Sexual Rehabilitation following stroke

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With thanks to: Joshua Sansom, Louisa Ng, Fary Khan Anita Brown-Major, Chris Cowan, Rebecca Nicks

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 Outline

• Sexual dysfunction following stroke, causes

• Management – sexual rehabilitation
  - (including current studies on ward):
    > Cochrane
    > SOX
    > Let’s Talk About Sex RCT
Myths

• *Stroke happens to old people*
• *Sexuality = intercourse*

• *Disability = not interest in sex, can’t handle sexual relationships*
• *Old = asexual*
• *Single = celibate*

• *All stroke survivors are heterosexual*

• *Doctors/health care professionals know how to talk about sex*
There are many terms...

- Sex
- Sexuality

**Sexual function/dysfunction**
- **Erectile Dysfunction** - erection not sufficient rigidity for sexual intercourse (“Impotence” > 75% of the time)
- **Ejaculation**
- **Vaginal lubrication**
- **Orgasm**
- **Menstruation**
- **Libido**

- Intimacy
- Relationships
- Sexual behaviour
- Sexual satisfaction/Relationship satisfaction
- Quality of life
- Fertility/Contraception
Definitions

Sexuality:

• Encompasses:
  sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction

• expressed in:
  thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships

(UNAIDS, 2006)
How common is sexual dysfunction after stroke?

• 47-75% or more of stroke survivors suffer a degree of sexual decline/dysfunction post stroke


* In the general population
  - 40-45% of women
  - 20-30% of men
  experience sexual dysfunction
  (increases with age, poor health, psychiatric and psychological disorders, socio-demographic conditions)

(Shah 2009)
The most common sexual problems after stroke

- Reduced libido (79% male, 66% female)
- Disorders of erection (62%)
- Disorders of ejaculation (78%)
- Vaginal lubrication (61%)
- Female orgasmic ability (77%)
- Coital frequency (64% male, 54% female report no coital activity 6 weeks after stroke)
- Reduced sexual satisfaction
- QoL reported to decrease by more than 40%

Sexual problems after stroke – Spouse/Partner

Decline in:
• Libido
• sexual activity and
• sexual satisfaction

• spouse depression

(McLaughlin et al, 2005)
Causes of sexual dysfunction post stroke
• “Sexual problems are never the consequence of stroke alone”

**Multi-factorial**
- Organic/Neurological causes, associated medical conditions, medications
- Psychological factors
- Interpersonal/Social factors
Primary Causes:

**Neurological causes**
- where stroke directly affects sexual function
  - Decline in libido and coital frequency
  - Decline in vaginal lubrication and orgasm
  - Decline in erection and ejaculation

Related/Underlying **medical issues*** that contribute to these effects:
- Depression and antidepressant use (SSRI)
- Pre-morbid medical conditions – e.g. *DM, HT, cardiac issues/cardiovascular disease, low testosterone
- Cardiovascular medication, including antihypertensives

Secondary causes

Sensori-motor problems from the stroke, e.g.:

- Hemiplegia
- Spasticity
- Pain
- Bowel or bladder dysfunction
- Post-stroke fatigue (Thompson, 2009)
- Dyspraxia

which affect sexual function due to issues such as loss of ability to position oneself during sexual activity
Tertiary causes

**Cognitive/behavioural issues**
- Altered perception of body image, visual-perceptual deficits
- Poor judgment/Emotional lability/Apathy/Disinhibition/egocentric/Anger/Frustration
- Low tolerance for delayed gratification
- Poor memory

**Psychosocial adjustment issues:**
- Body image
- Identity
- Loss of self-esteem/confidence
- Anxiety/stress/depression
- Fear of new stroke
- Fear of rejection/Performance anxiety
- Changes in role and relationship dynamic
• Some studies report that “medical factors have relatively less influences on sexual dysfunction as compared with psychosocial factors.”

(Cheung, 2002; Korpelainen 1999, Monga, 1986)
Rehabilitation management of sexual dysfunction post stroke
Interventions for sexual dysfunction following stroke
(Protocol)

Ng L, Sansom J, Zhang NY, Khan F
Sexual Rehabilitation
Interventions

Interventions can be classified into:

1) Pharmacological

2) Non-pharmacological
   - mechanical devices
   - physical therapy
   - psycho-educational interventions

3) Complementary medicine
   ginko biloba
   ginseng

- *used in combination*
Pharmacological Interventions

Pharmacological mx

- “first consider what meds can be stopped”
- Phosphodiesterase 5 inhibitors
- Intracavernosal injections
- Intraurethral suppositories
- Hormonal therapy

(Vecchio 2010)
Pharmacological interventions (continued)

- Phosphodiesterase 5 inhibitors
e.g. Sildenafil citrate (Viagra) for erectile dysfunction

• Act to increase cGMP levels and promotes smooth mm relaxation in corpus cavernosum

• works best if at least partial reflexogenic erections, and has sexual desire
• Contraindications: nitrate use for IHD – can cause death due to severe hypotension
• SE:
  priapism - prolonged erection lasting more than 4-6 hours (Rx - needle aspiration), headache, flushing, visual problems
  ineffective in some
Non-Pharmacological Interventions

1. Counselling

- P LI SS IT model  (Anon 1974)

Permission – “ok to talk about it”

Limited information - “commonly...”

Specific suggestions – “what about...choosing a suitable time, reviewing medications which may affect sexuality, finding safe and comfortable sexual positions, managing reduced vaginal lubrications, managing urinary continence issues, managing erectile difficulties...”

Intensive therapy

*Right time, right place, right person*
• National stroke foundation Clinical Guidelines for Stroke Management (2010)

• Guideline 8.5 states:
Stroke survivors and their partners should be offered: the opportunity to discuss issues relating to sexuality with an appropriate health professional, and written information addressing issues relating to sexuality post stroke
Sex and relationships after stroke

Fact Sheet

Summary
- Sometimes stroke changes sexual function but this is usually temporary.
- Stroke can affect your sexuality and your self-esteem – how you see yourself and your relationships with others.
- There are many strategies that may help improve relationships and help improve sex.
- If you have any fears or worries about sex after stroke the best thing to do is talk to your doctor or health professional to get information.

Sex and relationships after stroke are topics frequently overlooked although important to many people. This fact sheet provides some basic information and relevant resources that might help.

How does a stroke affect relationships?
For people in intimate relationships, the most frequent concerns are about changes in relationship roles, personalities and moods and communication skills. Sometimes the stroke will affect your ability to ask or understand what others are saying. Sometimes your partner may need to help with caring for you and this can change the way you see each other. For people working to start a new relationship, any disability from the stroke will be something you and your partner warn about, discuss and adapt to.

Strategies that may help improve sex
1. Start your sexual rehabilitation when you are ready.
- Some sexual problems can be treated during your rehabilitation. If you are not able to start the sexual rehabilitation because of your physical health, you may need to discuss this with your doctor or other healthcare professionals.

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How does a stroke affect sex?
Some people find out that they have problems with sexual function after they have had a stroke. Some sexual problems people experience after stroke are due to factors like relationship difficulties, disability, fears and worries, medications and other medical conditions.

Sexual activities such as masturbation and partnered sex can be affected by disability caused from the stroke. Problems with mobility and hand function can change people’s abilities to perform sexual activities for themselves or their partner. Stress, anxiety, depression and pain can also interfere with sex. Stroke can also affect sexuality, how people see themselves and their feminine and masculine roles. Many stroke survivors report having fewer sexual desires because of stroke and the fact that they can no longer experience sex.

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4. Investigate the cause of the sexual problem:
- Stroke is usually a cause of sexual dysfunction.
- If you experience problems with emotions, depression or problems with your sexual or emotional relationship, your doctor will need to examine and understand what is going on.

Sex and relationships after stroke

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1. Start your sexual rehabilitation when you are ready.
- Sexual problems can be treated during your rehabilitation. If you are not able to start the sexual rehabilitation because of your physical health, you may need to discuss this with your doctor or other healthcare professionals.

2. Get answers to your questions:
- Fear and worry can distort the sexual response system.
- If you are concerned about something you can ask your doctor or health professional.

3. Don’t fear that sex can trigger another stroke:
- You may be concerned that becoming sexually aroused or engaging in sex will trigger another stroke. This is not true and studies have not shown that sex can trigger a stroke.

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- Stroke is usually a cause of sexual dysfunction.
- If you experience problems with emotions, depression or problems with your sexual or emotional relationship, your doctor will need to examine and understand what is going on.

5. Adapt to the changes:
- It is possible to find new positions and ways of doing things that bring you and your partner pleasure.
- Start with activities you think may be easiest and progress to more challenging things as your confidence increases.
- Some people find that they can get help from a sex therapist.

6. Find an alternative contraceptive:
- Some contraceptive methods are not suitable for everyone.
- Some hormonal contraceptives may increase the risk of stroke. Speak to your doctor for advice about contraceptive choices if you want to prevent pregnancy.

7. Manage incontinence aids:
- Incontinence aids such as catheters and pads can require both practical and medical adjustments.

8. Regardless of the type of sex you are using, returning to moisturization or partnered sex is possible. You or your partner may need to be proactive in finding solutions that work best for you both.

9. Continue to have sex and experience in talking about sexual concerns.

10. See the recommendations after stroke fact sheet for more information.

Strategies that may help improve relationships
1. Think about your partner’s perspective:
- Your stroke may have imposed your partner too soon and they are feeling a sense of helplessness at what they are going through.

2. Don’t focus on negative things to be the same adjustments take time for you both.

3. Start with activities that you think may be easiest and progress to more challenging things as your confidence increases.

4. Some people find that they can get help from a sex therapist.

5. Be aware of your own needs and wants.

6. Find an alternative contraceptive:
- Some contraceptive methods are not suitable for everyone.
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Non-Pharmacological Interventions
2 - “Physical” therapy

e.g.
• PT mobility training to optimise bed mobility for sexual positioning and transferring in and out of bed
• Bolster between knees for adductor spasticity
• Nursing education on skin care and catheter mx
• Pacing and energy conservation strategies taught in OT
• Dyspraxia training with ST – kissing, oral sex
Energy conservation

"LET'S GO UPSTAIRS AND MAKE LOVE!"

"PICK ONE, COS I CAN'T DO BOTH!"
Technical information - Positions (post THR)

- Patient on Top
  Partner on the bottom

- Patient on the bottom
  Partner on the Top

- Patient lying on side
  with operated leg on top

- Patient and caregiver
  (hand on back for support)
Non-Pharmacological Interventions

3 - Mechanical Devices

• Lubricating gels

• vacuum constriction devices (VCD’s)
  Non-invasively produce erection and expansion of penis
  Cavernosal engorgement is then maintained with custom circular rubber tension ring at base of penis
  SE: cannot ejaculate externally, fiddly

• Penile implants
  inflatable or non-inflatable
Sexual Rehabilitation

Sexual rehabilitation:

• Assess existing sexual issues,
• Provide information on concerns and
• Support safe return to sexual activity

• Person-centred
• Time-based
• Functionally-orientated
How well are we managing sexual dysfunction post stroke?
How well are we managing sexual dysfunction post stroke?

- Sex and sexuality is the least discussed disability issue in the rehabilitation process

- 2012 Australian National Stroke Audit Rehabilitation Services Report

  - 2789 post-stroke patients audited across 111 Australian public and private hospitals,
  - only 17% of patients received information on sexuality (*12% in 2010)
• National stroke foundation
  Clinical Guidelines for
  Stroke Management (2010)

• Guideline 8.5 states:
  Stroke survivors and their partners should be
  offered: the opportunity to discuss issues relating
  to sexuality with an appropriate health
  professional, and written information addressing
  issues relating to sexuality post stroke
Why?

Barriers - Health Professionals

• Whose role? (gynaecologist, urologist, GP, rehab physician, which member of the rehab team)

• Poor knowledge, skill and training of rehabilitation professionals
  (McLaughlin, 2005)
• Commonest reported reason by doctors: Lack of training
  (Hautamaki et al. 2007 Finland)

• Embarrassment – self and patient

• No time
• Lack of confidence

(Keller 2006)
Why?

**Barriers – Stroke survivors and partners**

- Moral and cultural
- Shame
- Fear of embarrassment
- Frustration
- Uncomfortable/Uneasy to ask for assistance
- Belief that health providers are equally uncomfortable and ill-equipped

(Giaquinto 2003, Kautz, 2007, Schmitz 2010)
Overcoming these barriers...
• **SOX (Sexuality after stroke) Program** support clinicians through the practical steps involved in implementing guideline 8.5 (teach how to change practice in an organisation, build confidence and capacity)

• Series of workshops from 2012-2014
  Facilitated by Australian Research Centre in Sex, Health and Society (La Trobe Uni) in collaboration with Victorian Stroke Network

• Involve 6 networks/health services across Victoria

• Shared findings and implementation ideas.
• Quality improvement activity - needs analysis

• Organisational and medical record audits  
  (0/10 documentation relating to sexuality/intimacy, 2013)

• Staff survey

• client interviews
  - Feedback re fact sheet
  - Patients provided practical suggestions about how sexuality could be addressed
  - Importance of interdisciplinary approach to sexuality post stroke: many reported that the person most appropriate to discuss sexuality was the one they had build the most rapport with.
SOX (continued)

Outcomes:

• Staff education (awareness, goal setting form, workshop, re-audit 5/7 in 2/2015)

• Report and resources
  “SOX guidelines for interdisciplinary practice”
  - tool to explore roles of each discipline and communication strategies
Let’s talk about sex:
A pilot randomised controlled trial of a structured sexual rehabilitation program in an Australian cohort

Joshua Sansom, Louisa Ng, Nina Zhang, Fary Khan

International Journal of Therapy and Rehabilitation, January 2015, Vol 22, No 1
Our questions:

• Current guidelines recommend the assessment and management of post-stroke sexual dysfunction

• But little is know about what type of intervention (timing, content, intensity, setting) should be provided.

• How effective are these interventions?
RCT

Compared to
• **generic written information alone** (fact sheet), is a
• **comprehensive structured sexual rehabilitation program** (includes written material, individualised, multidisciplinary)
more effective in improving:

• sexual functioning (primary outcome)
• psychological function
• quality of life
• functional independence

in an Australian stroke cohort
• RPC inpatient rehab ward

• Inclusion criteria: stroke, **FIM** comprehension \( \geq 4 \), able and willing to consent, over 18

• Exclusion: Severe cognitive issues, unstable medical, neurological or psychiatric disorders

• All consecutively admitted patients -> consented -> randomized (computer-generated sequence by independent statistician)

**Intervention:**
• 15-30 minute session with rehabilitation physician +/- occupational therapy, physiotherapy, social work or psychology

• Fact sheet

**Control:**
• National Stroke Foundation “Sex and relationships after stroke” fact sheet only
Measures:
Baseline and 6 weeks (also 6 months)

• Socio-demographic, clinical information
• Patient preferences (perceived importance, timing, means of delivery, which discipline, and content)

• Sexual functioning – primary outcome
  Changes in Sexual Function Questionnaire Short Form (CSFQ-14)
• Depression, Anxiety and Stress Scale (DASS)
• Functional Independence Measure (FIM)
• Quality of Life - Stroke and Aphasia Quality of Life Scale 39-item generic version (SAQOL-39g)

Analysis - Descriptive analyses, Mann-Whitney U tests
Results

• 18 admitted -> 10 “yes”
  (5 “no, not relevant”, 3 excluded due to severe dysphasia)

• Intervention (n=4), control (n=6)

• Mean age 66.3 years (range 34 – 88 years);
  • male: female 1:1

• Most (67%) had a partner

• At baseline, 40% moderate-severe depression, 20% anxiety; 92% reported sexual dysfunction

• 58% sexual rehabilitation “important”
• 33% “1-on-1 discussion” with “doctor”
Results

• NO significant difference between groups at T2 (6 weeks) in sexual functioning (CSFQ), psychological functioning (DASS) and quality of life (SAQOL-39g)
Discussions – from both studies

• Individualised comprehensive program and generic written info equally effective (fact sheet enough, control allowed to raised issues)

• Which outcome measure?
  (no validated sexual dysfunction questionnaire for stroke population)

• Which discipline?
  (Intervention from allied health offered – but declined; ?too early)
  (Based on the “right personality” and on “a person” rather than the profession – SOX)

• Only half the patients wanted info – screening tool, (?not sexuality active, timing)

• No correlation between whether participants felt sexuality was important with whether they had a partner

• Misinterpretation of fact sheet (from SOX)*

• Other limitations: sample size, single centre, short follow up, excluded severe dysphasia, stroke recovery itself being confounder
Conclusion

• Sexual dysfunction is a common problem after stroke

• *Multi-factorial*
  - organic/neurological causes, associated medical conditions, medications
  - Psychological factors
  - Interpersonal/Social factors

• Studies and guidelines recommend assessment and management of sexual dysfunction *(NSF 201, RCP 2012, CSN 2014)*

• Guidelines are based on consensus, there are no RCT

• Little is known about the types or effectiveness of interventions
Conclusion

Our experience:

• Multidisciplinary approach with interdisciplinary goals
• Find the right time, right place, right person
• Training and support for clinicians, organisational change

• Raise the opportunity to discuss sexuality, make it clear to stroke survivors that it is okay to talk about their issues
• Provide written information – NSF fact sheet

• As for intervention...
Conclusion

So far...

• both individualised sexual rehabilitation programs and written information on sexuality post stroke appear to improve sexual function, psychological functioning and quality of life following a stroke

• further studies with larger sample sizes and longer follow up are needed to confirm and expand upon the findings of this study to enable optimal care for the sexuality needs of stroke survivors

watch this space...
Rehab goal = Return to sexual activity
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