Enabling people after stroke to retain intimate relationships

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Today’s Intention

• Consider what sexuality means
• Address the needs of people following stroke and their partners
• Reconsider our proactive management of sexuality in practice
Sexuality

The ways in which we experience and express ourselves as sexual beings.

Includes:

- Gender
- Gender identity
- Gender roles
- Behaviour
- Feelings
- Thoughts
- Values.
Sexuality

• Integral component of the psycho-social person
• Expressed through:
  – One’s concept of self
  – Functioning in response to giving and receiving physical pleasure
  – Relationships with others
• Relationships in which someone is involved within their world – not confined to their sexual world
• Not confined to physical functionality
Goals of Rehabilitation

• Return to the life that was before the stroke
• Preserve:
  – Identity
  – Social, personal and vocational roles
  – Relationships
• Maximise health related quality of life
The Reality?

For the person following stroke:

- Reduced stress tolerance
- Disinhibition in expression
- Frustration over physical impairments and dependency on others
- Feelings of inadequacy and loss of autonomy (secondary to paternalistic experiences and emotional over-protection)
- Rejection/neglect of the physical self
- Reduction/loss of physiological and psychogenic libido
  - Guilt versus sense of obligation/duty

- Alteration in relationship dynamics
  - Partner has become their carer/friend
  - Separate beds/rooms
- Loss of self:
  - Loss of role/change of identity
- Social fear
- Cognitive changes
- Fatigue
- Physical dysfunction

- Most of these are invisible and deeply personal

(Thompson and Ryan 2009; Hall 2013)
The Reality?

For the partner/spouse:

- Needs are lesser than the person who has had the stroke
- Care burden
  - Responsibility
  - Commitment to the relationship
  - Physical and emotional demands
- Emotional adjustment
  - Sadness, anxiety, loss
  - Feelings of guilt
  - Fear of uncertainty
- Social adjustment
  - Vocational
  - Personal time/interests
  - Isolation
- Reduction/loss of physiological and psychogenic libido
  - Change in relationship dynamics
  - Fear
- Loss of a marital/relationship partner
- Hope and resilience

(Coombs 2007; Thompson and Ryan 2008)
Stein et al. (2013)
- 71% - sexuality moderately/very important in their post-stroke rehabilitation
- 47% had sexual dysfunction
- 81% - insufficient information post-stroke
- 60% - preference of counselling
  - 26.5% wanted counselling before discharge home
  - 71% wanted counselling within 1 year following stroke
The Challenges

• Overcoming difficulty in person – professional talking about sexual issues
  – Numerous studies cite nurses and other professionals not discussing issues around sexuality
    • Recognise importance but feel awkward
    • Feel ill-equipped / knowledge deficit
• Post-stroke sexuality largely not discussed
• Individual/couple need tailored education for their unique needs
• Professional rapport and confidence needed
• Appropriate timing of post-stroke sexual education

(Schmitz and Finkelstein 2015)
The Challenges

• Not all relationships are conventional
  – Sexual orientation and sexual practices are not linear
  – People who identify as heterosexual, homosexual, bi-sexual or transgender should have the same level of care, support and rehabilitation, free from judgement
  – People can have very complex relationships

• Single status does not equate to asexuality

• Knowing the right moments
  – Priorities are different at different stages of rehabilitation
  – Rapport and trust are central to discussing vulnerable issues
Where Can we Start?

• Recognise the issues
• Being proactive
• PLISSIT (Annon 2015) / Ex-PLISSIT model (Davis and Taylor 2006)
  • Permission (P)
  • Limited Information (LI)
  • Specific Suggestions (SS)
  • Intensive Therapy (IT)
• Consider the need for therapy
Extended PLISSIT MODEL

(Davis and Taylor 2006)
Where Can we Start?

Make Your Support Available

Who would you like involved in your care?

How are you coping as a couple?

Is there anything personal or sensitive you would like to discuss?

Do you have any questions about how your relationship may be affected?
Interventions

- Be Prepared and Proactive
- Know Resources
- Communicate
- Use Tools/Scales to Supplement Assessment
- Complementary Medicine
- Non-Pharmacological Interventions
- Pharmacological Interventions
Conclusion

- Stroke is devastating in many respects, right to the core of who we are and our relationships with others
- Sexuality is not confined to sexual function
- Dignified care is about treating people as being of worth (RCN 2008) – being person-centred
- Lack of knowledge, understanding, skill or feeling awkward are not legitimate excuses
- Rapport, communication and working interprofessionally can provide effective solutions
References

References


Assessment

Sexual function assessment tools:
- International Index of Erectile Function (IIEF) (Rosen et al. 1997)
- Derogatis Interview for Sexual Functioning (DISF) and Derogatis Interview for Sexual Functioning-Self-Report (DISF-SR) (Derogatis 1997)
- Changes in Sexual Functioning Short-Form (CSFQ-14) (Keller et al. 2006)
- Sexual Function Questionnaire (SFQ) (Quirk et al. 2002)
- Arizona Sexual Experience Scale (ASEX) (McGahuey et al. 2000)

Sexual satisfaction assessment tools:
- Sexual Self-Perception and Adjustment Questionnaire (SSPAQ) (Steinke et al. 2013)
- Sexual Satisfaction Scale for Women (SSS-W) (Meston and Trepnell, 2005)
Possible Interventions

Pharmacological interventions
- Phosphodiesterase-5 inhibitors, Intracavernosal injections, Intraurethral suppositories (erectile dysfunction)
- Hormonal therapy

Non-pharmacological interventions:
- Mechanical devices (vacuum pumps, penile implants, penile prostheses and lubricating gels)
- Psycho-educational interventions (such as counselling and psychotherapy)
- Physical therapy (such as physiotherapy for bed mobility)

Complementary medicine interventions
- Ginkgo biloba (treatment of antidepressant-induced sexual dysfunction, erectile dysfunction)
- Ginseng (↑ NO levels – erectile dysfunction, psychogenic libido)

(Ng et al. 2014)