Intimacy, Sexuality and Reproductive Health after TBI

Yelena Goldin, Ph.D.
Clinical and Research Neuropsychologist
JFK-Johnson Rehabilitation Institute

Clinical Assistant Professor
Physical Medicine and Rehabilitation
Rutgers Robert Wood Johnson Medical School
Objectives

- Develop an understanding of the effect of traumatic brain injury on intimacy, sexuality, and reproductive health.

- Develop an understanding of the biopsychosocial factors related to changes/difficulties in intimacy, sexuality, and reproductive health in individuals with traumatic brain injury.

- Make recommendations for addressing changes/difficulties in intimacy, sexuality, and reproductive health for consumers and clinicians.
Why have this talk?

- Sexuality is an important area of our lives
- Changes in sexuality are common after a brain injury – more frequent than in the general population
- Suggested to be a major concern among consumers
- Often not talked about
- Often not addressed as part of rehabilitation
Current State of Knowledge

- NIH Consensus Conference in 1998 – sexuality is an important topic not addressed in rehabilitation

- Body of knowledge/literature has been slowly growing, but there are still significant gaps

- Common clinical and research tools do not include items on sexual functioning

- Lack of treatment standards and referral resources
Possible Obstacles

- Socio-cultural history of sexuality – deviant, sin, dirty, heterosexual – only recently becoming more liberal and open-minded

- Belief that people with TBI have more important problems to deal with

- View of people with TBI as non-sexual

- Lack of understanding about sexuality and TBI

- Embarrassment
Intimacy, Sex, and Sexuality

- **Intimacy** – “familiarity; something of a personal or private nature” – emotional connection (can be cultivated and expressed by means other than sex)

- **Sex** – “physical activity that is related to and often includes sexual intercourse” (may or may not be an expression of intimacy)

- **Sexuality** – “the sexual habits and desires of a person; expression of sexual receptivity” – identity, roles, behaviors
Stages of Sexual Response

- **Desire:** drive/need
- **Arousal:** body’s preparation for sex
- **Plateau:** sexual activity (tension builds)
- **Orgasm/Climax:** pleasure/release of tension
- **Resolution:** return to baseline
BioPsychoSocial Model of Sexual Functioning
Impact of Traumatic Brain Injury
Problems after TBI (as reported in research)

- ↓ Energy for sex
- ↓ Libido/sex drive
- ↓ Interest/desire
- ↓ Sensation
- ↓ Difficulties with initiating sex
- ↓ Discomfort/difficulty with body positioning and movement
- ↓ Climax/Orgasmic dysfunction
- ↓ Sex-appeal (Self-esteem/confidence)
- ↓ Verbal communication with partner
- ↓ Perceived or actual ability to satisfy a partner
- ↓ Importance of sex
- ↓ Frequency
- ↓ Relationship quality
- ↓ Quality of sex
Hyper-sexuality/Inappropriate Sexual Behaviors

- Substantially more distressing to caregivers – overt!
- Infrequent

- Research suggests that most sexually inappropriate behaviors are limited to sex-talk

- Behaviors that go beyond sex-talk
  - genital/non-genital touching, exhibition/public masturbation
  - occur as part of general disinhibition syndrome – should be addressed through intensive behavior modification
Physiological Factors
Specific Damage to the Brain

- **Brain stem**: disruption of information flow regarding sexually-relevant information.

- **Basal hypothalamus**: irreversible loss of libido.

- **Temporal lobe**: decreased libido, genital and sexual arousal.

- **Hypothalamus and limbic structures**: hypogonadism (endocrine disorder) and hypossexuality (decreased desire)

- **Frontal lobes**: disinhibition, sexually inappropriate behaviors, difficulties with gonadal arousal, impaired initiation, attentional difficulties, disrupted ability to fantasize, difficulties with orgasm.

- **Dominant hemisphere**: communication difficulties, impaired motor performance, depression, decreased libido

- **Non-dominant hemisphere**: impulsivity, lack of awareness, difficulty orienting body due to visual-spatial difficulties, difficulty interpreting and expressing non-verbal cues and emotional aspects of communication
Direct or Indirect Injury Effects

- Motor functions (paralysis, spasticity, paresis, balance, coordination)
- Medical complications
- Medication side-effects
- Fatigue
- Sensory changes
- Pain/Headaches
- Bowel/bladder control
- Seizures
- Alcohol/drug use
## Endocrine Dysfunction

Disruption/suppression of the Hypothalamic-Pituitary-Gonadal axis

<table>
<thead>
<tr>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Menstrual cycle abnormalities</td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>Decreased estrogen levels</td>
<td>Decreased testosterone levels</td>
</tr>
<tr>
<td>Abnormal ovarian function</td>
<td>Ejaculation difficulties</td>
</tr>
<tr>
<td>Decreased lubrication</td>
<td></td>
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<tr>
<td>Painful intercourse</td>
<td>Fertility Difficulties</td>
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</tbody>
</table>

Fertility Difficulties
Medication Side-Effects

- **Anticholinergics and anti-spasticity** – commonly prescribed to those with hemiparesis, spasticity and/or reduced muscle tone

- **Anticonvulsants** – penetration injury, brain surgery, abnormal EEG or brain hemorrhage

- **Antipsychotics** – severe agitation, psychosis, hallucinations or depression

- **Anorexiants** – loss of appetite

- **Antidepressants** – depression

- **Non-steroidal anti-inflammatory drugs** – pain, bone fractures, inflammation of the joints

- Sleep aids
Cognitive & Emotional Factors
Cognitive Impairments

- Attention
- Memory
- Awareness
- Language and communication (intimacy)
- Difficulty fantasizing (desire)
- Decreased initiation (desire)
- Social skills deficits
- Impulsivity
- Planning
- Organization
- Regulation of behaviors and emotions
Emotional and Behavioral

- Personality changes
- Adjustment and loss
- **Depression**
- Anxiety
- Difficulties with perception and expression of emotions
- Apathy
- Disinhibition
- Lability
- Self-esteem/personal appeal
Social
Social

- Decreased social contact
  - Lower rate of dating
  - Less opportunity

- Relationship changes
  - Partner frustration
  - Partner dissatisfaction (both sexually and emotionally)
  - Lower marriage rate/Higher divorce rate

- Role changes
  - Role reversal
  - Caregiver vs. partner

- Socioeconomic status

- Transportation obstacles

- Residential obstacles
Social

- Cultural views/beliefs (sex, intimacy, relationships, gender roles, etc)
- Cultural views on disability
- Cultural views about sexuality and disability
Family Planning

- TBI can but usually does not impact ability to conceive

- Endocrine dysfunction can present obstacles to conception, pregnancy and delivery

- Health and nutrition can be another area of focus

- TBI-related consequences may present challenges to attaining/maintaining relationships and to parenting: influence family planning decisions
Family Planning

- 485 (55% male) community-dwelling TBI participants and 132 (51% male) demographically-comparable control participants.

- Of the 485 TBI participants, 337 (55% male) aged 50 and younger at the time of TBI, were selected for further analysis.
Family Planning

- Individuals who sustained TBI prior to age 18 had higher biological parenthood rates post-injury than individuals injured as adults (22% vs. 8%, p = 0.01),

- BUT...they had children in significantly lower proportions overall (26% vs. 53%, p < 0.001).

- Individuals with longer time since injury had a significantly higher likelihood of having biological children post-TBI (p < 0.001; OR = 1.08).

- Women but not men with more attention/memory complaints were significantly less likely to have children after injury (p=0.047; OR = 0.176).
Family Planning

- The likelihood of having children after TBI is significantly lower.

- The more time passes after TBI, the greater likelihood of having children.

- TBI-related cognitive symptoms have a negative impact on the likelihood of women but not men having biological children after TBI.
Predictors of Sexual Functioning

- Severity of disability and Level of physical independence, but not injury severity
- Mood/Psychological adjustment
- Presence of endocrine disorder
- Years post injury
- Age and age at injury (younger adults fare best)
- Availability of partner
Current Knowledge Gaps

- Partner Issues
- Gender
- Specific medication effects
- Sexual orientation
- Treatment
ADDRESSING SEXUAL FUNCTIONING AFTER TBI
Healthcare Professionals

- Rehabilitation staff need to be proficient in discussing sexual concerns with patients.

- Understanding of post-TBI difficulties and expression of sexuality

- Clarify personal values

- Rapport and communication skills
Initiate Discussion

- Bring up the topic early on in the recovery process
- Establish working relationships that promote communication
- Discuss and clarify patient/partner values
- Let patient/partner know that you will listen and work to help them with sexual concerns
Provide Education

- Provide education about the effect TBI can have on the sexual functioning, intimacy, and sexuality of both the patient and his/her partner
- Answer questions and address concerns
- Normalize the experience
Prevention as Early Intervention

- Help prepare patients (and their families)
  - Make attempts to prevent traumatic events that can lead to the deterioration of sexual identity, self-esteem, self-confidence and body image
  - Address emotional, cognitive, behavioral and functional effects of brain injury
  - Prevent/break the vicious cycle
  - Teach skills that will prevent experiencing failure and help cope with the injury
  - Prepare patients and their families/partners to deal with social, intimate and sexual situations
  - Provide sufficient education, information, and resources
Assess

- Ask about sexual functioning
- A complete evaluation (including appropriate medical work-ups) to identify all potential factors of difficulty

Important assessment factors to consider:
- Pre-injury sexual status
- Cultural factors
- Relationship factors
- Cognitive and emotional factors
- Physiological factors
- Pre-existing and present illnesses (headache, pain, hypertension, vascular disease, diabetes, psychiatric, endocrine)
- Current medications that can affect sexual functioning
Important Considerations

Patient’s (and partner’s) needs/goals:

- Sex
- Intimacy
- Sexuality
Important Considerations

- Relationship Status
  - Availability of partner
  - Desire for partner
  - Sexual preferences
  - Obstacles to desired relationship status
  - Patient vs. others’ needs
Important Considerations

➢ Age and injury:

- Stage of sexual development
- Level of social and dating skills development
- Sexual experience
- Level of independence
- Life experience
Assess

- General Rehabilitation Assessment Sexuality Profile (Physician Only) – history, physical and diagnostic exam

- Generic Measure of Sexual Functioning – 28 items, 10 subscales of sexual problems (mainly physiological)

- Sexual Interest and Satisfaction Scale

- Derogatis Interview for Sexual Function–Self-Report

- Brain Injury Sexuality Questionnaire – developed and validated specifically for TBI
# Brain Injury Sexuality Questionnaire (BIQS)

**Name:**
**Date:**

1. Did you have a sexual relationship/s prior to your injury? □ Yes □ No
2. Are you in a sexual relationship now? □ Yes □ No
3. Do you have the opportunities to engage in sexual activities with your self or others? □ Yes □ No

Answer the following for **now compared to prior to your injury** on the following scale: Greatly decreased, Decreased, Same, Increased, Greatly increased

<table>
<thead>
<tr>
<th>Sexual Functioning</th>
<th>Greatly decreased</th>
<th>Decreased</th>
<th>Same</th>
<th>Increased</th>
<th>Greatly increased</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. The importance of sexuality</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Your sex drive</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. The frequency with which you engage in sex</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Your ability to give your partner sexual satisfaction/ enjoyment/ fulfillment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Your ability to engage in intercourse</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Your ability to enjoy sex yourself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Your ability to stay aroused during sex</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Your ability to climax</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Relationship quality and self-esteem</th>
<th>Greatly decreased</th>
<th>Decreased</th>
<th>Same</th>
<th>Increased</th>
<th>Greatly increased</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Your opportunity to engage in sex</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Your ability to verbally communicate with your sexual partner</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Your self confidence</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Your sex appeal</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. The quality of your relationship with your sexual partner</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Mood</th>
<th>Greatly decreased</th>
<th>Decreased</th>
<th>Same</th>
<th>Increased</th>
<th>Greatly increased</th>
</tr>
</thead>
<tbody>
<tr>
<td>17. Level of depression</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>18. Level of preoccupation with problems</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
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What do you think are the reasons for any changes you have noticed? (you may tick more than one)

□ No changes  □ Behaviour problems  □ Decreased mobility
□ Low confidence  □ Loss or decrease in sensitivity  □ Feeling unattractive
□ Pain  □ Decline in relationship  □ Tiredness/Fatigue
□ Difficulties in communicating  □ Limited access to intimate social contact  □ Arousal/sex drive problems
□ Other, please specify:

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**MONASH University**

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Approach

- A comprehensive, all-inclusive approach

- Evaluate and address the basic/specific factors that can affect sexual functioning: medical, cognitive, psychological and social aspects

- Advanced treatments as needed
Approach

- Make appropriate, assessment-guided referrals
- Offer Strategies
  - Timing/Fatigue management
  - Environmental restructuring
  - Planning
  - Positioning
  - Exploration
  - Socialization
  - Communication
Approach

➢ Basic interventions/treatments
  ➢ Lubricants
  ➢ ED medications
  ➢ Aides
  ➢ Promote wellness, relaxation, and exercise
  ➢ Medication adjustment
  ➢ Enhance couple communication
Approach

Discuss Alternatives:

- Intimacy
  - Physical contact without sexual activity
  - Emotional connection
  - Mental stimulation
  - Communication
  - Shared Activities

- Masturbation

- Media

- Internet
Safety

- Preventing victimization
  - Consensual sexual relationships (Sexual Consent and Education Assessment: Kennedy, 1999)
  - Education about sexual rights
  - Education about rights of others and appropriate expression of sexuality
  - Education about internet safety
Safety

- Contraception
  - Explore and find a method that works for your patient post-TBI
  - Develop strategies
  - Teach and reinforce being prepared
Safety

➢ Sexually transmitted diseases...

- Education
- Prevention
- Intervention
Remember to Include:

- Patient
  - AND
- Partner (if patient has one)
  - OR
- Caregiver(s)
The most effective and important tool is:

COMMUNICATION
Additional Resources


- Sexual Health Network [www.sexualhealth.com](http://www.sexualhealth.com)

- Our Bodies Ourselves [www.ourbodiesourselves.com](http://www.ourbodiesourselves.com)

- Products [www.disabled-world.com](http://www.disabled-world.com)
References


