CE

# Healthcare Professionals' and Patients' Views of Discussing Sexual Well-being Poststroke

Siobhan Fox[1], BA, PhD, Reema M. Antony[1], BSc, RN, Mary J. Foley[2], RGN, RNP, RANP, MSc,
Dawn O'Sullivan[1], RN, RNT, BSc, Nurs, MSc & Suzanne Timmons[1], MD, MB, BCh, BAO, MSc

**Abstract**

**Purpose:** Stroke can cause physical and emotional problems affecting sexual well-being; healthcare professionals (HCPs) are often uncomfortable discussing this topic with patients. We explored the perspectives of HCPs and stroke survivors about barriers to discussing sexual well-being poststroke.

**Design:** A mixed methodology was employed.

**Methods:** A postal survey of stroke survivors (*n* = 50), a focus group with HCPs on a stroke unit (*n* = 6), and a focus group with community-living stroke survivors (*n* = 6) were used in this study. Focus group data were analyzed thematically.

**Findings:** No patient surveyed (60% response rate) had discussed sexual well-being with an HCP. Focus groups revealed barriers on multiple levels: structural, HCP, patient, and professional–patient interface.

**Conclusions:** Healthcare professionals were poorly trained, adopted a passive role, and addressed sexual activity based on individual beliefs rather than having an agreed team approach.

**Clinical Relevance:** Relatively simple steps like inclusion in policy, training to empower HCPs, and the provision of written information for patients could help to improve practice.

**Keywords:** Rehabilitation; stroke; stroke rehabilitation; sex; sexuality.

One effect of stroke that is sometimes overlooked is its effect on the sex lives of stroke survivors and their partners (Cheung, 2008). Sexual wellness is understood to contribute to overall well-being and quality of life (Pangman & Seguire, 2000). However, the focus of rehabilitation on "functional ability" has led to a relative neglect of the emotional and social consequences of stroke, including sexual well-being.

Stroke survivors and their partners often report a decrease in sexual desire and/or activity following the stroke (Schmitz & Finkelstein, 2010). A systematic review of the social consequences of stroke in working-aged adults found 10 studies that investigated the effect on sexual relationships; these pooled results showed that a deterioration in sexual life was common (Daniel, Wolfe, Busch, & McKevitt, 2009). A large study of 192 poststroke patients and 94 spouses showed that satisfaction with sex life reduced from 89% prestroke to 49% poststroke for patients and from 93% to 31% for their spouses (Korpelainen, Nieminen, & Myllylä, 1999). Furthermore, these problems may persist for some years; in another study, only 41% of stroke survivors reported satisfaction with their sex life 3 years poststroke (Boosman, Schepers, Post, & Visser-Meily, 2011).

Physical and emotional problems may separately contribute to decreased sexual well-being poststroke (Tamam, Tamam, Akil, Yasan, & Tamam, 2008). First, medications and cognitive impairments negatively affect sexual relationships (Banks & Pearson, 2004). Also, stroke survivors and their partners may worry that sexual activity might cause harm or lead to another stroke (Schmitz & Finkelstein, 2010). Finally, qualitative research has reported significant relationship changes related to disrupted gender roles and changed patterns of interaction including additional responsibilities, for example, a partner adopting a caregiver role (Banks & Pearson, 2004; Schmitz & Finkelstein, 2010).

Research also shows that stroke survivors and their partners receive little to no information about recommencing

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**Correspondence:** *Siobhan Fox, BA PhD, Centre for Gerontology and Rehabilitation, Block 13, St. Finbarr's Hospital, Cork, Ireland, T12XH60. E-mail: s.fox@ucc.ie.*

*1 Centre for Gerontology and Rehabilitation, School of Medicine, University College Cork, Ireland*

*2 Assessment and Treatment Centre, St Finbarr's Hospital, Cork, Ireland*

Cite this article as:
Fox, S., Antony, R. M., Foley, M. J., O'Sullivan, D., & Timmons, S. (2020). Healthcare professionals' and patients' views of discussing sexual well-being poststroke. *Rehabilitation Nursing, 45*(1), 16–22. doi: 10.1097/rnj.0000000000000144

sexual activity from their healthcare professionals (HCPs) during their rehabilitation (Chadwick, Saver, Biller, & Carr, 1998; McCormick, Riffer, & Thompson, 1986; Schmitz & Finkelstein, 2010), yet many are interested in receiving sexual counseling as part of rehabilitation (Korpelainen et al., 1999). Some people may feel that, because of the lack of information, sexual activity is actively discouraged poststroke (McCormick et al., 1986). Although some people may be embarrassed to discuss issues related to sexual activity, participants are more willing to do so with a HCP with whom they feel at ease (Conine & Evans, 1982).

Less research has been conducted from the perspectives of the HCP to explore their views on discussing sexual well-being with their stroke patients. McLaughlin and Cregan (2005) conducted a small-scale survey study of Northern Ireland rehabilitation professionals. The authors found that, although the majority of staff had been asked for advice on sexuality issues, most had received no training in this aspect of stroke rehabilitation and cited this as the main barrier to their discussing these issues with their patients. Nurses were the professionals most likely to have experience of being asked about sexual health by their patients.

The literature strongly suggests that stroke survivors and their partners need and want help in dealing with sexual issues poststroke, but that they are not currently receiving this guidance during the rehabilitation process. It is important to examine the situation from the dual perspectives of patients and their HCPs to better understand the barriers to including sexual well-being as part of stroke rehabilitation and to explore how these may be overcome. Therefore, the aim of this study was to examine the perspectives and experiences of both HCPs and stroke survivors about discussing sexual issues and perceived rehabilitation needs poststroke.

## Method

### *Study Design*

A mixed-methods design was used, involving a survey (for stroke survivors) and two focus groups (one with stroke survivors and one with HCP). The survey was developed by the researchers, and the questions were designed to assess the areas most pertinent to the research question and were informed by the literature review and the researchers' own clinical experience. Ease of completion was a priority; hence, the questions were kept short, and simple language was used. A draft survey was piloted among a convenience sample of healthy adults for user-friendliness, and minor changes to the wording were made in response to feedback (see Table 2 for survey questions).

Two semistructured focus group schedules were developed to guide the discussions with stroke survivors and HCPs to further explore themes identified in the survey and in the literature review. This research was conducted and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research guidelines (COREQ; Tong, Sainsbury, & Craig, 2007).

### *Theoretical Framework*

The methodological orientation underpinning this study was thematic analysis; specifically, we followed the six-step framework of Braun and Clarke (2013).

### *Participant Selection*

Purposive and convenience sampling strategies were used.

**i. Survey.** Participants were recruited from a stroke register covering two acute stroke units. Fifty patients were purposively selected by the Stroke Clinical Nurse Specialist based on the following inclusion criteria: >18 years, not single/widowed, and >4 weeks poststroke of any etiology. Exclusion criteria were as follows: significant cognitive or communication deficits (as recorded on the stroke register) and member of a religious order.

**ii. Focus groups.** For the HCP focus group, participants were recruited from the larger stroke unit with this inclusion criterion: HCPs working on the unit for >6 months. Six HCPs representing six different disciplines were approached, and all agreed to participate.

The patient focus group participants were members of a local stroke support group who were identified by the support group facilitator (MJF) as being potentially suitable to take part. Inclusion criteria were as follows: patients who had a stroke >6 months previously, currently in a relationship and living in the community, can read and understand English, and have no significant communication or cognitive issues.

### *Setting*

This study was conducted in Ireland. Both the HCP and patient focus group were conducted in private, quiet rooms.

### *Data Collection*

Surveys were posted to stroke survivors, along with a self-addressed return envelope. Reminder letters were issued. Focus group sessions lasting 45–60 minutes were audio-recoded, with permission, and supplemented by field notes.

### *Research Team and Reflexivity*

**Personal Characteristics.** Author RA, a nurse working on a stroke ward, completed this research as part of an MSc requirement. RA completed training on qualitative methods and was supervised by experienced senior researchers. For example, RA regularly sent samples of coding and categorizing to the research team who reviewed these (e.g., to ensure codes accurately reflected the data, to check that pertinent aspects of the transcripts were coded) and provided detailed feedback.

**Relationship With Participants.** RA worked with the HCP who took part in the focus group. She did not know the stroke survivors previously. RA was introduced to the group by the stroke support group coordinator (MJF), who provided an overview of the research and asked for volunteers.

### *Data Analysis*

RA coded the transcripts overseen by the research team. Themes were not identified in advance but were derived from the data, that is, a data-driven approach was taken. The steps for conducting a thematic analysis as outlined by Braun and Clarke (2013) were followed, that is, (1) familiarizing yourself with your data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. Microsoft Excel was used to organize the coding and themes from the focus groups and to summarize the quantitative survey data.

### *Ethics*

Ethical approval was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals.

## Results

### *I. Focus Group With HCP Exploring Their Views About Discussing Sexual Activity With Stroke Survivors*

Demographic details for the six HCPs who participated in the focus group are presented in Table 1. Three major themes and four subthemes were identified.

**Table 1** Demographic details of healthcare professionals who took part in the focus group ($n$ = 6)

| | *n* |
|---|---|
| Gender | |
| Male | 3 |
| Female | 3 |
| Discipline | |
| Doctor | 1 |
| Nurse | 2 |
| Therapist | 2 |
| Healthcare assistant | 1 |
| Years of experience | |
| <1 year | 0 |
| 1–5 years | 2 |
| 6–10 years | 4 |

### *Focus Group Themes*

#### Balancing "Embarrassment" and "Importance" of Sex

An overarching theme was that HCPs are not discussing sexual well-being with their stroke patients and that they find the topic embarrassing.

> *One young female patient asked me "Can I have sex? I suppose I need to ask this because me and my husband [are] trying to have another baby." I was thinking "Get me out of here." (HCP1)*

However, HCPs in general acknowledged the importance of being open to such discussions with patients poststroke and discussed the main barriers that need to be overcome for this to happen, as discussed below.

#### How The Issue of Sexual Well-being Is Raised

Some HCPs had never had a stroke patient ask about sexual well-being; for others, it was an unusual but not an uncommon occurrence. The topic of sex was more likely to be raised, first, in a one-to-one setting and, second, during rehabilitation after the patient had left the hospital, as can be seen in HCP1's discussion:

> *…In their acute phase [in hospital], it doesn't come up that often. But I think once they go home, once they settle back into routine life, there it comes… Can I lead a normal life? Can I do my normal stuff? Can I be a successful partner?*

When sexual well-being was discussed, the topics raised by patients were safety of having sex, timing of resuming sex, erectile problems, and, at the other end of the spectrum, the normality of not wanting to have sex.

#### Barriers to Discussing Sexual Activity Poststroke

Barriers to the provision of information occurred at four levels: organizational level, HCP level, patient level, and HCP–patient interpersonal level.

**Organizational Barriers.** HCPs perceived that hospital management did not think that sexual well-being was an area of concern as it was not "included in the (hospital) stroke policy." Moreover, participants observed a lack of specialist service provision in this area, believed in part to be due to a perceived lack of demand for such services.

Concern was also conveyed about a lack of formal support or any obvious referral pathway should problems be identified. In addition, HCPs had not ever seen colleagues engaged in such discussions. This strengthened the feeling that sexual issues were not within their concern and that raising these issues could leave the hospital staff "exposed."

Finally, time pressure in the acute setting was another barrier. One HCP said that she would have no time to discuss this topic with a patient because she is under pressure to finish her other duties before her shift ends.

**HCPs' Personal Barriers.** At the individual HCP level, there was the perception that sexual well-being was not within their role and that they did not have the training to confidently discuss such topics. Some staff showed embarrassment around the topic, for example, three of the six participants did not use the word "sex" or a similar phrase at all during the focus group, rather referring to "it" and "those kinds of things."

Healthcare professionals often felt that there are more pressing matters for patients, even at later stages of rehabilitation. They tended to emphasize the "medical model" and problems with sexual well-being were perceived to be mechanical. For example, a focus would be to diagnose erectile dysfunction and prescribe medication to solve this.

> *[Sexual well-being] wouldn't be top of my list. I think making sure that they're on the right medication, that the blood pressure's well controlled, that they're medically stable would be my number one thing really… If it was a man who was struggling with erectile dysfunction or something, then I'd either consider suitability for Viagra, or I'd refer to a urologist and let them deal with it. (HCP3)*

Some HCPs did acknowledge the emotional side of sexual well-being but then were less certain how to deal with it. Some tried to create an environment favorable to such conversations, stressing the importance of making patients comfortable and then asking about broader topics, changes in home life, relationship, and so forth, thus creating an opportunity for patients to raise sexual health without specifically asking.

**Perceived Barriers at the Level of the Patient.** A minority of HCPs thought that sexual well-being would not be relevant to patients at all. However, certain biases were evident; HCPs suggested categories of patients whom they felt it would be inappropriate to discuss sexual activity with, mainly older people:

> *Obviously, a lot of our elderly gentlemen and ladies don't do that [have sex] anymore. (HCP5)*

Healthcare professionals identified other groups of people with whom the topic "would not be worth raising." This included young people because of the assumption that their sexual activity "goes back to normal." A minority viewpoint was that stroke would be unlikely to affect women's sexual well-being, as they are less interested in sex anyway.

**Barrier at the HCP–Patient Interface.** At the HCP–patient interface, some feared that raising the issue of sexual well-being could damage the HCP–patient relationship, as there was potential to embarrass or upset the patient or a fear that the patient would think negatively of the HCP for raising the issue. It was also debated whether a long-term professional relationship or the relative anonymity of someone they know less well might be preferred.

One HCP suggested having "sex-after-stroke" leaflets for distribution, similar to leaflets currently available on diet and exercise. They believed this would facilitate conversations with patients who might want to discuss sex but were embarrassed to ask.

## Results

### *II. Survey and Focus Group Exploring Stroke Survivors' Views About Discussing Sexual Activity With Their HCPs*

### Stroke Survivor Survey Results

Thirty surveys were returned (60% response rate). Demographic details and the key findings are displayed in Table 2. Overall, sexual activity was reported to have decreased poststroke. Notably, all respondents agreed that sexual activity poststroke should be discussed; however, none could recall any such discussion with an HCP. Opinions were mixed about whether it is the responsibility of the HCP or the patient to initiate conversations regarding sexual well-being.

### Stroke Survivor Focus Group Themes

In analyzing the focus group with stroke survivors ($n = 6$), three major themes and three subthemes were identified.

**Table 2** Stroke survivors survey result

| Demographic Characteristics | Response Categories | Participants, $n = 30$ n (%) |
|---|---|---|
| Gender | Male | 19 (63) |
| | Female | 11 (37) |
| Age (years) | 25–35 | 5 (17) |
| | 36–55 | 14 (47) |
| | 56–80 | 11 (37) |
| Length of time poststroke | 3–6 months | 10 (33) |
| | 7 months to 2 years | 15 (50) |
| | 3–5 years | 5 (17) |
| Survey questions | | |
| Were you sexually active pre stroke? | Yes | 27 (90) |
| | No | 3 (10) |
| Are you sexually active poststroke? | Yes | 21 (70) |
| | No | 9 (30) |
| Do you think it is necessary to discuss sexual well-being poststroke? | Yes | 30 (100) |
| | No | 0 (0) |
| Did you receive any information about sexual activity poststroke? | Yes | 0 (0) |
| | No | 30 (100) |
| Who do you think should initiate the conversation regarding sexual well-being poststroke? | Patient | 13 (43) |
| | Healthcare professionals | 17 (57) |

### Intimacy, Relationships, and Self-Perception

Participants agreed that intimacy between people, relationship building, and people's perception of themselves, including self-confidence and self-image, were vital to sexual activity. Having had a stroke can negatively affect self-confidence and self-image, affecting sexual activity and overall well-being.

Some discussed how the spousal relationship status is altered by a stroke; in many cases, the role of partner changes to the role of carer after the stroke.

> *I rely on my wife a lot…she takes care of my tablets, she does everything for me, there is so much pressure on her. It is not a husband-wife role anymore. It is a carer role. It is very hard. (Patient 2)*

Sexual desire can be affected after stroke, and reasons may be both physical and emotional; fear of recurrence of stroke and taking medications were discussed as possible causes of reduced sexual desire.

### Lack of Knowledge in Recommencing Sex After Stroke

All stroke survivors reported that they did not get any advice regarding restarting sex after having a stroke; they felt that HCPs focused on their physical recovery and that "emotional" issues were neglected. Because of this lack of information, some noted that their partners were not anxious to have sex, worrying that it would lead to another stroke.

> *You know I wanted to have sex…but…my husband treats me like a glass bottle [laughs]. He thinks he may do more damage. (Patient 1)*

Most patients thought it necessary to be provided with information regarding sex the same way HCPs advise them on physiotherapy, diet, exercise, smoking, and so forth.

### Stroke Survivors' Barriers to Discussing Sexual Activity With HCP

**Older Age.** Discussion indicated that older people often feel uncomfortable discussing sexual well-being with HCPs, particularly if they have to raise issues on their own, yet they all believed it is important to be informed about sexual health during their rehabilitation journey. Older adults may use indirect language and use words such as "intimacy" rather than "sex" when discussing sexuality with HCPs. However, older adults also indicated that sexual activity was less of a priority for them, compared with other issues.

> *I think it's prioritization really. I want to be able to get up and walk, I want to be able to dress… it wouldn't be until later that these issues would come up. (Patient 3)*

In comparison, younger patients reported that they are more willing to ask their doctor to get advice on restarting sex.

**Lack of Privacy in Hospital.** Participants said that limited privacy in hospitals could inhibit them from initiating discussions about sex. Three female participants who were sexually active had a desire to discuss their sexual health needs with their clinician but had not raised their sexual problems in consultations due to lack of privacy.

> *It is so hard to ask about this to my doctor in the ward. You will be in the middle bed and there are other patients beside you… it's embarrassing, no privacy at all. (Patient 4)*

A lack of privacy was also an inhibiting factor for older people who, as discussed previously, may be less likely to raise this topic in the first place.

**HCP–Patient Interface Barriers as Perceived by Patients.** Stroke survivors reported that HCPs would not initiate the topic of sexual well-being unless specifically asked by patients as, in their view, HCPs do not prioritize this topic.

> *I don't think my doctor will ask me "have you any concern regarding sexuality?" He may ask "do you feel safe enough to go home, do you need help to do your daily activities?" He will not give me any sex advice, maybe he does not think it's important. (Patient 5)*

Stroke survivors were of a mixed opinion as to who should initiate the topic of sexual well-being; however, most participants in the focus group would prefer that doctors/HCPs initiate this discussion.

## Discussion

Past research shows that sexual well-being is often ignored in stroke rehabilitation (Cheung, 2008; Schmitz & Finkelstein, 2010); this study adds to the literature by identifying barriers to such discussions from the perspectives of both HCPs and patients and suggesting recommendations for individual practice and wider policy changes.

The survey of stroke survivors showed that deterioration in sexual life was common, consistent with previous research (Daniel et al., 2009). All the stroke survivors in this study agreed that sexual health is an important area in the stroke care pathway and that information regarding sex after stroke should be offered to them. However, no participants in either the focus groups or survey had been given information about sexual activity poststroke; a lack of information was also highlighted in previous studies (Stein, Hillinger, Clancy, & Bishop, 2013).

Similar to previous research (Schmitz & Finkelstein, 2010), stroke survivors here reported feeling apprehensive or embarrassed asking for advice about sexual health from their HCPs and perceived (correctly, in the current case) that their HCPs are equally uncomfortable. This interpersonal barrier is a key finding. Introducing formal guidance documents for staff and information leaflets for patients may help to normalize and encourage discussions about sexual well-being.

Among the patients who participated in this study, older people were perhaps less likely to initiate the topic of sexual health poststroke than younger people due to different barriers; this is a consistent finding (Bauer, Haesler, & Fetherstonhaugh, 2016; Colton, 2008). Overall, stroke survivors were ambivalent about whose responsibility it is to initiate discussions about sexual health, but all felt such discussions were part of an HCP's role. The implication for practice is that patients may not outright inform their HCPs that they have a problem relating to their sexual well-being following stroke; however, they might hint that something is wrong. HCPs therefore need to be mindful of these cues and sensitively probe their patients for more information in a nonjudgmental and encouraging way.

These findings were further illuminated by the discussion with HCPs. In the HCP focus group, most perceived significant barriers to initiating discussions about sexual well-being with their stroke patients, including personal factors such as embarrassment. We saw that patients pick up on the feelings of discomfort from their HCPs. The attitude of the HCPs might negatively influence the outcome of the conversation or might inhibit it from happening in the first place. HCPs must be aware of their own feelings and attitudes and should consider how these may affect the therapeutic relationship.

Cultural barriers were evident; worryingly, some HCPs considered it inappropriate to ask about patients' sexual well-being at all as they felt that this could harm the HCP–patient relationship. Some HCPs assumed a lack of relevance to people who are "older" or to female patients. These views may be seen as ageist and discriminatory. It should not be assumed that the meaning and significance of sexuality in the lives of older adults necessarily declines, including those in ill health (Gott & Hinchliff, 2003). HCPs must not regard poor sexual well-being as an inevitable outcome of aging and should deliver care in a nonjudgmental manner.

Another significant barrier was that HCPs tended to consider poor sexual well-being in terms of a physical or medical problem. Healthcare professionals may feel more comfortable in framing the discussion in this way rather than from an emotional or psychological approach; however, discussions with stroke survivors here and elsewhere (Tamam et al., 2008) show that sexual health needs to be approached holistically for best care practices.

Organizational barriers further compound these problems. A lack of training and support leads to a feeling of a lack of responsibility and a lack of interpersonal skills in how to sensitively communicate sexual topics. At an organizational level, there is a need for policy makers and service providers to see sexual health care as an integral aspect of rehabilitation following a stroke. In addition, sexual rehabilitation also needs to be recognized as an important quality of life issue for all stroke patients, including older people and women, and clear protocols developed to guide and assist staff in this area of practice.

Despite the barriers, HCPs felt that standardizing the approach to discussing sexual activity with patients poststroke could be easily achieved through training and supports. As noted elsewhere (McLaughlin & Cregan, 2005), HCPs do not need to become qualified counselors; however, HCPs such as nurses working with stroke patients in rehabilitation should have the skills to open a space for comfortable discussion of any health topic causing worry for a patient, including sexual well-being.

Readers looking for further practical advice on dealing with topics relating to sexual health with their stroke patients are referred to the very informative article "Sex and Intimacy After Stroke" by Kautz and Van Horn (2017). The recommendations in this article are based on the PLISSIT model, which is an acronym for Permission, Limited Information, Specific Suggestions, and Intensive Therapy, in addressing sexual concerns. Evidence-based recommendations are given, including asking about intimacy and sexual concerns; discussing the safety of resuming sexual activity; and coping with the stroke sequelae of decreased desire, erectile dysfunction, vaginal dryness, paraparesis, pain, spasticity, fatigue, aphasia, concrete thinking, emotional lability, shame, embarrassment, fear, depression, and neurogenic bladder.

### *Strengths and Limitations of the Study*

A strength of this study was that the issue of discussing sexual health poststroke was explored from multiple perspectives—barriers as perceived by HCPs were underresearched previously—and both younger and older stroke survivors were included. We acknowledge the potential limitation of partners of stroke survivors having not been included, and as with most qualitative research, these findings cannot be generalized to other hospital settings. However, the depth of information gathered adds to our knowledge on barriers to discussing sexual activity in stroke survivors.

### *Conclusion*

Sexual well-being should be a key consideration in stroke rehabilitation. Patients would appreciate frank and open discussion with their HCPs on issues relating to sexual well-being following stroke. Although structural changes may be needed, for example, inclusion of sexual well-being in care pathways, relatively simple changes such as information provision and acknowledgement of the issue in standard care policies might allow individual HCPs to change practice by legitimizing the topic and making its consideration routine in practice.

## Key Practice Points

- Stroke survivors often report a deterioration in sexual well-being poststroke.
- Stroke survivors would like to have sexual well-being included in rehabilitation but feel that their healthcare team are only interested in their physical/medical needs.
- Many healthcare providers report being uncomfortable discussing sexuality with their stroke patients for personal (e.g., embarrassment) and professional (e.g., lack of guidelines) reasons.
- Patient care could be easily improved with relatively simple changes, such as information provision and acknowledgement of the issue in standard care policies.

### Conflicts of Interest

The authors declare no conflict of interest.

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