



Let's Talk: Promoting Healthy Sexuality in Youth with Acquired Brain Injury

By Caron Gan, RN, MScN, RP, RMFT, AAMFT Approved Supervisor, Advanced Practice Nurse/Family Therapist, Holland Bloorview Kids Rehabilitation Hospital

Sexuality changes are common after acquired brain injury (ABI), yet intervention and research are neglected areas of sexual health, especially in adolescents and youth with ABI (Moreno, McKerral, Lasprilla, & Gan, 2013; Simpson, Simons-Coghill, Bates, & Gan, 2017). This is a notable gap in clinical care, given the highest rate of ABI occurs between the ages of 15 and 24 years, a time when young people are learning to navigate social, peer, and intimate relationships, including sexual relationships. Moreover, influences of social media and the exposure to sexual content in mainstream media can be confusing, especially when cognitive skills that allow youth to critically analyze these messages and make safe choices can be affected by an ABI. The purpose of this paper is to highlight the importance of addressing the sexual health needs of youth with ABI and to encourage beginning conversations to promote positive sexual health.

Sexual health – What is it?

Sexual health is not just about being male or female, or the act of sex. It's also about relationships and how we feel about our bodies, ourselves and others. Sexual health is defined holistically as...

a state of physical, emotional, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. (World Health Organization, 2006, p. 5)

Why is promoting positive sexual health in youth with ABI important?

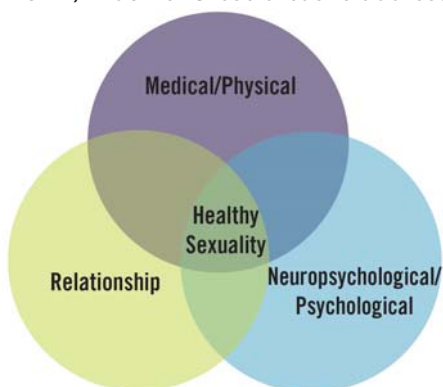
1. Youth with ABI are sexual beings like everyone else. Being sexual is a natural, pleasurable, and healthy part of a person's life.
2. Youth with ABI usually don't have the usual support systems for addressing their sexual health needs. They need accurate information about sexuality, what is fact, what is myth, what sex is, and ways of having fulfilling, respectful, and safe relationships.
3. Compared to individuals without ABI, youth with ABI have less experience and life skills around relationships. They may struggle with fitting in with their peers, forming and maintaining friendships, and figuring out their identity while trying to navigate the complexities of life after ABI.
4. The effects of the ABI may affect judgment, impulse control, or decision-making, which can heighten vulnerability to unsafe behaviours or poor choices.
5. Sexuality may be an area that is uncomfortable for parents and adolescents to discuss openly with one another. Parents may feel protective and be less inclined to broach the topic as the notion of viewing their child as a sexual being may be a departure from their priorities and concerns. It may not be an area of priority for parents unless problematic behaviours arise.

6. Sexuality is an area that is seldom addressed by professionals, in spite of its importance; as noted in a recently published scoping review on sexual health after pediatric ABI (Simpson et al., 2017). Research has also found that individuals with ABI experience lack of openness from professionals for questions related to sexual and reproductive health (Moreno, Gan, Zasler, & McKerral 2015).
7. Adolescence is a time of great change and coincides with developmental processes such as:
 - Physical, psychological, and social changes
 - Focus on appearance
 - Questions about sex and sexual exploration
 - Feelings of attraction
 - Identity formation
 - Increased awareness of sexual orientation
 - Friendships, intimacy, dating, and belonging
 - Developing healthy romantic and sexual relationships
 - Fertility and reproduction

Like their similar-aged peers, youth with ABI often have questions about dating, readiness to have sex, sexual orientation or LGBTQ relationships. They may, however, lack confidence in making friends, or wonder if others will find them attractive after the ABI. Young people with ABI need to know to whom they can talk so that they are sexually informed, know what to do to ensure safety and avoid unwanted behaviours, and receive support in forming satisfying and healthy relationships.

A framework for healthy sexuality

Healthy sexuality after ABI involves an interaction between three areas: medical/physical issues, neuropsychological and psychological changes, and relationship factors. This biopsychosocial framework requires an interdisciplinary team approach and has been proposed for adults with ABI (Gan, 2015; Moreno et al., 2013) and for teen survivors of brain tumor (Gan 2012). Each of these areas is addressed below.



Medical/Physical Issues

After an ABI, there can be hormonal changes and/or physical changes that can affect body image, sexual functioning, and the ability to self-pleasure. These may include:

- Altered sensations – hypersensitivity or hyposensitivity
- Changes in gross or fine motor/hand functioning
- Mobility and balance issues
- Fatigue, endurance, or sleep issues
- Pain
- Seizures
- Diminished or heightened interest in sex
- Early or delayed onset of puberty
- Fertility issues

Many medications (e.g., mood stabilizers, seizure medications, anti-anxiety medications) can have sexual side effects such as arousal problems, erectile and ejaculatory problems, or orgasmic difficulties. Steroids are often associated with increased appetite, weight gain and unequal distribution of body fat, all of which can affect body image. Some medications may also reduce the effectiveness of hormonal birth control methods, so it is important to discuss any medication concerns with the doctor or health care provider.

Neuropsychological/Psychological Factors

After an ABI, there may be social and behavioural changes which can impact peer, social, or romantic relationships. These might include:

- Alterations in social judgment, social awareness, and ability to read social cues
- Apathy or initiation difficulties
- Poor impulse control
- Behavioural disinhibition
- Personality changes
- Difficulties with irritability or emotional control
- Changes in memory, attention and concentration which can affect social communication

Risks of unplanned pregnancy, sexually transmitted infections (STIs), sexual assault, or exploitation are concerns often expressed by parents. The youth may need clear guidelines

around what is acceptable behaviour and what is not and help differentiating between safe vs. unsafe behaviours and healthy vs. unhealthy relationships.

Relationship Factors

Factors that can affect one's ability to develop or maintain healthy relationships can include:

- Limited life and sexual experience.
- Less developed social and relationship skills.
- Fewer opportunities to develop normal peer relations.
- Increased vulnerability due to social and neurocognitive challenges.
- Concerns around how to explain the ABI to others.
- Parental overprotectiveness.

Social skills deficits and communication impairments can make it difficult for youth to establish or maintain friendships. Psychological issues may include changes in body image, fitting in with peers, mood changes, anxiety, and reduced self-esteem, all of which can affect one's confidence and comfort with relating to peers.

How rehabilitation professionals can help

In helping youth in their journey to optimal health and sexuality, it is important not to assume that he/she understands what healthy sexuality is, or about healthy boundaries and relationships. Rehabilitation professionals working with young people with ABI can be more proactive in promoting positive sexual health by:

- Beginning the conversation and giving permission for youth and their parents to ask questions and talk about this important topic. Use teachable moments to offer important information about sexuality, relationships, or birth control.

- Using a positive approach when providing information and education about the effects of ABI and how this can affect sexual development, sexual health, and relationships. With accurate information and support, youth can make choices to be sexually healthy and happy.

- Providing access to information on sexual and reproductive health topics (e.g., contraception, having children, safer sex practices, HIV/STI prevention) by partnering with community agencies that focus on reproductive and sexual health needs of youth (i.e., Planned Parenthood).

- Providing opportunities for role-playing and fostering relationship skills, social interaction, and practising social skills. Meeting people, starting a conversation, choosing friends, learning to date, handling rejection, and learning appropriate boundaries are some of the social skills that may need to be taught or rehearsed in a group setting.

- Providing skills training and opportunities to build social competence: listening, assertiveness, being positive, showing interest, giving compliments, offering opinions, being respectful.

- Offering workshops to teach safety skills (i.e., healthy boundaries, sexual consent, signs of abusive relationships, online safety, dealing with unwanted behaviors or cyber bullying) to keep youth safe from abusive or exploitive relationships.

- Providing opportunities for discussion, maintaining open lines of communication and using a non-judgmental, positive stance so that the youth will feel comfortable raising concerns or questions. Start off with positive messages about sex before getting into the risks, dangers, or concerns.

- Helping parents understand the importance of opening the lines of communication, supporting them on how to broach the topic with their son/daughter, and using teachable moments to foster positive sexual health.

To safely negotiate the stage of adolescence into young adulthood, youth need to be supported in finding positive and healthy ways to express their sexuality. They need to know who they can talk to about sexuality and how they feel about the changes arising from their ABI. Like all youth, they need to know how to make healthy choices and what to do to avoid unwanted pregnancy, sexual diseases, loss of friendship, exploitation, or trouble with the law. Let us be proactive by beginning the conversation, legitimizing the importance of this topic, and providing equal opportunity for youth with ABI to acquire the knowledge and skills they need to engage in fulfilling, respectful, and healthy relationships.

References

Gan, C. (2005). Sexuality after ABI. Invited workshop, presented at the Third Annual TBI Conference. Expression of Sexuality and Behaviours Following TBI, Montreal, Quebec, Canada.

Gan, C. (2012). Sexuality and Teen Survivors of Brain Tumours, Pediatric Brain Tumour Patient Handbook 6th Edition, Brain Tumour Foundation of Canada.

Moreno, A., Gan, C., Zasler, N., & McKerral, M. (2015). Experiences, attitudes, and needs related to sexuality and service delivery in individuals with traumatic brain injury. *NeuroRehabilitation*, 37:99-116.

Moreno, A., McKerral, M., Lasprilla, J. & Gan, C. (2013). Sexuality after traumatic brain injury: A critical review. *NeuroRehabilitation*, 32:69-85.

Simpson, G., Simons-Coghill, M., Bates, A., & Gan, C. (2017). What is known about sexual health after pediatric acquired brain injury: A scoping review. Special thematic issue on Neurosexuality, *NeuroRehabilitation*, 41(2):261-280. doi:10.3233/NRE-172197.

World Health Organization (2006). Defining sexual health. Report of a technical consultation on sexual health 28-31 January 2002, Geneva. ♦♦♦