SEX AND THE Single Synapse: Maintaining Intimacy Following a Traumatic Brain Injury

Rolf B. Gainer, Ph.D.
CEO, Brookhaven Hospital

Michael Mason
Brain Injury Case Manager

Neurologic Rehabilitation Institute at Brookhaven Hospital

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How can we develop a better understanding of the problems and potential solutions related to sexuality and intimacy following traumatic brain injury?

- What issues affect the individual?
- What issues affect the significant other?
- What happens in relationships and families?
- What are the rehabilitation implications?
How do sexuality and intimacy relate to a satisfactory return to independence?

- 20% of the participants with TBI report “Satisfied with Life” at the 1, 5 and 10 year post injury points

Source: Traumatic Brain Injury National Data Center, Traumatic Brain Injury Model Systems Database Update, Millis, 2004
Misperceptions Regarding Sexuality and Brain Injury

- “The person has returned to a childlike state”
- “It’s our job to take care of them”
- Brain injury effects do not occur “below the belt”
- “Sex will/could cause problems”
- “It’s not the same person I married/ no longer the same”
- “I feel like I’m cheating”
- “Will they know what to do?”
Unique Reactions of Wives of Men with Brain Injuries

• No sexual outlet: 42%
• I’m married, but I don’t have a husband: 42%
• I’m married to a stranger: 32%

Maus-Claim and Ryan, 1981
Limited exposure of the problem in rehabilitation settings

- Frank discussion of sexual problems following TBI is often limited
- The focus on physical recovery overshadows return of the intimate aspects of living and relating
- Increased dependency forestalls addressing issues in rehabilitation and social role return phases
- Societal view that sexuality is rarely associated with disability
- Discomfort of others, including professionals, in discussing the problem
"OK, maybe a little hanky, but no panky!"
Research in Brain Injury and Sexuality

- Arrested sexual self concept due to age at injury. (*Blackerby, 1987*)
- Effect on motivation and initiation of frontal lobe injuries. (*Blackerby, 1987*)
- Lessened sexual arousal due to sensorium loss. (*Hayden and Hart, 1986*)
- Spousal frustration secondary to reduced interpersonal sensitivity. (*Lezak, 1978*)
- Sexual dysfunction more common in intellectually impaired group. (*Kostelijanetz, 1981*)
- Adaptation and Accommodation are neglected following TBI, (*Trudel, 2006*)

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Changes in Sexual Behavior Associated with TBI

Source: J. Ponsford, 2003

- Tiredness and fatigue: 47%
- Decreased mobility: 31%
- Low confidence: 31%
- Feeling unattractive: 23%
- Pain: 22%
- Difficulties in Communicating: 21%
- Loss/decrease of sensitivity: 19%

Other reported problems:
decline in relationships; limited access; arousal/sex drive; behavior N=208 (69% Male)
Sexual Behavior Post TBI

• Role of depression, anxiety, cognitive impairments, amotivational states and behavioral dyscontrol impact sexual functioning

• Location of lesion site associated with satisfaction/dissatisfaction with sex life (frontal vs. nonfrontal) (Sandel, 1996)
Difficulties Associated with Sexual Behavior Post TBI

- Sexual energy, desire and drive
- Reduction in sensation and orgasm
- Problems with positioning, movement and pain
- Changed body image, reduced self-confidence and mood state problems
- Decreased ability to sexually satisfy partner
- Sexual disinhibition
- Hypo and Hypersexuality
Gender Specific Differences

- Perceived desexualization of women with disabilities
- Problems with arousal, vaginal lubrication, pain
- Endocrine disorders and depression were predictors of sexual difficulties (Truesdel, 2005)
- Lower marriage rates for women with disabilities than men with disabilities
- Disabled women were as sexually involved as their non-disabled peers, but were experiencing disorders of sexual function at a higher rate. (Hibbard, 2000)
Age and Social Factors Associated with Sexuality and TBI

- Delayed entry into dating for individuals injured in childhood
- Social pressures against dating a disabled person
- Effect of low self esteem and self defeating behavior
- Limited mobility and community access
# Medications and Sexual Behavior

<table>
<thead>
<tr>
<th>Class</th>
<th>Example Medications</th>
<th>Sexual Effects</th>
<th>Additional Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antidepressant</td>
<td>Prozac, Elavil, Norpramin</td>
<td>Control/improve mood</td>
<td>Delay orgasm</td>
</tr>
<tr>
<td>Antispasmodic</td>
<td>Baclofen, Probanthine</td>
<td>Reduce/control spasms</td>
<td>None</td>
</tr>
<tr>
<td>Antihypertensives</td>
<td>Inderal, Beta Blockers</td>
<td>Control blood pressure</td>
<td>Decrease sexual drive</td>
</tr>
<tr>
<td>Antiseizure</td>
<td>Dilantin, Tegretol, Depakote</td>
<td>Reduce/control seizures</td>
<td>Decrease sexual drive, increase fatigue</td>
</tr>
<tr>
<td>Antihistamine</td>
<td>Actifed, Claritin, Atarax</td>
<td>Control allergy symptoms</td>
<td>Older meds decrease sexual drive</td>
</tr>
<tr>
<td>Anti-inflammatory</td>
<td>Advil, Naprosyn</td>
<td>Control inflammation, reduce pain</td>
<td>Increase sexual drive and response</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>Cipro, Penicillin</td>
<td>Control infection</td>
<td>Increase potential for yeast infections</td>
</tr>
<tr>
<td>Antiemetics</td>
<td>Reglan, Compazine</td>
<td>Control nausea</td>
<td>Decrease sexual drive and orgasmic response</td>
</tr>
<tr>
<td>Oral Contraceptives</td>
<td>“The Pill”</td>
<td>Birth control</td>
<td>Various types may increase or decrease</td>
</tr>
<tr>
<td>Androgen Anabolic Steroids</td>
<td>Winstrol, Anadrol</td>
<td>Minimize Wasting syndrome</td>
<td>Increase sexual drive, change of secondary characterisitics</td>
</tr>
<tr>
<td>Hormone Replacement Therapy</td>
<td>Estratest, Premarin</td>
<td>Adjust hormone levels post menopause</td>
<td>Increase sexual drive, prevent vaginal atrophy</td>
</tr>
</tbody>
</table>
Divorce and Brain Injury

- 50% of marriages and primary relationships fail within 24 months post-injury (*Burke and Weslowski, 1989*)
- Divorce/TBI rate does not exceed general divorce rate, but identifies TBI related factors
- Brain injury produces stressors within the social network that produce failure in relationships with family, friends and loved ones
- Problems involving social behaviors, including intimacy, sexuality and self-regulation create significant stressors in relationships
- Cognitive and emotional changes in the person effect the relationship
- Increased dependency needs and social role changes cause deterioration in primary relationship

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Psychological Issues Related to Intimacy Problems

• Depression/ sadness/ grief
• Amotivation/ loss of libido/hypososexuality
• Abulia/ apathy/loss of pleasure in living
• Manic states including hypersexual behavior
• Hypersexuality related to specific lesion sites or interictal periods
Couples Issues

Frequently reported issues include:

- Loss of interest
- Decrease in coital frequency
- Reduced expression of affection
- Perception of “sex appeal”
- Worsened communication between partners
- Sexual avoidance
- Sexual dysfunction, either party
Role of Compassion Fatigue in Intimacy

- Effects of stress
- Role changes for partners
- Coping with the physical, cognitive, behavioral and personality changes
- Demanding care schedule
"Yippie-ti-yo-ki-yay? Is that all you ever have to say?"
Sexuality and Brain Injury

What are the changes which affect sexuality?

- Physical
- Cognitive
- Behavioral
- Psychological
- Social Role
Pete and Charlene’s Story: Unresolved Losses

- Loss of a child
- Loss of memory
- Loss of connection
- Loss of understanding
Pete and Charlene’s Story: Pete Imprisoned by the Past

- Grief over lost child
- Grief over loss of relationship
- Feels alone in his grief
- No longer able to communicate complex issues to wife
Pete and Charlene’s Story: Charlene Caught in the Present

• Unable to recall lost child and entire marriage
• Unable to re-assume previous role as wife
• Frustrated by lack of independence
• Confused by plans for the future.
Cognitive Aspects of Sexuality

Sexuality is a complex function

- Problem solving
- Memory
- Sequencing
- Maintaining attention
- Shifting sets
- Denial
Stress and Relationships

Is this the same person?

- Understanding the effects of the person’s injury and relationship to intimacy
- Developing an effective and caring relationship
- Addressing old, maladaptive patterns
- Role of children and others
- Creating realistic expectations

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Cal’s Dating Story: From High-Energy to Hermit

- Active life as athlete
- High achiever
- Popular and sociable
- Experiences TBI
- Develops seizure disorder
Cal’s Dating Story: Post-TBI Problems

- Embarrassment of seizures
- Unable to maintain steady employment
- Social withdrawal
- Insecurity and low self-esteem
Cal’s Dating Story: Intimacy Problems

- Series of brief relationships
- Fear of rejection
- Fear of being honest
- Fear of needing support
- Efforts undermined by impulsivity and anger
Behavioral Changes Affecting Sexuality

- Impulse Control/reduced capacity to self-regulate
- Anger
- Withdrawal, alienation from others
- Denial
- Emergence of psychiatric and substance abuse problems
Initiating New Relationships

Starting Over Issues

• Self-image/self-worth
• Learning to date
• Explaining the disability issues
• Maintaining realistic expectations for both parties
• Specific education and information
Rob and Rose: Rob’s Injury

- Car wreck leads to brain stem injury
- 3 years of intensive rehab
- Quadriplegia
Rob and Rose: Getting back on track

• Goes back to college
• Finds job working with disabled
• Meets Rose, a therapist
Rob and Rose: Always a Couple

- Supportive communication
- Respect and dignity
- Open communication
- Realistic expectations
Maintaining Former Relationships

Coping with the changes

- What’s old?
- What’s new?
- Responding to problems
- Preventing the loss of the emotional bond
- Achieving a loving relationship
Social Role Return

- Increased dependence on others
- Different social/relationship role
- View of self with partner
- Partner’s response and view of partner’s response
- Adult individual living in parental home post-TBI
- Diminished social network
Intimacy Problems Increase After Brain Injury

- Wives of brain injured partners report “men are more self-oriented and exhibiting more childlike dependency (after the injury).” *Rosenbaum and Najenson, 1976*
- Inflexibility (20%), inappropriate public behavior (40%), self-centeredness (43%) and decreased self control (47%) mitigated against sexual readjustment. *Oddy and Humphrey, 1980*
- Wives report that they receive less expression of affection after injury. *Peters, 1990*
Changes in sexual functioning after injury

- Sexual arousal and orgasmic difficulties seen in 57% of individuals. (Kreutzer and Zasler, 1989)
- Spousal anorgasmia increased from 27% to 64% after the injury. (Garden, 1990)
- 67% of the TBI group report decreased self-confidence and sex appeal. (Kreutzer and Zasler, 1989)
Physical Issues Related to Sexual Dysfunctioning Following TBI

- Hypogonadism effect seen in 24% of severe TBI cases (coma more than 24 hours). (Clark, 1988)
- Inappropriate sexual behavior seen in 38% of individuals with frontal lobe injury. (Sabhesan and Natarajan, 1989)
- Temporal lobe injuries mediate sexual preference. (Lilly, 1983)
Physical Changes Following Brain Injury

• Lost/diminished functions and capacities
• Pain
• Fatigue
• Motor control
• Sensation/perception
• Strength/endurance
• Performance
Psychological Issues

- Depression
- Unresolved grief and loss
- Impulse control problems
- Perception of diminished self-worth
- Perception of unattractiveness
Violence and Sexual Behavior

- Impulse and anger control problems
- Individuals with history of violence more likely to become sexually aggressive post injury
- Role of memory and cognitive problems in sexual behavior
Partnering Issues

• Individual requires a high level of care from partner
• Role changes: independent to dependent
• Caregiver stressors
• Time
• Not knowing what would happen/fear
• Negative feelings/thoughts
• Psychological reaction of partner to TBI of loved one
• Withdrawal from relationship
• Response to physical, cognitive, behavioral and psychological changes

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Adding Sex to the Rehab Curriculum

- Discussing libido, intimacy, barriers to intimacy in counseling
- Address issues of sexual self-knowledge
- Identify methods to respond to physical barriers (positioning, pain)
- Assist individual to identify how a return to intimacy is part of rehabilitation and recovery
Using Interactional “Scripts”

Creating a method for initiating and maintaining a relationship

- Conversation, sexual talk
- Negotiating time and activities
- Understanding boundaries
- The “yes” and “no” words
- Attention to cues
- Responding to another person
Addressing Self-Regulation

- Controlling impulsive behaviors
- Relearning intimacy related behaviors
- Relearning non-sexual demonstrations of affection
Treatment and Rehabilitation Implications

- 94% of staff in a rehab setting anticipated sexual adjustment problems if sexuality was not included in rehab. (Hough, 1989)
- Early incorporation of self-stimulation in the normal adaptive awakening process. (Blackerby, 1987)
- Education and counseling in the middle stage of recovery. (Butler and Satz, 1988)
- Addressing pre-morbid factors through social skills training. (Blackerby, 1987)
- Use of behavioral treatment to address hypersexual conduct. (Zencius, 1990)
- Counseling and Education; (Zasler and Kreutzer, 1991)
Self-Image Issues Affecting Intimacy

- View of self as “different” or “damaged”
- Not feeling desirable or attractive
- Focused on physical deficit(s) as barrier
- Treatment needs to address self-concept issues
Creating and Maintaining a Sexual Relationship

• Intimacy as a mutually shared relationship
• Negotiating time, place and space
• Developing reciprocity
• Recognizing mutual wants and needs
• Picking a pace for intimacy
• Feeling respected, wanted and loved
Treatment for Behavioral Problems Affecting Intimacy and Sexuality

• Use of behavior learning strategies to address hyper-sexual behaviors
• Education and counseling for individual, couple and family regarding aspects of social role return
• Use of cognitive restructuring, alternative strategies, sexual aids and traditional behaviorally-based sex therapy techniques
• Addressing time and replace issues for uninhibited sexual expression rather than suppressing the behavior
Staff Training is Vital to Sensitizing Staff to Intimacy Issues

Training curriculum should include:

- Sexual dysfunctions
- Approaches to spousal education
- Establishing realistic expectations for sexual adjustment
- Effect of cognitive deficits
- Client perception of sexuality issues
- Dating resources
- Sex therapy and sexual aids
- Gay and lesbian issues

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Changing Perceptions about TBI and Sexuality

- TBI does not mean the end of sex
- Sexual needs should be addressed in both clinical and private settings
- Caregivers have sexual concerns, too
Presented as a learning activity for rehabilitation professionals by the Neurologic Rehabilitation Institute at Brookhaven Hospital and the Neurologic Rehabilitation Institute of Ontario

- Rehab that Works!
- Hospital, Community and Outreach
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