Relationships and Sexuality after ABI and/or Stroke

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What I hope you will take away from this presentation...

• Enhanced insight into the problems surrounding ABI/stroke and relationships.

• Specific challenges with ABI/stroke and sexuality factors (physical and mental factors)

• Increased comfort in addressing sexual behaviors with clients, families, and/or loved ones.

• How to respond to sexual behaviors and the risks of providing too much attention.

• Resource information
Acquired Brain Injury (ABI)/Stroke can cause changes in thinking, behavior, and body function, depending on which brain areas were affected and to what degree.

Generally, the more severe the injury/stroke, the more significant the symptoms and loss of function will be.
ABI Challenges with Forming and Maintaining Relationships

- Social Skills challenge: How one presents self can be critical to the start of a relationship.
- Impulsivity: Too quickly leading into advanced relationship statements and/or behaviors. (marriage, sex)
- On-going support to another is difficult for those with lack of initiation (not calling the other person)
- Memory deficits make recall of face/name difficult
- No ABI dating sites
- HIPPA prevented info sharing
ABI Challenges with Forming and Maintaining Relationships

- Depression is common after ABI and symptoms present challenges to relationships.
- ABI may result in the end of relationship due to timing and other factors of the ABI.
- ABI rehab often requires self focus and efforts to improve which may present challenge for relationships (learning about deficits and how to cope).
- Lack of scrutiny for partners leads to risk of poor quality and even risky relationships.
Challenges for those in on-going committed relationships prior to ABI

Memory Issues/challenges: Can be hurtful and damaging to relationships despite awareness that memory was affected by ABI. Resistance to use of memory devices can feel like a lack of “caring” about the ABI survivor’s partner.

Role changes: Transitioning from spouse to caregiver and back to spouse again! Huge transitions that require complete change in cognitions/behaviors involving roles and responsibilities.
Why Talk About Sexuality and ABI/Stroke?

- Sexuality is extremely important area of our lives.
- Sexuality changes are common after a brain injury/Stroke.
- An area of our lives that is often not talked about or addressed in ABI/Stroke rehab.
- Strong societal attitudes towards sexual issues for people with disabilities. (Gan,C.)
- Sexual behaviors may be a shocking but natural expression during the rehab process (rancho levels)
Causes of sexual challenges with ABI

Sexual functioning and arousal involve a number of areas of the brain. If those areas are damaged, a person may experience difficulties having sex. They may not feel sexual in the same way, even though their physical functions still work.

Other factors after brain injury may also contribute to, or even cause, the person’s sexual problems. These factors could include:

**Emotions** – depression, anxiety and stress can reduce sex drive.

**Medications** – certain medications can dampen libido.

**Associated injuries** – if, for example, the person’s brain was injured in an accident, they may have other injuries that directly affect their sexual functioning (such as a spinal cord injury).

The Better Health Channel (2017)
Changes related to sexuality after ABI

**Reduced libido** – about half of people with a traumatic head injury experience a drop in sex drive. The remainder experience increased libido or no change at all.

**Erectile problems** – between 40 and 60 per cent of men have either temporary or permanent impotence following their injury.

**Inability to orgasm** – up to 40 per cent of men and women report difficulties having an orgasm.

**Reduced frequency of sex** – possible reasons for this include disability, depression, relationship break-up and sexual problems.

The Better Health Channel (2017)
Other Influencing Factors

**Relationship breakdown** – a couple experiencing problems are less likely to have sex.

**Prior sexual difficulties** – brain injury can make worse any sexual problems the person was having before the injury occurred.

**Reduced confidence** – the person may feel less confident or attractive after the brain injury, which makes them less likely to feel sexual.

**Other illnesses** – such as diabetes or hypertension (high blood pressure) can reduce libido.

The Better Health Channel (2017)
Discussion of Sexual Ethical Dilemma

When two adult survivors of ABI/stroke have consensual sex but one or both has a guardian that wants this prevented/forbids this.

What are the decisional limits of a guardian? Wanting to respect guardian wishes vs. person-centered adult choices?

What is best way to address?

If there is direct experience with this, what did the agencies involved do?

Residence moves, Direct Eye sight supervision, …..?
Why is it important to define/study sexual behaviors and ABI?

“Inappropriate Sexual Behavior (ISB) amongst clients with neurological impairment, specifically Acquired Brain Injury (ABI) has received relatively limited research. There are multiple problems encountered in the definition and quantification of ISB, in particular the absence of standardized measurement tools to record ISB within an inpatient setting.”

Sexual behaviors and brain injury...

The impact of these behaviors on patients and caregivers can be significant. Ill-defined terminology and the absence of relevant assessment tools add to the specific challenges of understanding and managing ISB within a care or rehabilitation setting. It is concerning that the subjective attitudes of staff and the culture of an institution can dominate the approach taken to dealing with ISB for these client groups.

C. Johnson, C. Knight, and N. Alderman (2006)
What are Inappropriate Sexual Behaviors?

Types of inappropriate sexual behavior (defined in 1999 study)

**Exhibitionism** Exposing one’s genitals to others. Disrobing or engaging in masturbation in front of others.

**Touching genital areas** refers to breast, buttocks, or penis.

**Touching non-genital areas** refers to anywhere else on the body including patting a person on the knee, touching a person's shoulder, arm, back etc.

**Voyeurism** Looking for opportunities to watch others undressing, etc.

**Coercive sexual assault** refers to the forcible grabbing of a person, attempting to undress a person, attempting to have non-consenting intercourse with a person.

Simpson et al. 1999
This chart shows the relative incidents of Sexually Inappropriate Behaviors after TBI in a study by Simpson et al. 1999.
Other sexual changes you might see:

Hypersexuality (thinking about or wanting frequent sexual activity, e.g., masturbation in presence of others)

Hyposexuality, or a lack of interest in sex

Discomfort with intimacy

Trying to kiss, hug, or touch strangers

Making suggestive or flirtatious comments to or about others
Why is it important to know the function of ISB?

**What is the function of behavior?** The function of behavior is the reason people behave in a certain way. People engage in millions of different behaviors each day, but the reasons for doing these different behaviors fall into four main categories.

**The four main functions that maintain behaviors are:**

**Escape/Avoidance:** The individual behaves in order to get out of doing something he/she does not want to do.

**Attention Seeking:** The individual behaves to get focused attention from parents, teachers, siblings, peers, or other people that are around them.

**Seeking Access to Materials:** The individual behaves in order to get a preferred item or participate in an enjoyable activity.

**Sensory Stimulation:** The individual behaves in a specific way because it feels good to them.
Once it has been identified what function or functions are maintaining the behavior, you can start to implement an intervention that will help decrease the problem behavior and increase more appropriate replacement behaviors.
In my professional experiences, ISB may be exhibited during the rehab process and actually become reinforced so that it continues and increases due to the function of gaining attention from staff, family, and/or caregivers.

Be careful not to fall into this pattern! It is easy to do, with great intentions of teaching and redirecting, but these are also forms of attention. Please develop/practice a “poker face” and the ability to avoid a dramatic vocal response.

Please be aware of why a person may be exhibiting these behaviors before potentially overreacting/deciding how to respond to this behavior.

Behavior plans can be your guide for “what to do” in these situations.

Consult a behavior therapist if ISB is becoming a problem for an individual.
Possible interventions depending on the Survivor’s current functional needs:

Develop a “stop and think” non-verbal signal to let the survivor know that he/she is saying something inappropriate.

Use redirection (i.e., try to change the topic or focus of interest to something else).

Talk to survivor about what are and are not acceptable ways to act in public before you go out or witness the unacceptable.

Educate the survivor that having sexual feelings is normal. Sexual behavior, however, is a private matter.

Find a way for your family member to express his or her sexual needs (i.e., in the privacy of his or her room).

https://www.traumaticbraininjuryatoz.org/The-Caregivers-Journey/Session-Two/Behavioral-Effects/Sexual-Behavior
How can you help?

Please create positive new ideas and new approaches to ABI/stroke and sexual issues!

Please remember that sexuality and brain injury/stroke is not something to be put off by or frightened of. You can become an important part of helping to uncover the hidden issues to gain success!
Any Questions?

Thanks for your attention and efforts to provide quality services and/or support to survivors of brain injury!
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Amanda Callahan, LCADC
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