Addressing post–stroke sexual rehabilitation

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Acknowledgements

Sydney Sexuality Group

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• Stroke has a profound impact on the ways in which sexuality is experienced and expressed by stroke survivors (McGrath et al, 2019)

• Stroke Foundation Clinical Guidelines (2010, 2017) recommend that stroke survivors and partners be offered opportunity to discuss sexual intimacy & be provided written information addressing sexuality issues

• Research consistently shows that health professionals rarely address sexuality during stroke rehabilitation (Stein et al, 2013; Park et al, 2015; Rosenbaum et al, 2014).

• Failure to address sexuality may result in increased anxiety and depression and poorer quality of life outcomes

• Lack of research into sexual rehabilitation hinders health professionals ability to provide evidenced based care and highlights the need to develop a more comprehensive sexual rehabilitation intervention for stroke survivors & their partners
Aim

Present findings from a program of research that seeks to improve evidence-based practice in the area of stroke and sexuality
Stage 1:

To identify how post stroke sexuality is experienced by stroke survivors (*including people with communication impairments*) and their partners using the WHO’s broad definition of sexuality

Ref: McGrath, M; Lever , S; McCluskey, A; Powers, E. (2018) How is sexuality after stroke experienced by stroke survivors and partners of stroke survivors?: A systematic review and metasynthesis of qualitative studies, *Clinical Rehabilitation*, pp.1-1, (open access)

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Method

Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ

Methods for the thematic synthesis of qualitative research in systematic reviews

Sydney Sexuality Group
Results - Descriptives

Eligible papers:
• 136 unique papers identified, incl. addit. 8 studies found by hand-searching
• 43 met inclusion criteria for synthesis

Descriptives:
• Total 649 stroke survivors, sample sizes ranged 1-125 participants per study
• 60.2% (391) male, 39.4% (257) female, age range 20-105 yrs
• Total 267 partners, age range 31-90 yrs
• Most incl. heterosexual-coupled stroke survivors in Western contexts
• CASP scores ranged from 5 to 10/10

People with Communication Impairment (PWCI) inclusion:
• 10/43 papers excluded PWCI and n=16 no mention of communication
• 6 papers targeted PWCI specifically (only 1 focused on sexuality)
Results - Themes
Two major themes were central to the experience of sexuality after stroke

1. Sexuality is silenced
2. Sexuality is still important: muted and sometimes changed, but not forgotten
Silence - Individual Level

Silence within the Silence: Participants with aphasia reported it was harder to verbally initiate and talk about desire for sex, while their spouses reported that their partner with aphasia was no longer able to express their feelings or engage in sexually intimate conversation (Researcher: McLellan, 2014)

No, we don’t talk about such things - we talk about practical matters, No, we never tell each other how we feel . . . we can’t do that . . . I say nothing, I never tell him anything . . . (Survivor: Nilsson, 1999)
Silence – societal level

You’re supposed to be pretty straight and macho … [but] … I miss being that

“I will totally understand if … men don’t find me physically – like, sexually attractive anymore, because I’m disabled”
Sexuality – muted & changed but still important

“Stroke doesn't change the essence of who I am or what I want... It only changes what I can do. It doesn't change what I want”
(Survivor: Lever & Pryor, 2016)

“I became like a mum to him; I was helping him with everything!
(Partner: Arntzen et al., 2015*).
Sexuality – muted & changed, but still important

“I would say it has been for the better. **It was good before but it’s really good now, because it’s very tender and loving…** The sexual life has improved, really. I….it’s like **you feel you have to take care and enjoy it and life.”**
(Survivor: Nilsson, et al., 2017*).
Stage 2: 2 step on-line Delphi Study

To solicit expert opinion and develop consensus around how post stroke sexual rehabilitation services should be delivered including content, timing and method of delivery.

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Methods

On-line survey
• 2-round

Questionnaire
• Previous research
• Published programs
• 47 Statements – 6 categories

Stroke Survivors
Round 1 (n=30)
Round 2 (n= 19)

Partners
Round 1 (n=18)
Round 2 (n=8)

Clinicians/Researchers
Round 1 (n=54)
Round 2 (n=23)

Descriptive statistics calculated for each response for the whole group and each of the subgroups

Each statement the mean importance score, 25th and 75th percentile scores and interquartile range were calculated

To determine level of consensus around each statement a consensus score was determined by dividing the interquartile range by 2
Results (R1)

24/30 stroke survivors
17/18 partners
Had not received any information about sexuality after stroke

Results (R2)

16/17 stroke survivors
7/8 partners
Had not received any information about sexuality after stroke
Content for inclusion in sexual rehabilitation: priorities and consensus

18 Core topics

• stroke-related psychological changes impacting upon sexuality (7)
• communication issues (5)
• stroke-related changes in physical function impacting upon sexuality (2)
• changes in sexual function (2)
• general issues relating to sexuality (1)
• stroke-related cognitive & behavioural changes impacting on sexuality (1)
Examples of High Consensus & Priority Rating

- **Resuming sexual activity** after stroke

- **Conversations with intimate partners** – including expressing thoughts and need in relation to sexuality and understanding partners’ thoughts and needs in relation to sexuality

- **Fear of rejection** – concern regarding being rejected or seen in critical way which holds the individual back from expressing sexuality
Fatigue - fatigue which impacts upon ability to engage in activities related to expressing sexuality

Changes in attraction towards intimate partner - including challenges switching from being a caregiver or care recipient to being a partner

Loss of function of body parts which changes the way in which a person may be intimate with another or the ability to participate in sexual activities

Changes in self concept and self esteem – changes in the individual's belief about himself or herself including overall subjective evaluation of self-worth.
‘I feel these would be relevant to all stroke survivors and the partners. Additional information should be chosen on an individual basis depending on the personal situation’

‘All are extremely relevant, and each has a specific function regarding one’s sexuality and disability and their approach with this as an individual and as a couple’
## Timing of sexual rehabilitation

<table>
<thead>
<tr>
<th>Consensus</th>
<th>Tiered priority ratings</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. High, High to Intermediate</td>
<td>2. Intermediate; High to Low</td>
<td>3. Low; Low to Intermediate</td>
</tr>
<tr>
<td>High (&lt;1)</td>
<td>3 mths after initial diagnosis of stroke</td>
<td></td>
<td>Within the first 2 weeks following stroke</td>
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<td></td>
<td>6 mths after initial diagnosis of stroke</td>
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<td></td>
<td>1 year after initial diagnosis of stroke</td>
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<td></td>
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<tr>
<td></td>
<td>&gt; 1 year after initial diagnosis of stroke</td>
<td></td>
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<tr>
<td>Moderate (1)</td>
<td>1 month after the initial diagnosis of stroke</td>
<td></td>
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<tr>
<td>Low (&gt;1)</td>
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Delivery Method
# Disciplines involved in delivering sexual rehabilitation

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<tr>
<th>Consensus</th>
<th>Tiered Priority Ratings</th>
<th>2. Intermediate; High to Low</th>
<th>3. Low; Low to Intermediate</th>
</tr>
</thead>
<tbody>
<tr>
<td>High (&lt;1)</td>
<td>Rehab Physician</td>
<td>Neurologist</td>
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<td>Nurse with specialist knowledge</td>
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<td>Psychologist</td>
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<td></td>
<td>Sexologist/counsellor</td>
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<td></td>
<td>Nurse working in stroke services (acute or rehab)</td>
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<tr>
<td></td>
<td>Physiotherapist</td>
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<tr>
<td>Moderate (1)</td>
<td>O.T.</td>
<td>Geriatrician</td>
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<td>S.W.</td>
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<td></td>
<td>S.P.</td>
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<tr>
<td>Low (&gt;1)</td>
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Graythwaite Rehabilitation Sexuality and Intimacy Clinic offers a range of support options to assist people with acquired disability and their partners, to address sexuality and intimacy concerns in a confidential environment.
Conclusion

• Need to consider sexuality beyond the narrow aspect sex & sexual response cycle

• Need to include people with communication impairments as well as GLTQI stroke survivors

• Clinicians limited in what they can offer stroke survivors & their partners

• Research program is addressing the evidenced based practise gap

• Developed a sexuality intervention for inpatient stroke rehabilitation services

• Future Phase II clinical trial to determine feasibility and acceptability of the intervention
Thank you!!
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