RELATIONSHIPS, COMMUNICATION AND INTIMACY AFTER TBI

TBI affects the injured individual, their partner, family members and friends. Many studies have looked at marital stability versus marital satisfaction. What these studies show is that many pre-injury factors affect relationships and marriage following TBI, such as age, length of marriage, pre-injury educational levels, pre-injury psychological factors, etc.

Many individuals ask about marital stability and divorce following TBI; and the good news is a study that was done in 2008 by Virginia Commonwealth University that revealed the following:

- **Past studies were conducted in Europe where the social and legal systems were different than the US and they used smaller sample sizes and reported higher divorce rates in TBI.**
- **The VCU study used a larger sample size looking at 3-8 years post injury; and this study revealed that 3 out of 4 (90/120) of couples remained married following the injury. 977 persons with TBI from varied ethnic and cultural backgrounds were studied and research teams found that 85% of survivors remained married for at least 2 years post injury; and that divorce rates were much lower than the general population.**
- **Individuals who were older& had been married longer were less likely to get divorced; and those with severe injuries were more likely to remain married.**

Intimacy

Intimacy is defined as having a close, personal relationship with someone. The concept of intimacy involves a mutually consensual relationship where two individuals reciprocate feelings of trust, emotional and physical closeness toward each other.

Intimate Relationships Differ from Casual Relationships in the following Ways:

1. **Knowledge: Intimate relationships share a great deal of information with each other that wouldn't be shared in casual relationships. intimate partners in healthy relationships feel**

safe sharing their past histories, desires, deepest dreams, fears, traumas, and goals for the future.

2. **Care: Intimate partners thus show concern for each other's well-being, comfort in times of distress, and safekeeping the other from harm. Intimate partners tend to display genuine, selfless care for each other. The way that individuals display care can differ from one person to the next.**
3. **Responsiveness: Healthy intimate relationships involve partners who are mutually responsive to each other's needs, culminating in a feeling of being loved and appreciated. This means recognizing, understanding, and supporting each other, both in times of pain (e.g., being injured, losing a parent or a job) and gain (e.g., getting a promotion, etc.)**
4. **Trust: Confidence we place in another human being to act in a way of honor and fairness that is of benefit to both of us, or at the very least, that our partner will not cause us purposeful harm.**
5. **Commitment: there is a mutual desire for the relationship to continue indefinitely, which further allows the other components of intimacy to grow.**

Study by Gill, et. al. showed the following factors helped keep relationships strong following brain injury: Unconditional commitment, spending time together, a strong preinjury relationship, bonding through surviving the injury together, family bonds, social support, open communication, spirituality, coping skills, humor and experience with overcoming hardship.

Barriers to Intimacy included: brain-injury related changes, emotional reactions to changes, sexual difficulties, role conflict and strain, family issues, social isolation, communication issues. It is well documented that individuals with serious TBI experience social isolation and experience less social support.

Mourning: Following an injury there is a period of mourning. A sense of loss about how things used to be. Allow for this transitional period, but realize it will not last forever.

Complexity: When discussing intimate relationships following TBI, The study participants spoke about their efforts to achieve fullness and balance in their lives and relationships. They savored positive experiences to counter the difficulties and loss, including fulfilling interactions.

Findings:

1. **Caregiving spouses experience stress and emotional distress, (e.g. role strain and fatigue). Partners of individuals with TBI reported that their increased roles and responsibilities left them with little energy to devote to physical or emotional intimacy. They sometimes felt angry that their partner didn't understand their stress and fatigue, which also contributed to decreased intimacy. TBI survivors did express an awareness of their partners overwhelm; but felt guilt and did not have solutions to change the situation.**
2. **Greatest challenge to intimacy is change: functional limitations physically, emotionally and intellectually (increased sensitivities to sound, light, physical changes regarding pain, hormonal changes for women, headaches, etc.), "disconnect" with the person they previously shared everything. Most partners felt that the "core" or "soul" of their partner was intact, which gave them hope and the desire to work on intimacy.**
3. **Intimacy was perceived by most participants as "more than sex." Intimacy is considered to be complex, subtle and a delicate balance of communication through gestures, talking, creativity, flexibility, etc. As individuals mature, intimacy oftentimes becomes more complex and less centered around sexual expression. It has been suggested that TBI can be considered another "life transition" that can broaden a couple's perspectives and concepts of intimacy.**
4. **Communication emerged as a key factor: Frequent and open communication was described by couples as a relationship strength. After the injury, there may be decreased communication due to difficulties with verbal expression, decreased ability to self-initiate speech which was interpreted as lack of interest; problems self-monitoring which was interpreted**

as not taking things seriously. Sometimes the TBI survivors were concerned that their partners were angry because of the increased workload. TBI may add an extra layer of uncertainty in a relationship because of decreased communication. Perceptions about each other go undiscussed and may undermine intimate bonds.

<u>Implications for Improving Intimacy</u>:

1. **Look at the partners as a team**
2. **Look at the goal of overcoming the injury together as a way to strengthen the relationship bond through rehab, mental health services, etc. For example, the speech pathologist can teach ways to communicate more effectively. The psychologist can support emotional growth and interactional strategies.**
3. **Stress Management training can be provided to caregiving partners to manage caregiving roles and reduce overall stress.**
4. **Mindfulness techniques can help awareness.**
5. **Provide help finding personal assistants for caregiving responsibilities, to help decrease the stress.**
6. **Connecting couples with disability advocacy groups and organizations to provide additional resources.**
7. **In addition to standard rehabilitation treatments, provide couples counseling, relationship advice, with a specific focus on negotiating intimate relationship issues.**
8. **Working on social communication skills (e.g. asking questions, giving compliments, etc.), can be worked on at all levels of rehabilitation during speech-language therapy sessions, counseling sessions, physical therapy, etc.**

<u>Communication</u>:

Johnson and Turkstra (2012) studied communication in individuals with TBI and reported that individuals with TBI had impairments in social communication which may lead to unsuccessful social interactions. There are oftentimes impairments in "inference comprehension," which means that it may be difficult to understand the "implied meaning of a message" rather than just the literal meaning. Being able to apply inferences to conversations requires

individuals to be able to draw on a knowledge base, remember information from the past and predict into the future.

When communicating with others we use verbal cues, nonverbal cues as well as subtle inferences that require us to "read between the lines," or pick up information that is not stated directly. Studies on communication following TBI reveals that problems with working memory and decreased cognitive flexibility, may cause individuals to communicate less effectively with others. This may also lead to a perceived insensitivity to the communication needs of others, failure to initiate social contacts, and failure to respond appropriately to questions and social contexts.

<u>Sexuality After Traumatic Brain Injury</u>:

Studies of the survivor's perspective regarding sexual difficulties revealed that 58% had sexual dysfunction following their injury.

Some studies used the Sexual Interest and Satisfaction Scale or the Psychosexual Assessment Questionnaire to assess individual's post-injury. Various studies showed that reduced libido or erectile dysfunction occurred from 30-57%.

In another study, 59% of individuals reported decreased sexual functioning, 86% noted a decrease in sexual drive, and 79% reported marked decreases in their level of self-confidence.

One study of rehabilitation professionals revealed that 79% reported that sexual adjustment was as important as any other rehab area; but only 9% felt comfortable discussing the issue with patients.

For TBI survivors, 52% reported decreased self-confidence; 47% reported increased fatigue; 42% reported higher levels of depression; and 29% had decreased ability to communicate with their partner following the injury.

Moreno. et. al in 2013 performed a study and reported that considering the brains role in sexual functioning, it's clear that sexuality can be influenced after TBI because of changes in neurotransmitters, the role of the brain stem in sexual arousal, the role of hormones in sexual response, the importance of the frontal

lobes in regulation of sexual behavior, initiation of sexual contact, difficulties in verbal language and communicating things to partners.

Individuals with TBI reported problems with cognition, verbal fluency, social interaction, post-traumatic stress, anxiety, aggression, personality changes, etc. Physical problems interfere with sexual functioning, such as headaches, sleep disturbance, increased pain, sound and light sensitivities, fatigue, oral motor problems that interfere with kissing, etc. Medications may also have sexual side effects, causing decreased libido, erectile dysfunction, etc. It may be necessary to consult your doctor regarding adjusting dosages, etc.

<u>Hormones and Pituitary Functioning</u>

Injury to the pituitary gland, hypothalamus and surrounding structures may occur in TBI. This may cause sex hormone deficiency, which can lead to decreased sex drive in males, infertility in women, etc.

A great deal of research has been devoted to studying post-traumatic hypopituitarism in both males and females. Studies indicate that approximately 28-68% of individuals have PTHP after they recover from the acute phase of their injury. Deficiencies in this area can "impair recovery and rehabilitation after TBI since it causes fatigue, weakness and inability to respond to stress. Hypothyroidism causes apathy, muscle weakness and cognitive dysfunction. It can cause decreased exercise capacity, impaired cardiac function, social isolation and reduced psychophysiological well-being, in addition to its effects on libido and fertility, and estrogen deficiency in females.

The importance of an early diagnosis is crucial since adequate hormone replacement therapy can result in improvement in the outcome of recovery.

According to Bondanelli, et. al. PTHP should be evaluated in TBI patients with unexplained symptoms (hypotension, weight loss, weight gain, fatigue, loss of libido, depression) or suspicious biochemical alterations, and in those who do not achieve the expected recovery. Females should have hormone testing such as TSH, free T3 and T4, growth hormones, ACTH, etc.

Craig Hospital performed a study a number of years ago on reproductive functioning in young females and found changes in menstrual cycles occurring for an average of 8.4 months post injury, which also affected ovulation cycles.

Progesterone

They also studied the effects of using Progesterone early post injury to relieve edema (brain swelling) and promote recovery. They reported a window of opportunity 48 hours after the injury that was beneficial in using Progesterone, for both males and females. These studies are in Phase III of clinical trials and some accounts of neuroprotective properties have been reported.

If you have an injury ask your physician or pharmacist about dosages, etc. of progesterone for early intervention.

Resources

For issues regarding female hormones, talk with your physician or gynecologist. In Denver one referral source is C.C. Huffnagle, RN CNP at the Women's Health and Menopause Center (303-837-1060).

For issues regarding erectile dysfunction, it is best to see a urologist. When googling urologists in your area make sure they specialize in erectile dysfunction and be sure to mention you have had a brain injury when you see the doctor.

For psychological support regarding relationships, communication, and sexuality: American Association of Sexuality Educators, Counselors and Therapists-Colorado (202-449-1099); Colorado Crisis Services (1-844-493-8255); Colorado Professional Organizations: Psychologists, Social Workers, Professional Counselors and Marriage and Family Therapists. Each of these organizations has professional membership lists and can be found online. They indicate whether they specialize in brain injury and couples counseling.

For physical problems such as pain, headaches, sleep disturbance, fatigue, light sensitivity, etc. it will be important to see your managing physician, who can refer you to the appropriate type of physician/therapist to manage specific symptoms.