shoemaker et al., 2014; Nossum et al., 2013). Smartphone applications are an accessible way for patients to access continued education, specifically on sexual health and intimacy which can be uncomfortable topics. The use of applications for patient education is new and is a creative way to engage patients in their own care. An online platform allows patients with brain injuries to explore topics and definitions at their own pace in a safe environment. Patients will be empowered to ask OTPs for specific questions that *Comfort* may be unable to assist with.

Comfort is an innovative and creative solution to addressing sexual health and intimacy for patients with brain injuries. As discussions surrounding sexual health and intimacy remain underexplored in the context of brain injuries, this paper contributes to the growing body of literature on approaches to improve the overall quality of life of individuals post brain injury. Occupational therapy practitioners will be the leaders in addressing sexual health and intimacy with patients by introducing them to *Comfort* and holistically assisting them on their journey to improve their health.

APPENDIX A – Figure 1

Figure 1

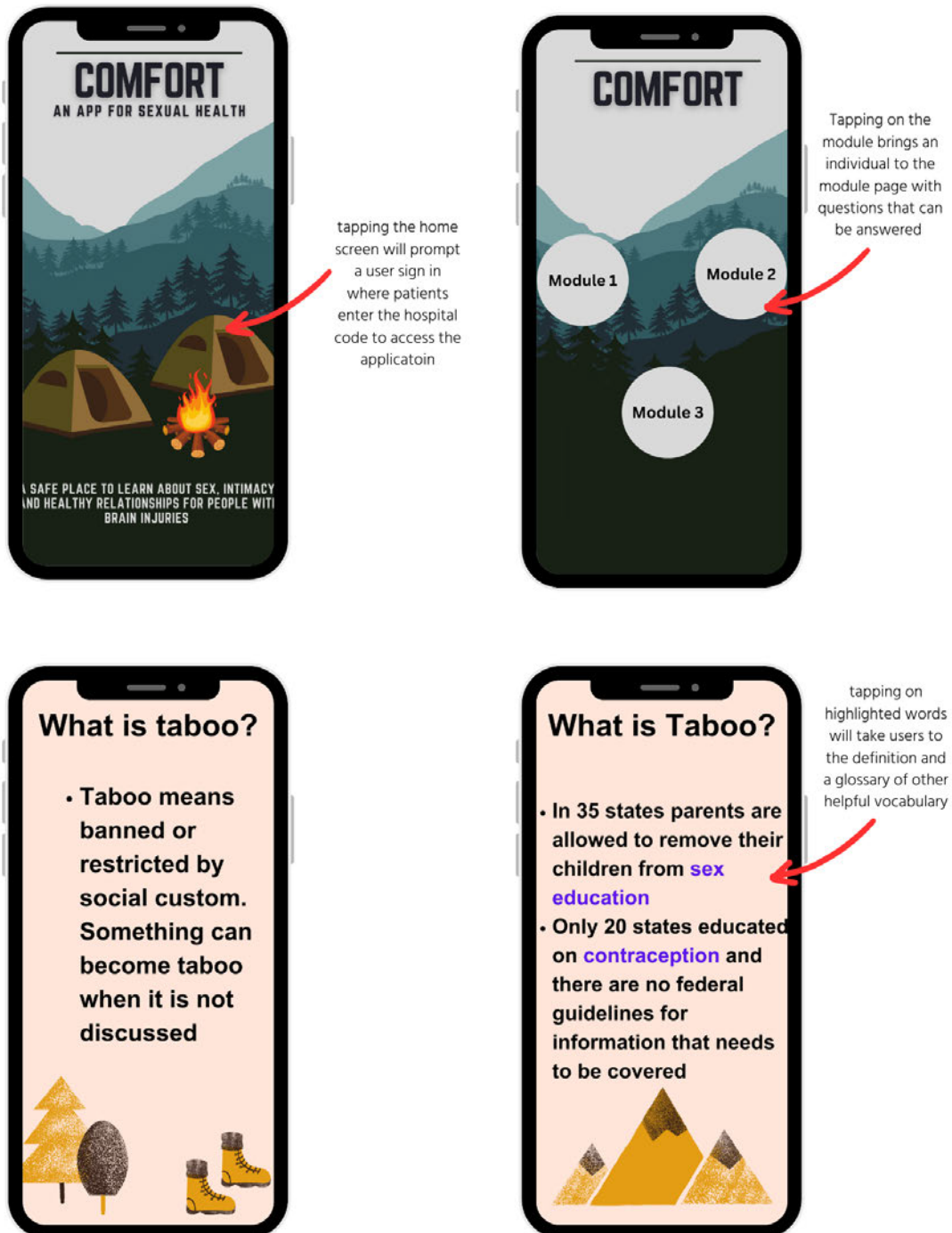
Model of the Problem



APPENDIX B – Figure 4

Figure 4

App Design Mockup



APPENDIX C – Module Content Example

Formatting of application:

Each question will appear and individuals will be able to choose which question(s) they want answered. There will be a separate section within each module providing key terms and definitions. While in the module, key words will be highlighted and individuals will be able to click on these words for their definitions.

Module 1:

Taboo and safety

Objective: the participant will identify three resources for sexual health and intimacy by the end of module 1.

What is Taboo?

- Taboo means banned or restricted by social custom. Something can become taboo when it is not discussed
- In 35 states parents are allowed to remove their children from sex education
- Only 20 states educated on contraception and there are no federal guidelines for information that needs to be covered
- When people are not given information on sexual health and intimacy it is hard to ask questions or learn more about those topics
- Online search engines like Google and YouTube can provide information on sexual health but this information may not relate to brain injuries and is not checked for accuracy
- The culture in the United states of not talking about sexual health creates an environment where these topics are shut down or avoided.
- Questions about sexual health and intimacy can be directed to: occupational therapists, nurses, doctors, physical therapists, or anyone on your healthcare team.

Who can you talk to about sexual health and intimacy?

- Providers may not bring the topic of sexual health up because they do not want to offend anyone
- Asking questions to providers can be difficult as appointments are typically short, writing down questions before a doctor's visit can help to make communication clear
- When questions come up about sexual health it is helpful to know safe places and people to reach out to
- Questions about positioning, pain, erections, penetration, and anatomy can be directed to any doctor, nurse, occupational, or physical therapist. You may be referred to specialists such as: urologist, neurologist, pelvic therapist, gynecologist, sex therapist
- Using language and terms that are medical and anatomical can help to make questions and conversations more clear

What feelings can come up when discussing sexual health and intimacy?

- Individuals may have little or no interest in sexual health and may be asexual
- Having conversations about sexual health and intimacy can lead to a variety of emotions such as
 - Joy
 - Surprise
 - Discomfort
 - Shame
 - Interest
 - Excitement
 - Curious
 - Confusion
 - Etc.
- While reading the modules and questions think about what emotions you feel, do certain topics or words bring up negative or positive emotions
- It is good to know if certain words or topics are off limits to you and you can tell your doctors and partners that you are not ready to discuss these

Why should we talk about sexual health?

- Talking about sexual health makes it easier to have questions answered and create a community
- Safety is key to reaching goals and feeling better
- Questions that are communicated to doctors can have personal and individual responses that are safe
- Getting personalized answers can lead to increased pleasure and satisfaction during sex and intimacy
- Talking about sexual health and intimacy will also help to create healthy boundaries on what is safe for you and what is not, these can be communicated to healthcare providers and partners
- Talking about sexual health and intimacy can also help in identifying signs of healthy relationships and unhealthy relationships
 - Healthy: open communication, boundaries, consent for activities, respect
- Below are a list of key words and definitions:
- Sexual Health – Enjoying emotional, physical, and social well-being in regard to your sexuality.
- Intimacy – The closeness you feel when you share your private and personal self with someone else.
- **Executive functioning** – group of complex mental processes and cognitive abilities that control skills required for goal directed behavior
- **Consent** – Consent is an agreement to participate in a sexual activity (including kissing, oral sex, genital touching, vaginal or anal penetration, and anything else). Before being sexual with someone, you need to know if they want to be sexual with you, too. Both people must agree — every single time — for it to be consensual. Without consent, any sexual activity is sexual assault or rape.

- Breasts – The two glands on the chest. Considered sex organs because they're often sexually sensitive and may inspire sexual desire. Like mammary glands in other mammals, they produce milk during and after pregnancy.
- Clitoris – Sex organ whose only known purpose is sexual pleasure. The clitoris swells with blood during sexual excitement. The outer part of the clitoris is located at the top/front of the vulva, right next to urethra (hole you pee out of). The inner part of the clitoris, which is much larger, includes a shaft and two crura (roots or legs) of tissue that extend up to five inches into the body on both sides of the vagina to attach to the pubic bone.

Module 2: Brain Injuries and Sexual Health

Objective: The participant will recognize 5/5 symptoms of brain injuries and the impact they may have on sexual activity by the end of module 2.

How do brain injuries affect the brain?

- Types of brain injuries –
 - Non-traumatic – the brain injury was not caused by an outside force (lack of oxygen to the brain caused by cardiac arrest, near drowning, illness, stroke)
 - Strokes can be:
 - Ischemic – block blood to the brain from a clot or reduced flow from inflammation
 - Hemorrhagic – an artery bleeds into the brain
 - Traumatic – brain injury caused by external force (falling, car crashes, etc.)
- Each section of the brain controls different actions
 - Frontal lobe (most commonly damaged in traumatic brain injury) –
 - Parietal lobe – sensation (sight, touch, taste, smell)
 - Temporal lobe – manages emotions, stores memories, language, process information from your senses
 - Occipital lobe – visual perception, processing information from sight
- Traumatic and non traumatic brain injuries can impact any part of the brain which can result in a wide range of symptoms

What do these changes mean for my sexual health?

- How symptoms can affect sexual health
 - Weakness – brain injuries can result in weakness to one side or a general weakness, this can impact positioning and confidence.
 - Headaches – can affect libido and can be brought on/worsened with positioning/stimulation
 - Pain – nerve pain, pain from surgical incisions, or generalized pain can affect libido

- Overstimulation – fabrics, lights, music, and more can cause overstimulation which can result in headaches and fatigue impacting libido
- Changes in cognition – differences in the ability to plan ahead, decreased problem solving, and impulsive behaviors can impact sexual health
- Vision changes – changes in vision can make it difficult to focus on the left or right side, double vision can make it difficult to coordinate movements and can result in headaches

What are resources and support that I can access?

- Doctors that can help with specific problem areas
 - Urologist – erectile dysfunction, pain during urination, incontinence, changes in libido, reproductive health
 - Pelvic health therapist – pain during sex, incontinence
 - Neurologist – erectile dysfunction, nerve pain, headaches and migraines
 - Gynecologist – pain during sex, libido changes, reproductive health
 - Sexual health therapist – trauma surrounding sexual activity and intimacy, psychological changes regarding sexual activity and intimacy
- Community resources
 - Brain Injury Alliance
 - Brain Injury Alliance of New Jersey
 - Planned parenthood
 - Access to primary care physicians, STD testing, mental health counseling, and more
- Lived experiences
 - Personal blogs and podcasts
 - Local stroke support groups
 - Local traumatic brain injury support groups

What can I do to work around symptoms that may arise from my brain injury?

- Avoid positions where neck is flexed to avoid putting excessive pressure on head
- Create a routine for intimacy to decrease the risk for overstimulation
- Identify triggers for migraines, headaches, and pain with occupational therapists and healthcare providers
- Identify times of day when symptoms are better or worse and plan intimacy during times where symptoms are better

APPENDIX D – Figure 5**Figure 5***Phases of Comfort*

PHASE 1	PHASE 2	PHASE 3
<ul style="list-style-type: none">• Modules 1-6• Resources for each module• Occupational therapist to assist with onboarding• Months 1-6	<ul style="list-style-type: none">• Modules 6-10• Interactive resources Q and A with Occupational Therapist via app• Symptom monitoring calendar• Months 6-12	<ul style="list-style-type: none">• Modules 10-15• Peer support forum monitored by occupational therapist• Months 12-24

APPENDIX E – Table 1

Table 1*Module 1–6 Outline*

Module	Educational Content	Sexual Health Model Pillar
<p>Module 1: Taboo and Safety Obj: The participant will identify three resources for sexual health and intimacy by the end of module 1.</p>	<ul style="list-style-type: none"> • Why is the topic of sexual health so uncomfortable? What is taboo? • Why is it important to talk about sexual health and intimacy? • What feelings come up when discussing sexual health and intimacy? • Who can you (ask questions to?) talk to about disability and sex? 	<ul style="list-style-type: none"> • Talking about sex (1) • Culture and sexual identity (2) • Challenges (5) • Spirituality (10)
<p>Module 2: Brain Injuries and Sexual Health Obj: The participant will demonstrate understanding of how brain injuries impact sexual health by the end of module 2.</p>	<ul style="list-style-type: none"> • How do brain injuries affect the brain? • What do changes in the brain mean for sexual health? • What can you do for these changes and how can you take control of your sexual health? 	<ul style="list-style-type: none"> • Culture and sexual identity (2) • Sexual Anatomy Functioning (3) • Challenges (5) • Body image (6) (7)
<p>Module 3: Consent Obj: The participant will identify how brain injuries impact consent by the end of module 3.</p>	<ul style="list-style-type: none"> • What is consent? • How does a brain injury affect consent/ does it? • How to address the topic of consent with doctors, partners, etc.? 	<ul style="list-style-type: none"> • Positive sexuality (8) • Talking about sex (1) • Sexual healthcare and safer sex (4)

Module	Educational Content	Sexual Health Model Pillar
<p>Module 4: Positioning and Safety Obj: The participant will identify safe and unsafe positions 3/3 times after completing module 4.</p>	<ul style="list-style-type: none"> · What positions are safe for sex and intimacy after a brain injury? · What positions can aggravate my symptoms? <ul style="list-style-type: none"> • Can my cognitive symptoms affect safe sex? 	<ul style="list-style-type: none"> · Sexual healthcare and safer sex (4) · Sexual anatomy functioning (3) · Masturbation and fantasy (7)
<p>Module 5: Energy Conservation Obj: Participants will understand energy conservation techniques and when they are useful after completing module 5.</p>	<ul style="list-style-type: none"> · What positions can be useful for energy conservation? · How can I plan out sexual health and intimacy for energy conservation? · Why does energy conservation matter? 	<ul style="list-style-type: none"> · Intimacy and relationships (9) · Masturbation and fantasy (7) · Positive sexuality (8) · Sexual anatomy functioning (3)
<p>Module 6: Relationships and Intimacy Obj: Participants will demonstrate an understanding of effective relationship communication after completing module 6.</p>	<ul style="list-style-type: none"> · How will planning out time for intimacy affect my relationship? · How can I communicate with my partner about symptoms? · Will these changes affect how I feel about my relationship? 	<ul style="list-style-type: none"> · Intimacy and relationships (9) · Body image (6) · Talking about sex (1)

APPENDIX F – Table 2

Table 2

Communities of interest Information Matrix

Communities of Interest	Type of Involvement (Planning, Implementing, Reflecting)	Possible Role(s)	Specific Interests
Program creator, as the researcher	P, I, R	Organizing use of the app, coordinating disciplines to discuss and utilize the app	Success of the app, usable data
Occupational therapists who introduce the app to patients	P, I, R	Introducing the app to patients, data collection	Expanding the role of occupational therapy, satisfaction in the workplace
Patients with acquired brain injuries	P, I, R	Providing insights into needs and desires, utilizing app to improve relationships and QOL, data collection	Improved QOL and decrease in anxiety and depression, increased knowledge on sexual health and intimacy
Hospitals and organizations	I, R	Assistance with analyzing data and research design	Positive patient outcomes and patient satisfaction, monetary benefits, research design
AOTA, NJOTA	R	Information on dissemination and outreach to occupational therapists	Ensure research quality and assist with changes in policy for occupational therapists to address sexual health and intimacy in a variety of settings

APPENDIX G – Table 3

Table 3

Communities of interest Program Evaluation Research Questions

Communities of Interest	Types of Program Evaluation Research Questions
Program creator, as the researcher	<p>Formative:</p> <ul style="list-style-type: none"> ● Does the app effectively communicate clinical educational materials on the topic of sexual health and intimacy to patients in a way that is transferrable to their everyday lives? <p>Summative:</p> <ul style="list-style-type: none"> ● Does the app increase patient’s quality of life, decreased anxiety and depression, and increase self-confidence?
Patients with acquired brain injuries	<p>Formative:</p> <ul style="list-style-type: none"> ● Was the information on sexual health and intimacy relevant? ● Were the educational materials presented in a way that was easy to understand? ● Was the app easy to navigate and find desired information? ● Does the app provide enough resources for supports? ● What do patients want to learn more about regarding sexual health and intimacy? ● What type of educational instruction do patients prefer? ● What areas of sexual health and intimacy were not addressed in the app that should be? <p>Summative:</p> <ul style="list-style-type: none"> ● Did patients gain knowledge about safe positioning during sexual activity? ● Did patients gain skills to navigate sexual health and intimacy? ● Did patients gain self-confidence regarding sexual activity and intimacy? ● Did patients experience a decrease in anxiety and depression? ● Did patients experience an increase in quality-of-life scores? ● Do patients feel confident utilizing the information they have learned on the app?

Communities of Interest	Types of Program Evaluation Research Questions
Hospitals and organization	<p>Formative:</p> <ul style="list-style-type: none"> ● Does the app match up with the hospital/organizations mission? ● Are the occupational therapists comfortable introducing the app to patients? ● Are occupational therapists identifying sexual health and intimacy as an area of need for patients? ● Are healthcare workers in the system open to the use of the app and receiving referrals through the app? ● Are patients reporting satisfaction with the app? ● Are occupational therapists currently addressing sexual health and intimacy with patients with acquired brain injuries? <p>Summative:</p> <ul style="list-style-type: none"> ● Does the research show a change in referral rates to other healthcare workers within the system? ● Does the research show a change in patient satisfaction with hospital stay? ● Does the research show a change in readmission rates? ● Does the research data show an improvement in patient care while utilizing the app? ● Does the research show a change in occupational therapy frequency of addressing sexual health and intimacy? ● How many patients followed through utilizing the app post admission?
AOTA, NJOTA	<p>Formative:</p> <ul style="list-style-type: none"> ● Do patients report an increased understanding of the role that occupational therapists play in addressing sexual health and intimacy? ● Are occupational therapists addressing sexual health and intimacy more in their independent clinical work because of the app? ● Are the long-term goals of the project realistic and achievable? ● Do other healthcare workers recognize the role that occupational therapists play in addressing sexual health and intimacy for patients with acquired brain injuries? <p>Summative:</p> <ul style="list-style-type: none"> ● Can the research data be used to demonstrate increased awareness of the role of occupational therapists in addressing sexual health and intimacy? ● Will the research data demonstrate the importance of the role of OT for providing services related to sexual health and intimacy?

Communities of Interest	Types of Program Evaluation Research Questions
	<ul style="list-style-type: none">● Will the app assist in addressing the gap in practice of addressing sexual health and intimacy in the inpatient setting?

APPENDIX H – Table 4**Table 4***Dissemination Budget*

<u>Activity:</u>	<u>Cost:</u>
Hospital Conference	<ul style="list-style-type: none"> • New York Healthcare Expo: \$1,500 • American Occupational Therapy Association: \$500
In-person Presentation	<ul style="list-style-type: none"> • Occupational Therapist to present: \$200 • Print outs and information packets: \$50 • Travel cost: \$150
Podcast	<ul style="list-style-type: none"> • Occupational Therapist to present information: \$200
Inservice	<ul style="list-style-type: none"> • Occupational Therapist to present: \$200 • Print outs and information packets: \$50 • Travel cost: \$150

Total \$3,000

APPENDIX I – Table 5

Table 5*Consultant Budget Year 1–2*

Title:	Services	Salary/Pay
App Developer x2	<ul style="list-style-type: none"> • Controls back end of application • Ensure proper navigation • Allow for data collection via app 	\$90,000 salary
Occupational Therapist	<ul style="list-style-type: none"> • Work with app developer and designer to ensure accessibility for brain injuries • Ensure content is relevant and applicable to patients • Ensure that application is able to be navigated by target audience 	\$55 an hour
Designer	<ul style="list-style-type: none"> • Controls the front end of the application • Works closely with occupational therapist to ensure accessibility of application 	\$78,000 salary

APPENDIX J – Table 6**Table 6***General Budget Year 1–2*

Title:	Cost per month:
Application	\$250
Work Space	\$300 for prn use
Internet Access	\$75
Canva	\$14.99
Xcode for iOS	\$14.99
Amazon Web Services	\$29
Dissemination	\$3,000 (annually)

APPENDIX K – Table 7

Table 7

Potential Funding Sources

Title:	Services	Grant Amount
Brain Injury Association of New Jersey	<ul style="list-style-type: none"> • Must be situated in a research institution or corporate or non-profit environment where sufficient guidance from experienced brain injury researchers is available. U.S. citizenship is required. • Funded up to \$25,000 total for up to two years with 80 percent of funds issued upon notice of grant award (or other flexible start date as noted below) and 20 percent issued upon receipt of a final report • Applicants submit contact information and upload a Letter of Interest not to exceed 2 single-spaced pages (not including references) in PDF format. The Letter of Interest should include a concise description of research ambitions that explains how the proposal addresses BIAA priorities and the way(s) funding will result in a larger opportunity • Invited applicants upload a proposal that describes the problem, how it relates to BIAA’s priorities, scientific method, key personnel and the resources in the environment to be utilized. The narrative should also describe how the results of the plan will be used (such as for a larger grant submission or dissemination through publication). The budget and work plan should be uploaded as separate documents 	\$25,000
Small Business Innovative Research	<ul style="list-style-type: none"> • Organized for profit, with a place of business located in the United States • More than 50% owned and controlled by one or more individuals who are citizens or permanent resident aliens of the United States, or by other small business concerns that are each more than 50% owned and controlled by one or more individuals who are citizens or permanent resident aliens of the United States; and • No more than 500 employees 	\$50,000–\$250,000 for first year

Title:	Services	Grant Amount
International Society for the Study of Women's Sexual Health	<ul style="list-style-type: none"> <li data-bbox="524 380 1247 558">• Mission of the SBIR/STTR programs is to support scientific excellence and technological innovation through the investment of Federal research funds in critical American priorities to build a strong national economy. <li data-bbox="524 590 1247 768">• Applicants must be an undergraduate, graduate or medical student; resident in a graduate medical education training program; or a post-doctoral/post-residency fellow during the award. International grant applications are encouraged. <li data-bbox="524 772 1247 835">• The applicant's mentor must be an ISSWSH member 	\$7,500
Designer	<ul style="list-style-type: none"> <li data-bbox="524 869 1247 905">• Controls the front end of the application <li data-bbox="524 909 1247 978">• Works closely with occupational therapist to ensure accessibility of application 	\$78,000 salary

APPENDIX L – Executive Summary

Introduction

Occupational therapy’s scope of practice involves activities of daily living (ADLs) and sexual activity (American Occupational Therapy Association, [AOTA], 2020). Occupational therapy practitioners (OTPs) have reported that sexual health and intimacy is rarely addressed in occupational therapy sessions (Young et al., 2020). Although sexual health and intimacy can be difficult topics to navigate for healthcare professionals, they must be addressed to increase safety and quality of life for patients. Patients with brain injuries are unlikely to find information on sexual health and intimacy that is relevant to their needs. The limited information on sexual health for individuals with brain injuries is limited to academic papers, which are targeted toward healthcare professionals. Online and publicly accessible information on sexual health related to brain injuries is very limited and is often comprised of firsthand experiences that are valuable, but not to be taken as facts. To bridge this gap, *Comfort* is an application for smartphones that will make information about sexual health and intimacy more accessible for patients with brain injuries during and after their inpatient rehabilitation stay. *Comfort* will provide information in a patient-centered, holistic, and occupation-based manner. Occupation-based education focuses on the occupation or activity of sex and intimacy, breaking down the activity to look at what is needed to fully participate.

Project Overview

Comfort is an application that will provide education and resources on sexual health and intimacy specific for individuals who have brain injuries. *Comfort* will be

introduced to patients by an OTPs during an inpatient rehabilitation stay. Patients will be able to utilize the application during therapy sessions and on their own. The application will initially launch with six learning modules that answer common questions about sexual health and intimacy. After one year of development and testing, modules seven to ten and user experience updates will be released. This update will include a section for users to ask anonymous questions to occupational therapists about sexual health and intimacy. *Comfort* will continue to expand modules as more hospitals adopt it for use.

Comfort will be funded primarily through hospitals that purchase the application. The Brain Injury Association of New Jersey and the International Society for the Study of Women's Sexual Health have grants that will assist with startup costs of the application.

The success of *Comfort* will be measured through the Patient Health Questionnaire (PHQ-9), knowledge checks, and a patient satisfaction questionnaire. The PHQ-9 is a standard test to measure severity of depression that is administered on admission and discharge from inpatient rehabilitation hospitals. After each module a short quiz will be provided as a knowledge check point. These will ensure that participants are gaining and retaining key information. Patient satisfaction will be measured through a brief survey from *Comfort* to determine if the application provides desired information.

Comfort will depend on participants choosing to utilize the application on their own during an inpatient stay and after discharge. The application will be designed to meet the needs of patients. Self-determination theory (SDT) has been applied to the design of the application to ensure that patients are motivated to continue use. *Comfort*

will incorporate the elements of autonomy, relatedness, and competence to ensure learning and internal motivation (Gagné & Deci, 2005). Patients using the application will be able to choose topics that are most important to them and will have the option to skip past information that they do not have questions about. The educational content will be broken down into modules with key questions that are associated with each topic. The patient can click on questions that they have or that most relate to them to learn more information. This increases individuals' autonomy as they can choose what they learn. It will also increase competency as patients gain knowledge on topics that are important to them. The application will be designed with consideration of the symptoms associated with brain injuries.

Accessibility

In consideration of vision and cognitive function relative to brain injury, the format of the application will have muted colors with high contrast, large font size, and backgrounds will have minimal distractions. Arial font will be utilized in the application as it is widely accepted as one of the most accessible fonts (SiteImprove, 2023). These design elements will assist with eye strain and headaches that can come from using screens post brain injury. Additionally, *Comfort* will have built in rest breaks after every 10 minutes of engagement with the application as a prompt will appear to guide patients in movement or breathing exercises. Each module will be nonlinear, and patients can access the information that is most relevant to them.

Key Findings

To date, research on sexual health and intimacy has been through a medical and psychiatric lens. Cardiology, neurology, pelvic health, and oncology have all examined how sexual health and intimacy impacts health outcomes in their field. Findings from studies performed with the medical model do not examine interventions for sexual health and intimacy, instead they look at the relationship between sexual activity and health outcomes (Palmer & Herbert, 2016; Tulloch et al., 2021). Other studies point to the importance of addressing sexual activity and relationships for specific diagnoses such as epilepsy and multiple sclerosis (Kazemi et al., 2019; Rathore et al., 2019). Psychologists have also examined the impact relationships have on outcomes. These studies demonstrate the importance of relationship satisfaction on mortality, medical adherence, and diabetes management (DiMatteo, 2004; Holt-Lunstad et al., 2015; Wooldridge & Ranby, 2023). *Comfort* will assist with filling this gap by providing patient-centered, holistic, and occupation-based education on sexual health and intimacy.

Recommendations

Occupational therapy practitioners have a unique ability to address sexual health and intimacy for all patients through a holistic, occupation based, and patient-centered lens. The success of *Comfort* will demonstrate the importance of addressing these topics with adults, including those receiving inpatient care due to brain injury. Occupational therapy practitioners will have support through *Comfort* to address sexual health and intimacy in a setting that is supportive for both practitioners and patients. Implementing *Comfort* in hospitals around the United States will ensure that the crucial topics of sexual

health and intimacy are being addressed for individuals with brain injuries.

Conclusion

Sexual health and intimacy are not being addressed in healthcare through a holistic, patient-centered, and occupation-based lens. When patients with brain injuries are not provided with diagnosis-specific information on sexual health and intimacy during their inpatient hospital stay, they will be burdened with seeking out information online on their own. *Comfort* provides a supportive virtual environment to address topics that can be uncomfortable for patients and providers. If hospitals provide access to *Comfort*, OTPs can address sexual health and intimacy during sessions and ultimately help decrease depression and increase satisfaction for patients with brain injuries.

APPENDIX M – Fact Sheet

COMFORT:

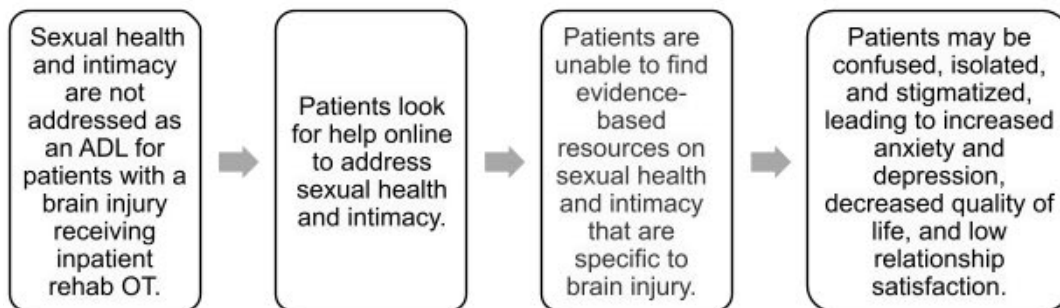
An application to provide education on sexual health and intimacy for individuals with brain injuries



Katherine Giaquinto, OTR/L, Doctoral Candidate

Background		Scope
<ul style="list-style-type: none"> - Sexual health and intimacy are included as an activity of daily living (ADL) in the Occupational Therapy Practice Framework 4th Edition. (AOTA, 2020) - Holistic education on sexual health for brain injuries is inaccessible to patients seeking information. - Sexual health and intimacy impact quality of life. (Stein et al., 2019) 		<ul style="list-style-type: none"> Occupational therapy (OT) practitioners can expand their practice by addressing sexual health and intimacy with patients in the inpatient rehabilitation setting. Occupational therapy will trailblaze how sexual health and intimacy are addressed for individuals with brain injuries.

The problem with current practices and access



COMFORT: Accessible Sexual Health and Intimacy Education

Participants

- Adults in inpatient rehabilitation for brain injuries ages 18+

Duration & Location

- The application is accessible on a smartphone.
- Modules are immediately available to users.
- Content is available indefinitely.

Guiding Theories & Evaluation

- **Self-Determination Theory:** autonomy, competence, relatedness will all be utilized to create modules and design application
- **Sexual Health Model:** 11 pillars of the model will be used to develop educational materials
- **Evaluation:** Patient Health Questionnaire (PHQ-9), knowledge quizzes, and patient satisfaction surveys

Why is COMFORT designed for patients with brain injuries?

Traumatic and non-traumatic brain injuries can result in physical, cognitive, and psychological changes that impact sexual health and intimacy. Comfort is designed to ensure safety with positioning and prevent increased symptoms from brain injuries.

Marketing & Dissemination Timeline		
Pre-launch	Year One	Year Two
→ 1 Hospital purchases → In-services provided at the hospital for OT buy-in → COMFORT developers meet with local brain injury service providers to spread awareness of application and ensure design will be accessible to individuals with brain injuries	→ 3 Hospitals purchase → OTs introduce app to patients during sessions <u>Modules 1-6 released</u> ↳ Modules take approx. 15 minutes to review ↳ In-app prompts for brain rest breaks ↳ Brief knowledge check after module completion	→ 10 hospitals utilize the COMFORT App in total → OTs introduce app to patients during sessions <u>Modules 7-10 released</u> ↳ Add on: User generated question section with answers from OT providers



App Design Features for Users with Brain Injuries

- Muted colors
- Sans serif (Arial) font
- Large font
- High contrast
- Variety of media
- Knowledge checks for each module
- Guided breaks between content
- Discreet application design

Outcomes

- Increased knowledge of
 - positioning
 - symptoms of brain injuries
 - impact of brain injuries on sexual health and intimacy
- Increased patient satisfaction scores
- Increased safety during sexual activities
- Decreased depression
- Decreased isolation

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CURRICULUM VITAE

