



Sexuality and Intimacy Following Stroke: Perspectives of Partners

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Abstract

Intimacy and sexuality can make vital contributions to quality of life but may become complicated or problematic for stroke survivors and their partners/spouses. Several studies have focused on survivor feelings and perceptions of post-stroke sexuality, but partners are generally neglected. The purpose of this project is to identify partner perspectives and experiences related to intimacy and sexuality following a stroke. Nine participants were interviewed in person or by phone about relationship changes and their information, supports or resources regarding intimacy and sexuality. Transcripts were analyzed using techniques of thematic analysis. Four themes were identified: (1) maintaining closeness and togetherness, (2) redefining sexuality and intimacy after stroke, (3) coping with lack of resources, and (4) wishing health professionals would discuss these topics. Results of this study indicated that partners are very concerned about intimacy and sexuality but feel unprepared to address these personal concerns post-stroke. Clinicians can open the lines of communication about sexuality and intimacy to support couples' quality of life. Further resources and training as well as policies need to be developed to address sexuality and intimacy effectively with stroke survivors and their partners.

Keywords Stroke · Sexuality · Intimacy · Family caregiver · Quality of life · United States

Background Information

Sexuality and intimacy play a significant role in overall quality of life, however, this arena can be problematic for stroke survivors and their partners [1]. According to Harris, Adams, Zubatsky, & White [2], intimacy signifies the emotional aspects of a relationship, such as feelings of warmth, closeness, and connectedness, while sexuality refers to the physical aspects of a relationship such as sexual functioning and intercourse. Intimacy and sexuality can mean different things to specific individuals and couples. Clarifying the meaning and importance of sexuality and intimacy with each person is an important part of the rehabilitation process [2].

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Despite being very important concerns for many stroke survivors, intimacy and sexuality are seldom discussed in medical or health care settings. Research has been done on sexuality post-stroke from the perspective of the stroke survivor, but perspectives of spouses or partners are generally neglected. Stroke can threaten quality of life of the stroke survivor's spouse or intimate partner, exposing them to limitations and stigma [3].

Sexuality and intimacy post-stroke have been the focus of a growing number of studies with stroke survivors showing that male and female stroke survivors reported numerous common barriers after a stroke. Many of these limitations are physical, such as reduced libido, reduced frequency or complete cessation of sexual activity, erectile dysfunction for men or reduced vaginal secretion for women, and comorbid conditions, such as diabetes and heart disease [4, 5]. Others reported fatigue, weakness, spasticity, general pain, restricted mobility and problems with desire, arousal, and orgasm as reasons for decreased sexual activity [6, 7]. Physical limitations can be accompanied by psychosocial limitations. Perceptions and attitudes towards sexuality change drastically after a stroke and changes in physical appearance can lead to self-consciousness and lessened feelings of desirability [4, 5, 7]. One stroke survivor reported not wanting to engage in sexual activity because he felt he would be unsuccessful and “[he didn’t] want to sign up for experiences of failure—[he] had a lot of that since [he] had [his] stroke” [6]. Several studies found a strong correlation between post-stroke depression, anxiety, and sexual dysfunction [6]. A study of participation post stroke revealed that higher levels of depression were correlated with decreased quality of life, issues with sexual activity and sexual dissatisfaction [8]. The most common sexual limitation among stroke survivors is the fear that sexual activity will cause a recurrent stroke [5–7]. Many couples cease sexual activity post-stroke due to fear of harming or further disabling the stroke survivor. Often a combination of these barriers prevents couples from engaging in intimate and sexual endeavors.

Following a stroke, the relationship between the survivor and partner changes dramatically and may require adaptation and modifications [2]. For the rehabilitation process and post-stroke care to proceed smoothly, good communication between partners is crucial. Several empirical studies revealed that lack of marital communication after stroke is a very common experience [2–4]. Relating to one another is more difficult for couples following a stroke and this is especially influenced by the nature of the pre-stroke relationship. The quality of marriage pre-stroke plays a very important role in the post-stroke relationship. Harris et al. [2] found that prior negative marital experiences led to feelings of resentment about caring for a spouse with Alzheimer’s that could undermine a relationship; conversely, positive relationships before the onset of illness commonly led to preservation of intimacy.

Stroke presents many threats to communication between partners. Aphasia can greatly impact on the nature of a relationship between survivor and partner. When a stroke survivor can no longer share feelings and emotions this can contribute to their partner’s loneliness, anger, and frustration [3]. Even for those who have unaffected speech, sexuality and intimacy are often difficult and awkward topics of conversation [5]. Many couples found that poor communication was more difficult to handle than physical limitations [6]. A lack of communication poses a threat to intimate relationships and the maintenance of sexuality post-stroke.

Healthcare providers can alleviate the stress of discussing sexuality and intimacy between partners. A study of post-stroke patients found that about half of the participants were interested in receiving sexual counseling at some point during the rehabilitation process [4]. However, many couples reported that sexuality was seldom addressed by clinicians, and when it was addressed, it was only in response to a patient’s initiative [3]. Stroke survivors feel that healthcare professionals should have skills to speak about sexuality in a

comfortable manner while still maintaining good rapport [7]. In one study, 75% of patients reported that they would like to have received information regarding sexuality but only 15.2% of participants reported receiving information. Among those participants, 77.8% felt that they had not received enough information in general regarding sexuality [7]. Stroke survivors thought this topic should not be addressed immediately after the stroke but they did not have suggestions about best timing [8]. Stein et al. [7] found that most study participants preferred to receive information about sexuality from a physician, nurse, or therapist. Survivors wanted to discuss concerns about sexuality and intimate relationships post-stroke rather than receiving formal intervention; unfortunately, many patients do not have the opportunity to express their concerns [9].

Gaps between patient preferences and information delivery were also illustrated in studies investigating the perspective of healthcare professionals. Healthcare professionals explained the barriers to the discussion of sexuality in rehabilitation settings. One of the most prominent reasons was that most professional disciplines do not feel that sexuality is within their scope of practice and therefore avoided the topic or referred patients to specialists [5, 7, 9]. Clinicians also felt that there was not enough time during the acute phase to discuss sexuality and that if the topic were to be raised, they were not adequately trained to provide advice or interventions [5, 6, 9]. Several other common barriers included embarrassment, fear of ruining the clinical relationship, and a perception that sexuality is unimportant to stroke survivors [5, 9]. Many healthcare professionals also reported that it would be inappropriate or especially uncomfortable to discuss sexuality with certain populations including those who live alone or in nursing homes, widows, those with cognitive impairments, gay and lesbian patients, or simply those who are “older” [5]. Healthcare professionals were much more likely to discuss sexuality with younger patients who they perceived as more likely to be sexually active [9].

Providing patients with the opportunity to discuss sexual issues during rehabilitation requires that healthcare professionals are adequately trained to address the topic. In one study, clinicians from a rehabilitation setting reported discomfort discussing sexuality because they lacked the opportunity to learn how to do so [9]. Some healthcare professionals preferred to address sexuality indirectly such as discussing continence, relationships, or sleeping arrangements before broaching sexuality. Indirect language was sometimes used to allude to sexuality, but it was not often brought up outright [9]. Since patients and partners are often too embarrassed to bring it up, Kitzmuller & Ervik [3] proposed that all healthcare workers be trained and encouraged to initiate conversations about sexuality with all patients.

Several clinicians reported that they did not discuss sexuality because it was not included in the hospital stroke policy or they were unaware of any policy or procedure, and the conversation was therefore deemed unimportant by hospital management [5, 9]. In some workplaces, resources were available but clinicians under-utilized them or were unaware of their existence [5].

Spouses or partners were rarely included in studies about sexuality, despite their crucial role in the rehabilitation process. Only a few qualitative studies addressed the needs of caregivers who are spouses/intimate partners. They discussed the emotional aspects of caregiving, coping mechanisms, changing perceptions of their partner, and sexuality or emotional intimacy [2, 3]. To cope with the impact of stroke on their lives, they reported attending support groups, talking with friends, exploring other options for the care for their loved one and changing their perceptions of what characterized intimacy [2].

Post-stroke care is especially difficult for partners of survivors who undergo personality changes such as becoming withdrawn, passive, and considerably different in functional,

emotional, and cognitive abilities [3]. A common theme was the difficulty of figuring out where their caregiving role ended and their spousal role began; the caregiver role can be so exhausting that the spousal role seemingly disappears [3, 6]. By the end of the day, partners found themselves exhausted from the constant care, and yet unable to sleep due to the fear of a recurrent stroke [3]. Fatigue and lack of sleep undermine wellbeing as well as intimate relationships.

Embarrassment has been commonly reported among stroke survivors as a reason for ceasing sexual activity [6]. Partners also reported embarrassment as a reason to forego sexual relations and restrict intimacy. Couples preferred to give up sexual activity rather than endure a potentially embarrassing situation, especially if they had tried and failed in the past [3]. Discussions of sexuality were rare because spouses or partners felt that it was important to shield the stroke survivor from topics that might be emotionally stressful [3].

Spouses report feeling neglected by healthcare professionals; they were not often provided the opportunity to talk about personal issues with healthcare professionals as time in therapy revolves around the needs of the stroke survivor.

As a leading cause of disability in the United States and worldwide, stroke poses extensive potential problems in the lives of stroke survivors who frequently find that they experience a significant decrease in sexuality and intimacy with their partners. Korpelainen et al. [4] reported that around a half of stroke survivors (49%) and a third of their spouses (31%) were dissatisfied with their post-stroke sexual life. Despite a growing body of research regarding sexuality from the perspective of a stroke survivor, little research has examined that topic from the partner's perspective. A decrease in intimacy and sexuality can be associated with a decrease in quality of life for a stroke survivor and their intimate partner [8]. A better understanding of sexuality from the perspective of the partners of stroke survivors is needed to design an effective protocol for discussing sexuality in the rehabilitation setting. The purpose of this study is to examine changes in intimacy and sexuality after stroke, from the spouse/partner perspective.

Methods

This study used a qualitative approach with interviews about changes in intimacy and sexuality among spouses or partners of stroke survivors.

Recruitment

Participants were recruited by phone from a stroke registry at a major teaching hospital. Individuals on that registry had given permission to be contacted about possible interest in future research studies. Colleagues in community settings were also given flyers about the study to share with clients or to distribute at stroke support groups. Each participant provided informed consent prior to participating in the study in accordance with the research protocol that was approved by the University Human Research Protection Office. This included consent to the digital recording of the interview, that participation was voluntary and participants were informed that they had the right to skip any questions or to withdraw at any time during the interview.

Specific inclusion criteria were: (a) spouse or partner of someone who has had a stroke; (b) English speaking and able to answer questions; (c) age 20 years or older; (d) at least 3 months have passed since the onset of the partner or spouse's stroke; and (e) any

ethnicity/race, female or male. Individuals were excluded if they did not meet these criteria or were unable to participate in an interview. When individuals agreed to participate, they were scheduled for an interview in person or by phone.

Measurement Tools/Data Collection

Demographic information was collected with a questionnaire that included questions about employment, volunteering, race/ethnicity, education, age range, gender, marital status, and length of relationship with stroke survivor. Following the demographic questionnaire, open ended semi-structured interviews were done. Topics included changes in enjoyable activities since the partner's stroke; changes in relationship, sexuality and intimacy; and sources of information or support about intimacy and sexuality. A full list of trigger questions is included in the Appendix.

Participants

The nine participants in this study included seven females and two males. Ages ranged from 40 to 70 years and they had been in their relationships between 6 and 47 years. Six participants were Caucasian, one was Hispanic, and two were African American. Four interviews were done in person and five took place over the phone.

Data Analysis

Interview recordings were transcribed verbatim and carefully read at least twice by two study team members before separate initial coding of transcripts. Codes were derived from meaningful units, then themes were constructed using thematic analysis techniques [10]. Study team members shared their separate coding and identification of themes. Discrepancies were discussed to formulate consensus about analysis.

Results

Four main themes were identified across interviews to characterize the changes in sexuality and intimacy post-stroke from the partner's perspective. Those themes were: (1) Maintaining closeness and togetherness, (2) Redefining sexuality and intimacy after stroke, (3) Coping with limited resources or support, and (4) Wishing health professionals would discuss sexuality and intimacy issues early and often.

Maintaining Closeness and Togetherness

Many partners reported an improved relationship post-stroke. It was mentioned often that the stroke did not change the relationship; in some cases, the stroke strengthened the relationship. One couple was dating at the time of the stroke and decided afterward to move in together, got married, and began planning to have a family. Another woman described her relationship with her husband as being good before, but getting even stronger afterwards.

The bond that we had even before he had his stroke, I think it's just been enhanced.

I actually think that the stroke made us realize how much we did want to be together.

Some couples started doing new things they hadn't done previously, such as going on walks and exercising together. Other participants spoke about maintaining their relationships by continuing activities they had done prior to the stroke, such as watching movies and television together, sharing meals, and holding hands.

We still sit next to each other and hold hands, that kind of a thing.

Describing whether the stroke changed their closeness and ways of doing things together, one participant declared

It hasn't. We were able to overcome them. We had to learn a different way of communicating, and I've noticed too, that we don't necessarily have to talk to communicate.

Another proclaimed that the stroke did not interrupt their enduring dedication:

It's made us even closer ... we're just carrying out the vows that we took when we got married, and that's in sickness and in health ... We were already close but we've become even closer.

Although stroke was traumatic, participants reported resilience and determination to maintain emotional bonds. Rising to meet the challenges was difficult, but for some couples even strengthened the relationship.

Redefining Sexuality and Intimacy After Stroke

Participants often reported that sexuality and intimacy meant something different now. While many mentioned ceasing all activity immediately after the stroke, those who resumed sexual activity talked about the way things changed. One person described an important interaction shortly after her partner's return home:

I just literally got him undressed ... and I got undressed and I just held him for about two hours. It wasn't sexual, it was just very intimate. It was still really emotional and powerful.

Another described subtle and valuable everyday intimacy:

Our intimacy with each other is looking at each other, giving each other a wink or a blink...our conversations where we can laugh and talk about things that we are interested in... It's that type of intimacy now.

Overall relationship changes were reported across interviews as well. One participant mentioned how her spouse would get frustrated by changes in physical strength, but once they worked together to figure it out, their relationship improved and he gained more confidence. Another participant talked in depth about her husband's changes in emotional regulation. This required her to alter her view of intimacy into something more spiritual rather than physical. A similar experience was described by a man whose wife experienced anger and frustration as well as other problems with emotional regulation after her stroke. He mentioned how he decided to let her initiate sexual activity rather than continue his prior pattern of pursuing her and feeling like he was forcing her to do something she may not want.

Three participants discussed how sexuality, while important, was not crucial to sustaining their relationship or marriage. One participant described being close socially,

emotionally, and culturally with her partner rather than focusing just on physical connections. Another participant talked about how seriously she took her marriage vows and how other aspects of their relationship were more important than sex.

I don't just love him because I sleep with him. When you marry somebody, if you really take the vows seriously, it's for sickness and in health. I would much rather have him than the sex.

One of the most common experiences across participants was ceasing sexual activity immediately after stroke due to the therapy and recovery processes. A few participants expressed the importance of patience and perseverance when it came to resuming intimacy and sexuality. Sexuality and intimacy often look different post stroke and a few participants felt strongly about working together to establish a new sex life.

One participant emphasized that it's important not to push a stroke survivor too hard, but persistence is still important. Another felt it was important to balance precaution with persistence by not moving too quickly while continuing to pursue more sexual interaction.

I think it's really just being patient with one another and just working through the challenges.

Someone proclaimed that it was scary to have sex for the first time after her husband's stroke, but discussed how important it was to persevere.

Even though there's hesitation, you still have to make sure that you get back into something.

It was apparent that each of these participants found their own ways to redefine how they continued their relationship in terms of sexuality and intimacy.

Coping with Lack of Resources or Support

When asked about supports and resources they received about sexual intimacy, participants reported receiving no information during their partner's hospitalization and minimal information, if any, after discharge.

There was no discussion about sexual intimacy or anything.

I can't say we really had any sources. I can't remember the topic ever coming up with anybody in the hospital.

Participants were unhappy that they did not receive any information and wished there was discussion about sexual intimacy during the rehabilitation process. Without any resources, they felt unprepared for sexual activity when they returned home.

We were in the dark ... because we didn't even know if he would be able to have sex. We got no information whatsoever.

We had no idea what to expect. We totally went into it blind after the stroke because we were lost initially. We didn't know what would function, what wouldn't function.

Lack of education meant the fear of another stroke interfered with sexual pleasure:

It was a little scary to have sex for the first time. I don't even remember how it happened, but it was different...I was kind of like; I don't want to hurt him. I don't want

to cause anything else to happen, like I even had a hesitation, like okay, if we have sex can I move a blood clot?

Participants reported that intimacy and sexual function were ignored during hospitalization or rehabilitation. This caused confusion, disappointment and frustration.

Wishing Health Professionals Would Discuss this Issue Early and Often

Several participants felt that intimacy and sexuality should be addressed soon after stroke to provide at least a little information for them, then revisited with more depth over time. Each person provided unique perspectives on when and how to address this topic. Some were less concerned at first because they were focused on their partner's recovery. However, others felt strongly that it should at least be acknowledged very early so they knew it could be addressed more as time progressed.

I think they should have something right from the get go. I'm a big believer in repeat, repeat, repeat. ... so, I think if they could start it early and then keep repeating it, I think it would be very helpful.

One participant suggested that sexuality should be addressed privately with the stroke survivor first, and then addressed with the partner afterward. The most important thing, according to another participant, was to start a line of communication and keep it open. This includes an open line of communication with a professional who has experience and can provide recommendations and also open the door for the couple to discuss concerns. Another participant would have liked resources at discharge because, for her, sexual intimacy became more of an issue once her spouse returned home and things started to calm down.

In addition, some participants felt that support groups would be an extremely helpful resource to supplement and expand on information from health professionals. They believed that firsthand information from someone with experience can be even more valuable than handouts or discussions with health professionals. One person declared that

The best person to talk to is somebody who's been there, and done that, and come out on the other end.

One participant described how the hospital where her husband was treated had classes about managing various comorbid conditions and proposed that it would be helpful to provide an optional class on intimacy and sexuality. She emphasized that this would be a good place to provide support and information about sexuality for people who wanted to know more.

Participants expected to receive information, encouragement and guidance from health professionals and were disappointed that this was not provided.

Discussion

The aim of this study was to gain insight about spouse/partner perspectives on sexuality and intimacy post stroke. The four themes provide valuable information regarding relationship dynamics post-stroke, what information partners received from health care providers, and their preferences for receiving such information.

The first theme on maintaining closeness and togetherness contradicted past research about sexuality and intimacy after stroke. Prior research revealed that many marriages and relationships experienced hardships post-stroke due to strain with communication, relationship changes, and not knowing where the caregiver role ended and the spouse/partner role began [3, 6]. Participants in this study discussed how their relationships were maintained or even improved after stroke. This could be explained by findings of Harris et al. [2] revealing that the nature of the relationship pre-stroke often determined what the relationship would be like post-stroke. Perhaps participants in this study had stronger prior relationships than did participants in other studies. In addition, the open ended nature of this inquiry permitted participants to speak freely about all aspects of their intimate relationships post stroke and was not focusing exclusively on problem or challenges related to sexuality. This approach could have provided a more complete picture of their range of experiences.

The second theme, redefining sexuality and intimacy after stroke, is not well represented in the current literature. This study reveals new perspectives on how participants changed their views regarding the meaning of sexuality and intimacy. Participants mentioned holding, gazing into one another's eyes, or lying together rather than engaging in physical sex. Some mentioned that intercourse was not the only important part of a relationship and it was replaced with increased intimacy after stroke. Such information could benefit couples who are navigating the adjustment process after stroke. Relationships could be supported by specific activities and experiences, encouraging couples to explore other dimensions of intimacy.

None of the participants in this study received any information or support regarding sexuality or intimacy during the acute phase, in rehabilitation or beyond. This finding concurs with other studies showing that intimacy and sexuality were seldom if ever discussed with survivors and even less with their partners/spouses, or when this was discussed it was only when the patients or couples initiated the discussion [3]. Many participants reported being unhappy that they did not receive any information or support about intimacy or sexuality. This endorses the existence of a prominent information gap that demands attention.

Participants felt that health professionals should address intimacy and sexuality early and repeat or expand that dialogue during rehabilitation and afterward. This reinforces previous research showing that 50–75% of research participants were interested in receiving sexual counseling at some point during the rehabilitation process, although only 15.2% of participants actually received any such service [4, 7]. The present study revealed that some partners prefer to get information about sexuality early while others prefer waiting until rehabilitation or after return home. This finding suggests that it would be beneficial to acknowledge sexuality and intimacy early as a potential concern. Such a move could give the stroke survivor and partner the opportunity to get more information at that point, but to also inform them that sexuality and intimacy among a range of topics can be discussed at any point—whenever they feel the information is relevant to their needs.

Sexuality and intimacy are not adequately addressed in the discharge information provided to stroke survivors and their partners. That void may have many explanations: clinicians are unsure whose scope of practice includes sexuality concerns, the lack of training on how to discuss sexuality and intimacy with patients, and clinicians concerns that this topic will compromise patient rapport [5, 6, 9]. While participants in this study reported getting nothing about sexuality or intimacy, it is possible that the topic was addressed at least somewhat but the couple was not ready to absorb the information.

Several models provide introductory training on ways to address sexuality in various healthcare settings, such as the PLISSIT model [11] the Sexual Health Model [12] and

the Extended PLISSIT model [13]. These models focus on individuals with acquired disability or chronic conditions. Utilizing such models in hospitals and rehabilitation settings could enable clinicians to address concerns about intimacy and sexuality post-stroke. Guo et al. [1] suggested that, with proper procedures in place, healthcare professionals are more inclined to discuss sexuality and intimacy with their patients. Making information and support available to partners/spouses whenever they may need it would also contribute to addressing concerns regarding intimacy and sexuality.

There are several limitations in this study. First, all participants received initial care from the same large teaching hospital in a midwestern city of the United States. This may limit the variety of experiences to those employed in this particular hospital setting. Participants were mostly women and all participants were heterosexual. Future studies should incorporate a wider variety of perspectives from men, LGBTQ individuals, and people from other places. Longer term contact with participants would also provide the opportunity to discover how these experiences might evolve at different stages in the recovery process. Lastly, this small convenience sample was not a representative sample of the entire population of spouses/partners of stroke survivors. However this study does provide rich first-hand accounts of the lived experiences of participants and therefore other people who have experienced stroke, their partners and clinicians may find resonance with their own personal and clinical concerns. Other strengths of this inquiry include the option to participate either by phone or face to face. Being able to choose how to engage in the research may have afforded participants the opportunity to speak more candidly about their experiences and concerns.

Clinical Implications

The results of this study shed light on the importance of addressing sexuality and intimacy with stroke survivors and their partners. Many participants felt ill equipped to address intimacy and sexuality and often did not know where to find information or which health professional to consult. Clinicians can develop resources, open lines of communication about sexuality, and address couples' concerns when they need support. These findings indicate that health care providers need training on how and when to address intimacy and sexuality to effectively provide relevant and timely information for stroke survivors and their partners. This study also reinforces the need for support groups and suggests that groups address the topic of sexuality with their members.

Conclusion

Sexuality and intimacy can be difficult topics to approach with patients and their partners, however it is important for healthcare providers to introduce information and resources on these topics. This study reinforces findings from prior research and introduces further depth that partners are not receiving adequate information or support following a stroke. They are left feeling unprepared to resume sexual activity when they return home. This information gap suggests that rehabilitation managers should consider finding ways to ensure that clinicians are better able to effectively address these topics. Clinicians could advocate for policies that promote the availability of sensitive, relevant and timely information on relationships, intimacy and sexuality as well as appropriate training and resource development. Each health profession can identify ways to address this important aspect of rehabilitation,

then ensure that they have adequate practice standards and competencies. Following stroke, couples deserve information to help them navigate changes and maintain their relationships, perhaps in new ways as needed. With knowledge, support and assistance regarding sexuality and intimacy, stroke survivors and their spouses or partners can be better prepared to enjoy and sustain fulfilling relationships that are fundamental to quality of life.

Appendix

- What kinds of things did you enjoy doing with your spouse/partner before the stroke? Are you still doing those things? (If not, can you tell me why not?)
- How has your relationship with your spouse/partner changed after his/her stroke?
- Has sexual intimacy with your spouse changed since his/her stroke? What is the biggest change? How have those changes affected the closeness you have in doing things together?
- Do you think that physical changes or emotional changes in your spouse since the stroke have had more effect on sexual intimacy in your relationship?
- What kinds of support, resources, or information did you get from health professionals about sexual intimacy during your spouse's hospital or rehab stay? And after discharge? How satisfied were you with that support/information?
- What other types of support have you received in regards to changes in sexual intimacy? (i.e. Social support, family/friends/support groups, churches/temples/community groups)
- What resources have you used to get more information about sexual intimacy aside from healthcare providers? (i.e. Internet searches)
- What resources do you wish were available to get more information about sexual intimacy?
- In your opinion, when or how should sexual intimacy be addressed with spouses of stroke survivors?

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interests.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

References

1. Guo, M., Bosnyak, S., Bontempo, T., Enns, A., Fourie, C., Ismail, F., Lo, A.: Let's talk about sex!-improving sexual health for patients in stroke rehabilitation. *BMJ Qual. Improv. Rep.* 4(1), 1–4 (2015)

2. Harris, S.M., Adams, M.S., Zubatsky, M., White, M.: A caregiver perspective of how Alzheimer's disease and related disorders affect couple intimacy. *Aging Ment. Health* **15**(8), 950–960 (2011)
3. Kitzmuller, G., Ervik, B.: Female spouses' perceptions of the sexual relationship with stroke-affected partners. *Sex. Disabil.* **33**(4), 499–512 (2015)
4. Korpelainen, J.T., Nieminen, P., Myllylä, V.V.: Sexual functioning among stroke patients and their spouses. *Stroke* **30**(4), 715–719 (1999)
5. Mellor, R.M., Greenfield, S.M., Dowswell, G., Sheppard, J.P., Quinn, T., McManus, R.J.: Health care professionals' views on discussing sexual wellbeing with patients who have had a stroke: a qualitative study. *PLoS ONE* **8**(10), e78802 (2013)
6. Rosenbaum, T., Vadas, D., Kalichman, L.: Sexual function in post-stroke patients: considerations for rehabilitation. *J. Sex. Med.* **11**(1), 15–21 (2014)
7. Stein, J., Hillinger, M., Clancy, C., Bishop, L.: Sexuality after stroke: patient counseling preferences. *Disabil. Rehabil.* **35**(21), 1842–1847 (2013)
8. Seymour, L.M., Wolf, T.J.: Participation changes in sexual functioning after mild stroke. *OTJR: Occup. Particip. Health* **34**(2), 72–80 (2014)
9. Richards, A., Dean, R., Burgess, G.H., Caird, H.: Sexuality after stroke: an exploration of current professional approaches, barriers to providing support and future directions. *Disabil. Rehab.* **38**(15), 1471–1482 (2015)
10. Braun, V., Clarke, V.: Using thematic analysis in psychology. *Qual. Res. Psychol.* **3**(2), 77–101 (2006)
11. Annon, J.: The PLISSIT model: a proposed conceptual scheme for the behavioural treatment of sexual problems. *J. Sex Educ. Ther.* **2**(1), 1–15 (1976)
12. Farnam, F., Janghorbani, M., Raisi, F., Merghati-Khoei, E.: Compare the effectiveness of PLISSIT and sexual health models on Women's sexual problems in Tehran, Iran: a randomized controlled trial. *J. Sex. Med.* **11**(11), 2679–2689 (2014)
13. Taylor, B., Davis, S.: The extended PLISSIT model for addressing the sexual wellbeing of individuals with an acquired disability or chronic illness. *Sex. Disabil.* **25**(3), 135–139 (2007)