

How is sexuality after stroke experienced by stroke survivors and partners of stroke survivors? A systematic review of qualitative studies

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Abstract

Objective: To synthesise how post-stroke sexuality is experienced by stroke survivors and partners of stroke survivors.

Methods: MEDLINE, PubMed, SCOPUS, CINAHL and PsycINFO were searched from inception to May 2018 using a combination of relevant Medical Subject Headings and Free Text Terms. Only papers published in English reporting original qualitative research were included. Methodological quality was assessed using the Critical Appraisal Skills Programme Qualitative Research Checklist. All text presented as ‘results’ or ‘findings’ in the included studies was extracted and subjected to a thematic analysis and synthesis which was discussed and agreed by the research team.

Results: The initial search yielded 136 unique papers with a further 8 papers identified through reference checking. Following full-text review, 43 papers were included in the final synthesis. Two analytical themes were identified: sexuality is silenced and sexuality is muted and sometimes changed, but not forgotten. These themes were made up of six descriptive themes: struggle to communicate within relationships, health professionals don’t talk about sexuality, sexuality and disability is a taboo topic, changes to pre-stroke relationships, changed relationship with the stroke survivor’s own body and resuming sexual intimacy – adaptation and loss.

Conclusion: Stroke has a profound impact on how sexuality is experienced by both stroke survivors and partners of stroke survivors. Despite this, post-stroke sexuality is rarely discussed openly. Stroke survivors and partners value sexuality and may benefit from strategies to support adjustment to post-stroke sexuality.

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Introduction

Sexuality contributes to quality of life for stroke survivors and their partners.¹ Best practice guidelines recommend that all stroke survivors and their partners receive tailored information and counselling regarding sexuality.^{2,3} Yet health professionals feel underprepared to address sexuality with stroke survivors^{4,5} and rarely provide information or ask about sexuality.^{6,7} While there have been many published reviews of the impact that stroke has on sexuality,^{1,8} most focus on sexual activity and do not include the World Health Organization's (WHO)⁹ wider aspects of sexuality such as gender identity and roles, self-concept, sexual orientation, intimacy, eroticism and reproduction. Post-stroke sexual dysfunction is caused by multiple aetiologies including organic (lesion site, pre-existing comorbidities, medication, etc.) and/or psychosocial factors (fear of recurrence, self-esteem, anxiety and depression).^{10,11} Therefore, the primary aim of this review was to investigate how post-stroke sexuality is experienced by stroke survivors and their partners, using the WHO's⁹ broad definition of sexuality.

Methods

We followed recommendations outlined in the enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement.¹² Using thematic synthesis,¹³ we developed an analytical framework to understand how sexuality is experienced by stroke survivors and their partners.

Search strategy

Comprehensive searches of MEDLINE, PubMed, SCOPUS, CINAHL and PsycINFO were conducted in May 2018 for studies published up to that date. Studies were included if they were published

in a peer-reviewed publication in English and reported original qualitative research relating to one or more aspects of sexuality following stroke from the perspective of adult stroke survivors or their partners (aged 18 years or more). Studies that did not meet these criteria were excluded. Data extraction was completed by the first author using a study-specific checklist. The following information was recorded: (1) study design; (2) primary research question; (3) type of participants (stroke survivor or partners); (4) sample characteristics including gender, sexual orientation, relationship status, country of origin, presence or absence of communication impairment; (5) data collection methods; (6) key interview questions asked of participants; (7) approach to data analysis; and (8) key findings. Methodological quality of each study was reviewed independently using the Critical Appraisal Skills Programme Qualitative Research Checklist¹⁴ by the first and second authors, who then conferred. Disagreements were resolved and consensus reached through discussion.

Data analysis

Text labelled as 'results' or 'findings' in a study was pasted or entered verbatim into QSR's NVivo software (Version 11).¹⁵ The first author coded each line of text according to its meaning and content. To increase dependability of coding, the second author independently coded 10% of the data and both authors discussed the emerging codes. This process of analysis generated 369 unique codes. Three of the authors identified similarities and differences between codes and created a preliminary coding tree structure. Codes were revised and new codes created to generate six descriptive subthemes. A summary of the descriptive subthemes was prepared, independently reviewed by all authors and considered with regard to the research question. Group discussion was used to

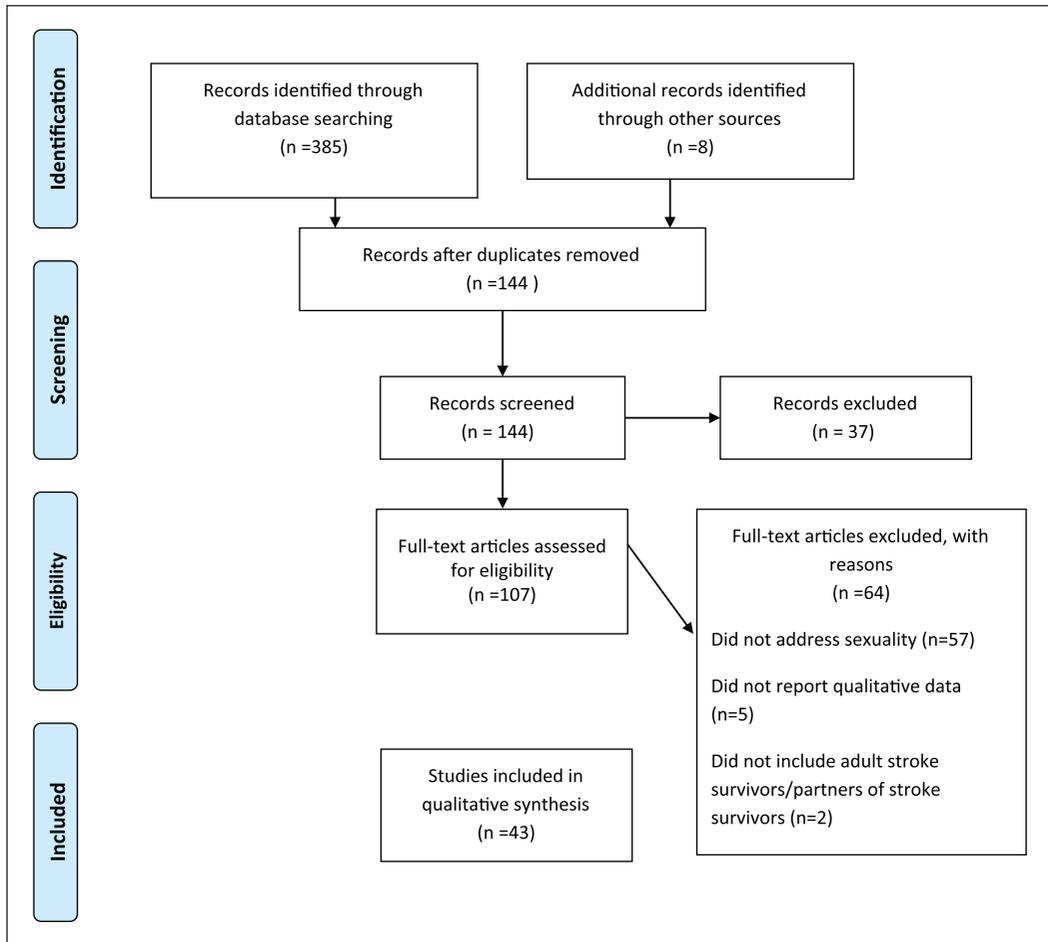


Figure 1. Flow of papers into and out of the review.
Source: Adapted from Moher et al.¹⁶

develop two core themes, describing and explaining how sexuality is experienced by stroke survivors and their partners.

Results

The search strategy identified 136 unique papers, of which 35 met the inclusion criteria. A further 8 papers were identified through hand searching resulting in 43 eligible papers for synthesis (see Figure 1 and Table S1 (online-only Data Supplement)). In total, 649 stroke survivors were included in the studies, with sample sizes ranging

from 1 to 125 participants per study. More stroke survivors were male (60.2% male, $n = 391$) compared to female (39.4%, $n = 257$). A total of 267 partners were included, with sample sizes ranging from 1 to 36 partners per study. The age of stroke survivors ranged from 20 to 105 years, while the age of partners ranged from 31 to 90 years. People with communication impairments were largely excluded from 10 out of 43 papers, while a further 16 papers made no reference to either including or excluding people with communication impairments and provided limited description of participants' communication abilities. Six papers^{17–22}

Table 1. Relationship between analytical themes, descriptive themes and codes.

Analytical theme	Descriptive themes	Examples of codes contributing to the descriptive theme	Raw data
Sexuality is silenced	Struggle to communicate within relationships	Lack of shared understanding	Mutual understanding in the relationship had been lost and the close relatives felt estranged, living side-by-side with the person who had suffered the stroke but without anything to talk about ²³
	Health professionals don't talk about sexuality	Being unprepared by professionals for the impact of stroke on sexuality	None of the participants in this study, many of whom reported that they were experiencing considerable difficulty communicating with each other, had received any guidance about the likely impact of the stroke on their relations ²⁴
	Sexuality and disability is a taboo topic	People with disabilities are not sexually desirable	Participants often had a negative opinion of their own personal value and sexual desirability, believing that others would not find them attractive, and in selecting potential romantic partners would choose persons without a visible disability first ²⁵
Sexuality is muted and sometimes changed but not forgotten	Changes to pre-stroke relationships	Alterations to pre-existing marital roles and responsibilities	Pre-defined roles became blurred after the stroke and this resulted in considerable role conflict ²⁶
	Changed relationship with stroke survivor's own body	A body that is alien	Because of paralysis, loss of function and fewer opportunities to attend to personal hygiene, she felt alienated from her body ²⁷
	Resuming sexual intimacy adaptation and loss	Impact of stroke on ability to engage in sexual activities	When I think of my partner and remember positions and things that we used to get into and the fact that I can't do those positions anymore ²⁸

specifically targeted people with communication impairments during recruitment although only one of these papers¹⁸ was specifically focused on sexuality after stroke.

Most studies included heterosexual coupled stroke survivors. While some studies included stroke survivors with other sexual orientations, none specifically explored the experiences of participants identified as lesbian, gay, bisexual or transgender. Most studies were completed in Western contexts including the United States ($n=10$), Canada ($n=7$) and Norway ($n=7$). One study had a global reach and drew data from online blogs.¹⁷

The most common approach to data analysis was phenomenology ($n=11$), followed by content analysis ($n=10$) and thematic analysis ($n=5$). Scores on the Critical Appraisal Skills Programme

(CASP)¹⁴ ranged from 5 to 10. Lower scores were typically due to researchers not articulating their relationship to participants, or providing limited description of the data analysis process.

Synthesis

Two major themes were central to the experience of sexuality after stroke: 'sexuality is silenced' and 'sexuality although muted and sometimes changed, is not forgotten'. Table 1 illustrates the contribution of the raw data, codes and descriptive subthemes to the two analytical themes. Data from the original studies have been used to illustrate themes. Where original quotes and data from study participants are presented, the letters 'SS' have been used to represent stroke survivors and the letter 'P' for partners. Where the original researchers' interpretations are

presented, the letters ‘RI’ have been used to represent researcher interpretation.

Analytical theme one: sexuality is silenced. The theme ‘sexuality is silenced’ refers to the ways in which the onset of stroke appears to trigger silence regarding sexuality. At an individual level, this silence manifests itself in the form of difficulties in communicating sexual needs and desires to intimate partners. Health professionals contribute to the silence surrounding sexuality by rarely discussing the topic during clinical interactions, while social norms and expectations regarding sexuality and disability add a further layer of silence.

Struggle to communicate within relationships. Even in the context of pre-existing intimate relationships, stroke survivors and their partners appear to struggle to openly talk about sexuality:

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. (SS)²⁹

Reasons for this struggle included the following: (1) not wanting to cause distress within the relationship,^{30–32} (2) believing that the stroke survivor was no longer capable or interested in engaging as an intimate partner,^{33,34} (3) fearing rejection^{28,35} and (4) lack of shared understanding of the experience of stroke.^{24,36,37} Communication impairments compounded the struggle:

The aphasic subjects reported it was harder to verbally initiate and talk about desire for sex, while their spouses reported that the aphasic partner was no longer able to express their feelings or engage in sexually intimate conversation. (RI)¹⁹

This silence resulted in damage to the relationship, and in some cases, increased feelings of isolation and loneliness:

Mutual understanding in the relationship had been lost. (RI)²³

The feeling is that I miss my husband. I need a shoulder to lean on, someone to talk to, and someone

who comforts me. I just don’t have that ... maybe these are moments of loneliness. (P)³⁸

Health professionals don’t talk about sexuality. The silence around sexuality experienced within relationships is reinforced by health professionals who do not acknowledge the impact of stroke on sexuality and fail to discuss post-stroke sexuality:

Despite coming into contact with multiple physicians, nurses, rehabilitation specialists, and a social worker, no one initiated discussion of post stroke sexuality with the participant. (RI)³⁷

As a result, stroke survivors and partners were unprepared for the impact of stroke on their sexuality, were uncertain about the validity of their concerns and were uninformed about where to get support:

None of the participants in this study, many of whom reported that they were experiencing considerable difficulty communicating with each other, had received any guidance about the likely impact of the stroke on their relationships. (RI)²⁴

Sexuality and disability is a taboo topic. Silence surrounding post-stroke sexuality is also reinforced by pervasive social messages and norms regarding the private nature of sexuality which prevented stroke survivors or their partners from discussing their concerns with others:

The partner of one man with aphasia suggested that, when asking about experiences of aphasia, one should ask about intimacy. She then pointed out that Māori would not usually talk about such things. (RI)¹⁹

Subjects related to sexuality are considered taboo and often discussed reluctantly. (RI)³⁴

Although these social norms are rarely made explicit, they exert a powerful influence on the ways in which masculine and feminine identities are constructed and frequently fail to accommodate those who do not meet expectations of corporeal wholeness. For male stroke survivors, male identity and masculinity were closely linked to physical strength and function, while for females the emphasis was on

bodily aesthetics. In both groups, there was a struggle to maintain positive self-regard and self-image:

You're supposed to be pretty straight and pretty macho ... [but] I miss being that. (SS)³³

I have trouble walking with a high heel, and then with a skirt, you can't spread your legs all the time to get in and out of a car. (SS)²⁸

For people not in an intimate relationship at the time of their stroke, or whose relationship subsequently ended, these social norms decreased their self-confidence and willingness to seek new relationships:

Why should a lady want to go out with me if you can go out with someone who does not have a disability? (SS)²⁵

I can't see anybody wanting to be with a disabled person ... I will totally understand if ... men don't find me physically – like, sexually attractive anymore, because I'm disabled. (SS)²⁸

Analytical theme two: sexuality although sometimes muted and changed is not forgotten. The second theme refers to the ways in which stroke survivors and their partners experience altered sexuality and respond to these changes. These changes are underpinned by altered pre-existing relationships between stroke survivors and their partners, and an altered relationship with the stroke survivor's own body. The consequences of these changes manifest themselves in decisions made by stroke survivors and their partners to resume, adapt or lose sexual intimacy.

Changes to pre-stroke relationships. For most couples, stroke-related functional loss fundamentally changed the nature of their pre-existing relationship. Physical and cognitive impairments, communication difficulties and post-stroke fatigue meant that pre-existing roles and responsibilities (often allocated according to gender norms) had to be reallocated or were conducted differently. Female stroke survivors highlighted the impact of stroke-related impairments on their engagement in

roles such as wife, mother and homemaker. Male stroke survivors focused more on engagement in physically demanding roles and tasks, which included providing protection and security for their families:

I can't do things for my family, like protect them. If an intruder came in, I couldn't even defend my family. I wouldn't even have the strength to fight off a child. (SS)³⁰

Disruptions in role performance were experienced both as a pragmatic concern, which required reallocation of tasks to the healthy partner, and as an assault to self-worth and self-esteem:

It's awful to rely on the wife; it makes me feel so bad. It's not supposed to be like that. (SS)³⁹

For some, the inability to complete valued roles led to a diminished position within the relationship. For others, they were still ascribed the relevant role status, even if they were unable to successfully complete that role:

Sam's partner summed up the situation when she said 'He's still the man of the house ... I just run it'. (P)¹⁹

Partners also experienced role destabilization which impacted on their own sense of identity, particularly when they moved from being an intimate partner to being a primary caregiver for the stroke survivor. A male stroke survivors' wife put it this way:

I became like a mum to him; I was helping him with everything! (P)³⁹

This type of role shifting was particularly prominent among female partners of stroke survivors, who experienced a heightened sense of responsibility for the well-being of their male partner. This was enacted through close monitoring of their partners' actions which, while intended to help, was often experienced as disabling by male stroke survivors and, ultimately created a parent-child dynamic within the relationship:

It was this hyper-vigilance that led some patients to express dissatisfaction with the marital relationship, as their wives were constantly on guard. (RI)⁴⁰

Becoming a caregiver meant adapting to an unplanned future. Partners expressed frustration and despair about the impact of stroke on their future lives. While most relationships survived, for some there was a sense of obligation rather than a desire to remain in the relationship. Partners felt that their needs had been forgotten:

I feel trapped by my husband and sometimes I would like to run away. (P)³⁰

Spouses felt they had been left alone grieving without healthcare workers' support. (RI)⁴¹

The impact of stroke on pre-existing relationships was not always negative. Some couples were able to regain a sense of harmony despite the changes associated with the stroke:

It's a bad thing to happen (the stroke) and a bad way to get together, but I think that's just brought the family a lot closer. ... I think we've got more time for each other. (P)⁴²

Changed relationship with the stroke survivor's own body. Just as stroke brought about fundamental changes in relationships between survivors and partners, stroke also changed the relationship with the stroke survivor's own body. Stroke survivors became more aware of their body, which was foregrounded in everyday life:

No longer could a person sit, run, walk, stand, or lie down without consciously thinking about the movements each action entailed. (RI)⁴³

This 'no longer silent body' (RI)⁴⁴ was in direct contrast to the pre-stroke body which could be relied upon to function effectively without monitoring. Post-stroke, 'the body had become unpredictable' (RI),⁴⁵ strange, uncomfortable and separate to themselves:

I'm not comfortable with my body ... I don't know if my body's working properly. (SS)³⁷

The altered relationship with their body was frustrating for many stroke survivors who viewed their post-stroke body critically. They anticipated and/or experienced similar levels of negative evaluation from others:

They felt that they were being looked at and were afraid that other persons thought them stupid. (RI)⁴⁵

Resuming sexual intimacy: adaptation and loss. Despite changes in intimate relationships and the stroke survivor's relationship with their body, sexuality continued to be important and was not forgotten:

But that [stroke] doesn't change the essence of who I am or what I want, before and after. It only changes what I can do. It doesn't change what I want. (SS)²⁸

Returning to sexual intimacy was a milestone for many participants. Stroke survivors were relieved to find that their sexual response 'doesn't seem to have been affected' (SS).²⁸

The decision when to resume sexual intimacy was influenced by the presence of stroke-related impairments. Intimate activities were reported to be less spontaneous because of stroke-related changes:

Every step has to be planned out carefully. 'Can I do this?'. There's no spontaneity in it anymore. (SS)²⁸

Stroke survivors with communication impairments had difficulty expressing sexual desire to their partners, while those who experienced altered bodily sensations had limited desire for intimate contact from others:

Even with my husband ... I don't want to be touched quite yet. (SS)³⁷

For some stroke survivors with high levels of post-stroke fatigue, sexual intimacy was deprioritized due to other more demanding roles:

Their job claimed all of their energy, and they became too exhausted to fulfil their spouses expectations. (RI)⁴¹

Being intimate with a partner also meant exposing the post-stroke body. For some stroke survivors, this generated high levels of anxiety as they struggled to deal with their partner's response to them and this often resulted in avoidance of sexual intimacy altogether:

I thought he didn't want to have intercourse due to the asymmetric view of my face, my dependence on crutch and maybe my appearance. (SS)³⁴

Despite changes in the nature of intimate activities changed, there was an acknowledgement that sexual intimacy after stroke could be satisfying:

His tiredness affected his sexual ability but he and his wife had found ways to have a functional sexual life despite the problem. (RI)⁴⁶

Discussion

This first systematic review and thematic synthesis of qualitative research on the experiences of sexuality after stroke indicates that sexuality is largely silenced. The review suggests that stroke survivors and their partners struggle to communicate about sexuality, and health professionals rarely address this topic during rehabilitation. The silence is further compounded by strong social norms which limit the extent to which people with disabilities are expected to have, or are supported to express their sexuality(ies). Our research also suggests that sexuality remains important but is fundamentally altered by stroke. Stroke brings about changes in relationships between stroke survivors and their partners and requires the stroke survivors to adjust to living with a changed body.

The finding that sexuality after stroke is shrouded by silence confirms previous research indicating that sexuality is a neglected part of stroke rehabilitation.^{4,5} Health professionals' reluctance to address sexuality can be attributed to lack of knowledge and confidence in providing interventions.⁴⁷⁻⁵⁰ There is a need for tailored education and training to address this knowledge gap. However, for stroke survivors and their partners, the silence observed by professionals and the lack

of services to address post-stroke sexuality implies sexuality has limited relevance for post-stroke life. Furthermore, the lack of available information⁵¹ means that stroke survivors and their partners are left to re-negotiate sexuality without adequate support. For many, this means that sexuality is lost, potentially leading to an increased incidence of anxiety and depression and poorer quality of life outcomes.¹¹

For those who described positive sexuality following stroke, the ability to openly discuss their thoughts and feelings about sexuality appears to be important. For clinicians, this suggests that there is a need to raise awareness about the potential impact of stroke on sexuality and to include questions about sexuality as a routine item in rehabilitation. Interventions to address post-stroke sexuality are underdeveloped and typically have focused on sexual activity.^{52,53} Interventions shown to be effective for cancer survivors,⁵⁴ people with spinal cord injury and other neurological disabilities⁵⁵ may be useful; however, consultation with stroke survivors and their partners is needed to ensure that interventions address stroke-specific issues (e.g. aphasia). Research is needed to (1) develop evidence-based interventions to support rehabilitation in this area, (2) identify what outcomes are most important to stroke survivors and their partners and (3) determine how these outcomes may be measured.

To our knowledge, this is the first systematic review and thematic synthesis of qualitative research regarding sexuality after stroke. In developing our review, we followed the guidelines set out in the ENTREQ statement¹² including keeping detailed records of our search strategies. We performed a comprehensive search of the literature up to and including May 2018 to identify potentially relevant publications. This ensures that to some extent, our review can serve as a comprehensive and up-to-date summary of the published research on how post-stroke sexuality is experienced by stroke survivors and their partners.

As with all studies, there are a number of limitations to this review. While our search strategy was comprehensive, we did not include non-English publications. Thus, the majority of included studies

were conducted in Westernized contexts. It is therefore possible that findings may not be generalizable to other cultural contexts particularly those having different social norms and expectations regarding sexuality. The process of data extraction and interpretation was influenced by our own assumptions as researchers interested in sexuality. We deliberately adopted a broad understanding of the concept of sexuality and were guided by the definition published by the WHO⁹ which suggests that sexuality includes concepts such as sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Adopting this definition meant that we included a wide range of studies, many of which did not explore post-stroke sexuality as their primary aim. Instead concerns about sexuality were identified in the context of adaptation following stroke. It is possible that additional findings may have emerged had the original research been focused exclusively on post-stroke sexuality.

Furthermore, it is possible that our position as female researchers may have influenced our interpretation of gender differences between men and women. To enhance the trustworthiness of findings, we engaged in frequent discussions about our position as researchers relative to the data and regularly returned to the original data set to seek plausible alternative explanations and confirm our findings.

The quality of the original research was variable. While we did not exclude any studies on the basis of quality, readers should take methodological quality (reported in Table S1) into account when interpreting and applying the results to other contexts. While some studies did include people with stroke-related communication impairment, most did not. It is likely that people with communication impairments will face additional challenges relating to sexuality, particularly communicating within relationships. Furthermore, participants in the original studies mostly identified as heterosexual and were involved in intimate relationships at the time of the data collection. How much their experiences can be generalized to stroke survivors with diverse sexualities, or who are not in a relationship is unclear. Further work to directly report

on the impact of stroke on sexuality is warranted (including related communication impairments) and that research should attempt to recruit stroke survivors and partners with diverse sexualities and various relationship status.

Future research could also specifically focus on understanding how rehabilitation services for stroke survivors and their partners should be delivered to optimize post-stroke sexuality. Our review suggests that negotiating sexuality after stroke is challenging. The process is made more difficult by the absence of information to guide and support stroke survivors and their partners. Stroke survivors and their partners make decisions to prioritize some aspects of sexuality over others; however, longitudinal studies are needed to understand how these decisions are made. Such information could support development of sexual rehabilitation programmes and clinical practice guidelines for sexuality after stroke.

Clinical messages

- Stroke survivors and partners of stroke survivors experience alterations in sexuality following stroke.
- Although sexuality is rarely spoken about following stroke, it remains important to the patient.

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