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Women's Self-Concept, Sexual Activity, and Intimacy After Sustaining a Traumatic Brain Injury

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Women's Self-Concept, Sexual Activity, and Intimacy After Sustaining a Traumatic Brain Injury

Abstract

A traumatic brain injury (TBI) can have a profound impact on how people think and feel about themselves and their abilities, values, goals, personalities, physical characteristics, and roles. Preliminary research findings suggest that barriers to developing a positive self-concept after injury in women include the desire to be perceived as "normal" after the injury or the feeling that society dismisses their injuries. In the field of occupational therapy, it is critical that therapists and researchers understand that self-concept can be altered after sustaining a TBI. This outcome can have a significant impact on participation in valued occupations, including participation in sexual activity and intimacy. There is a need for further research, education, and practice initiatives that explore women's self-concept after TBI and the relationship between self-concept and sexuality. Through these explorations, occupational therapists can better understand how to address sexual activity and intimacy in this population.

Comments

The author declares that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

intimate partner relationships, self-concept, sexual activity, traumatic brain injury, women

Cover Page Footnote

This article is dedicated to all of my past, present, and future clients. Thank you for our time together and for teaching me how to be a better occupational therapist.

Credentials Display

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A traumatic brain injury (TBI) is a sudden onset condition characterized by a dysfunction of the brain that results from an impact or jolt to the head or from an outside object penetrating the brain (Centers for Disease Control and Prevention, 2020). This injury can cause widespread neurological changes to the brain's structures and functions, profoundly impacting TBI survivors' lives as they learn to adjust to what may be a combination of physical, cognitive, and psychosocial sequelae (Anson & Ponsford, 2006). During the adjustment to these changes, individuals also experience alterations in self-concept, or how they perceive or feel about their own abilities, values, goals, personalities, physical characteristics, and roles (Stangor, 2014).

This article argues that there is an opportunity for occupational therapy to explore the relationship between women's self-concept and participation in intimate partner relationships after sustaining a TBI, and describes an existing opportunity to promote positive self-concept through facilitating participation in healthy intimacy. This article's aims are the following: (a) discuss occupational therapy's established role in addressing sexuality, (b) explain how occupational therapists can use the Model of Human Occupation (MOHO) to promote participation in sexual activity and romantic intimacy, (c) discuss current research involving women's self-concept and connectedness to others after TBI, (d) describe women's experiences involving sexual activity and romantic intimacy after TBI, and (e) propose initiatives in which occupational therapy can address sexual activity and participation in intimate partner relationships.

Occupational Therapy and Sexuality

In 2020, the American Occupational Therapy Association (AOTA) published the fourth edition of the *Occupational Therapy Practice Framework* (*OTPF*) and included sexual activity as a basic activity of daily living, 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). In addition, the fourth edition added participation in intimate partner relationships as a form of social participation. Participation in intimate partner relationships is defined as "engaging in activities to initiate and maintain a close relationship, including giving and receiving affection and interacting in desired roles; intimate partners may or may not engage in sexual activity" (AOTA, 2020, p. 34).

In 2013, AOTA published a fact sheet outlining occupational therapy's role in addressing sexuality. In this resource, AOTA asserts that occupational therapy is a safe place for addressing sexuality where therapists have the opportunity to use empathy to listen to clients' concerns regarding sexuality, then offer assistance with problem-solving (MacRae, 2013). Furthermore, AOTA identifies three interventions offered by occupational therapists: (a) health promotion through support groups, educational programs, and stress-relieving activities; (b) remediation through restoration of skills, such as motion, strength, endurance, effective communication, and social engagement as part of meeting sexual needs; and (c) modification through changing the environment or routine to promote engagement in sexual activity (MacRae, 2013). This article acknowledges that the barriers to participation in sexual activity and intimacy include a lack of knowledge and support, physical and cognitive dysfunction, ineffective or reduced communication and social engagement, and environmental and contextual barriers. Furthermore, MacRae (2013) emphasizes that body and cognitive functions, performance skills, and contexts can affect participation in sexual activity and intimacy, but the article does not identify other key mental functions that may be barriers to participation in these occupations.

In addition, despite the inclusion of these occupations in the *OTPF*, there has been little progress made in the practice of occupational therapy in relation to sexuality (McGrath & Sakellariou, 2016; Rose & Hughes, 2018). Positive sexuality, including sexual self-esteem, sexual satisfaction, and sexual

pleasure, are all positively associated with physical, mental, and sexual health, as well as overall well-being (Anderson, 2013). Therefore, there is an opportunity for occupational therapists to facilitate participation in sexual activity and intimacy as a means of facilitating overall health and wellness. Occupational therapy literature suggests that the lack of progress is a result of a knowledge gap among therapists, fear of causing offense or anger, and lack of clarity regarding professional roles and concerns regarding damage to professional reputation (McGrath & Lynch, 2014). However, McGrath and Sakellariou (2016) argue that these barriers are the result of the context in which occupational therapy came to be.

Occupational therapy's development is embedded in America's historical contexts and a culture that values the Protestant work ethic. In this context, hard work and productivity were valued above rest, relaxation, leisure, and socialization. Therefore, rehabilitation has been shaped by a culture that values productive occupations and independence over participation in intimate partner relationships and co-occupations (McGrath & Sakellariou, 2016). To promote the profession's value and competence in addressing intimacy, there is a need for occupational therapy research to create and publish models that guide therapists in addressing intimacy and sexuality. Furthermore, there is an additional need for the Accreditation Council for Occupational Therapy Education to implement standards involving student knowledge of disability, intimacy, and sexuality. While practice models that specifically pertain to intimacy are needed, the field of occupational therapy can also draw on existing conceptual models to support the knowledge and practice of occupational therapy to promote participation in intimacy.

Applying the MOHO to Practice

In the profession of occupational therapy, conceptual practice models seek to explain specific phenomena (Taylor, 2017). In this case, MOHO conveys three phenomena that describe engagement in occupations. The first phenomenon embedded in MOHO describes how people are motivated to do the things that fill their lives (Taylor, 2017). This phenomenon is depicted as a volitional subsystem. The second phenomenon involves the everyday pattern of doing that makes up everyday life, referred to as the habituation subsystem (Taylor, 2017). The third phenomenon MOHO addresses describes that when people do things, they exhibit an extensive range of capacity for performance of that occupation (Taylor, 2017). This phenomenon is portrayed in the performance capacity subsystem. All of these subsystems are internal and influence a person's engagement, lack of engagement, or the nature of the engagement in an occupation. In summary, MOHO is an occupational therapy model that aims to explain how occupation is motivated, patterned, and performed (Taylor, 2017).

This article will focus on the volition subsystem in order to highlight an opportunity for occupational therapists when addressing sexual activity and intimate partner relationships with women who sustained TBIs. The volitional subsystem consists of three components: (a) personal causation, or perceived effectiveness or ability; (b) values, or the importance attached to what one does; and (c) interests, or the enjoyment or satisfaction one feels when doing things (Taylor, 2017). As discussed, self-concept is often affected after sustaining a TBI, where drastic changes to function can have a resulting impact on what people feel and believe about their abilities, values, and interests, all of which are components of the volitional subsystem (Stangor, 2014; Taylor, 2017). MOHO supports that a change in motivation for activities, perhaps as a result of a disabling condition, can influence one's participation in previously preferred occupations, including sexual activity and intimacy.

Women's Self-Concept After TBI

The onset of a TBI abruptly and profoundly impacts the body, as well as TBI survivors' understanding of their own embodied self (Alston et al., 2012). Carroll and Coetzer (2011) suggest that after experiencing a TBI, people often compare their current self to their pre injury self, where their current self is viewed more negatively. While more research is needed to further our understanding of the unique impacts of TBI on women, preliminary findings suggest that there are both internal and external barriers to developing a positive self-concept after injury. A TBI can cause visible bodily changes and physical impairments. However, a TBI can also solely result in cognitive, emotional, and behavioral changes, sparing physical function. The nature of this hidden disability adds to the complexity of adjusting to a new self-concept after injury (O'Reilly et al., 2018).

A unique theme found in women's shared experiences after mild to moderate TBI involves feeling the need to be perceived as "normal" by others, both physically and cognitively (Alston et al., 2012). While the desire to be perceived as normal is an internal barrier that inhibits women's adjustment to a new self and the development of a positive self-concept, other women feel as though their disabilities are hidden and therefore dismissed by others in society (O'Reilly et al., 2018). Women with a TBI describe these hidden disabilities as being trivialized by others, resulting in women feeling as though society does not understand them (O'Reilly et al., 2018). The dismissal of women's experiences after injury is an external barrier that negatively impacts their self-concept, leaving them feeling less valued and concerned with being a burden (O'Reilly et al., 2018).

There is a clear need to create practice models and occupational therapy interventions that promote positive self-concept in women after TBI in the context of relationships with others in society, including intimate partner relationships. The promotion of self-concept is explicitly stated as an outcome of occupational therapy in the *OTPF* and is within the scope of occupational therapy practice (AOTA, 2020). Through applying MOHO, occupational therapists can assist women with developing and enhancing their sense of personal causation in relationships, facilitate their ability to identify and communicate their values in relationships, and promote identification of current and new interests as they pertain to participation in intimate relationships. In doing so, there is an opportunity to promote motivation for engagement in healthy intimacy and a sense of connectedness.

Women's Experiences Involving Sexual Activity and Intimacy After TBI

Clinical findings support that both men and women experience changes in sexual functioning and participation in sexual activity after sustaining TBIs (Goldin et al., 2014). Furthermore, research findings demonstrate that fatigue, self-esteem, reduced sex drive, reduced importance, and reduced satisfaction in sex and intimacy are common factors that influence engagement in sexual activity after TBI (Kreuter et al., 1998; Strizzi et al., 2015). Through the application of MOHO, occupational therapists can understand that these are the performance capacity factors that can result from a TBI, and therefore can have a significant impact on one's motivation to engage in romantic intimacy and sexual activity (Taylor, 2017). Furthermore, Moreno et al. (2015) found that individuals with a TBI experience overall lower sexual quality of life when compared with healthy controls. While some research endeavors have evaluated sexual changes following TBI, much of the existing literature describes sexual outcomes in males and people who have sustained moderate and severe TBI (Grashow et al., 2019; Latella et al., 2018). There is a paucity of research that explores experiences with intimacy that extends beyond sexual changes after TBI, particularly with regard to women's experiences. To identify how occupational therapists can address this area, occupational therapists and occupational scientists have an opportunity to understand women's unique perceptions, experiences, and self-concept.

Implications for Occupational Therapy

There is a need to research, understand, and address the problem of women's negative self-concept after TBI as well as understand how this influences their participation in intimate partner relationships. Furthermore, there is an opportunity to promote participation in healthy intimacy as a means of developing a positive self-concept. While the field of occupational therapy needs practice models to help guide clinicians in doing so, MOHO can help therapists understand their role in addressing this area. Through application of MOHO, occupational therapists can help motivate and empower women to participate in healthy intimacy after injury. The following are some suggestions for occupational therapy interventions guided by MOHO, as well as recommended initiatives for the field of occupational therapy:

Occupational Therapy Interventions

- Occupational therapists can facilitate women's ability to identify former, current, and newfound interests in the context of sexual activity and/or intimate relationships. This could be through the identification of and planning for dates at home or in the community. This could also be through promoting women's engagement in preferred or new co-occupations with a significant other. In addition, occupational therapists can also help women identify their interests with regard to sexual expression and activity after injury.
- Occupational therapists can help women identify and communicate their values post TBI. This could occur through helping women to identify the things that are important to them in the context of intimate partner relationships, whether it be characteristics that they look for in a partner or their values involving sexual or romantic expression (e.g., spending time together, doing things for one another, words of affirmation).
- Occupational therapists can use occupations as a means of helping women to build positive self-concept and enhance personal causation after injury. This could be through promotion of agency and choice over one's situation, identifying new ways to independently engage in preferred occupations, or implementing interventions that target improvement in self-esteem (e.g., selecting an outfit for a date, engaging in self-care).

Initiatives for the Profession of Occupational Therapy

- Conduct and disseminate research that inquires about women's experiences involving sexual activity and intimacy after experiencing a TBI using occupational therapy and occupational science lenses.
- Create assessments that collect data regarding women's sexual self-concept after TBI and perceived changes in sexual and intimate participation post TBI.
- Create occupational therapy practice models that guide therapists in facilitating interventions that enhance clients' self-concept after TBI.
- Include language that captures psychological client factors, including self-concept, that influence sexual and intimate participation in occupational therapy models and frameworks.
- Encourage the Accreditation Council for Occupational Therapy Education to implement standards involving student knowledge of disability, intimacy, and sexuality.
- Encourage educators to incorporate initiatives in occupational therapy programs that target building empathy, active listening and communication skills, and clinical reasoning skills for enhancing participation in intimate partner relationships.
- Offer continuing education targeted toward teaching occupational therapists how to address sexual activity and intimacy in people who have sustained TBIs.

Conclusion

There has been scant TBI research that explores changes in women's self-concept as it relates to intimacy as well as women's experiences involving romantic intimacy after TBI. There is an opportunity for both occupational therapists and occupational scientists to explore women's unique experiences and perceptions of themselves after injury, develop practice models to support participation in intimacy, and apply MOHO to promote participation in intimacy and positive self-concept post TBI. In doing so, occupational therapists can better understand the occupational barriers that women face after experiencing a TBI and implement interventions to meet this population's occupational needs.

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