Relationships & Sexuality after Brain Injury

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OBJECTIVES

1. Discuss impact of brain injury on relationships and sexuality
2. Identify aspects of sexual dysfunction related to Brain Injury
3. Review intervention suggestions
4. Ethical considerations
Managing Expectations

• Harris poll of over 38,000 men in Canada
• What is a woman’s ultimate sexual fantasy?
• 97.9 % of men said women would want to have two men at once!

• (Caron Gan, RN, MScN, RMFT)
Managing Expectations

• However, most men do not realize that in the fantasy, one man is cooking and the other is cleaning.
And for the Men

Why do women close their eyes during sex?

They can't stand to see a man have a good time.
Social Isolation

• “Social isolation is perhaps the most profound life change for persons with traumatic brain injury. A decrease in the number and depth of social relationships over time has been documented by researchers.

(Sander and Struchen, 2011)
Social Isolation

Over half of individuals with moderate/severe brain injury report limited social contacts

30% have none outside of family members

(Hoofien, Gilboa, Vakil, Donovick, 2001)
SEXUALITY

• “Sexuality is closely tied to one’s identity, self esteem, and need for intimate relationships, all of which can be shaken after a brain injury.”

   (Moreno, Lasprilla, Gan & McKerral, 2013)
Relationships are Tough in the best of circumstances!

- Johnny Depp
- Gwen Stefani
- Ben Affleck
Why Bother?  
Rewards of a healthy sex life

- Decreased muscular and emotional tension
- Increased pain threshold
- Reduced physical stress
- Improved sleep
- Reduces stress in relationship

(Incrocci & Gianotten, 2008)
Why Bother?

SKIN HUNGER
Skin Hunger

*There is a primal reassurance in being touched, in knowing that someone else, someone close to you, wants to be touching you. There is a bone-deep security that goes with the brush of a human hand, a silent, reflex-level affirmation that someone is near, that someone cares*.

( J. Butcher; Center for Intimate Relationships)
Skin Hunger

- When hugged before a stressor, people had lower stress reactions to stressful situations.
- Huggers had smaller increases in their blood pressure—both systolic and diastolic numbers.
- Hugs: increase oxytocin in humans, which builds bonding and nurturing behaviors.
- Thought to increase lifespan of elderly: less fatigue, better disposition.
Social Issues/ Myths

We all need to be touched, but Prejudice or BIAS may exist:

- If you are disabled, you have no interest in sex
- If you have cognitive difficulties, you have no right to sexual expression
- It could be risky, you will get taken advantage of by others
Issues Within Relationships after BI

• “Dysfunctional sexual relationships after brain injury are common, with both hypersexuality and hypososexuality.”  (organic)
• Usual relationship interrupted: person seems different  (personality change)
• Person feels different and this may limit forming new relationships  (self image)

(Parker, 1996)
Why Sexuality is Affected by BI

Basic social relationships are difficult but....

• “Sexuality....an excellent example of an integrative function, requiring the integration of physical, cognitive, and psychosocial components in order to be adequately expressed.”

(Zasler & Kreutzer, 1991)
A Primary Sex Organ

The Brain: arousal, moving, feeling, thinking, sensation
Physical Impact of BI

- Cosmetics (appearance changes)
- Strength and stamina
- Coordination, spasticity
- Speed of movement, Flexibility
- Pain
- Bowel and bladder issues
- Hormonal changes
- Vestibular issues
Cognitive Impact

- Decreased information processing speed
- Distractible: overwhelm, overstimulated
- Inability to tune out distractors
- **Reduced ability to focus; Fantasize?**
- Initiation: How do I start? plan?
- Decreased judgment
- **Decreased insight** (George Clooney)
Cognitive Impact

- Knowledge of rules, norms; recalling past
- Rigid, concrete thinking
- **Perseveration**
- Memory
- Ability to learn or benefit from new learning to improve future performance
- Time awareness
Communication Impact

• HUMOR?? FLIRTING?
• Turn taking, interrupting
• Listening ability
• Eye contact, non-verbals
• Literal interpretations vs. subtleties
• Lack of perspective taking
• Pillow talk: basic word finding and clarity
• Speed of processing
Behavioral Impact

- Impulsive: poor delay of gratification
- Sexually provocative comments
- Stand too close
- Touching
- Staring
- Anger control/agitation
- Fatigue (organic or depression)
Behavioral Impact

• Lethargy
• Disinhibited: urges without acting on them
• Poor planning
• Poor frustration tolerance
• Appropriately “marketing” yourself
Emotional Impact

- Self image; body image
- Depression (lack of initiative and planning)
- Anxiety (avoidance)
- Flat affect
- Childish, silly
- Labile
- Personality traits: paranoia, narcissistic
Emotional Impact

- Apathy
- Paranoia
- Shame: how to handle rejection
- Dependence
- Anger, short fuse
- **EGOCENTRISM**
Psychosocial Impact

• **Limited sexual history**
• **Transportation**
• **Finances**
• **Loss of friends**
• **Decreased leisure activities**
• **ISOLATION** and **WITHDRAWAL**
Barriers to Relationships

At a basic level, the urge to connect with others in order to feel good about oneself, may lead to sexually intrusive acts.

A survivor explains……
What to listen for:

1. a strong desire to connect; normal again
2. wanting contact, avoiding loneliness
3. times of poor judgment, disinhibited
4. unrealistic expectations about a romance
5. figuring it out….be yourself!

_A survivor explains……_. 
Behavioral Dyscontrol: Sexually Intrusive Behavior

• Sexual thoughts, feelings, actions are natural human behaviors
• There is a high incidence of sexual dysfunction after brain injury (50%-70%)
• Neurological changes from brain injury may lead to sexual behaviors which are intrusive or “inappropriate”
Neurological Basis Suggested

- Frontal lobe (especially disinhibition)
- Fronto-temporal
- Limbic system
- Temporal lobe epilepsy associated with sexually aberrant behavior
- Bilateral temporal lobe lesions associated with hypersexuality.
Incidence

“an estimated 7.9% of men with TBI may display such behaviors at some stage after their injury.”

(Simpson, Blaszczynski, Hodgkinson, 1999).
Staff Reports

Seventy percent (70%) of rehabilitation professionals surveyed reported sexual touching was a common problem in their facilities; twenty percent (20%) reported use of sexual force was common.

(Mateer, 2000)
Staff Survey (2015)

Respondent Demographics (n = 66)

Gender Distribution:
- Male: 69.80%
- Female: 30.20%

Years Worked in BI:
- 5 or less: 30.60%
- 6 to 10 years: 22.60%
- More than 10: 46.90%

Role at ReMed:
- Facilitation staff: 49.20%
- RCM/Therapist/Nurse: 27.00%
- Other role: 23.80%
Those reporting SIB effects

Among staff who did report moderate or extreme stress response to SIB:

- 71% sexual aggression
- 50% threat of sexual aggression
- 29% grabbed
- 29% touched in unwanted manner
- 29% suggestions of intimacy
- 12% brushed against me
Most Stressful Experience?

• I met with the client in his apartment... Frequently he would make suggestive remarks... it was exhausting as they were impossible to predict and required constant boundary setting.

• Hearing about statements /sexual comments clients have made to the young female staff.

• When I go into a client’s home and he is sitting there in the nude, and asks me if it is ok.
Most Stressful Experience?

• I don't find any of those experiences to be very stressful. The worst sexual behavior a client presented to me was showing me his genitals. I just told him to put it away and he apologized.
Back to the Brain Injured Individual

- May be feeling isolated
- May be dealing with appearance and performance changes
- Wanting to CONNECT
Consider Context

1. SINGLE: isolation may lead to inappropriate or impulsive actions; sense of hopelessness; overtures seen as sexual harassment.

2. SINGLE and LIVING WITH FAMILY: dependent, overprotective, no privacy or control
Single’s Risk: Unhealthy Partnerships
(Greengross, 1976)

• Individuals seek out disabled for own personal needs:
  – 1. due to self image problems
  – 2. high needs for control
  – 3. financial abuse
  – 4. do a favor
  – 5. dedicated to disabled: structure life around relationships
Consider Context

MARRIED AND LIVING WITH PARTNER

• Stressors: financial, supervision
• Role changes: childishness/parental roles
• “restricting activities, giving regular feedback about appropriate/inappropriate behavior, providing assistance with ADL, assuring follow-up with professionals’ recommendations”
What Partners Say

• 47% wives and mothers: TBI client is preoccupied with or disinterested in sex
• 42% wives: “are married but do not have a husband”
• “My husband, the one I married, he died but part of him is still there…..”
Relationship Quality Challenges

• Increased stress and strain
• Reduced shared social activity
• Poorer mental health
• Significant changes in previously held role expectations
• Communication

(Knox, Douglas, Bigby, 2015)
Marital Stability after BI

Extreme variability
Divorce rates ranging from 15% to 78%

(Goodwin, Kreutzer et al, 2011)

Methodology:
- severity
- time post injury
- pre-onset contributing issues
Marital relationships

There is significant evidence that many spouses experience increased levels of burden after TBI and that this burden may increase over time.

(Knox, Douglas, Bigby, 2015)
Issues For Partners

- Caregiver role: the longer dependency persists, the more difficult it is to resume original role as sex partner
- Changed partner: intellectually, appearance, communication problems
- Fear of additional injury
“The biggest thing is trying to live for two people”: Spousal experiences of supporting decision-making participation for partners with TBI.

(Knox, L., Douglas, J., Bigby, C. *Brain Injury*, 2015, 29(6); 745-757)

- Structured interviews
- N= 4 couples
- Non-injured spouse as lead decision maker
Decision making
(Knox, Douglas, Bigby, 2015)

- Decision making as a binding activity
- Each participant considers the needs of the other(s)
- Requires joint goal setting and emotional controls
- Seeing the person in a positive light
- Learning from experience
- Being committed to the relationship
- Finding a way to communicate
- Understanding the functional implications of BI on partner
Challenges to Intimacy
(Gill, Sander, Robins, Mazzei, Struchen, 2011)

• ....the greatest challenges for all participants are centered broadly on change. Survivors struggle with functional limitations, loss of control, comparisons with their pre-injury relationship.....Most partners felt their loved ones had changed in profound and far reaching ways…however, felt that the “core” or “soul” of their loved one was still intact.
COMMUNICATION EMERGED AS A PREDOMINANT THEME REGARDING INTIMACY IN RELATIONSHIPS
Relationships: research needed

• What about homosexual relationships: facing social pressures, expectations?
• What about any relationship that is formed after injury onset: missed the education continuity of person’s identity
• Women’s Issues
Women’s Challenges
(Hang, Caringal, Sokoloff, Kontos, Yoshida, Colantonio, Archives of PM&R , 2016)

Key Themes:

• 1. An ideal woman: inability to meet roles/expectations
• 2. A body unfamiliar: fatigue, pain, hormonal imbalances
• 3. A new sexuality: increased vulnerability, why bother (pain, paralysis), decreased inhibition and increased libido
As If Behavioral, Cognitive, and Social changes weren’t enough!!.....
Sexual Functioning: General Population

Sexual Dysfunction:
- sexual desire disorders
- sexual arousal disorders
- orgasmic disorders
- sexual pain disorders

40-45% women and 20-25% men: at least one form of sexual dysfunction

(AAPM&R)
Sexual Dysfunction (general)

Consensus statement, 4th International Consultation on Sexual Medicine, 2015

Women: most frequent sexual dysfunctions are desire and arousal. Many women have multiple.

Men: most frequent are premature ejaculation and erectile dysfunction
Human sexual response cycle

Desire
Arousal
Plateau
Orgasm
Resolution

- **Brain Injury effects**: decreased desire; increased desire; decreased arousal; difficulty or inability to reach orgasm
Sexual Dysfunction

- 40-60% of individuals complain of sexual dysfunction post TBI
Sexual Function after TBI  
(Hibbard, Gordon, Flanagan, Haddad, Labinsky, 2000)  

Compared Individuals with TBI with Individuals with no disability  
TBI: more frequent difficulties with sex drive, ability to initiate and achieve orgasm, physical problems related to positioning and sensation, body image influencing feelings of comfort during sex
Sexual Functioning

• Significant difference between individuals with TBI and healthy controls on all aspects of sexuality (decreased sexual functioning, relationship and self esteem, lower mood)

• Factors impacting lower levels of sexuality: Age, anxiety, depression, self esteem, less time in PTA, shorter time post injury, lower ADL independence.

(Ponsford, Downing, & Stolwyk, 2013)
Multicenter study of sexual functioning (TBI)

- Sander, Maestas, Pappadis, Hammond, Hanks, 2016
- N=70, 1 year post injury
- Derogatis Interview for Sexual Functioning; Global Sexual Satisfaction Index
Multicenter study of sexual functioning (TBI)

- 44% spouses reported dissatisfaction with sexual functioning
- 62% spouses: decrease in sexual activity
- 34% spouses: decrease in sexual drive
- 34% spouses: sexuality less important than pre-injury
- Greater sexual dysfunction with older age
Predictors of sexual function and satisfaction at 1 year post
Sander, Maestas, Nick, Papppadis, Hammond, Hanks, Ripley, 2013

• 255 TBI clients (187 male; 68 female)
• Derogatis Interview for Sexual Functioning, Global Sexual satisfaction index; participation assessment
• Older persons and females (2.5 x males) at greater risk for sexual dysfunction
• As age increases, odds of sexual impairment increased 3 fold (ages 24 to 49)
• Greater social participation predictive of better sexual functioning
Sexual Function after TBI
(Hibbard, Gordon, Flanagan, Haddad, Labinsky, 2000)

• MEN: most sensitive predictor of sexual dysfunction was level of depression

• WOMEN: most sensitive predictors of sexual dysfunction were endocrine disorder and level of depression
IMPORTANCE OF CONSULTATION WITH PHYSICIAN WHO CAN ASSESS POTENTIAL MEDICAL OR PHYSIOLOGICAL ISSUES
Brain Regions
(Moreno, Lasprilla, Gan, McKerral, 2013)

• Brain Stem: arousal, affective response, orgasm

• Frontal lobes, limbic and paralimbic: regulate sexual behavior, libido, initiation of contact, sexual preference

• Subcortical: (Hypothalamus and pituitary) initiation/control of sexual behavior, feelings of pleasure, injury associated with impotence, involved in sexual desire, lubrication, sexual orientation
Erectile Dysfunction

Why and when?

- Organic dysfunction
- Neurogenic dysfunction
- Vascular compromise/trauma
- Central neurotransmitter dysfunction due to drugs
  - antipsychotics, antidepressants, antihypertensive agents
Hormonal Disruption

- Check hormonal levels when
  - Decreased libido, impotence
  - Ejaculatory dysfunction
  - Amenorrhea
  - Oligomenorrhea
  - Dysfunctional bleeding
Common TBI Medications Affecting Sexual Function

- Antipsychotics: anorgasmia, painful ejaculation, priapism
- Antidepressants: decreased libido, erectile difficulties, decreased orgasm
- Stimulants: decreased libido, impotence, orgasmic and ejaculatory issues
- Anticonvulsants: impotence, decreased libido, arousal problems, effect on oral contraceptives
- Antihypertensives: decreased libido/sexual response
Changes in Sexuality after TBI

- Damage to parts of the brain involved in sexual functioning
- Changes in neurotransmitters
- Hormonal changes
- Medication side effects
- Fatigue
- Depression
- Changed relationships/communication/priorities
Changes in Sexuality after TBI

- Changes in movement, thinking (attention, fantasy) emotions/depression, social communication, self esteem
- Use of alcohol and drugs
- Medical problems
- Bowel and bladder
- Headaches
- Decreased contacts and access
What TBI Survivors Say

- Anxiety, depression, decreased personal satisfaction affected sex drive
- Decreased frequency of intercourse
- Decreased ability to achieve erection or orgasm
- “None … had received sexual information or counseling after injury”

(Kreuter, et al., 1998; n= 92)
Critical to Address Staff Discomfort

68% of patients are hesitant to discuss sexual concerns for fear of embarrassing their physician (Marwick, 1999)

In a study of 1132 health professional students (eg therapists) 50 % uncomfortable dealing with clinical situations with sexual connotations (Weerakoon, Jones & Pynor, 2004)
Sexuality: PLISSIT Model

• Permission: reassurance about normality of concerns; permission to ask questions
• Limited Information: don’t go outside comfort zone of what is asked
• Specific Suggestions: transfers, positioning
• Intensive Therapy: referrals
Be Alert to Professionals’ Biases

“Something the patient took for granted before the injury may result in an overwhelming feeling of inadequacy post injury.”

• red high heels
• a certain hair style
• an ironed shirt
• Openness of organization to clients dating, living together, weddings
Sexual Adjustment Counseling

- Exploration: discussion of intimate concerns
- Understanding: Focus on behaviors, on responsibility of BI client relative to educating others about needs.
- Action Phase: facilitate step by step plan e.g. “pleasuring”
Educational and Counseling Needs

• Educational meeting with family: consider context, developmental stage, religious and cultural issues

• Groups: Social skills training, Men’s Group, Women’s Group

• Individual: Permission, Behavioral rehearsal, role play, strategies, expectations
Issues To Be Taught As A Part Of Education Regarding Sexuality

- Contraception
- Safe sex practices
- Sexually transmitted diseases
- Self stimulation
- Adjustment to disability
- Sexual aids: meds, devices
- Community prejudice of the disabled
- Acceptance of self; comfort with being alone
Education and counseling should include dealing with risk of rejection which is unavoidable for all of us!

The need to connect can lead to disappointments or risk
## On-Line Dating Option

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Percent of marriages in the last year in which the couple met on a dating site</td>
<td>17 %</td>
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<tr>
<td>Percent of current committed relationships that began online</td>
<td>20 %</td>
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On-Line Dating CAUTION


**SCAM ALERTS:**

1. Partner from another country
2. Person who wants to be “saved” eg abused
3. If ANY mention of money is made
4. Requests for personal info, even address
5. Premature terms of endearment
Creative Individual Interventions

- Personal Appearance: grooming parties
- Prom Night or other gatherings
- Massage Class: can be physically close without being sexual
- Social Peer Mentoring
- Videotaping role played interactions
- DANCE!
Creative Individual Interventions

• Importance of role play and feedback
• Observation in community
• Practice use of condom (physical and cognitive)
• Surrogates
  http://www.surrogatetherapy.org/what-is-surrogate-partner-therapy/
• Trip to Vegas
Sexuality Counseling and Education

ALTERNATIVES TO INTERCOURSE

• Closeness, communication
• Cuddling
• Masturbation, self pleasuring
• Social Media, videos
Medical Interventions

Men: Erectile dysfunction
• Vacuum pump: pulls blood into penis
• Alprostadil. Injected in penis 20 minutes prior
• Pills

Women:
• Vaginal lubricants women
• Pain or involuntary contractions of muscles treated with insertion of devices into vagina with size gradually increased
Legal and Ethical issues?

• There are no consensus guidelines for capacity to consent to sexual activity
• May differ by jurisdiction, between physicians
• “medicalized” (like making treatment decision)
• choosing to have sex may be “more akin to choosing an ice cream flavor” (Casta-Kaufteil, 2004)
- Donna Lou Rayhons case in Iowa: charges of felonious sexual abuse for husband by stepchild
- Did Alzheimer’s patient in nursing home have capacity to consent? Husband visited twice a day, sat with her, prayed rosary, she always seemed happy to see him. (Preferences)
- Not guilty: “The nonprofit Alzheimer's Association said it was not taking a position on the case but noted the importance of conversations about patients' capacity for decision-making.” (NYT, 2015)
Criteria to Assess Capacity for Sexual Consent

1. Voluntariness: demonstrate preference
2. Safety: recognizes danger, protect from harm
3. No exploitation: of or by the client
4. No physical or psychological abuse: eg STOP
5. Ability to say no: verbal or nonverbal
6. Social Appropriateness (Time and place)

(Wilkins, 2015)
Sample Sexual Consent Capacity Interview Questions (Hillman, 2017)

Knowledge:
How do you know if partner wants to…or to stop
When, where
Is there anything bad might happen
How will others react
Do you know how to obtain, use needed materials eg lubricants, condoms, porn
Sample Sexual Consent Capacity Interview Questions (Hillman, 2017)

Reasoning:

Is this something you did in past? How did you feel?

Is this consistent with your values and beliefs?

If partner wants to stop, what would you do?

How will you decide if there are any risks?
Sample Sexual Consent Capacity Interview Questions (Hillman, 2017)

Voluntariness:
Do you feel pressured? How and by whom?
How important is this to you on a 1-10 scale?
Has anyone threatened or hurt you?
Can you tell me how you would let your partner know you want to stop sexual activity?
Sexuality and Disability

Absence of 

sensation does not mean absence of feelings.

Inability to move does not mean inability to please.

Presence of deficits does not mean the absence of desire.

Inability to perform does not mean the inability to enjoy.

(Haseltine, Cole, & Gray, 1993)