Sexuality Following Neurologic Injury

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Abstract

• CARF (Commission on Accreditation of Rehabilitation Facilities): Medical Rehabilitation accreditation standard focuses on sexuality of the person served. Although a standard of care for accreditation, the issue of sexuality can be difficult to address for various reasons such as comfort level, bias, or narrow focus in goal planning.

• There is a need to highlight what is missing and provide correct answers.

• There is also the need to examine the process from start to finish, to better understand the strengths and areas for growth that facilitate the best outcome for the individual.

• To that end, we present three case studies, all with sexuality issues: a twenty-five year male with traumatic brain injury, a forty year old female with spinal cord injury, and a 68 year old male with amputation. Each case examination will review the person, the person within a system of healthcare and the person within the accreditation standard on sexuality. Lecture, role play and audience participation provide an experiential learning experience. With the goal to maximize outcome, specific recommendations, resources and talking points for consultation are identified.

Disclosures

• Sigmund Hough receives a salary from VA Boston Healthcare System, Spinal Cord Injury Service; and as Editor-in-Chief of the journal Sexuality and Disability, a Springer International publication.

• Trisha Hicks works at Magee Rehabilitation Hospital and receives a salary.
Learning Objectives

- Participants will be able to identify at least two client sexuality resources to share during consultation.
- Participants will be able to identify at least two staff sexuality resources to share during consultation.

CARF International

Mission
The mission of CARF is to promote the quality, value, and optimal outcomes of services through a consultative accreditation process and continuous improvement services that center on enhancing the lives of persons served.

Vision
Through responsiveness to a dynamic and diverse environment, CARF serves as a catalyst for improving the quality of life of the persons served.

Core values
CARF believes in the following core values:
- All people have the right to be treated with dignity and respect.
- All people should have access to needed services that achieve optimum outcomes.
- All people should be empowered to exercise informed choice.
- CARF’s accreditation, research, continuous improvement services, and educational activities are conducted in accordance with these core values and with the utmost integrity.

In addition, CARF is committed to:
- The continuous improvement of both organizational management and service delivery.
- Diversity and cultural competence in all CARF activities and associations.
- Enhancing the involvement of persons served in all of CARF’s activities.
- Persons served being active participants in the development and application of standards of accreditation.
- Enhancing the meaning, value, and relevance of accreditation to persons served.

CARF International

- Founded in 1966 as the Commission on Accreditation of Rehabilitation Facilities.
- The CARF International group of companies currently accredits more than 50,000 programs and services at 25,000 locations. More than 10 million persons of all ages are served annually by 7,000 CARF-accredited service providers.
- CARF accreditation extends to countries in North and South America, Europe, Asia, and Africa.
Changes related to Injury

- Sensation
- Movement
- Bowel and bladder
- Skin care
- Spasticity
- Medications
- Autonomic dysreflexia
- Safe sex

Changes that impact males

- Erectile function
- Ejaculatory function
- Reproductive changes
- Sexual health
- Relationship with oneself and with others

Changes that impact females

- Menstrual cycle changes
- Decreased lubrication
- Contraception
- Pregnancy
- Sexual Health
- Relationship with oneself and with others
Relationship Changes

• Communication
• Relationship roles
• Dating and Socializing
• Intimacy and caregiving
Quick Post Test

Your Personal Slide of Sexuality

Why is this so difficult?
- Beliefs and values
- Sensitive nature
- Discomfort
- Lack of knowledge
- Lack of training
- Lack of access
- and.............
And with Whom, What and Where?

Sexuality

Frameworks to address sexuality

- Holistic view
- Circles of Sexuality
  - Sensuality
  - Intimacy
  - Sexual Identity
  - Sexual Health and Reproduction
  - Sexualization
  - Social, cultural contexts
Frameworks to address sexuality

- Bancroft’s Model (adapted)
  - Direct: erectile dysfunction, decreased lubrication
  - Indirect: sensation changes, incontinence
  - Iatrogenic: colostomy, suprapubic catheter
  - Contextual: cultural, social, relational components
- Sanders/Tepper Model
  - Primary
  - Secondary
  - Tertiary

Challenges in Addressing Sexuality

- Comfort, Beliefs and Values
  - Identified as greatest UNMET need for individuals with spinal cord injuries (Kennedy et al. 2006)
- Biases: who determines if this is addressed?
  - Paraplegics rated return of sexual function as their top priority (Anderson, 2004)
- Narrow focus in goal planning

Current Gaps

- Program to program
- Lack of resources
- Responsibility: physicians vs. psychologists
- Lack of training
Clinical Standards of Care for Sexuality

- WHO: publications on developing sexual health programmes
- Human Rights Campaign: Healthcare Equality Index offers foundational policies and practices to LGBTQ patient-centered care
- Paralyzed Veterans of America: Clinical Practice Guidelines-Sexuality and Reproductive Health in Adults with Spinal Cord Injury
- National MS Society: Pregnancy, Delivery and the Post Partum Period-A Handout for Women to Give to Their Physicians
- Brain Injury Association of America: Sexuality is a Family Matter
- Model Systems Knowledge Translation Center

Clinical Standards of Care for Sexuality

- Areas for assessment and intervention
  - Primary effects: sexual functioning
  - Secondary effects: changes to mobility, sensation, pain, bowel/bladder function
  - Tertiary effects: social/cultural/relationship factors

Case Presentation

- 3 separate cases: TBI, SCI, Amputee
- Considerations:
  - Individual
  - Individual within healthcare system
  - Individual within accreditation standards
Thomas

- 25 year old male with Traumatic Brain Injury following motorcycle accident, status post craniotomy
- Works in IT as systems analyst, former Marine
- Married to wife for 2 years
- Presentation: status post crani, poor memory, insight, left hemiplegia, left handed

Isabel

- 40 year old female with spinal cord injury, C4 incomplete following spinal tumor removal
- Lives at home with her mother and stepfather
- Recently engaged to girlfriend following divorce several years ago, has 2 adult children (ages 20, 22)
- Presentation: sensate, neurogenic bowel and bladder, lacks mobility, mild obesity, poorly controlled spasticity

Jamal

- 68 year old male with below knee amputation following severe infection of left leg
- Lives at home with 33 year old wife in rural area
- Presentation: uncontrolled diabetes, prosthetic training, experiences phantom limb pain, continent, PMH: prostate cancer-in remission
Sample References


Resources: Patients, Partners, and Professionals

• General
• Spinal Cord Injury
• Traumatic Brain Injury
• Amputation
• Multiple Sclerosis
• ALS

Resources-Providers/Professionals

• American Association of Sexuality Educators, Counselors, and Therapists
• Paralyzed Veterans of America: Sexuality and Reproductive Health in Adults with Spinal Cord Injury: A Clinical Practice Guideline
• Sexuality and Disability Journal
• SCIRE Project: https://www.scireproject.com
• Miami Project to Cure Paralysis: Dr. Nancy Brackett and Dr. Charles Lyrne
• Smitten Kitten blog (lube): www.badvibes.org/whats-in-your-lube/
• Model Systems Knowledge Translation Center
Resources-Patients and Partners

- Videos:
  - Website: Dr. Mitchell Tepper, www.drmitchellepper.com
  - Kessler Rehab: Sexuality Reborn
  - Facingdisability.com

Resources-Persons Served and Partners

- Written:
  - Paralyzed Veterans of America: Sexuality and Reproductive Health in Adults with Spinal Cord Injury: What you Should Know
  - PleasureABLE: Sexual Assistive Device Manual
  - Dr. Mitch Tepper: Regain that Feeling
  - Dr. Stan Ducharme: Sexuality after Spinal Cord Injury
  - Robert Baer: Is Fred Dead?

Resources

- Model Systems Knowledge Translation Center Factsheets:
  - National MS Society: http://www.nationalmssociety.org/
- The Ultimate Guide to Sex and Disability

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Sample References


Additional References will be made available.
Questions?