RECOVERY: INTIMACY AFTER STROKE
2018 NORTHEASTERN ONTARIO STROKE CARE SYMPOSIUM

SHAWNA MCCUSKER  RSW, MSW
TRACEY PALMER  RN, CRRN, BA SEXOLOGY

NOVEMBER 9TH 2018
DISCLOSURE OF COMMERCIAL SUPPORT

- This program has not received financial support
- This program has not received in-kind support
- Potential for conflict(s) of interest: nil
The secret to great sex lies more in the state of your mind than in the state of your body, in the feelings in your heart more than in the feelings in your genitals, and in the quality of the connection more than in the quality of the erection.

Mitchell S. Tepper, PHD, MPH
Seven themes identified related to sexual issues and the role of rehab in addressing these issues:

1. Sense of loss and functional changes affect sexuality
2. Relationship changes affect sexual functioning
3. Difficult to talk about sex
4. Little or no discussion of post stroke sexuality by rehab professionals
5. Need to tailor education about sex to the individual/couple
6. Timing is key in presenting the information
7. Provider rapport and competence is vital
• What is sexuality?
• What is sex?
• What is intimacy?

What we do!
The more narrow one’s definition and perspective of what sex is, the higher the risk of dissatisfaction …
Evolves throughout one’s lifespan

Who we are!
Biological
Psychological
Emotional
Social
Cultural/ religion/ beliefs

Rests on a much broader foundation – of trust, open and honest communication, shared goals and expectations, and mutual respect and concern. Verbal and non-verbal ways, in which partners connect with one another and enjoy their unique closeness
RELEVANT ISSUES AROUND INTIMACY/SEXUALITY POST-STROKE

- Woods Sexuality Model (1987)
• ↓ or lack of sexual desire
• Difficulty or inability to obtain or maintain an erection
• ↓ Vaginal lubrication and clitoral engorgement
• Difficulty or inability to ejaculate
• Absence or decreased frequency and/or intensity of orgasm
### Relevant Issues around Intimacy/Sexuality Post-Stroke

**Sexual Function**

- Co-morbidities
- Altered mobility, strength and balance (positions)
- Altered sensation, hypersensitivity
- Δ bladder and bowel function
- Pain, numbness, spasms, tremors, tone, bradykinesia, rigidity, ataxia, dysarthria
- Fatigue
- Meds and side effects
- Fertility
- Change in visual fields/ neglect
- Difficulty concentrating/ impulsive/ memory changes
- Altered receptive or expressive speech/ ability to initiate
- Emotional lability
Inability to perform according to previous expectations (traditional roles, loss of income)

Decreased sense of control (mind, body, health)

↓ self-esteem and sense of self-worth

Altered physical appearance and body image concerns (sense of sexual desirability)

Altered sense of self/loss of identity (feeling of estrangement from former self)

Increased propensity for depression, anger, irritability, intolerance post-stroke which can lead to feelings of guilt, despair and low self-esteem
RELEVANT ISSUES AROUND INTIMACY/SEXUALITY POST-STROKE

- Sexual Roles and Relationships

- Role shift (from independence to dependence)
- The effect of impairments in sensorimotor function and self-care on partners
- Fear that another stroke will occur
- The belief that an active sex life belongs to “healthy people”
- Lack of perceived sexual desirability
- ↓ social interactions/isolation
- Aphasia: communication skills are essential for forming and maintaining social and sexual relationships
- Cultural and religious beliefs (sexual attitudes)
- Sense of meaningfulness, comprehensibility and manageability of the new life situation
SOCIODEMOGRAPHIC FACTORS

• Age and/or gender are not independently related to SD occurrence

• There is no clear correlation with marital status, marriage/partnership duration or educational level

• An active sexual life before stroke is a major determining factor for sexual activity after stroke
Patients should be given the opportunity to discuss sexuality and sexual functioning with their healthcare provider. Discussion should occur during acute care, rehabilitation and as the patient transitions back into the community. Verbal and written information should be provided and adapted to patients who have communication limitations (such as aphasia).

Patients and/or partners should be offered education sessions that address expected changes in sexuality, strategies to minimize sexual dysfunction, and frequently asked questions.
Across cultures and stroke severities, patients after stroke want to learn and talk about sexual health, but are not receiving the information that they want from healthcare providers

- 81% of patients report receiving insufficient information about post-stroke sexual dysfunction (Park et al., 2015)

- At one hospital in Toronto, it was identified that close to no patients were given the opportunity to discuss their sexual health concerns (Guo et al., 2015)
There is typically no standardized point during the rehabilitation stay that sexual health concerns are discussed with patients.

The onus is instead on the patient/partner to approach a healthcare provider with their concerns, which can be difficult for many reasons (taboo nature of sexual health, lack of awareness that they can seek help for sexual health concerns).

Unlike other commonly addressed stroke rehabilitation issues, sexual health does not tend to have clear ownership among team members.
Interventions addressing post-stroke sexuality are limited.

- Some research studies have demonstrated improved sexual health for patients using one-on-one counselling and the provision of information booklets.

- Other interventions have consisted of patient education sessions following discharge from hospital.

- Both an individualized sexual rehabilitation session and the provision of generic written material in the inpatient setting have been shown to be equally effective in improving outcomes (Sansom et al., 2015).
A project with the aim to provide all stroke rehabilitation inpatients with the opportunity to discuss sexual health concerns with their healthcare providers.

Changes implemented included: a reminder system, standardization of care processes for sexual health, patient-centered time points for the delivery of sexual health discussions, and the development of a sexual health supported conversation tool for patients with aphasia.

By the end of the ten month project period, the percentage of patients provided with the opportunity to discuss sexual health during inpatient rehabilitation increased to 80%.
The occupational therapists (OTs) on the team proposed that discussions about sexual health concerns could take place during their intake assessments.

A paper-based checklist was already being used to keep track of issues that they address with patients, and sexual health was added to this checklist as a reminder mechanism.
A script was provided with four components:

1. **Normalize the situation** – “often people after stroke will have concerns about sexual functioning, intimacy, and relationships”

2. **Give examples to help patients understand** – “for example, people might have questions like ‘is it safe for me to go back to intimate and sexual activities with my partner’? Or concerns like ‘my relationship with my partner has completely changed’

3. **Offer to listen to the patient’s concerns** – “we want to help you because sexual health is an important part of being healthy and having a good quality of life. Do you have any concerns right now?” If patients do not have any concerns at the time of the discussion, they will be informed that they can feel free to bring up concerns later in their rehabilitation process.

4. **Inform patients of other resources** that they can access to learn about sexual health after stroke.
A visual supported conversation tool for sexual health was implemented to allow patients with aphasia to also have the opportunity to discuss their sexual health concerns.

SLPs used the supported conversation tool to screen patients with aphasia about their sexual health concerns.

OTs and SLPs communicated during team rounds to ensure that patients were not be missed.
<table>
<thead>
<tr>
<th>Changes After Stroke</th>
</tr>
</thead>
<tbody>
<tr>
<td>vision</td>
</tr>
<tr>
<td>weakness</td>
</tr>
<tr>
<td>talking</td>
</tr>
<tr>
<td>walking</td>
</tr>
<tr>
<td>mood</td>
</tr>
<tr>
<td>thinking</td>
</tr>
<tr>
<td>intimacy</td>
</tr>
</tbody>
</table>
This quality improvement project successfully implemented the Canadian Best Practice Recommendations for Stroke Care with respect to sexual health.
Tools for Person's with Aphasia

TOOLS FOR PERSON’S WITH APHASIA

https://www.aphasia.ca/shop/intimacy-and-relationships-talking-to-your-doctor/
REVIEW OF FINDINGS

- Sexual dysfunction is a common problem after stroke.
- The Canadian Stroke Best Practice Recommendations identify the need for stroke patients to be given the opportunity to discuss sexuality and sexual functioning with their healthcare provider.
- There are a number of different intervention strategies that can be taken including the systematic implementation of discussion opportunities throughout inpatient rehabilitation admissions or one-time outpatient education sessions post-discharge.
- Accurate diagnosis and implementation of SD management as part of comprehensive stroke rehabilitation protocol will enhance the emotional and functional outcome in stroke survivors, which can significantly improve overall quality of life.

**BARRIERS TO PROVIDING SEXUALITY EDUCATION…**

- **Time & resources**
- **Language barrier**
- **Availability of written information**
- **Worry about causing offense**
- **Fear of opening up a can of worms**
- **Concern about the reactions of parents/residential staff**
- **Availability of policy guidance**
- **Service user may sexualize the consultation**
- **Waiting for pt to ask**
- **No access to training**
- **Not my responsibility**
- **Not viewed as an important issue**
- **Lack of knowledge and ability**
- **Too embarrassed/personal discomfort**
- **Not viewed as an important issue**
OVERCOMING BARRIERS…

Three-Pronged Approach to Nurses’ Self-Reflection about Sexuality developed by Dr. V. Polomeno R.N., B.Sc., M.Sc.(A.), Ph.D. Associate Professor University of Ottawa-School of Nursing and myself.

First Prong: Nurses’ Comfort Level with Sexuality

Second Prong: Nurses’ attitudes about sexuality

Third Prong: Nurses’ knowledge about sexuality
### First Prong

**Comfort Level**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge is power</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Say the words that make us giggle or blush</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Expect to be embarrassed the first few times</strong></td>
<td></td>
</tr>
<tr>
<td><strong>It’s OK not to have all the answers</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Role playing with peers</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Group discussions through case studies</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Seek out the “sexpert” on your unit/ dept</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Introduce the topic by putting it in context (indicator and contributor to health and QOL)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Practice, practice, practice</strong></td>
<td></td>
</tr>
<tr>
<td><strong>When did talking about BM’s become “normal and OK”</strong></td>
<td></td>
</tr>
</tbody>
</table>
## SECOND PRONG

### Attitude

- Self-reflection (validated questionnaires are available)
- Be aware of your personal beliefs and attitudes
- Be non-judgmental
- Don’t make assumptions
- Use gender neutral language
- Know your limits and refer accordingly
- Be aware of the varying cultural beliefs and practices
- Use neutral and normalizing statements
<table>
<thead>
<tr>
<th>Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Be inquisitive, ask questions</td>
</tr>
<tr>
<td>• Read, read, read</td>
</tr>
<tr>
<td>• Continuing education workshops, webinars, conferences, classes</td>
</tr>
<tr>
<td>• Literature search by librarian</td>
</tr>
<tr>
<td>• Seek out the experts</td>
</tr>
<tr>
<td>• It’s OK not to have all the answers</td>
</tr>
<tr>
<td>• Be aware of models and framework that are available to help guide your education</td>
</tr>
<tr>
<td>• Go from least sensitive to more sensitive</td>
</tr>
<tr>
<td>• Ask open ended questions</td>
</tr>
<tr>
<td>THINGS TO CONSIDER</td>
</tr>
<tr>
<td>---------------------</td>
</tr>
<tr>
<td>• Never assume heterosexuality</td>
</tr>
<tr>
<td>• Do not make assumptions based on gender, age, religion/ culture, diagnosis, partnership status</td>
</tr>
<tr>
<td>• Consider the partner and the possibility of caregiver stress/ burnout</td>
</tr>
<tr>
<td>• Do not judge- we are not aware of the pre-existing dynamics in the couple</td>
</tr>
<tr>
<td>• Safety first; provide reassurance re: fears</td>
</tr>
<tr>
<td>• Individual versus couple meeting</td>
</tr>
<tr>
<td>• Focus on abilities and strengths</td>
</tr>
<tr>
<td>• Redefine the goal: pleasure, closeness versus orgasm</td>
</tr>
</tbody>
</table>
The factors that contribute to the decline are the direct pathophysiological effects of the brain lesion, the presence of medical comorbidities, side effects of medications, and the complex emotional reactions that often include clinical depression.
A stiff penis does not mean a solid relationship
Urinary incontinence does not mean genital incompetence
Absence of sensation does not mean absence of feeling
Inability to move does not mean inability to please
The presence of deformity does not mean the absence of desire
Inability to perform does not mean inability to enjoy
Loss of genital function does not mean loss of sexuality
QUESTIONS

trpalmer@toh.ca
smccusker@toh.ca

Thank you!
PATIENT RESOURCES

- Heart and Stroke Foundation of Canada
  - Sex and Intimacy after Stroke Frequently Asked Questions

- American Stroke Association
  - Sex After Stroke – Frequently Asked Questions

- Stroke Foundation - Australia
  - Sex and relationships after stroke fact sheet
Psychology Today – Sex Therapy
Therapists in Ottawa
  • www.therapists.psychologytoday.com
Sex and Relationship Therapy Clinic
Capital Choice Counselling – Sex Therapy and Sexual Health
Ottawa West Professional Services – Couples Therapy and Sex Therapy
Centre for Interpersonal Relationships
ADDITIONAL RESOURCES

- **Come As You Are** – [www.comeasyouare.com](http://www.comeasyouare.com)
  - The planet’s only co-operative sex store with an approach to sexuality that is one of respect, openness, communication and responsibility
  - Provides a general overview of adapting sex toys developed from over fourteen years of working with folks living with disabilities who have been adapting sex toys

- **Susan’s Sex Support** – [www.sexsupport.org](http://www.sexsupport.org)

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

- **Sinclair Institute** [www.intimacyinstitute.com](http://www.intimacyinstitute.com)


- **BCIT 2 part course** “Sexual Health Rehab” [www.bcit.ca](http://www.bcit.ca)


Cheung RTF. Sexual functioning in Chinese stroke patients with mild or no disability. Cerebrovasc Dis 2002; 14(2): 122-128


REFERENCES


REFERENCES


Schmitz M, Finkelstein M. Perspectives on poststroke sexual issues and rehabilitation needs 2010 Top Stroke Rehabil 2010; 17(3):204-213.

REFERENCES


Schmitz M, Finkelstein M. Perspectives on poststroke sexual issues and rehabilitation needs 2010 Top Stroke Rehabil 2010; 17(3):204-213.


MUST READS…

Canadian Guidelines for Sexual Health Education
ADDITIONAL BOOKS

**Sexual Healing**

**Regain That Feeling**

**The Ultimate Guide to Sex and Disability**
ISBN 1-57344-176-7

**Sexual Dysfunction**
ISBN 978-1-4625-2059-6
ADDITIONAL BOOKS