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**YOUNG WOMEN'S EXPERIENCES AND PERCEPTIONS OF SEXUALITY
AFTER TRAUMATIC BRAIN INJURY**

A Thesis in

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by

Emily J. Tarconish

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The thesis of Emily J. Tarconish was reviewed and approved* by the following:

Liza Conyers
Professor of Rehabilitation Counseling
Thesis Adviser

Margaret Lorrach
Professor of Rehabilitation Counseling
Director of the Centre for Women's Students
Thesis Adviser

Spencer Niles
Department Head for Counselor Education

*Signatures are on file in the Graduate School.

Abstract

Traumatic brain injury (TBI) is the leading cause of disability for persons under 45 years of age, affecting 2 million Americans every year. Two age groups, including 0-4 and 15-19 years of age, most frequently acquire TBI and men encompass approximately 62% of those injured (CDC, 2010). As a result, most of the literature describes generalized experiences of symptomology, which are based on accounts provided by men (Ponsford, 2003). The purpose of this study is to examine young women's experiences of brain injury paying particular attention to how the symptoms of injury affect and have affected their experiences and perceptions of sexuality, and their sexual behaviors.

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Chapter 1

Introduction

Young Women's Experiences and Perceptions of Sexuality After Traumatic Brain

Injury

Traumatic brain injury (TBI) is the leading cause of disability for persons under 45 years of age, affecting 2 million Americans every year (CDC, 2010). Two age groups, including 0-4 years and 15-19 years of age, most frequently acquire TBI and men encompass approximately 62% of those injured. As a result, most of the literature describes generalized experiences of symptomology, which are based on accounts provided by men (Ponsford, 2003). The purpose of this study is to find out about women's experiences of brain injury, paying particular attention to how the symptoms of injury affect and have affected their experiences and perceptions of sexuality, and their sexual behaviors.

When an individual experiences a brain injury, he or she may face physical, cognitive, personality, behavioral and emotional changes depending on the severity of injury and the region of the brain that is damaged (Farace & Alves, 1999). Also, a majority of TBI causes pervasive damage and a vast combination of symptoms because of diffuse axonal injury, or a stretching and shearing of individual axons in the brain. Because of these factors, brain injury symptomology is vast and can manifest in very different ways for every survivor (Farace & Alves, 1999).

Physical TBI Sequelae

Physical consequences may impact an individual's mobility, movement or sensory abilities (Brain Injury Association of America, 2010). These may encompass weaknesses in muscle movement, balance and coordination, and becoming easily

fatigued. Sensory changes, such as those involving hearing, vision, taste, touch, and smell may occur and can decrease one's ability to perceive the external environment (Brain Injury Association of America, 2010). While physical impairments may result from a TBI, most of the consequences are invisible to outside observers, including those that affect cognition.

Cognitive TBI Sequelae

Brain injuries frequently impact a survivor's cognitive abilities, causing problems with memory, planning, sequencing, attention, reading, writing, thought processing, problem solving, organization, thought flexibility, communication, learning, self perception, perception of others, judgment, and decision making. All of these skills may be altered or greatly reduced (Brain Injury Association of America, 2010). Studies have measured common cognitive changes one to two years after brain injury, and a consensus shows that some of the most salient effects include difficulties with slowed thinking and information processing, impaired concentration and memory (Draper & Ponsford, 2008).

Draper and Ponsford (2008) found that significant cognitive impairments, including detriments in processing speed, memory, and executive function, with correlations between greater injury severity and lower levels of function, also existed ten years after injury. Assessments that measured these effects included The Symbol Digit Modalities Test (SDMT), The Trail Making Test (TMT), The Digit Symbol Coding (DSC), The Digit Span (DS), The Rey Auditory Verbal Learning Test (RAVLT), *The Doors and People tests*, *The Hayling and Brixton Tests*, The Controlled Oral Word Association Test (COWAT), *Porteus Maze Test—Vineland Revision*, and The Sustained Attention to Response Task (SART) (Draper &

Ponsford, 2008). Although these instruments can detect cognitive deficits, they cannot and do not explain how these effects will manifest for survivors years later in their places of employment, schools and communities. Even if this study did follow-up with participants on this issue, the sample contained individuals over the age of 26 and more than 55% male, therefore, its results may not extend to women, or a population younger than 26 years. Draper and Ponsford (2008) also mentioned that members of their sample may face another consequence of brain injury, impaired self-awareness, which could result in underreporting of symptoms.

Impaired Self-Awareness

Impaired self-awareness may cause an individual to have little or no understanding of his or her functional limitations or may be in complete denial of the disability. When this condition is a direct result of neurological injury, it is defined as “anosognosia”; whereas, when experienced as a psychological mechanism, impaired self-awareness is described as “denial.” Trudel, Tryon & Purdum (1998) compared patients with TBIs’ self ratings of maladaptive behaviour to therapists’ ratings and found a significant difference between their perceptions. The mean participant rating, 524.05, was significantly higher than the mean of therapist rating, which was 502.59; the difference between these scores, 21.46, shows that patients overrated their abilities (Trudel, Tryon & Purdum, 1998). The sample observed in this study consisted of 79% men, all of whom sustained severe traumatic brain injuries. Utomoto and Fann (2004) explained that although those with severe brain injuries tend to underestimate their functional limitations, individuals with mild and moderate TBI often overestimate their problems. Uomoto and Fann (2004) explain, “each group may possess unique characteristics with regard to self-perception and self-evaluation of the cognitive condition, (p. 336).”

Kortte, Wegener, and Chwalisz (2003) describe the psychological component of impaired self-awareness, denial, as “an unconscious defence mobilized against the painful realization of the implication of one’s condition, as well as potential prognosis, (p. 131).” It may emerge as a coping mechanism to avoid emotional distress by minimizing awareness of brain injury deficit (Kortte, Wegener, and Chwalisz, 2003).

Brain injury can trigger a state of ambiguous identity, in which a survivor is no longer sure of his or her abilities and characteristics (Landau and Hissett, 2008). He or she may be unable to complete physical tasks at which he or she used to excel; a survivor may have difficulty concentrating, remembering or paying attention. He or she may be overwhelmed with emotions and easily enraged with friends and family. When none of these behaviors, thoughts and feelings are familiar to a brain injury survivor, he or she may question his or her identity (Landau and Hissett, 2008).

Feelings of ambiguous identity may be furthered by altered reactions from the survivor’s friends or family members. Those acquainted with the survivor may not understand his or her behavioral changes and may treat him or her differently. Landau and Hissett (2008) describe this concept as “boundary ambiguity” (p. 69). They explain that “Many MTBI subjects have reported a huge ‘disconnect’ between the people they present to the world, versus whom they feel they’ve become inside” (p. 75). As survivors overcome or adapt to altered levels of functioning, they find ways to integrate these experiences or changes into their identities; bystanders cannot share these experiences, and often, have difficulty adjusting to the changes. Not only can this affect the survivor socially and emotionally, leaving him or her feeling abandoned, but it also may isolate him or her when he or she needs to confide in or communicate with someone.

Behavioral TBI Sequelae

Personality and behavior are controlled by the frontal lobe, the most common region to be injured in a brain injury (Centre for Neuro Skills, 2010). The frontal lobe, one of the largest neurological structures, controls many of the physical and cognitive tasks previously discussed. This brain region also regulates some of the most intimate aspects of an individual, including inhibition of behavior, emotion, and judgment (Brain Injury Association of American, 2010).

The orbitofrontal cortex provides humans with the ability to inhibit their behaviors and responses (Brain Injury Association of American, 2010). Inhibitory responses are applied constantly in everyday life; brain injuries, however, often have trouble regulating these behaviors, also called disinhibition (The Brain and Spine Foundation, 2011). Disinhibition may be present in survivors of brain injuries in various ways, including decreased awareness, impulsivity, and problems in communication skills (Kim, 2002). Decreased awareness and insight can cause individuals to be unable to monitor their behavior or understand others' reactions to it, creating another impediment to realizing the implications of their actions and adjusting them.

Impulsivity is another consequence of disinhibition and may cause individuals to act on urges, without considering social or personal rules and consequences of the behavior (Acquired Brain Injury Outreach Service, 2007). A final example of disinhibition may involve an individual's experiencing changes in the way he or she communicates. He or she may speak out of turn, dominate the conversation, or completely disregard what others say; the opposite can occur too, in which an individual may not respond or pay attention during conversation. Disinhibited

communication may also include making inappropriate, suggestive or offensive comments, without understanding their implications, not understanding the verbal or nonverbal cues of others, such as disapproval, trouble with social communication skills, including eye contact, social distance or space, and appropriate vocal tones, volumes or touching (Acquired Brain Injury Outreach Service, 2007).

Disinhibition and impulsivity can hinder an individual's abilities to make decisions. Decision making involves complex mental processes that may be impeded for survivors of brain injury. When facing a decision, one must consider similar situations that have occurred in the past and their outcomes, how these situations may relate to current options, and evaluate the possible positive and negative consequences of each choice (Centre for Neuro Skills, 2010).

Another problem that may occur when the frontal lobe is damaged can involve problems receiving signals from or interpreting the external environment. An individual with frontal lobe damage may take risks, and evince a non-compliance with or disregard for social rules (Brain Injury Association of America, 2010). Also, as survivors may not understand one's social environment, they may be unable to interpret the intentions or prerogatives of others. Milders, Ietswaart, Crawford & Currie (2006) found that 28 men and five women who experienced moderate to severe TBIs were less able to distinguish social inferences than participants in a control group; these results were present both soon after injury and one year later.

Other behavioral changes that can occur include reduced motivation, increased stress, denial, egocentrism, anger management, frustration, irritability or agitation, and reduced coping skills (Brain Injury Association of America, 2010). When a survivor of a brain injury develops altered, or strange, behavior, it can make those

around him or her feel uncomfortable and elicit distant or detached reactions; people who did not experience a brain injury may not be able to understand how and why the injured party seems to have changed. Similarly, brain injury survivors may not understand why their friends and family act differently toward them and may feel rejected. Compounding this, survivors often face frustration dealing with impairments and confusion due to their physical or cognitive limitations. All of these reactions can lead individuals to experience mood disorders, such as depression and anxiety.

Emotional TBI Sequelae

Approximately 25% of individuals with TBI experience major depression, which may produce feelings of loss, demoralization, discouragement or dysphoria. Symptoms including fatigue, irritability, suicidal thoughts, anhedonia and disinterest are common 6-24 months after TBI (Rao & Lyketsos, 2000). Bay, Sikorskii, and Saint-Arnault (2009) found that after TBI, depression and depressive symptoms manifest in varying ways; in the first six months after injury, autonomic and anxiety symptoms are most common; more than six months after injury, depression is more associated with psychosocial concerns and vegetative symptoms, such as morning awakening, anhedonia, and cognitive difficulties.

While some of the depressive symptoms may have organic causes, dealing with the physical and cognitive limitations that may result from a TBI often negatively affect one's mood. Survivors of brain injury also frequently develop poor self-concept, self-esteem, and perception of body image. Vickery, Gontkovsky, Wallace, & Carosli (2006) define self concept as "a collection of beliefs about an individual's own functioning in various life dimensions, such as physical self-concept and social self-concept ... and underlies all perceptions, beliefs, and feelings about

oneself.” These authors explain that survivors of TBI report significantly poorer views of post-injury self concept as compared to before their injuries (2006). These effects can contribute to experiences of depression.

Apathy also may accompany depression and affects approximately 60% of TBI survivors (Rao & Lyketsos, 2000). Rao & Lyketsos (2000) define this condition as “a syndrome of disinterest, disengagement, inertia, lack of motivation, and absence of emotional responsitivity” (p. 98), but classify it separately from depression, as apathy is usually present without the negative affect and cognitive deficits commonly seen in depression. Approximately 10% of brain injury survivors experience apathy without depression.

Survivors of brain injury also frequently develop poor self-concept, self-esteem, and perception of body image (Vickery, Gontkovsky, Wallace, & Caroselli, 2006). Further, anxiety disorders occur in 11-70% of TBI survivors in various forms, including generalized anxiety disorder, panic disorder, and obsessive-compulsive disorder, phobic disorder and posttraumatic stress disorder (Rao & Lyketsos, 2000). Behavioral dyscontrol, which involves the erratic implication of emotions, cognitions, and behavior, may function as an expression of the survivor’s depressed, anxious or otherwise altered mood (Rao & Lyketsos, 2000). Studies suggest that mood disorders in survivors of TBI may begin during the first months after injury, but can last for years.

Reduced cognitive, communication, and behavioral skills can make it difficult for survivors to form and maintain relationships with friends or sexual partners (The Acquired Brain Outreach Service, 2007). Being unaware of impairments, an individual may approach sexual relations as if he or she is completely cognizant; the

survivor may not know that his or her perception of others' intentions and decision making abilities are not fully functioning. He or she may not be able to gauge what the dating partner wants, and therefore, may not be able to decide whether it aligns with his or her desires. Also, as decision making and judgment are impaired, one can imagine that a survivor may not think about or consider the consequences of practicing unsafe sex, including pregnancy or sexually transmitted infections. These outcomes may be incredibly relevant if a survivor's disinhibited behavior and judgments manifest in sexual acts; whether or not and how this happens for women with TBI, however, is unknown.

TBI and Sexuality

The World Health Organization describes sexuality as “a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction” (World Health Organization, 2011). Individuals with brain injuries may experience biological complications with sexuality, such as inability to maintain an erection or vaginal lubrication (Ponsford, 2003); in addition, many of the cognitive, behavioural, and emotional sequelae previously discussed, may influence an individual's sexuality, even if he or she does not experience physical changes.

Commonly injured regions of the brain, including the frontal system, limbic structures, and temporal lobes, all influence expression and experiences of sexuality, including endocrine functions, sexual responsivity, motor control, sensation, and psychosocial responses (Trudel, 2006). Further, emotional and behavioral changes, such as depression, anxiety, cognitive impairment, amotivational states, and

behavioral dyscontrol can impact an individual's experience of sexuality (Trudel, 2006).

Studies are slowly beginning to emerge on the topic of sexuality and TBI; however, most of the literature revolves around the symptoms experienced by, and how they influence the sexuality of, men. Although the following studies focus on men's experience of sexuality after TBI, and thus, their results may not apply to women, they do exhibit ways in which a brain injury can influence one's sexuality. Dombrowski, Petrick, & Strauss (2000) describe changes that occur after brain injury that can affect sexual behavior, including shifts of mood or the rapid changes in basic drives that direct behaviour, such as sexual impulse control; they also suggest that unawareness of impairments may influence sexual behavior. Previous studies, including Kreutzer and Zasler (1989), found a decrease in sex drive, erectile function, and less frequent intercourse for survivors of TBI (Aloni & Katz, 1999).

Griffith, Cole, & Cole (1990) suggested that secondary sexual dysfunctions, such as cognitive and psychological deficits, may influence social and interpersonal skills, sex drive, and sexual interest, and thus, affect sexuality and sexual behavior. Griffith et al. (1990) found these results after conducting several case studies, including one on a 36-year-old Caucasian woman who sustained a TBI when she was 17-years-old, a 28-year-old Caucasian man who sustained a TBI when he was 13-years-old, and a 34-year-old Caucasian man who sustained a TBI when he was 17-years-old. The men were determined to have exhibited disinhibited touching, sexual comments and staring at women in increased proportions after their injuries. The article suggested that not understanding responses from others and social rules and norms may have contributed to these behaviors, in addition to social isolation after injury. The women included in this analysis exhibited disinhibited sexual behaviors,

such as attempting to perform oral sex in public, frequently discussing sex, and “almost always” acting in a sexually provocative manner when encountering men (Dombrowski, Petrick, & Strauss, 2000). She was also noted to be obsessed with her physical appearance and measures her self-esteem according to how attractive she is to the other sex (Dombrowski, Petrick, & Strauss, 2000). Although a woman was studied in this analysis, she represented a severe injury, spending 72 days in a coma; therefore, its results may not extend to a population of women who sustain mild or moderate injuries. Further, this study examined the sexuality of three individuals living in a long-term supported living program, thus observing how changes in sexuality occur and progress in a sheltered situation; therefore, the results may also not represent the experiences of those living in an unsupervised environment.

Luiselli, J.K., Sherak, F. L., Dunn, E. K., & Pace, G. M. (2005) surveyed staff at a neurorehabilitation clinic about the patients’ sexual behaviors. Staff reported public masturbation, sexual talk or writing, sexual touching of staff or other patients, or exposing genitals in public as the most common deviant behaviors seen in their 6-20 year-old patients, 79% of whom were boys. Further limiting these results by gender, the survey questions that provided this information were constructed using frequently identified behaviors observed by psychologists and psychiatrists who work in TBI clinics for children and adolescents, which tend to contain a majority of boys and young men (Luiselli, et al., 2005); therefore, it is not clear how well the survey questions captured the sexual experiences of girls and young women with TBI.

Ponsford (2003) surveyed a group of individuals, containing 69% men, one to five years post-injury about the changes in their sexual behavior. Results included that 36-54% of participants reported a decrease in importance of sexual satisfaction and to engage in sexual intercourse, reduced sex drive, a decline in their ability to give their

partner sexual satisfaction and to engage in sexual intercourse, and a decreased enjoyment of sexual activity and ability to stay aroused and to climax (Ponsford, 2003).

Ponsford also found that participants reported decreased levels of self-confidence, sex appeal, higher depression, and decreased communication levels and relationship quality with their partners (Ponsford, 2003). Ponsford (2003) discussed physical manifestations of altered sexuality as hypersexuality or reduced desire, as caused by biological changes, ejaculatory dysfunction, anorgasmia, reduced sensation or poor lubrication; she did not address if these occurred in different proportions for men and women. She also mentioned TBI symptoms that would influence sexuality secondarily, including changes in body image, self esteem, depression, and anxiety. It was not clarified how these changes would affect sexuality and sexual behaviors and if it did so in different ways for men and women (Ponsford, 2003). She also mentioned that cognitive impairments, including impaired behavioral control, communication, social judgment and egocentricity, may affect sexuality, but again, no details were provided as to how this occurred for men and women (Ponsford, 2003). The absence of literature addressing the differences in men's and women's experiences of sexuality and sexual behaviors after TBI is ironic, as other differences have been found between genders in general experiences of TBI.

More recent studies, including those of Hibbard et al. (2000), and Trudel (2006) have included more equal numbers of men and women in their samples. Studying a more diverse gender pool produced a wider range of concerns involving sexuality, including:

- 1) Difficulties influencing sexual energy, desire, and drive

- 2) Reduction in sensation and orgasm
- 3) Problems with positioning, movement and pain
- 4) Changed body image, self-confidence and mood
- 5) Decreased ability to sexually satisfy a partner (Trudel, 2006, p. 18).

Hibbard found that women with brain injuries participated in sex as much as women without injuries, but experienced decreased sexual functioning, including difficulties with sexual arousal, pain with sex, difficulties with masturbation, and decreased vaginal lubrication. Women with mild TBI reported these problems more often than those who had severe TBI (Trudel, 2006). Study participants also described experiencing sexual disinhibition and hypersexuality; however, these issues were typically reported by participants who had more severe injuries (Trudel, 2006).

After brain injury, women can undergo a range of sexual experiences, including a decrease in sexual function or increased and impulsive sexual behaviors. Regardless of what part of this spectrum women experience, women with disabilities, including TBI, may be at increased risk to tolerate abusive relationships or coerced sexual encounters due to psychological reasons and the complex challenges of adapting to an acquired disability (Trudel, 2006). Trudel (2006) presents that there are “ample anecdotal accounts” of women who have TBI who have “gone along with things that were physically or psychologically hurtful, or at best not pleasurable,” (p. 19)

Differences Known Involving How Men and Women Experience TBI

Differences between men and women before acquiring TBI, such as premorbid IQ and psychosocial factors, have been found to affect their outcomes after injury (Farace & Alves, 1999). While these individual characteristics have been correlated

with the quality of recovery, research has yet to compare if the quality of outcome is different for men and women who possess similar traits before injury (Farace & Alves, 1999).

Another difference that may exist between genders after TBI involves the distinction in men's and women's functional organization patterns in the brain. Farace and Alves (1999) discussed how women's brains seem to have more bilateral capability, and suggested that traumatic injury to women's brains may be more diffused, thus affecting greater areas of function, whereas, men's injuries may affect fewer, more isolated areas (Farace & Alves, 1999). As men and women experience TBI differently, due to distinct physical responses psychosocial conditions, there is a need to study how brain injury affects women.

Correlates Between Mood and Sexuality

As it is likely for women with TBI to develop depressive symptoms, it is important to consider the influences these states will have on their sexual experiences and behaviors. Negative mood and frequent mood variation have been found to correlate with increased sexual activity for adolescents (Fortenberry, Temkit, Tu, Graham, Katz, & Orr, 2005). For college-aged women, depressive symptoms are related to decreased sexual satisfaction and pleasure, although no mention was made as to how mood affects their sexual activity (Fortenberry, et al., 2005) As young women with brain injuries experience increased levels of depression, depressed mood, and other erratic emotional behaviors, the current study will explore how these states affect their sexual behaviors. This question is especially relevant for this age group as research describes the culture of casual, and often frequent, sexual encounters, or

“hookups” (Hamilton & Armstrong, 2009) that pervades high school and college settings.

The Culture of Sex on High School and College Campuses

High school and college campuses remain environments in which casual sexual acts are increasingly common. Fielder and Carey (2010) report that 81% of college students have reported in one or more “hookups” or casual sexual encounters that range from kissing to sex with a casual partner, during their academic careers (Fielder & Carey 2010). In a survey conducted by England, it was found that 72% of college students participated in one hookup, about 40% participated in two to three, 40% participated in four to nine hookups, and 20% participated in ten or more (Hamilton & Armstrong, 2009). Among the 80% of students who had intercourse in college, 67% had done so during a hookup with a non-committed partner (Hamilton & Armstrong).

Casual hookups are also occurring in middle and high school environments. Bay-Cheng, Robinson, & Zucker (2009) surveyed adolescent high school girls and found that 30% of the respondents engaged in manual stimulation with a male partner, 8% had engaged in fellatio, and 12% had engaged in cunnilingus. They cited Brewster and Tillman’s finding that over 27% of female adolescent virgins had experienced oral sex with a heterosexual partner, and 87% of female adolescent non-virgins had experienced oral sex with a male partner (Bay-Cheng, et al., 2009). They also explained that 38% of adolescents participating in a National Longitudinal Study of Adolescent Health reported that their sexual encounters were not with a romantic partner (Bay-Cheng, et al., 2009).

Several factors may influence the increased prevalence and acceptance of casual sexual behavior, including cultural norms, including sexualized views promoted by the media, the immediate social environment, and situational factors, including substance use (Fielder & Carey 2010). Some students express that they prefer casual sexual encounters, as opposed to long-term relationships, because it allows them to feel more freedom and independence (Fielder & Carey, 2010). College students also suggest that perceived social norms and messages from the media influence their involvement in casual sexual hookups. Fielder and Carey showed that college students overestimate how much their peers engage in hookups and with how many people. Misperceptions such as these have been associated with increased sexual activity and persons having a higher number of sexual partners (Fielder & Carey, 2010). Also, students cite messages from the mass media encouraging casual sex as influencing their decisions and desires when, how, and how much to engage in sexual encounters. Alcohol use was also reported as frequently being a factor during casual hookups. Grello, Welsh, and Harper (2006) found that 65% of individuals surveyed describing being intoxicated before participating in their most recent episode of casual sex (Fielder & Carey, 2010).

Young people in high school and college are constantly bombarded with expectations and suggestions to engage in casual hookups; in addition, sexually aggressive attitudes endorse, and may even force, women to participate in casual sexual behavior. Anderson, Simpson-Taylor, Herrman (2004) surveyed middle and high school girls and university women to discover the prevalence rape-supportive attitudes and sexual coercion. They showed that while some girls or women in each group experienced acts of sexual coercion, university women experienced the most. Also increasing with age was the consensus of what it takes for a woman to give

consent to a sexual act. “Compared to the middle and high school students, university students agreed less about the conditions under which a man could assume a woman wanted to have sex,” (Anderson, Simpson-Taylor, Herrman, 2004, p. 84). For instance, both university men and women agreed that a lack of verbal or physical resistance indicated that she wanted to have sex. “Because men are the ones who are supposed to make sex happen, the mere fact that the woman is not resisting his overtures either verbally or physically may be interpreted by the man as a cue that the woman wishes to have sex with him,” (Anderson, Simpson-Taylor, Herrman, 2004, p. 86). The article showed that college students are becoming increasingly likely to “perceive behavior in a sexualized manner,” (Anderson, Simpson-Taylor, Herrman, 2004, p. 87).

Whether influenced by participation in casual hookups or attitudes or sexual aggression, large percentages of young women report experiencing sexual aggression.

“Muehlenhard and Linton (1987) found that 77.6% of the college women in their sample had experienced sexual aggression on a date, with nearly 15% having experienced date rape ... More recently, Gross, Winslett, Roberts, and Gohm (2006) found that 27% of the college women in their sample reported experiencing sexual aggression and that 18.8% experienced being the victim of a completed rape since enrolling in college,” (Winslett & Gross, 2008, p. 542).

Young people, ranging from middle school to college settings, report increased expectations from peers, the media, and social culture to engage in sex, engaging in more casual sexual activity, and encountering increased aggressive or coercive attitudes toward sex. How young women with brain injuries, who may possess altered

emotions, responses to and perceptions of others, impulsivity and disinhibition, respond to the circumstances of sexualized culture is unknown and will be examined by the current study.

Substance Use and Sexuality

Using intoxicating substances can impair judgment and increase impulsivity, which may lead to unplanned or unwanted sex, the non-use or misuse of contraception, and increased sexual activity (Fortenberry, et al., 2005). Substance use patterns, and the effects of substance abuse, are well-known for survivors of TBI; however, how these factors influence sexuality for survivors, specifically women, is unknown. TBI may not only increase an individual's substance use, for a number of reasons, including to cope with impairments or increase sociability (National Institute of Alcohol Abuse and Alcoholism, 2005), but substances often affect an injured brain more quickly and intensely than a healthy brain (National Institute of Alcohol Abuse and Alcoholism, 2005). This study will also examine if participants, post-TBI, used more substances as compared to before injury, and if so, how this affected their sexual behaviors.

De-emphasis of Women's Sexuality

The absence of literature on young women with TBI reflects the de-emphasis of women's sexuality in broader research and the conceptualization of sexuality as masculine. Men's behaviors tend to be standardized and accepted as the norm; whereas, women's behaviors are often judged in comparison to those of men's (White, Bondurant, & Travis, 2000). This condition extends to research in sexuality. Sexuality is often considered in terms of intercourse and reproduction, two concepts which characterize men in dominant roles (Tiefer, 2000). Tiefer (2000) explains, "...in the

sexological model of sexuality the normative standard has been men's sexual experience, or perhaps more accurately, stereotypes pertaining to men's sexual experiences," (p. 102). Gender roles in regards to sexuality emphasize men's promiscuity and women's timidity, or cautiousness; these ideas are encouraged by sociobiological theories that explain men's abundance of sperm, and thus, their evolutionary obligation to spread it, and women's precious monthly egg, which much be reserved and protected. As biological models still seem to dominate conventional thought, women's sexuality is not only discouraged, but de-emphasized in research. This lack of attention is especially prevalent in regards to the sexuality of young women (Welsh, Rostosky, & Kawaguchi, 2000). Further, women with disabilities are labeled as sexuality inappropriate, victimized or asexual (Tepper, 2000). Therefore, much literature and research addressing sexuality shies away from describing the experiences, perceptions, and behaviors of women, especially those who are young and/or disabled as others may not want to recognize or normalize these portrayals. Exploring the sexualities of young women with TBI, a disability that has many cognitive, behavioral, and emotional sequelae, is a necessary step to occupy the current vacancy on the subject.

The Current Study

As most of the symptoms caused by TBI have been reported and described by a majority of men, the experiences of 38% of survivors, or 760,000 women who endure TBI, may not be accurately portrayed in general accounts of symptomology. Further, the literature leaves a major gap on addressing how young women (ages 15-25), members of one of the highest age groups to report TBI, experience sexuality after brain injury.

Many women in this age group may live in environments, such as in high school or on college campuses, in which casual sexual encounters are common and sometimes expected (Hamilton & Armstrong, 2010). The current study will examine how young women with brain injuries respond in this environment and how it affects them in recovery.

Substance use, such as alcohol or recreational drug use, is often problematic for people who have brain injuries, and may also be increasingly available in high school and college campus settings. This study will also seek to understand how young women with brain injuries are influenced by substance use and how, if at all, it influences their experiences of sexuality and sexual behaviors.

As no research exists to assess how young woman experience brain injury and how it influences their sexualities and sexual experiences, a grounded theory method will be used to uncover this phenomenon. Grounded theory (GT), or “The discovery of theory from data,” (Tan, 2009, p. 94) was created by Glaser and Strauss in 1967 to address the failure of quantitative research methods to capture the lived experience (Plewes, 2002). GT is used to generate theory by grounding that theory in data gathered by the researcher, as opposed to using data to confirm or disconfirm hypothesized theory. GT is especially applicable to address unexplored issues and individuals’ personal experiences that have not been focused on in the literature, or as Tan writes, “if the researcher seeks to create a theory about issues of importance in people’s lives and specifically focuses on human interaction or aims to explore new territory,” (2002, p. 94). This method helps researchers to conduct exploratory studies that answer “what is going on” and “how” and to “conceptualize the relationships among the generated concepts and categories,” (Tan, 2009, p. 94). GT interviews will be used in this study to allow participants to offer subjective descriptions of how they

experienced symptoms related to their injuries and their perceptions about how these impairments affected their sexualities and sexual experiences and behaviors.

Chapter 2

Method

This study used open-ended interviews to examine young women's experiences of TBI and its effects on their sexuality in a high school or college setting. The researcher/interviewer interviewed 12 students from the Pennsylvania State University who identified as women and have had an experience with a brain injury between the ages of 15-25. The interviews were transcribed, coded, and analyzed.

Researcher-Interviewer

The researcher-interviewer is a white female who identifies as a heterosexual woman. She is expected to complete her master's degree in Rehabilitation Counseling in May 2011 at The Pennsylvania State University. She was between the ages of 23-24 years old while conducting the research and experienced a severe traumatic brain injury at the age of 15.

Participants

Twelve full-time university students from the Pennsylvania State University were selected to participate in the study. Participants ranged in age from 18 to 25 and experienced brain injuries when they were between the ages of 15 and 25. These individuals were recruited through advertisements that were distributed throughout university classrooms, academic departments, and via sports team coaches.

Eligibility

Participants contacted the researcher through email if they were interested and next were sent an eligibility form to determine if they had experienced brain injury between the ages of 15-25, identified as women, were currently above the age of 18.

If they were currently seeing a medical doctor regarding their brain injuries, they were required to obtain a signed consent from their medical doctor that confirmed that they were capable of participating. If participants were eligible, they were emailed an informed consent, which they were asked to digitally “sign” if they read, understood, and found themselves capable and willing to participate in the study.

The first twelve individuals to respond and meet the eligibility criteria were selected to participate. The researcher/interviewer emailed them to schedule an interview date and time, and participants were given the option to use Skype for their interviews or have the researcher/interviewer call their phones.

Procedure

Data Collection

Semi-structured interviews were conducted by the primary researcher with each participant over a period of 6 months to collect data for analysis. Before the research began, approval to perform this research was obtained from the university’s Social Sciences Institutional Review Board.

Interviews were conducted using Skype, an internet call service, and lasted from 25 minutes to one hour and 30 minutes. Calls were recorded using PrettyMay, a digital recording program that saved interviews as MP3 files on the researcher/interviewer’s secured computer. The researcher/interviewer called participants at the scheduled time; Skype to Skype calls were free, and Skype to phone calls cost the caller 2.3 cents a minute. The researcher/interviewer made all outgoing calls and funded this fee when calling participants’ personal phones.

Once both parties were connected, the researcher/interviewer asked the participant if she read the informed consent and if so, found herself able and willing to

participate. Once the participant affirmed, the researcher/interviewer reminded her that the interview and study were completely confidential and pseudonyms would be used to categorize participant responses; participants were also informed that at any time in the interview, they could decline to answer a question or request a break or discontinuation of the interview. These options were presented as the researcher/interviewer recognized the sensitive and personal nature of the interview questions and did not want to pressure participants into relaying information that made them uncomfortable. Breaks were allotted if participants were to become fatigued during the interviews and wanted to continue at a separate time.

Interviews were semi-structured and asked participants to describe their experiences with brain injury/disability, and post-concussive symptoms, including how these experiences may have been unique for them as young women. The researcher/interviewer asked participants to describe their experience of social expectations and involvements, including participation in romantic and sexual relationships, post injury, and to portray if and how they were different from before injury, keying in on what symptoms most contributed to these changes, if any were experienced.

Data Analysis

Data analysis is a continual process that begins as the interviews are conducted, and progresses as the interviews are transcribed, read, coded, and through categorizing key themes and concepts that are found in the data. While listening to the recorded interviews, and eventually transcribing them, the researcher/interviewer identified tentative ideas and began to sort them into groups. Notes and memos were made throughout this process, allowing the researcher to constantly reflect on her analysis and advance and expand the emerging themes in the data.

After the interviews were transcribed by the researcher, the researcher began the process of coding the data. To begin, every phenomenon described by participants were named and categorized. This process, called open coding, allowed the researcher to examine individual words, sentences, and paragraphs in the transcription, labeling each with a word that represented the concept that was described by the participant.

Following this “fracturing the data,” (Merriam & Associates, 2002, p. 149), the next step, axial coding, pooled the concepts back together to find connections, overlapping themes and interrelations among them. This strategy helps to define “causal and intervening conditions, phenomena, contexts, action/interactional strategies, and consequences,” (Merriam & Associates, 2002, p. 149) that may be present in the data.

The final stage of coding, selective coding, organized the themes into a core category, which came to represent a substantive theory describing the phenomena. This theory encapsulates the set of categories that were identified in the data and describes their interrelatedness; the theory was developed through constant comparative coding and analysis. As Merriam and Associates (2002) write, “The identification of a core category, one that accounts for most of the variation in a pattern of behavior, [is] essential for the development of the theory,” (p. 149).

Validity

Validity is the idea that the researcher is accurately capturing and portraying the phenomena at hand. It refers to “the correctness or credibility of a description, conclusion, explanation, interpretation,” (Maxwell, 2005, p. 106). When pertaining to a qualitative study, validity may be demonstrated through determining alternative explanations for one’s findings and finding ways to rule out these threats.

Two of the biggest factors that may influence a qualitative study's validity include researcher bias and participants' reactivity to the interviewer. Researcher bias entails the researcher inserting his or her views into the participants' narratives, which may skew the account of the participants' experience. Two ways this may occur include the researcher only selecting data that fit into her existing theory or her fixating on data that "stand out" to her. The researcher confronted these issues by becoming aware of her own perspectives on the topic of young women and their experiences with brain injury and sexuality.

As a 15-year-old girl, the researcher survived a severe traumatic brain injury, which extended her high school education by a year and changed her relationships with peers, family, and friends. She watched her identity change as she learned to live with disability, and adapt, accommodate and readjust, in order to graduate from high school and pursue a college education. The struggles the researcher experienced involved changes to her physical, emotional, social, and mental self and the most personal parts of her identity as a young woman. When approaching this study, she did not want to contaminate others' stories of living with and recovering from brain injury; therefore, she became aware of her interpretations of what she experienced and recognized that they manifest from a unique combination of her personal self before injury, the way her brain was injured, and the resources to which she had access in recovery. All three of these factors were unique to her and she sought out in this study to uncover how other young women experienced TBI, as they inevitably faced different circumstances in self, injury, and rehabilitation. By recognizing this and actively applying it when interviewing participants, the researcher remained dedicated to authentically portray the stories of young women and their experiences with TBI and sexuality.

Another source of threats to the validity of one's study includes participants' reactivity to the interviewer. When interviewing, the interviewer automatically influences the story participants disclose. The researcher used open-ended interviews to attempt to minimize the possibility of offering leading questions or influencing participants' responses. Also, as the researcher was aware of her own experiences with TBI, she made conscious effort to not think of participants' accounts in comparison to her own, but instead, worked to understand how participants uniquely experienced TBI and recovery.

In addition to recognizing the researcher's bias and possible influences, this study utilized several strategies to exhaust the possibility of alternative explanations, including using rich data, respondent validation, searching for discrepant evidence, and triangulation. Rich data was used as the data came from verbatim transcriptions of the interviews that took place. The researcher used participants' own words, phrases, and quotes to accurately illustrate their experiences.

Respondent validation, or member checks, occurred as the researcher emailed copies of her interpretations of and conclusions from what participants described during the interview and asked for participants to respond, indicating their approval or suggesting changes. This strategy helped to avoid misinterpretation of the phenomena and again to exclude the researcher's personal biases.

Searching for discrepant evidence, or cases that did not fit the developing theory, was another strategy used to truthfully depict the women's experiences. When these cases were found, the researcher determined what factors caused the cases to be different and how they interrelated to the rest of the concepts and themes found in

interviews with other participants. Using this iterative process allowed the substantive theory to emerge as new data was collected and used to refine the existing theory.

Triangulation was also used to demonstrate validity. This method entails “collecting info from a diverse range of individuals and settings, using a variety of methods,” (Maxwell, 2005, p. 112) and reduces the risk of coincidental associations and the systematic bias that may be present within the interview method.

“Triangulation allows a better assessment of the generality of the explanations that one develops,” (Maxwell, 2005, p. 112). Theory triangulation was applied to this study as several professionals, including three rehabilitation counseling professors, read the data and its conclusions and verified the primary researcher’s interpretations.

As Maxwell (2005) explains, validity in a qualitative study is “not verifying conclusions, but testing the validity of conclusions” (Maxwell, 2005, p.109). This study used rich data, respondent validation, searching for discrepant evidence, and triangulation to assess the validity of the conclusions that were drawn from the data.

Generalizability

This study selected a purposeful sample of young women who have endured TBI between the ages of 15-25, and therefore, rendered its results to a population whose members possessed similar traits, which demonstrates internal generalizability. “Internal generalizability refers to the generalizability of a conclusion *within* the setting or group studied, while external generalizability refers to its generalizability beyond that setting or group (Maxwell, 2005, p. 115).

Many studies addressing brain injury recovery present quantitative findings that claim to be externally generalizable to individuals with brain injuries. However,

as the participants typically encompass more men than women, their results may not be applicable for a population of young women with TBI. In response, this study specifically explores a sample of individuals, young women with TBI, who may experience different physiological and social responses to brain injury due to their gender. As this group is a unique population among individuals who experience TBI, a qualitative study was selected to explore this phenomenon as it exists for this specific population.

Chapter 3

Results

To gain a comprehensive understanding of how these women's sexualities and sexual experiences were affected by TBI, the researcher asked that participants explain all symptoms which they found relevant to the study, including physical, cognitive, emotional, behavioral, or not otherwise specified. Therefore, much of the results section addresses symptoms that participants do not immediately connect to or describe in terms of sexuality. As both brain injuries and sexuality are complex phenomena that manifest in distinct ways for every individual, interviews followed the sequence previously mentioned to allow participants to show the researcher how their lives changed, how these changes may have affected their sexualities and how this process did or did not happen.

Physical and Cognitive Symptoms Experienced by Young Women with TBI

Using an open-ended approach, participants were able to direct the interviews and discuss whatever aspects of brain injury they found most salient. When asked "What symptoms did you experience?" and "Which symptoms did you most notice?" seven out of ten first focused on the physical effects of brain injury. Six of these participants, including "Allie," "Rachel," "Kelly," "Ashley," "Ann" and "Ellen," had mild injuries and one of them, "Marie," received a mild to moderate diagnosis, as it was never specified for how long she was unconscious before she was found by medical personnel.

Headaches, dizziness, nausea, irregular sleep patterns, and fatigue were the most commonly mentioned physical symptoms. Nine out of ten participants mentioned experiencing a constant headache for days or weeks. Many of these women described severe sensations. "I had a lot of pressure in my brain, so in my

head I felt like my head was going to explode,” Allie said. Ellen compared her head to a “hundred pound weight.” Rachel indicated being unsure of when exactly the injury occurred during a rugby match, but suddenly felt nauseous and “out of it,” as her head began to pound. Kelly echoed a similar experience, recalling hitting her head multiple times during a game, but not realizing the severity of one of the blows until after the game.

Participants also described experiencing changed sleeping patterns and fatigue, which were often interrelated. Some needed more sleep, including longer rest periods at night and naps during the day. Others mentioned feeling “always tired,” no matter how much sleep they had. “I’m up, I say I wake up at least 3 to 4 times a night. And it’s not long. It’s not long periods of time that I’m awake, but I’ll wake up, you know, toss and turn for a couple minutes and fall back to sleep. I would say, almost every night,” Ashley said. “I can’t remember the last time in the morning that I woke up feeling rested.” Participants explained that simple activities, such as walking to class, that caused them little fatigue pre-injury now exhausted them. In addition, many of these women indicated that average tasks, such as doing homework or making dinner, took much more time after injury, which contributed to it being a tiring process. Marie described that during times when she felt increased fatigue, her symptoms would be worse.

Although physical symptoms, such as headaches and fatigue, were most commonly mentioned first during interviews, most participants listed changes in memory and cognition next. The primary change in cognition included difficulties with short-term memory or learning new information. As all of the participants in this study were in high school or college at the time of injury, they quickly identified deficits when performing academic tasks. Cindy, a participant who survived a severe

TBI, explained, “After injury, I would study so hard and a test question would show up and I’d think to myself, ‘I remember studying this,’ but I couldn’t remember.”

Further, Ellen recognized that it “definitely took my brain longer to encode things.”

Allie shared some of the struggles she experienced and accommodations she had to make for herself academically.

I feel like I still need that extra time to study. I don’t like to be rushed in a lot of things, it’s hard enough, even in classes I feel like I’m rushed to take notes.

I have like anxiety in classes because I feel rushed to absorb as much as possible, like what if I zone out? I do have trouble concentrating in class. I’d look at my notes and be like why are these slides blank? Why don’t I have notes for them? I’d miss important things because I’d just like zone out.

All but one participant described facing similar difficulties in school, such as taking longer periods of time to learn new information or not being able to retain new information for very long. Due to these issues, several women reduced the amount of courses they took to accommodate the increased time it took them to prepare for classes.

The one woman, Ashley, who did not mention problems in school did notice changes in memory in everyday tasks, such as forgetting words in speech or for what reason she walked into a room. While most people have casual slipups, such as these, Ashley differentiated that for her, it was “to a different extent,” and seemed to happen more often to her than to other people. Rachel similarly noted, “I would be absent minded about things. Like forget when people told me something or what they told me. Or leave things places where I don’t ... I just have no recollection of doing it.” Several other participants mentioned being unable to remember friends’ names, or unable to associate friends with the context in which they knew them.

Four women, two of whom had severe injuries, one who had a moderate, and one who had a mild TBI, still experience issues with short-term memory and need to take extra steps to accommodate their impaired abilities to remember new information.

Still, I have a little bit of trouble forming new memories. I definitely have trouble remembering. I have to write myself notes all the time. When I was in college, I had to write everything down. Even things as far as ‘Make sure I do a load of laundry so I have clothes to wear tomorrow.’ I had to write everything down or I wouldn’t remember.

The other three women expressed that it takes them longer to study and learn information for school. The rest of the women described memory problems persisting for days, weeks, months, or years, but eventually disappearing or lessening to no longer be noticeable. Most participants do not remember the actual impact of their injuries or the events immediately preceding them.

Other cognitive changes that participants addressed included impairments with concentration and attention, with specific regards to academic work, confusion, usually immediately following injury, slowed thinking, and impaired decision making or difficulty making decisions.

Although all participants described deficits in thinking or learning, five of them identified experiencing “slowed thinking,” or processing speed. Most of these women realized this change in academic settings. Allie described attempting to complete problems after her injury that she would have no problems with prior to injury. She explained reading the problems over and over to understand what the question was asking and then take much longer to recall the information required to

solve it. “It made me realize how people could just speed through things and I was still a little bit slow, trying to figure out what the question was asking.” Hannah described a similar experience, adding that her slowed thinking lead her to a sense of confusion. “Sometimes I’d be sitting there and be really confused, like have no idea what people were saying. Like, people were saying the football score last night and I didn’t even know we had a football team ... I think that I was just slower in general.” Two other participants described having trouble processing what was happening in a conversation and finding the correct words to respond. Marie would type words unknowingly when composing emails that she did not intend to be in the text, “like there was a little voice in the back of my head that decided something should be included.”

Participants who mentioned slowed thinking primarily related it to academic work. Decision making, however, was more often related in a social context. Both participants with severe injuries and two who had mild injuries related increased stress or difficulty making decisions. Cindy explained that she “often insists that others make decisions,” for her because she didn’t trust her own decision-making abilities. Allie echoed this sentiment. “I would always second guess everything. It would take me a lot longer to make a decision. I would be like ‘Do I really want to do this for sure?’” and admitted that when she was frustrated, her ability to make logical decisions would decrease. The two women with severe injuries described experiencing impulsive decision making based on their emotions. Kim described,

For me, I don’t know. I do make ... I used to make really rash decisions, like impulse decisions. I would make decisions, like going places or what’s important in my life and instead of thinking about it, I would make the

decision right away. They were irrational decisions, based on my emotions in the moment.

One participant related that she recognized her poor decisions, in regards to staying out late and consuming alcohol, after injury, and would ask her friends to help her to make healthy decisions when this happened. She conveyed that this strategy helped her to curtail her impulses to stay out late when having fun with friends. Another participant, however, related that when others recognized her poor decision making, they ridiculed and made decisions for her.

I couldn't stand up for myself. I only went based off of other people's decisions for me. You know ... and then they judged me based on my impulse decisions. 'Oh, she can't make the right decisions, so we'll make it for her.' She described this influence coming from both her parents and peers.

Emotional Symptoms Experienced by Young Women with TBI

Experiencing changes after brain injury, including both physical and cognitive, had emotional impacts on all the women interviewed for this study. Participants described being restricted from activities for a period after injury, or being too tired to attend social occasions. Reduced involvement in prior groups and hobbies was frequently cited as a cause of depression. Several participants received injuries playing in sports events and were not able to immediately return to these recreations.

I wasn't allowed to exercise, which is a huge part of my life. I love exercising. I got a little more depressed, a little more upset that I wasn't able to do the things I was able to do. It was just very hard for me to go from being active

every single day of my life to not being able to do anything. That really just ... hurt me a lot. It depressed me a lot.

One participant could not confine her depression to single situations or deficits. She described feeling depressed in most aspects of her life after injury. "Everything, just people, memories of... I don't know, family [made me sad]. Just anything, pretty much. My whole life made me sad."

In addition to depression, caused by various factors, participants also described increased emotional responses to life events. Many described it as being more "moody." Illustrating their fluctuating moods, participants made statements, such as "I would just get upset over little things. I was like crying more than usual," and "One moment I'd be really happy, like hanging out with my friends, and the next moment I'd be really angry, wanting to go home."

Two participants, those with severe injuries, described not only increased variable emotional responses, but an extreme experience of any mood they felt. Cindy stated, "I was constantly, I don't know, either really down, or really happy. I was really emotionally charged." Kim explained that after three injuries, her moods are still intense and cycling. "My emotions are very ... it's not ever steady. Up and down a lot. One moment I'm sad and one moment ... I mean most of the time I'm sad, really."

Self Esteem Changes Experienced by Young Women with TBI

Another aspect of self in which participants noted change after injury was self-esteem. Participants recounted feeling less confident in abilities they previously possessed, including academic, social, and athletic. Rachel explained that after injury, she felt "not able to do anything." Similarly, Hannah explained, "I felt like I looked

stupid and couldn't do anything right." Comments, such as these, were made by participants to explain the way they felt in response to the challenges they faced after injury, such as receiving lower grades, taking increased time to complete assignments, or participating less in activities in which they used to thrive. These changes often impacted participant's identities by influencing the ways they thought of themselves. Hannah described this phenomena when she talked about her inability to continue playing with her rugby team. "My self-esteem went down because I was the head captain and I was out. I was supposed to be the leader and I couldn't even walk in a straight line anymore."

Cindy described how the biggest influence on her self-esteem, which dramatically decreased, was comparing herself and her abilities to the way she was before her injury.

I was a wreck for a long time. I hated myself. I think a lot of that stems from constantly comparing myself to "me," the version of myself before the accident. I wanted to be her again so badly. I just thought I was perfect. I was beautiful. I totally idealized that version of me and I was so angry with myself that I couldn't be her. I was so mad at myself and I couldn't understand why I couldn't make myself act like that again, be that again.

Cindy also talked about her reduced self-esteem relating to body image. Although many women struggle with weight issues or trying to achieve what they see as the ideal body, participants discussed how these concerns were amplified for them after injury due to impulsive eating, inability to exercise, or altered emotional states. Cindy recalled gaining a "significant amount of weight" due to her impulsive eating habits. "Impulsivity with food was definitely a factor and that was one area where I

had to watch. Even if I wasn't hungry, I'd be like 'Oh, I want to eat.' I had trouble with portion sizes. I would eat a lot." Cindy also mentioned that her poor body image was intensified by her depression. Ellen talked about reduced self-esteem and poor body image as a result of not only her injury, but also returning to a gymnastics community in which these ideals are constantly emphasized.

Growing up doing gymnastics my whole life, you're pressured to have the quote unquote perfect body and you're constantly comparing yourself to others. But I mean, it's pretty much, all girls go through that whole body image and self-esteem, but with gymnasts, it's a little bit more amplified. We take it a little bit more to heart when we see that our bodies aren't good enough.

Ellen described after being injured and unable to exercise or participate in physical activity, she was more critical of herself and her body. Kim's distorted perception of her body lead her to feel "devalued" and contributed to her development of eating disorders, which will be discussed later.

Three participants did not experience drastic changes to their self-esteem. Marie stated that humor helped her to deal with the changes she experienced. For example, due to her physical injuries, parts of her body looked deflated from muscle loss, and to help her deal with it, her friends kindly teased her and helped her not to dwell on these aspects of injury. Kelly and Ashley reported no changes in self-esteem and did not present any explanations as to why.

The emotional change that was most easily noticed by participants and those around them was increased anxiety and frustration after injury, which often manifested into irritability and anger outbursts. The two most frequently cited causes

of irritated states included others not understanding brain injury and what the participants experienced and participants missing prior abilities. “I noticed was being irritated a lot. For example, with my mom when she would tell me ‘Oh, you have to work harder,’ I would like literally get close to flipping out on her. There was even one time when I yelled at her and was like ‘You don’t understand because you’ve never been through this,’” Allie said. One participant accounted that it was difficult to tell if others understood and had difficulty reading the intentions behind their words or actions. “I kind of have this inward battle in my head. Like, is this person really saying that right now? Did she mean to sound that way?”

Although these triggers for anger and irritability may have been situational, participants acknowledged having lower tolerance to stress and “flipping out” more easily and frequently. Participants described being “easily set off” and making “big deals” out of events that weren’t important. Kelly recalled having an argument with her romantic partner and realizing how exaggerated her response was. “[It was] something so small, you know, it wasn’t a big deal. But at the time, I thought it was the biggest deal in the world.” Ashley attributed her irritability in part to the brain injury, but also to another symptom— not getting enough sleep. “I was just more irritable, like anyone who hasn’t slept well. You’re just more irritable. My frustration level was higher, whereas, my patience level was lower.” She discussed experiencing frustration and having outbursts on the phone when casually talking with her parents. She said this happened every day.

Only “flipping out” on parents and romantic partners were common. Participants described that their anger outbursts were typically contained to people to whom they were close. One participant guessed that although it didn’t seem like she

had control over her irritability, she must have somehow regulated it to not show it to people who would not accommodate this behavior.

If it would have been my roommate or someone that I worked with, I mean, those were people that ... the repercussions were different. So I guess to an extent there was a certain level of control, but like I was never in control of feeling pissed off at my parents, like it wasn't really something I thought of, just like, I really don't want to talk about this stupid shit again.

Another similarity among participants who experienced increased frustration and irritability was feeling regret afterward. Several participants expressed realizing their interactions were uncalled for and were triggered by effects of their injuries. Ashley expressed feeling remorse for her angry outbursts, particularly when they were directed at her romantic partner.

I would feel bad about it later. It was something I would apologize for later, or particularly with Meg, not so much with my parents because we didn't really. It was kind of one of those things that happened. We didn't really talk about it again. But I would apologize to Meg usually.

As was the case with most symptoms, angry outbursts and irritability increased and became more intense in accordance with injury severity. Cindy compared her quick mood changes to "exploding."

I was really easily irritable and when I would become irritated, I would like explode. I don't even want to call it anger, it was like rage. I would yell and swear and cry. I would cry hysterically because I knew there was something wrong with me. These kinds of outbursts were not normal. They were weird.

She also explained how she had no control over when and how they would occur. “I wanted to make it stop and I couldn’t. You really actually feel as if you don’t have control over yourself. You don’t control your emotional responses to other people, to things that happen, to anything.” Although her responses were more intense than those experienced by other participants, she described knowing that they were different from what her neurotypical peers experienced, which only spurred them and her depressed mood more. “I would know in my mind that something was off, that normal people didn’t act like this, that something was off. And knowing that would make me feel even more like shit. Horrible. But I couldn’t help it.”

Four participants endured multiple TBIs, ranging from two to five distinct injuries. Although they may not have experienced new symptoms with each recurring injury, these participants described a worsening, or increase in severity, of symptoms after repeated injury. Additionally, all participants explained that their symptoms were the worst immediately following injury, and lessened, or were able to be adapted to, over time.

Changes in Social Interaction and Connection Experienced by Young Women with TBI

Another result of injury that participants addressed included decreased levels of social interaction with peers and their abilities to connect to those around them, with particular regards to others not understanding their experience with brain injury. Fatigue was a key reason why participants saw and interacted with their friends less. Participants explained that due to her level of exhaustion, socializing became less of a priority. Marie described:

I was so focused on what was required of me and just the pure exhaustion of trying to recover that I didn't even think about not going out on a Friday night. I didn't even think twice about you know, eating dinner by myself. It didn't even bother me. Just the fact that I was able to get to that meal was a huge achievement.

Some participants recalled their friends being slightly resistant to accommodate their reduced participation, especially when it would hinder their own. Ellen described having trouble leaving hang-outs early because sometimes, her friends didn't want to go home when she experienced fatigue. "Sometimes when I would be like 'Hey guys, I'm really tired, can we go home? ... I have a brain injury, sorry, and I kind of want to go to bed now, I'm tired. It was just hard sometimes to get them to leave parties or go places,'" she said.

Other participants mentioned not wanting to hang out with friends due to other symptoms, such as having headaches or being sensitive to noise. Also dealing with these factors, Kelly shared that she didn't want to deal with the pressure of being in social situations. "I just wanted to lay around and not talk to people. It wasn't like, I wouldn't say social anxiety, but if I knew I was going to go to a place where I'd know a lot of people were going to be, I'd have to like be part of the conversation and add something to it, I didn't want to. I wanted to be mellow and not deal with it." Many participants echoed this experience and described "being distant" from their friends. As participants needed more time to take care of themselves and deal with their symptoms, some recalled their social groups becoming irritated with or eventually excluding them.

After my accident, all of my friends more or less tried to be there for me. But I got tired, so I wasn't invited to sleepovers anymore. I got tired. I had big fatigue issues after my accident. I slept a lot and would want to go to bed and everyone was like "Really?" I stopped being invited to sleepovers.

Although the time span of reduced social interactions varied for participants depending on injury severity, while having symptoms, most participants described experiencing some form of social isolation from friends. Kim recalled, "I was losing all of my friends. Nobody wanted to be around me because I was no fun." She described friends from before her injury questioning her changed behavior, mood, and interactions and not understanding why at the time. "I didn't see anything wrong with me at that moment," Kim said. Similarly, Cindy remembered friends confronting her after injury with concerns about the changes she experienced due to TBI. "All of my friends from before the accident, it wasn't like they would ignore me, they would say hi to me in the hallway. But people would tell me straight up, 'You are too different. It is hard for me to be around you,' and that sucked." The participants who experienced loss of friends or reduced interaction with them said it often negatively impacted their mood and although they couldn't participate in the capacities they did before injury, they wanted their friends to help them through their recoveries. "I just wanted community because I did feel isolated," Ann said.

Participants named different reasons for their friends' lack of understanding and ability to accommodate. As previously mentioned, others viewing the participants as "changed" made it difficult for some to be around them. As many participants were in high school during their injuries, some thought that their peers were too young to understand the complexity of a TBI. Ann explained,

I was young. I was a sophomore when this happened. I just turned 15. Not a lot of people got concussions in sports of anything yet, and then later, like senior, junior year, you know, when all of my friends were playing sports, they got really mild concussions, where they had to sit out for a week, then they kind of understood a little more what I was going through. So I think the lack of knowledge and experience made it harder for them to understand.

Another common feeling included the lack of general understanding about brain injuries. “It’s really frustrating because concussions are not ... it’s not a well known injury, and it’s really frustrating for people to be like, ‘Aren’t you better yet?’” Rachel said. Although TBIs are becoming increasingly common, some participants felt that this injury is not typically discussed until a person has experienced it. Even if individuals do pursue knowledge on brain injuries, participants expressed that sometimes, one cannot understand it unless she has undergone the injury and recovery herself.

TBI Community Offered Support

Participants who were injured in a sport or employment in which TBIs are more common, such as rugby or gymnastics or being in the armed services, tended to experience more understanding from those around them, as their teammates and friends were more familiarized with brain injuries and how their symptoms manifest. Further, they were surrounded by a community of people who have had injuries or have experienced those around them having TBI. Kelly discussed the normalcy of brain injuries, or concussions, among women on a rugby team. “At least all of us have been concussed on the team, whether reported or not. But it’s not really... I have very few non-rugby friends, so it’s just common place. It’s not that big of a deal to us.” She

described not only more understanding from teammates about symptoms and being absent from activities, but also more awareness of the precautions one should take when getting a brain injury. Ashley characterized the increased level of understanding from her teammates with “They were able to sympathize, empathize, whatever you want to call it, and understand in general.” Participants stated that having this community of people who understood TBI provided them with an outlet to talk about their symptoms and experiences and eased their sense of isolation, if any was experienced. Ellen elucidated a similar level of awareness from her gymnastics team members, many of whom were experiencing issues with self-esteem, body image and concussions.

I talked to a lot of my friends at the gym in gymnastics about self-esteem and how we felt about our bodies. We all came to the general consensus that we all felt the same and that we felt that our bodies weren't good enough. And then there were a few other people that I knew who were going through the same thing with concussions and they understood the whole aspect of what you had to go through with doctors, and the cognitive testing. They understood the whole process. So there were people I could talk to.

Even without a TBI community, some participants were comforted by and found understanding in individual people who have had experience with brain injury. Ashley explained how her romantic partner, an athletic trainer, frequently worked with athletes who had brain injury. Because of her occupation, she was better able to understand her partner's symptoms. “She kind of knew. She knew what to expect and it didn't really faze her.” Similarly, Rachel's sister had endured a brain injury and was “a little bit more understanding because she was going through all of the same things

that I was going through.” Rachel clarified that her sister was one of the few people with whom she could share her experiences of injury and feel understood.

Even if participants’ peers did not themselves experience a brain injury and possess the understanding that participants found comforting, many of them made accommodations based on the assumption of symptoms. “They knew I was frustrated. They just couldn’t understand it. But if there was something wrong, they would probably think ‘Oh her head hurts, or she’s dizzy, so I’m not going to think too much of it,’” Ellen explained. Other participants, all of whom included those who received one mild injury, received similar sympathy from friends.

One of the most important ways participants identified as helping them deal with injury was when friends ignored symptoms or changes and “acted like everything was normal.” Marie described how her friends used humor to help her deal with symptoms and the effects of medication. She also mentioned that they did not talk to her about her feelings, knowing this would make her feel uncomfortable. She was unsure if they talked about her without her knowing. Other participants described friends just “letting things go” when they would exhibit confusion, fatigue, or other symptoms.

Increased Dependence on Others

Experiencing deficits in various aspects of their lives, participants found themselves relying on assistance more from those around them, including additional physical, cognitive, emotional, and social support. “I think if anything, the injury made me a little bit more humble. I tend to be ... particularly I was very independent. Everything was, I can do it myself kind of thing and then I tended to let other people in, because at that point, I couldn’t do everything myself,” Ashley said.

Participants who had physical injuries or weaknesses described depending more on others to physically accommodate them, such as when being mobile or helping the individual leave activities when she became fatigued. In relation to cognitive difficulties, participants pursued tutoring services or sought additional help from classmates. Participants also stated that they relied more friends more to make decisions or for emotional support. This included being understanding during mood swings, or irritability, or guiding participants when they experienced crisis. Ann described experiencing a period of intense loneliness and depression, during which she had thoughts of suicide. During this period, she found herself particularly dependent on her romantic partner. “I depended on him a lot because I felt like that was the closet person to me, so that was the one person I could go to.” She explained that protecting her relationships with those to whom she was close was very important to her because they were there when I needed something. There were there when it happened.”

Rachel also described another key concept in participants’ interviews, being more vulnerable to social influence. Many participants accounted paying more attention to what their peers were doing or what they were interested in and wanted to share their activities, interests, or behaviors. Rachel explained, “I did feel a little bit more pressured into doing things,” and “It was what everyone else was doing had more of an influence on what I should be doing.” This attitude manifested in different ways, including wanting to fulfill the expectations others had for participants, such as academically, socially, or sexually, or wanting to share experiences with their peers. Participants who experienced these urges expressed that doing this satisfied their needs to “be normal” or return to who they were before their injuries.

Needing Control

Although some participants embraced the opportunity to receive added support from those around them, others were resistant and wanted to control their own situations. Several participants, identifying independence as one of their key values, said it was difficult to let their peers help them. Two participants with mild injuries described being a bit more stubborn and trying to have more control over their deficits by independently compensating in different ways, such as studying more. Marie described her increased stubbornness about allowing friends to push her wheelchair. “I wouldn’t even stay in the wheelchair. I insisted on crutching everywhere.”

Kim struggled with receiving advice from friends about her impulsive behavior with particular regards to her erratic eating behaviors, the only area of her life in which she identified as having control. She described being unable to control her symptoms and their behavioral and emotional manifestations, and in turn, those around her tried to make more decisions for her. After injury, Kim craved control of something and eating was her answer. “Everything that . . . it was one thing that I could control, food. I used . . . that was my control mechanism. I used that, but the only thing I did, was hurt myself.” She also emphasized that “The eating disorder was the only control that I had.” While no other participants affirmed having eating disorders, Cindy accounted having trouble controlling her urge to eat.

Only the two women with severe injuries described having intense issues with control. However, participants with mild injuries attempted to control their symptoms by compensating for them in different ways, such as alleviating cognitive symptoms through tutoring or additional studying or physical symptoms by gaining additional rest.

Changes in Sexuality Experienced by Young Women with TBI

Mirroring the complexity involved in an individual's sexuality, the women in this study described various levels of change to their personal experiences of sexuality after injury. Both women with severe brain injuries reported drastic increases in thinking about and participating in sexual behaviors. All but two of the women with mild injuries experienced increases in sexual behaviors, although many of them suggested there may have been confounding factors that influenced this, in addition to or possibly more than their brain injuries. One of the other two women with mild injury experienced no change to her sexuality and based this on her adamant Christian background and influence, and the other woman experienced a moderate decline in sexual drive.

Cindy and Kim, both with severe injuries and intense symptoms, described feeling losses of self and abilities after injury. Dealing with physical, cognitive, and emotional deficits, both participants described sex as one thing that they could still be good at. "I felt like if I'm not pretty, I'm not funny, I'm not very nice, I'm not very smart, how else can I show that I am worth something? Sex is the easy answer. What do all guys want? Sex. It's easy to be good at. It's fun. I would say those were all influences," Cindy explained. Participating in sexual acts was something achievable, despite the other deficits these participants described, and it helped them to feel accepted again after injury.

For me, it was seeking acceptance. That is what lead me ... the people who I slept with, I just wanted to hook them. I wanted to give them something that there weren't getting anywhere else so they wouldn't go anywhere else, which is so sad to say, which is gross.

Cindy also described wanting to compensate for the parts of her that changed because of brain injury. “Closer to right after the accident, I knew I felt like if I couldn’t quite be my old self again, well my old self didn’t have sex, but my new self is really good at sex,” she said.

Both Cindy and Kim described drastic increases in the frequency of sexual acts in which they participated and their number of partners after injury. Both women labeled themselves as “definitely promiscuous” and cited their brain injuries as the major cause of this change. Cindy said, “My brain injury made me hungry for sex. It made me much more concerned about immediate pleasure and gratification and much less concerned with future rewards and future repercussions.” Kim resonated this feeling, saying that hooking up felt “good in the moment,” although afterward, she would have to block out these occurrences because she felt “ugly.” Not only did sex help these women “block out” the pain they were otherwise feeling in their lives, but it also helped them to feel a sense of control.

After injury, both women thought of sex in terms of power, as one partner is dominant and in control of the other. This was a way for them to be in control. “It was a way of, I thought of it, I’m not being used, I’m using people. I became ugly. I was using people for whatever I wanted and it wasn’t very nice,” Kim expressed. Cindy described the same phenomena, “I almost wanted to do it better than the boys. If I’m playing you, you can’t play me. I just got myself caught up like that.”

Sex became an achievement or fixation for these women. Each of them developed rules or routines involving sex. Cindy described a creating an intricate book for herself to keep track of all the individuals with whom she was sexually active.

I made a book for myself. It's a list of names. Every single person, male or female, that I've ever kissed. And then there are tons are different symbol. Like one symbol means this person ate me out. There's another symbol that means I performed oral sex on the person. There's another symbol that means the person went up my shirt. There's another symbol that means we slept together. There's just a ton of different symbols and it's all written down, so I'll always know.

Kim maintained a "two-week rule" and vowed not to see anyone after they had been hooking up for this long. She expressed not becoming emotionally involved with anyone in order to reaffirm the idea that she was in control of the situation. "After two weeks, no matter how nice you are, or anything, I would have to leave. And it was just... I don't know. It wasn't healthy. It was nothing anything deep at all."

Cindy and Kim both shared the sentiment that being in college meant being in a culture that supports casual sexual relationships and provides a place where they are attainable. They thought that being on a college campus encouraged their focus on sex and gave them opportunities to pursue it. Cindy described sex being "easy" and "free" and one of the easiest ways for her to compensate for her deficits. Kim also noted the pervasive attitude that casual sex is acceptable in college. "Being in college really favors everything so you believe it too. Like, it's okay for you to do it because everyone's doing it, so why not?"

Although only the two women with severe injuries experienced drastic changes to sexuality, such as fixation on sex and hooking-up with others, most women reported experiencing increased participation in sexual acts or with more or random partners after injury.

Increased Participation in Sexual Acts or with More Partners After Young Women Experienced Brain Injury but Attributed to Causes other than Injury

Most of the women with mild injuries discussed hookup up more often or with more or random partners after injury. These participants stated that while their injuries could have contributed to their increased level of sexual experience, other factors, such as “getting older” or not being in a serious relationship, were probably responsible. These women ascribed their increased sexual behavior to various factors, including evolving attitudes toward sexuality, or breaking-up with serious partners. Ellen experienced both circumstances and felt that these factors caused her increased sexual behavior. She explained, “Before my injury I was in a serious relationship and after my injury, I was just looking to go out and have fun with my friends and whatever happened, happened.” And then after her injury, and subsequently breaking-up with her boyfriend, “I was just kind of fed up, I didn’t want to be in a relationship with anyone, I just wanted to be my quote unquote own woman,’ and go out and have fun. Be the typical college girl, and hook up with as many guys as I want because I can because I’m single.” She stated that this attitude prevailed for “only a few months,” and then she seemed less interested in random hookups.

Kelly also ended a relationship shortly before her injury, and then after, did participate in more random sexual encounters. She explained that after the injury, both the timing of her being single, and an increased level of confidence led her to try her first random hookup experience. “It was like my first time ever trying random and it was intoxicated and sloppy and I got mono, so, not the best life choice I’ve ever made. But the other one was still, it was also intoxicated and sloppy and just pointless, basically.” She also reported an increased number of sexual partners after injury, but said it may have been due to her being single, although she did acknowledge that her

injury may have contributed to these changes. “I mean, I don’t remember consciously ... I obviously wasn’t thinking, ‘Oh, I hit my head, I wanna have sex with everybody,’ but I guess that I was more interested.”

Marie and Rachel both suggested that their age played a major factor in their decisions to be more sexually active. Marie reported being more sexually active with a serious partner before and after injury and engaging in one non-serious sexual interaction after injury, which she hadn’t done before injury. These changes, however, she felt were related to her changing attitude toward sexuality and her age. She discussed how she expected her attitude toward sexuality to evolve during her transition from high school to college, in the middle of which she experienced her injury coincidentally. Rachel also had a steady partner and noticed an increase in her sexual activity after injury, but wasn’t sure if this change was due purely to age or may have been influenced by her injury.

Marie and Rachel also suggested that feeling pressured to participate in sexual acts may have contributed to their increased sexual behavior. Marie describes having intercourse for the first time the night before her injury, and early in her recovery, she felt guilty for being injured and “not be able to continue where we left off.” She said she put pressure on herself, although her partner never did, to “live up to,” where she was sexually before injury. Rachel felt similar pressure to fulfill sexual expectations set by those around her. “After I had the concussions, it was kind of like ... I was thinking a lot about everyone else was doing it and it kind of made me feel like I should be doing it.”

Although Hannah reported hooking up with more people after injury, she did not define these incidents as casual, but as intimate encounters with people whom she

could see herself settling down. Hannah suggested not only her age as a triggering force for this attitude and wanting to be sexually active more, but also her changing attitude toward life after injury. “Recovering from a broken neck at that time, they were worried about me being paralyzed, so when I realized that could have been my chances, I think I more or less slowed down and realized this is not what I want for my life and it made me have a lesson on how to live and stuff.” Hannah described “craving” an emotional, long-term relationship, and it being difficult to attain in a college setting. “Yes, people get into serious relationships, but a lot of people are out to look for their hookup for the weekend, or a place to stay. Whereas I’m more searching for somebody who could remain emotionally stable throughout a lifetime, versus just the here and now.” She classified herself as “needy,” but clarified that this was a personal, life-long trait.

Ashley also identified increased confidence, or “comfort level,” as a reason for her increased sexual activity. She explained that she “tends to make friends quicker than before,” but this could be due to her branching out socially. Relating that she is currently in a serious relationship, Ashley recounted that she and her partner were “sexually active pretty quickly into their relationship,” as compared to those she has been in prior to injury. She characterized herself as having “always been pretty sexual,” however, so she suggested that her increase in activity she suggested may have been due to a natural progression.

Decreased Sexual Drive and Participation in Sexual Acts Experienced by One Young Women with Brain Injury

One participant, Allie, experienced a decrease in sex drive after her injury. She proposed that as she endured her injury while she was deployed, this could be a

consequence of both TBI and Post Traumatic Stress Disorder (PTSD). She described not only a decreased interest in sexual activity, but also being easily frustrated by being around a romantic partner frequently. “Sex wise, it just didn’t interest me. And when it was going on, it was like “Ok, when is this gonna be over?”

Allie explained that she responded to the changes she experienced after injury by focusing on school. In turn, her sexual activity became one of her lowest priorities. “I really get so wrapped up in school and wanting to do well, sex kind of gets thrown in the backseat.” When she was in a relationship after injury, she cited wanting to be left alone. “I’m a pretty independent person. I don’t really need someone to be around me all the time. And I felt like he was around me all the time and I was like ‘Leave me alone.’” She also affirmed that she is not interested in a romantic relationship because it may require her to give up some control. “I would you know, never want to be with someone who has that sort of control over me.”

Allie explained being unsure if her declined sex drive was due to the deployment or the brain injury, but she stated that her sex drive is “extremely a lot lower.” During the deployment, she experienced having “bottled up sexual drive” and although not being able to engage in sexual activity, she masturbated to alleviate this feeling. “All of a sudden not having any sex you’re just like craving it I guess.” When she returned from her deployment after injury, however, she “didn’t have any interest or any desire to do that.”

No Changes in Sexual Behavior, Desires, or Thoughts Experienced by One Young Woman with Brain Injury

Ann was the only participant to describe no changes to her sexual desires or behaviors after injury. Both before and after injury, she had only kissed partners and

she plans to maintain this status until marriage, due to her Christian values, which she was able to retain after injury. “I’ve been a Christian my whole life, since I’ve been like two. I grew up like that. To me, that was easy because I have ... I was always rooted in that.” Although she experienced pressure from a romantic partner after injury to engage in sex, she was able to refuse participation and ended this relationship. Ann explained that her strong values to save sex until marriage were able to remain intact due to her strong support network in her family and church.

My parents are Christians. My two older brothers, they are both Christians as well and believe the same thing. And I was involved in my church, which we had a small group and we all kind of believed the same thing as well. I guess I have support with that.

Ann described that she did not experience any changes in sexual behavior, although she does think about sex more after injury. She attributed this change to age.

Changes in Substance Use or Responses to Substance Use Experienced by Young Women with Brain Injury

Participants also talked about changes in substance use or the effects of substance use after their injuries as influencing their social and sexual selves. Allie and Kim both mentioned using alcohol to deal with stress caused by their injuries. “With the brain injury and the anxiety forced me to go out a little bit more to just go out and drink a little more, go out with friends and relax. Which is I guess why I wasn’t putting in the time I needed to after injury. I knew I had to put in more time, but I didn’t want to all the time,” Allie said. Kim described using drinking to “bury the pain” of her depression after injury.

Most women also expressed that due to their injuries, they experienced the effects of substance, namely alcohol, more intensely. “I would get drunk really really easily,” Cindy said. These exaggerated effects often caused participants to make irrational and impulsive decisions more so than when they would drink before injury. Even those who did not notice impulsivity after injury noticed changed when they drank. “I would just be more willing to do things that I wouldn’t normally do, obviously sober, but when I was intoxicated it would be more ... I don’t know. I would do things that were outside of what my personality usually is,” Rachel said. She cited having unprotected sex as one of the consequences when she would drink after injury. Several other participants also engaged in more risky sexual behavior when drunk.

Although Allie initially turned to alcohol to help her deal with the effects of brain injury, after researching alcohol and TBI, she learned that drinking after injury can have dangerous results, and she limited her consumption. Other participants knew or learned about these effects and similarly waited until further into their recoveries to drink. They attributed not experiencing any changes in alcohol consumption or the effects of alcohol to waiting to drink until their symptoms subsided. Marie and Ann did not experience any changes in substance use after injury.

Disbelief of Women who have Brain Injury Symptoms

Participants described experiencing more resistance and less accommodation because of TBI being an invisible and misunderstood injury. They also felt that this perception was amplified because they were women. Participants stated that women are not expected to get TBIs and therefore they face disbelief. Allie shared her perspective of how her teacher’s seemed to view her:

They usually think ‘Oh, just football players get concussions now because that’s what’s on like ESPN or anytime they’re talking about sports on TV, or hockey players ... but when a woman has it, it’s like ‘Oh, what did you do? You weren’t playing football or hockey ... a female having one is kind of rare so they kind of look at you like ‘You didn’t really do anything, how did you get this?’ or in class teachers just kind of look at you like you’re retarded or something like that.”

These women also portrayed how they seemed to receive less support from others because of disbelief. They described family members, peers, and professors pressuring them to “hurry up” or “stop exaggerating” the effects of their injuries. Marie was dissatisfied with the lack of support she received from the Penn State Community. “I was really disappointed by the way that the Penn State community operates with people with disabilities ... like the general awareness, the respect, the responses and the support that they offer to them.” She cited reasons such as no one holding doors for her, and professors not understanding why she required more time for assignments. Rachel described similar experiences and qualified women as being seen as “weak” for having a disability. “People don’t see an actual physical effect on you, and women are often seen as weaker as men ... if women are giving into something that no one else can see the effects of, more so, they’re seen as being weak for having that, for being affected by something like that.” She concluded, “As a woman, I feel like it’s even more so seen as a weakness if you have a concussion.”

Participants Wished Rehabilitation Professionals Would Have Warned Them about Changes

One theme that was present with every woman interviewed included wanting psychologists, counselors, doctors, or other rehabilitation professionals to have better informed them about the emotional, social, or sexual changes they experienced after brain injury. Some participants did not even realize that they were eligible for these types of services, such as counseling or psychological help, or what the options for these services were. Rachel expressed that had she known about her options and had access to someone who could help her understand her injury, it may have been easier to deal with.

I think it might have helped a little bit because I would have, a lot of times there would be things I wouldn't understand. Like, why I felt like that, or why I was getting upset. Or why I was forgetting little things. I think if someone would have sat me down and explained like what might happen, it would have helped me to like recognize them and to recognize, okay, this isn't me going crazy, it's because of the injury.

Participants also conveyed that because few people understood their injuries and symptoms, usually only those who have experienced them themselves, it would have comforted them to know that what they experienced after injury was "normal." Ann shared that she wishes she saw a counselor who,

... would have been able to explain what I went through was normal.

Whenever I'd go through that, a lot of other people did too. I felt like I was the only person going through this and that no one understood. Maybe if I would have seen a counselor or talked to a doctor about it more, it probably would have been easier to accept the fact that that happened to me.

Participants also related that knowing their symptoms were normal may have helped them to deal with their frustrations and deficits. They wished that they would have received warning of possible ways their symptoms may manifest and suggestions of how to deal with them. Ellen described,

There were times when I thought I was never gonna get through it and I would just become really depressed and didn't want to do anything because I just figured, 'what's the point? I'm never gonna be the same again.' But I feel if there was a psychologist or counselor there to help me and be like 'hey, don't get yourself down, you'll be fine,' if I had someone there, I think I would have been better emotionally.

The two women who experienced drastic changes in sexual experiences both saw counselors and psychologists after their injuries. However, they addressed that these professionals did not discuss issues of sexuality with them, and so they were caught completely off-guard by these experiences. Cindy related that being educated about possible changes to her sexuality would have alleviated much of her anxiety and reduced guilt she felt for the changes she experienced.

It would have been nice to know that I was expected to be to become more... it would have been good to know that I didn't have to be mad at myself. That I didn't have to feel dirty. I felt dirty for a long time. No one ever told me that this was normal. This is what people with brain injuries experience. I wondered, 'Is there something wrong with me?'

Kim also shared that if she "knew this was coming," she could have prepared and tried to avoid situations that exacerbated her negative sexual experiences. She suggested that rehabilitation professionals should be candid with brain injury

survivors about social and sexual changes they may experience, as it was difficult for her to bring up on her own when she worked with counselors. “They should have give you all of the information. No one really wants to ... I mean, I didn’t want to tell them ‘I did all these things wrong.’”

CHAPTER 4

Discussion

After analyzing the interviews that were conducted for this study, several conclusions, implications and recommendations for counseling professionals working with young women with brain injuries were suggested. Further, additional research needs to be conducted on the various topics and concerns that were uncovered in this exploratory study to uncover the ways in which they manifest for different survivors or brain injury. The women interviewed in this study detailed how brain injury impacted their lives uniquely. Although several trends were found among the ten participants, further study could focus on specific areas of change for young women with brain injuries and could diversify the accounts rendered by a larger number of participants.

When the women were asked to explain the most salient symptoms experienced after brain injury, they first mentioned physical problems, such as headaches, nausea, fatigue, and dizziness. The second area of deficit that was named included cognitive symptoms and thirdly, participants talked about emotional changes. Participants brought up sexual health and changes to behavior last and with the most reluctance. This pattern may illustrate how physical health is still viewed as more important than cognitive, emotional, and sexual, as it was identified first by participants. Another explanation may be that mental and emotional health continues to be stigmatized, especially for young people. There may be other explanations for this focus, however.

Many of the women described their TBIs as invisible and misunderstood injuries. It is possible that they first discussed the visible aspects or more familiar

aspects of their injuries because those were what were best understood by others in their past. For example, one participant recalled that it was difficult to explain her new thinking patterns and the way she struggled to learn to peers, family, and professors. These experiences were difficult for her to convey to others. When she told these people she had a headache, however, it was probably an easier experience to share, as headaches are typically a universal experience. This phenomenon may explain why participants discussed physical symptoms first during interviews.

Another explanation for this focus may entail that physical changes were what those around the survivor first focused on. One participant accounted that her cognitive symptoms were dismissed as both doctors and caretakers concentrated on her physical rehabilitation. It wasn't until one of her professors noticed cognitive changes and suggested she undergo testing did she recognize and begin to actively work on her cognitive deficits. Not only were cognitive symptoms examined secondly to physical in most cases, but emotional and sexual changes were rarely addressed if at all.

Only the two women who had severe injuries, and one, Hannah, who had a mild injury, sought psychiatric services or help from a counselor for after their injuries. Marie saw a psychologist when she was hospitalized immediately after her injury but discontinued these services after being released. Despite the de-emphasis on psychological or emotional recovery, all of the participants interviewed expressed experiencing some form of emotional change. Further, most participants stated that they wished they would have known about services that were available or would have utilized professional counseling to help them deal with the changes they experienced. This theme illustrates the need to make psychological and counseling services available to young people who experience TBIs so they can address and provide

resources to deal with the issues that are unique to this group. Another implication of this finding may also be the need to continue raising awareness about the cognitive and emotional symptoms that accompany brain injury, which may reduce stigma and emphasize the importance of addressing these aspects of brain injury for young people.

When discussing self-esteem, participants often connected this to being unable to fulfill multiple roles, including as students, athletes, physical beings, social beings, and sexual beings. As brain injury increased the length of time it took to complete most tasks, such as studying or walking to class, and participants were additionally slowed down from fatigue, they found themselves having less time to fulfill a multitude of roles, which negatively impacted mood. Reflecting on this trend, counseling professionals should recognize that this issue may affect young women with TBI and help them to understand and accept their limitations, paying particular attention to the issues that specifically affect women. For example, Ellen discussed the amplified pressure of having the “perfect body” as a female gymnast and other participants echoed the idea of self-esteem being related to body-image and sex-appeal. These issues should be specifically addressed when counseling young women with brain injuries, in addition to understanding limitations and planning functional ways to meet ones goals while experiencing symptoms.

Another vast concern for participants was others, including family, professors, peers, and romantic partners not understanding the experience of having a brain injury. This contributed to participants’ experience of depressed or frustrated mood, not receiving needed support or accommodations, and social isolation. This finding may suggest a need for counseling professionals to invite survivors to bring members

of their participants to therapy sessions or awareness raising activities in order to expand understanding of TBI and enable others to better support survivors of TBI.

The level of support and understanding participants received from peers did seem to reflect the environment in which they received their injuries and the levels of awareness others in these communities possessed. For example, the two women with severe injuries who were injured in car accidents reported receiving minimal or waning support from friends. This may be related to their social circles not necessarily being familiar with brain injuries. These women reported increased emotional stress due to their friends' treatment of them after injury. Women who were injured in sports or military settings, groups in which TBIs are common and therefore discussed more frequently, described receiving more understanding and comfort from their peers. "TBI Communities" were encouraging to survivors of brain injury and helped them to deal with their symptoms. It may be helpful to provide more opportunities for survivors of TBI in high school or college settings to find TBI Communities where they can interact with others who are familiar with or who have experienced brain injuries. Creating brain injury support groups on high school and college campuses may be a useful implication to offer young women with brain injuries a place to find community and understand their injuries in a group setting. These sessions may also include brain injury professionals, such as psychologists or counselors, to inform the participants objectively about the common consequences of brain injury.

Another reason brain injury support groups may be helpful on campuses includes providing a setting to discuss the unique issues members of this group may face, such as changing sexuality and how it manifests in a high school or college setting. Two women acknowledged drastic changes to their sexuality and admitted that being in a college setting provided them with opportunity to exploit their

changing sexual needs, suggesting that for these women, hypersexuality was not a purely biological consequence, but one also influenced by social norms that pertain to this age group and social setting. Six other women recognized that their sexuality did increase, but suggested that their brain injury may not have necessarily impacted this change. This may reflect that the unique effects of brain injury are difficult to separate from the multitude of other changes young women experience during this stage of their lives. Another explanation may be that the women did not associate their changes in sexuality with their brain injury in order to normalize and claim control over their sexual experiences. One of the women who experienced drastic change in her sexual behavior admitted not having control over her sexual motivation or desire. The women who disclosed increased sexuality but did not attribute it to brain injury suggested that it was “due to age,” and therefore, was inevitable, but a choice. It is possible that the women chose not to ascribe brain injury to influencing their sexuality as that would be losing a source of power and control. It may also be possible that sexual behavior was not affected by brain injury and that normal human development and residing in a college setting, was responsible for their increased sexual behavior. Further study of this issue with this specific population, young women who have brain injuries, may help to clarify these conclusions. There may also be a need to study young women with mild, moderate, and severe TBIs separately, as their experiences with sexual behaviors and perceptions varied in this study, according to injury severity.

Although only one participant disclosed having a decreased sex drive and interest in sex, women with these experiences may also benefit from support groups as they would have access to a broader pool of women with TBI and may meet others who deal with similar experiences. In addition, this participant was also uncertain if

TBI or PTSD caused these changes, and researchers pursuing further study of this issue may help to elucidate the complex causes of her experience.

Participants also addressed changes in their substance use or the effects of using substances after injury. This result may also suggest a need to address specific issues that affect young women with brain injury, especially when they are in a college atmosphere that supports drinking. Another use of brain injury support groups on college campuses may help survivors of brain injury to understand why their brains respond differently to alcohol after injury, inform them about why many people turn to substance use after TBI, and open a discussion about how to deal with these issues in college.

Conclusions

The original intention of this study was to focus on how young women experience sexuality and changes to their sexual perceptions and behaviors after traumatic brain injury. During open-ended interviews with participants, however, the women focused on physical, cognitive, and emotional symptoms and only skimmed the topic of sexuality and suggested that it might have been affected. This pattern raises several questions and proposes further areas of study, including “Why did only women with severe injuries attribute changes in sexuality to their brain injuries?” “Did these women’s sexuality and sexual behaviors change at similar rates to their neurotypical peers?” and “How would women’s experience and understanding of sexuality after brain injury be affected by their participation in support groups?”

The findings of this study also suggest several implications for mental health professionals who work with young women with brain injuries. There may be a need for these professionals to form TBI support groups on high school and college

campuses to address the ways brain injury manifest for this population and the additional challenges that may be present in a high school or college setting for these individuals. Participants suggested that counselors needed to be more informative about ways in which symptoms may manifest for them to normalize the experience and prepare them for changes that they may face in recovery.

While this study did not focus exclusively on sexuality after TBI for young women, also addressing physical, cognitive, and emotional changes participants experienced, it did show the complexity of brain injury and opened questions about how these comprehensive changes may or may not influence sexuality after a brain injury in a high school or college setting. This study evinces a need for psychologists and counselors to be made more available to this specific population in order to inform them of changes they may experience and help them to find resources to deal with brain injury.

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