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ORIGINAL PAPER

# Female Spouses' Perceptions of the Sexual Relationship with Stroke-Affected Partners

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**Abstract** Sexuality is known to be important for couples' function after stroke. Although maintaining a satisfying sexual life has a positive influence on self-esteem and predicts overall quality of life, there has been little focus on healthy spouses' sexuality after stroke. The purpose of this Norwegian study is to provide an interpretation of the influence of stroke on female spouses' sexual relationship with their disabled partner after stroke. Sexuality is understood as an integral and inseparable part of a person's personality and a basic aspect of being human. A phenomenological hermeneutic approach inspired by Merleau-Ponty was chosen. Narrative interviews were conducted with twelve female spouses who had lived 3–25 years with their stroke ridden partner. The data analysis resulted in four main themes: Married to a "stranger"; The shift from partner to caregiver; Sexuality wrapped in silence; A void to live with. These themes highlighted the influence of the residual disabilities, emotional experiences and overall life changes on spouses' sexual life with their partner. Spouses experienced their partner as changed and sometimes as having become a stranger. The former mutual relationship was turned into a caregiver/care receiver relationship. Spouses felt they were confronted with emotional turmoil that interfered with their sexual life. Communication problems added to couples' difficulties and some spouses decided to end the frustrating sexual relationship with their partner. Although the spouses managed to find different coping strategies, the loss of a fulfilling sexual life added to their burden. Health professionals did not address sexuality. Specialized training programs are needed to increase professional awareness and competency regarding sexuality after stroke.

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## Introduction

The sudden and life changing consequences of a partner's stroke are known to have a negative influence on the life of the healthy spouse. Stroke represents a threat to spouses' life satisfaction and health-related quality of life [1–3]. Spouses face existential crisis after stroke and feelings of fear, estrangement and loneliness occur [4, 5].

However, there are few studies dealing with sexuality as an important part of stroke couples' marital relationship. In the existing studies, there seems to be an agreement on the devastating effects of stroke on sexual life for stroke survivors and their spouses [6–10]. According to Schmitz and Finkelstein [11], both stroke survivors and spouses report considerable changes in sexual frequency, functioning and desire. Stroke survivors' partners seem to play an important role in the decline of sexual activity after stroke, as partners' fears, anguish or lack of excitation withhold them from encouraging sexual activity [10]. Korpelainen's [6] findings show that spouses experience a significant decline of libido, coital frequency, arousal and satisfaction with sexual life post-stroke.

According to Lemieux et al. [7], spouses of aphasic stroke survivors experience their partner's emotional instability as interfering with sex and they report reduced frequency of intercourse. These spouses miss the emotional intimacy that comes from talking about their relationship and for half of them the importance of and satisfaction with sex declined. In a study by Giaquinto et al. [10], nearly 90 % of the participating spouses had problems maintaining the sexual relationship with their disabled partner due to fear of relapse, anguish, lack of excitation or even horror.

Persons who experience illness that affects brain function seem to be especially at risk of being hindered in expressing their sexuality, since cognition, emotions and functionality may be affected and will influence the marital relationship [12]. Mitchell-Pedersen's [13] findings indicate that spouses of cognitively disabled stroke survivors experience impaired intimacy and that the quality of the pre-stroke relationship seems to be important for coping with the challenges in sexual life after stroke.

Couples who experience sexual problems after illness resulting in permanent disabilities are exposed to cultural and social limitations, stigma and desexualization [14]. Schmitz and Finkelstein [11] conclude that although stroke survivors and their partners may feel uncomfortable talking about sexuality with health care providers, they are in need of help and support to face their complex sexual concerns post-stroke.

Although changes in spouses' lives after stroke have been thoroughly analysed, their experiences of the sexual relationship post-stroke have been poorly described. In the existing studies stroke survivors' and spouses' perspectives are often mingled. Studies providing qualitative in-depth explorations of spouses' perceptions of the sexual relationship with their disabled partner are lacking.

It is claimed that the purpose, value and experience of sexuality are similar for men and women [15, 16]. Nevertheless, male sexuality is often associated with masculine values such as being strong, active and able to perform intercourse [17] whilst female sexuality is perceived as responsive rather than active and with a lower biological urge [18]. According to Basson [18], female sexuality is complex and variable and depends on relational and emotional factors. Leiblum [19] states that major components of women's sexual satisfaction are commonly ignored, such as the pleasure from sensual touching, communication, trust and intimacy. Basson [18] suggests that non-sexual rewards and gains may have far more relevance to women than the biological urge when women seek sexual experiences.

Studies dealing with sexuality after illness in a gender perspective are missing, especially in regard to stroke. Therefore, the aim of this study is to provide an interpretation of the influence of stroke on female spouses' sexual relationship with their disabled partner.

## Methods

A phenomenological hermeneutic approach inspired by Merleau-Ponty [20] was chosen to illuminate the meaning of participants' experiences in the context of their life world. Merleau-Ponty's" ([21], p. VII) view on lifeworld has been interpreted as a "being towards the world", meaning that human intentionality has its origin in embodiment ([20], p. 475). As human beings, we access and act upon our world through our lived bodies, as we simply *are* our bodies and we are perceived by others by means of *being* bodies. Through the body as a sense-giving orientation all experience is structured ([22], p. 338). The perception of our own and others' bodies opens for our familiar dealing with the world and our own experiences intersect with others' experiences like gears ([20], p. xxii).

Embodiment also prepares the ground for our sexual experiences. According to Merleau-Ponty ([20], p. 196) sexuality is not a finite and isolated dimension of existence, rather it colors "… one's being towards the world…" and should be understood as one more form of intentionality. "There is interfusion between sexuality and existence, which means that existence permeates sexuality and vice versa. Sexuality is "… coextensive with life…" as it deeply influences the form of experiences: "… it is always present in our lives like an atmosphere" ([20], p. 195). As human beings, we find ourselves situated and involved in both a physical and a social world ([20], p. 419). Sexuality is therefore situated in man's socio-historical situation, as he states: "Man is a historical idea and not a natural species" ([20], p. 198) and socio-cultural features will always be part of man's sexual existence.

### The Study

#### *Research Setting, Participants and Recruitment*

This study is part of a larger research project to illuminate the long-term experiences of stroke couples [23]. Data collection was performed in rural and urban areas in six counties in Norway.

Twelve female spouses participated. Eleven were ethnic Norwegians and one was from a non-Western culture. Nine spouses were recruited by their husbands and three by participating friends. The stroke survivors had been recruited by leaders of local branches of the Norwegian Stroke and Aphasia Organizations and by leaders of home care nursing. Spouses should have lived with their disabled husbands for a minimum of 3 years after stroke onset.

#### *Interviews*

The first author conducted one narrative interview with each spouse. Interviews were conducted in participants' homes (10) or in hotel rooms (2). Each interview lasted between

60 and 120 min. Interviews were held in Norwegian, audio-recorded and transcribed verbatim by the first author. Field notes of silent data (emotional expressions, gestures) recorded during the interviews were considered during data analysis as part of the context.

Initially the spouses were asked to narrate their own and their partners' pre-stroke life. They were encouraged to tell about the effect of stroke on their own life and on the couple's relationship. Sexuality was one of the areas that were explored by asking spouses about any changes they experienced in their sexual life with the partner.

### *Data Analysis*

Data analysis was guided by van Manen's [24] phenomenological hermeneutical approach regarding phenomenological themes and phenomenological writing [25]. The aim of phenomenological writing is to enable the reader to grasp the essential meaning of participants' experiences. The analysis process started immediately after each interview. The first author listened to the interview and wrote interpretive and reflective notes. Interviews including field notes were read several times to grasp the text as a whole. In the next step, the interview texts were examined for expressions of meaningful units focusing especially on the sexual part of the relationship. These expressions were condensed, clustered and compared across the interviews and with the understanding of the text as a whole, including the contextual notes. Van Manen's ([24], p. 172) recommendations about reflecting on the four human existentials of lived body, lived space, lived time and lived human relations were followed during data analysis. The existentials of the lived body and lived human relations emerged particularly vividly in the data as sexuality is one of the lived body's expressions, which colors and is colored by human relationships. These reflections together with the writing and rewriting process during analysis facilitated the formulation of themes aimed at capturing participants' experiences. The themes were reflected upon by both authors before they decided on the final themes.

## Results

Four main themes and four subthemes emerged to illuminate the life-changing consequences of stroke on female spouses' sexual relationship with their partner. The four main themes were: Married to a stranger; The shift from partner to caregiver; Sexuality wrapped in silence; A void to live with.

### Married to a 'Stranger'

Spouses perceived that their partner had undergone considerable changes in functional, emotional and cognitive ability due to the stroke. Their residual paresis (Table 1) had a negative influence on functionality and appearance and their movements and reactions were slower than before. Spouses stated that their husbands were no longer able to engage in sexual activity and they described their partner as withdrawn, passive and without initiative. In some cases husbands were perceived to show more positive behavior in social or work-related settings than at home. Although spouses felt compassion with the disabled partner and grieved the loss of their familiar partner, they felt irritated by their husband's failing interest in contributing to family activities and lack of responsiveness. Spouses'

**Table 1** Demographic characteristics

| | |
|---|---|
| Spouses' age at time of onset (years) | 40–62 ($M = 52$) |
| Duration of marriage at time of onset (years) | 2–43 ($M = 31$) |
| Duration of marriage at time of interview (years) | 5–57 ($M = 39$) |
| Time range since stroke onset (years) | 3–25 ($M = 9$) |
| Husbands' disabilities: | Paresis: *$n = 11$ (dependent on crutches $n = 5$, partly or mainly dependent on a wheel chair $n = 5$)*<br>*Aphasia: $n = 6$*<br>*Emotional instability $n = 6$*<br>*Cognitive impairment $n = 8$ (loss of memory, reduced concentration or orientation)*<br>*Dementia: $n = 1$*<br>*Other problems post-stroke: fatigue, neglect, epilepsy* |
| Couples with children living at home at stroke onset | 0 |

competing feelings of sorrow, compassion and irritation led to uncertainty about the marital relationship.

> …someone asked me recently: Would you have done the same thing today? [stayed with the disabled husband]. You know I don't dare to answer this question…. I don't dare to tell because of the things I've learned… [crying].

Spouses found their partners' cognitive and emotional changes harder to accept than the physical limitations. Irritability, emotional instability and depression were difficult to adapt to. Some spouses perceived that their partner had lost intellectual and empathic capacity or experienced that their former strong and capable husband had turned into a fragile and vulnerable person. Other spouses perceived their partner's behavior as childish and demanding. Sometimes the changes were so extensive that the disabled partner was perceived as a completely different person. These experiences strongly influenced the sexual relationship.

> In the evening when we undressed in the bathroom, he looked so different and it struck me, he's a stranger to me, I cannot undress with a stranger present…so during the first time it was a huge transition. I had to pull myself together and to think: it is him after all…now I've got used to it, but of course the relationship between us is a completely different one… .

Husbands suffering from extensive brain damage were perceived to have changed personality completely. Their aggressive behavior and restlessness and the consequences of their memory loss threw these spouses into a turmoil of ambivalent emotions.

## The Shift from Partner to Caregiver

### *Feeling Exhausted*

When stroke survivors were dependent on help at home, spouses had to assist their husbands in activities of daily living including help in the bathroom and toilet. Roles and relationships in the marriage changed and the sick partner became dependent on the spouse's help in multiple settings. An imbalance within the marital relationship emerged.

Being obliged to fill all these new roles was an exhaustive endeavor for spouses and some of them even experienced health problems in the aftermath of their husbands' stroke.

> Some days I'm completely exhausted…before I had no sick leaves at all but this has changed after he got sick. I have to use all my energy at home…I get exhausted so easily now, I have so little capacity…I'm no longer the patient person I used to be. I'm so tired and some days I think I'm finished.

Lack of sleep and fatigue contributed to spouses' exhaustion along with the mental strain of adapting to the consequences of stroke. Spouses conveyed that they had not been prepared by health care workers for the challenges involved. Going through the crises and adapting to the caregiver role had been extremely demanding.

> It was such a huge grief going through those first years…I couldn't speak to anyone about it… It would have helped to speak with health care workers, measures should be taken…I wish there were better possibilities for rehabilitation and assistance. That's important, as otherwise we'll both become patients, the two of us.

Spouses felt a huge burden of responsibility to improve their husbands' wellbeing. They supported their husbands' rehabilitation efforts and motivated them to go back to working life and leisure activities. In addition they had to balance between caregiver duties, alterations in family and parental roles and their own working life. There was neither energy nor time left to attend to their own needs and desires, including their own sexuality. "*Those first years I didn't even think about it* [sexual needs], *there were so many other things. It was quite enough for me just to keep on my feet…*".

### *Fleeing the Bedroom*

For some spouses the shared bedroom had become an area that aroused ambiguous feelings. The bedroom had turned into a sort of institution. During daytime spouses had to accept that their home environment was marked by technical aids and remedies. During night time it seemed harder to accept that their living space was invaded by the equipment. Some spouses decided to move out of their former shared bedroom. For other spouses this wish could not be fulfilled as there was only one bedroom in the flat.

Sometimes the bedroom turned into an area where conflicts arose. Spouses related how they wanted their sick partner to go to bed earlier than they did, in order to get a little space on their own. Conflicts arose when their partner refused to do so. Another area of conflict was if spouses felt they had to watch over their sick husbands' sleep, being afraid of their unusual breathing and snoring because they feared another stroke. The fact that many spouses had experienced their husbands' stroke during night time seemed to have left deep scars of fear.

> I panicked when I lay down beside him. I was so afraid. He got epilepsy after the stroke. All those thoughts came when I tried to sleep. The slightest sound and I still feel the same … when he turns around and moans…and then I have to ask him if there's something going on because it's better to ask too much than to find him [dead]….

Sometimes those prolonged fears interfered with the sleeping patterns of both the spouses and their husbands. Husbands got irritated at being disturbed in their sleep by spouses who checked on them to see if they still were alive. Thus the bedroom became an area filled with negative feelings for spouses. It was no longer a space that provided relaxation and intimacy.

## Sexuality Wrapped in Silence

Lack of communication about challenges in the marital relationship after the stroke was a common experience. Talking about their sexual relationship seemed to be especially difficult for the couples. Only one couple had experienced that health care workers had prepared them for the occurrence of these challenges. Although spouses missed having someone to talk to, they did not make any effort to seek advice. Standing on their own with the multiple problems that occurred called forth a deep feeling of loneliness in those spouses who could not share anything with their severely brain damaged husbands. Spouses with partners who did not suffer from cognitive impairment also revealed that they had not talked about sexual issues with their husbands.

> We haven't had any intimate relationship after the stroke…It was a silent agreement…we accepted it…we're old-fashioned, we don't talk about everything.

Spouses tended to shield their husbands from discussing issues connected with emotional strain. Talking about the sexual relationship was considered such an issue. Spouses who perceived their partners as weakened or still sick did not want to upset them. These perceptions surfaced even more during periods where husbands suffered from depressive reactions or showed emotional instability.

> Because I know he's sick I can't argue with him. I spare him and it piles up inside me… nothing reaches the surface ever…. [long pause].

Some spouses experienced loss of social network and complained about having few people they could rely on. Other spouses revealed that they did not want to discuss their sexual problems with friends as they did not want to compromise their husbands.

Spouses whose husbands suffered from aphasia perceived this disability as the worst consequence of the stroke. When their partner had lost the ability to share thoughts and convey emotions, spouses experienced loneliness in spite of living as a couple. Feelings of frustration and anger arose when mutual understanding was seriously disturbed. These communication hindrances affected the sexual relationship as the disabled husbands could no longer express their feelings and the couples were no longer able to discuss their sexual problems. Sometimes spouses felt that their husbands were living in a world of their own.

> He has everything there [points to her head], but he can't express himself, he takes everything in but can't get it out…There's nothing left, [referring to the sexual relationship] but it doesn't matter to me, I've come to terms with it…I don't know how he feels, I've tried to ask him but he doesn't say anything.

## A Void to Live with

### *Facing and Setting the Limits*

For most spouses the sexual relationship ceased to exist. It seemed that spouses preferred to end unsuccessful sexual activities rather than enduring them and feeling embarrassed: "*I don't think he's capable physically, we've tried but it was a mess, only frustrations for both of us…*". Spouses who had experienced frustrating sexual encounters set limits to their partners' sexual advances and withdrew from sexual activity. Some spouses related that there had been a joint decision between the partners to end the sexual relationship.

Some spouses experienced that their husbands had totally lost interest in sexual activity and even intimacy. These spouses did not want to insist, being afraid of making their partner feel uncomfortable. They felt more concerned about their husbands' wellbeing than their own and they were ready to provide comfort when sexual intercourse failed.

> I can't punish him because he's sick and not able to… [break]. He got these Viagra pills from his doctor and I think it's good that he talks openly with his doctor. But if he can't manage to [break] he gets very upset afterwards, then I tell him: Oh my goodness, it's not a matter of life and death.

When the negative experiences took over, the sexual relationship often ended in silence, "as a natural consequence of the stroke" as expressed by one of the spouses.

Exaggerated sexual needs of the sick partner occurred. These spouses got exhausted and were forced to set limits to their husbands' advances. One of the couples sought an open approach by consulting their doctor. With the doctor's help, the couple was able to return to the fulfilling sexual relationship that they had experienced before the stroke.

Spouses' limits were not always accepted by the sick partner, especially if the stroke had caused serious cognitive disability. Living with a sick partner who no longer could understand the spouse's limits led to a life situation that was injurious to the spouse's health.

### *Coming to Terms with the Loss of the Sexual Relationship*

Spouses' grief about an altered life situation could last from months to several years. During this time spouses had felt that the loss of a sexual life was only a small part of the whole. "… it became a void but nevertheless a void you could live with, the world must go on… not the smallest problem, but still a small one…" [compared with the other consequences of stroke].

In the beginning, the loss of the sexual relationship with the partner was overshadowed by fear for the partner's life and future health situation. Gradually spouses experienced multiple losses. Having been deprived of the sexual relationship with the partner was only one of the multiple facets of a life situation that had turned upside down.

> [holding back her tears] It was tough, it really was [silence]. But it was him, I certainly saw his handicap, but emotionally I think I reconciled myself to it…but I've rejected sexuality and those things… although our sexual life is not that great, our relationship is still good.

Spouses adopted different strategies in coming to terms with the loss of their sexual relationship with their partner. Some spouses turned to an attitude they described as "come what may". Other spouses experienced ambivalent feelings towards the sick partner. Thoughts about leaving their partner had crossed their mind. Due to heavy feelings of responsibility or expectations from their sick partner or other family members this choice had not been a real option. These spouses said that the initial compassion they had felt for their sick husbands had turned into self-pity when confronted with all the challenges and renunciations in the aftermath of stroke.

Other spouses tried to forget about their own sexual needs and expressed attitudes like: *"you have to make the best of it", "it doesn't really matter to me" or "you have to be glad* *for the good memories you still have…"*. Nevertheless it shone through that the loss of the sexual relationship left a void.

> Surely, when one is so young as I was then, 54 years old, it's obvious that you miss it [the sexual relationship], it was an important part of my life, at the same time, it does not affect me too badly, it isn't something I must have. I think it's worse for him…

Strong love in long-lasting relationships with firm foundations helped spouses to overcome the loss of their sexual relationship with their husbands.

> …we had had a happy marriage for 30 years, so you can't be bitter or think that you'd still like to have the same. I decided to think that I should be glad about the relationship we'd had. I decided to be satisfied with the way we had to live together [after the stroke]. I think that was the way I perceived it; at least it's the way I think about it today.

For spouses who felt that mastering the multiple obstacles after stroke had brought them closer to the partner, care, devotion and caresses were a means to fill the gap after the sexual relationship had ended. Humor was an important means to help couples deal with these challenges.

## Discussion

The aim of this study was to provide a phenomenological interpretation of the life-changing consequences of stroke on female spouses' sexual relationship with their husbands. The four themes and four subthemes show that there is an interfusion between sexuality and existence in spouses' lives [20, p. 196]. The multiple burdens spouses had experienced came on top of their husbands' physical, cognitive and behavioral changes and represented a serious threat to the sexual relationship. Sexuality as a basic aspect of the spouses' lives could not be separated from other life dimensions which were all strongly influenced by the consequences of stroke. This finding is in accordance with Bernhard and Dan's [26, p. 135] statement that women's sexuality should be seen as "*an expression of mutuality, involving not only physical gratification but also a sense of herself as a woman in the context of her life, her relationships, and emotions*".

Sexuality grounded in feelings of familiarity with the partner was threatened by the physical and cognitive changes and the unpredictability of the partner's behavior and reactions. Spouses' perceptions of the stroke-ridden partner as a stranger strongly interfered with continuation of the sexual relationship as experienced before the stroke. These findings are in accordance with the results from studies dealing with couples' sexual relationship after stroke, head injury and chronic illness [4, 27–29]. In these studies perceptions of strangeness and unfamiliarity are found to interfere seriously with intimacy and to threaten the marital relationship. The illness with its consequences becomes an "intervening layer" that prevents spouses from retrieving their former intimacy with their husbands [28, p. 330].

In the present study, failure of communication was caused by attempts to protect each other from emotional distress or by an aphasia-related breakdown of communication. The couples could no longer share their thoughts and feelings, and openness within the marital relationship was compromised. According to Esmail et al. [14], sexuality is not simply based on physical performance but on emotional closeness. Communication failure endangered the emotional closeness of spouses in this study and left them with burdening feelings of loneliness. Eriksson and Svedlund [28, p. 331] point to similar findings when describing “lost affinity” in the marital relationship. In their study, being shut out of the disabled partner’s feelings and thoughts led to a loss of intimacy and communion with the partner. Smooth communication as a precondition for couples’ sexual wellbeing has been described in several studies dealing with the sexual relationship after stroke and head injuries. Korpelainen et al. [6] found that inability to discuss sexuality was the most significant variable that explained why couples experienced sexual dissatisfaction after stroke. In Schmitz and Finkelstein’s [11] study, couples expressed a general discomfort talking about sex with their partner as well as with health care workers after stroke. Nevertheless, Schmitz and Finkelsteins’ participants expressed that they missed information and counseling and wanted the rehabilitation team to address sexuality.

According to Sternberg’s triangular theory of love [30], intimacy together with passion and commitment form the three sides of the love triangle. Sternberg describes intimacy as confiding in the partner, sharing genuine feelings and maintaining a shared communication style that strengthens the couple’s bonds. Findings in the present study show that couples’ communication and sharing abilities were at risk. In addition, the passion side of the triangle was endangered as spouses perceived their partner as unfamiliar or strange due to the physical, cognitive and behavioral changes. These perceptions and sometimes even negative feelings towards the partner did not prepare the ground for maintaining passion between partners. The shift from being a partner towards being a caregiver also had negative consequences for spouses’ perceptions of their husbands as desirable sexual partners. The settings for different role performances could not be kept apart and couples’ bedrooms became an area where the blending of roles became obvious. Before the stroke the living space of the bedroom had provided relaxation and intimacy. After the stroke it turned into a space of fear and conflict where relational changes became vividly present.

Nevertheless, these participants’ marriages had survived for many years [Table 1] after the stroke in spite of the challenges. The commitment side of Sternberg’s [30] love triangle seemed to be the glue that held the relationship together even when intimacy and passion faded. In most cases, the participating spouses expressed a strong commitment and devotion to their partner and they felt a powerful duty to remain within the marital relationship in spite of the hardships involved. As one of the spouses expressed it, living on the good memories was one way of dealing with the loss of the sexual relationship. Most spouses’ marriages had lasted for many years [Table 1] before stroke onset and it seemed that these relationships had strong foundations. Mitchell-Pedersen [13] found that the sexual relationship after stroke varied according to the quality of the couples’ relationship pre-stroke. Couples who had always been able to self-disclose were able to maintain passion and intimacy after stroke, unlike couples who had lived in individual isolation even before the stroke.

Sexuality is commonly viewed as a phenomenon of surplus. According to Zasler and Martelli [12, p. 79], it is also seen as a complex and integrative function that presupposes smooth interactions between psycho-behavioral, physical and cognitive wellbeing. Laan and Both [31] state that women’s sexual distress is related to the context and the circumstances of their sexual lives, where a myriad of different relationship issues can be blamed for the absence of sexual feelings. Both psychological distress and the male partner’s erectile difficulties can bring about loss of sexual interest or avoidance in women [32]. In the present study, spouses’ physical exhaustion, emotional distress and even depressive reactions may have interfered with devoting time to sexual thoughts and activities. In addition, spouses often felt embarrassed on their own and on their husbands’ behalf when sexual intercourse failed. The disappointment and shame female spouses felt about failures to re-establish the sexual relationship after stroke guided decisions to end the sexual relationship. Sometimes that decision was a shared one between partners, in other cases the spouses decided on behalf of their partner. Choosing not to discuss this decision with the partner may have contributed to an already existing imbalance in the marital relationship due to the partner's role losses and dependence. On the other hand, it must have been important for these spouses to set limits to reduce the consequences of unsatisfying and sometimes intrusive sexual activity. Nevertheless, the decision may also have deprived them of other forms of intimacy with the partner that were still available.

Some husbands' complete loss of interest in sexual activity left spouses without any choice. Although female spouses commonly expressed that the stroke was followed by even greater losses and that they preferred giving up an unsatisfying sexual relationship, they also conveyed that loss of the sexual relationship left a void. This concurs with the experiences of female spouses living with men with erectile dysfunction after prostate cancer [33].

Most of the female spouses in the present study were in their fifties when their partner suffered the stroke and felt they were too young to renounce their sex life. At this age women usually face climacteric changes causing troublesome symptoms [32, 34]. According to Trudel et al. [32], regular sexual activity can reduce the physiological effects of menopause. In addition, a functional sexual life usually helps women to deal with the threats of a fading body image caused by climacteric changes accompanied by the dawning worries of aging, which is not welcomed in Western societies [30, 32]. Being exposed to menopausal changes and at the same time deprived of the partner's sexual attention and confirmation may have added to the spouses' burden in the present study.

Although Western societies have become more open towards sexuality, prejudices and taboos against sexuality in mature age and in people living with disabilities still seem to exist [14, 32, 35]. A literature review on marital aspects of the elderly shows that individuals remain sexually active all their life even if their sexual interest and activity fade [32]. Studies of the sexual life of elderly women conclude that sexuality plays an important role during the aging process [26, 32, 36]. Participants in these studies describe themselves as active and satisfied with a variety of sexual activities, sometimes in spite of considerable health problems. Elderly women's attitudes towards sexual activity seem to remain positive and open in spite of aging [26]. Loehr et al. [36] found that sexuality remained an important issue in aging women's lives that they willingly addressed. Nevertheless, these women conveyed that they might not volunteer this information to their family doctors if they were not asked.

In the present study, spouses experienced that issues of sexuality were seldom addressed by clinicians and if so, only in response to couples' questions and concerns. Similar results were found in a study of female spouses' experiences of the sexual relationship during chronic illness [33]. Only one of the spouses in the present study had sought health professional advice together with her husband. It was apparent that the other spouses struggled with the loss of sexual intimacy in the relationship. These findings underline the need for health care workers to take the initiative to address sexuality after stroke. Several other stroke studies emphasized addressing sexuality as a part of the rehabilitation program as there is a mismatch between patient preferences and counseling related to sexual dysfunction after stroke [11, 37–40]. There may be several reasons why health care professionals do not address sexuality systematically. Saunamäki et al. [41]. Found that nurses were reluctant to discuss sexuality with their patients due to lack of time or lack of competence. Health care professionals express that they lack training to provide sexual counseling [38, 42]. It is known that the improvement of knowledge and skills regarding sexual issues correlate positively with health care workers' ability to provide information and guidance [41, 43], both of which are important issues for improving care for couples affected by stroke.

## Methodological Considerations

As sexuality is a value-laden topic it is possible that not all the experiences of spouses' sexual relationships post-stroke were disclosed in the interviews. Nevertheless, the participants showed an open attitude during the interviews and all of them related their sexual relationship after stroke even though they knew that they could refrain from doing so.

The sample size of this study is small and the findings cannot be generalized. Careful descriptions of the sample will hopefully allow readers to consider whether the results may be transferred to other settings. The participating spouses were aged 43–65, none of them had young children at the time of the stroke event and most of them had been married to their partner for many years. To investigate how younger spouses in less stable stages of family life experience their sexual relationship after stroke would have enhanced the results. Moreover, cultural and ethnic differences between spouses were not explored.

The authors aimed at research strategies which would ensure trustworthiness in all parts of the research process. During the interviews the first author asked questions to gain more insight into spouses' experiences and to ensure that their statements were understood correctly. During the interpretive analysis the authors tried to keep close to the interview text and used field notes of silent data to arrive at the most plausible interpretations.

## Conclusion

This study shows that female spouses' marital life is threatened by the multiple consequences of stroke and that their sexual wellbeing is suffering. Female spouses' sexual relationship with their partners cannot be viewed separately from post-stroke life as a whole, since role changes, emotional changes and exhaustion endanger both marital life and the sexual relationship. The former mutual partnership turns into a caregiver/care receiver relationship and the loss of sexuality is placed in the shadow of the multiple losses. When sexual activity fails, spouses tend to end the intimate relationship because they feel embarrassed on their own and their partner's behalf. Lack of communication between partners adds to their problems and issues of sexuality are easily silenced. Spouses seem to be in need of guidance and support but do not find that health care workers address sexuality during the rehabilitation process. Therefore health care workers should receive education and training to feel comfortable in addressing sexuality after stroke, as an issue that is important for the wellbeing of spouses and their partners.

## Implications for Practice

Spouses need to be prepared for the challenges that may occur when trying to re-establish their sexual relationship after stroke. Sexuality should be addressed as part of post-stroke rehabilitation programs and guided couple sessions and/or individual sessions will be needed depending on the relationship between the partners. Nurses and other health care professionals need to be trained in discussing sexuality with their patients. Specialized training programs should be developed and integrated into health care workers' education programs to increase awareness and competency in this field. Future research should explore how this may be accomplished in the best way possible.

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**Ethical standard** The study has been performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments. Ethical approval was granted by the Regional Committee for Medical Research ethics, Northern Norway REK NORD 55/2008.

**Informed consent** Written informed consent was obtained from all individual participants prior to inclusion.

## References

1. Bright, F.A.S., Kayes, N.M., McCann, C.M., McPherson, K.M.: Understanding hope after stroke: a systematic review of the literature using concept analysis. Top. Stroke Rehabil. **18**, 490–508 (2011)
2. Achten, D., Visser-Meily, J.M.A., Post, M.W.M., Schepers, V.P.M.: Life satisfaction of couples 3 years after stroke. Disabil. Rehabil. **34**, 1468–1472 (2012)
3. White, C.L., Poissant, L., Cote-LeBlanc, G., Wood-Dauphinee, S.: Long-term caregiving after stroke: the impact on caregivers' quality of life. J. Neurosci. Nurs. **38**, 354–360 (2006)
4. Bäckström, B., Asplund, K., Sundin, K.: The meaning of middle-aged female spouses' lived experience of the relationship with a partner who has suffered a stroke, during the first year postdischarge. Nurs. Inq. **17**, 257–268 (2010)
5. Kitzmüller, G., Häggström, T., Asplund, K., Gilje, F.L.: The existential meaning of couples' long-term experiences of living with stroke. Illn. Crisis Loss **20**, 339–362 (2012)
6. Korpelainen, J.T., Nieminen, P., Myllyla, V.V.: Sexual functioning among stroke patients and their spouses. Stroke **00392499**(30), 715–719 (1999)
7. Lemieux, L., Cohen-Schneider, R., Holzapfel, S.: Aphasia and sexuality. Sex. Disabil. **19**, 253–266 (2001)
8. Palmer, S., Glass, T.A.: Family function and stroke recovery: a review. Rehabil. Psychol. **48**, 255–265 (2003)
9. Thompson, H.S., Ryan, A.: The impact of stroke consequences on spousal relationships from the perspective of the person with stroke. J. Clin. Nurs. **18**, 1803–1811 (2009)
10. Giaquinto, S., Buzzelli, S., Di Francesco, L., Nolfe, G.: Evaluation of sexual changes after stroke. J. Clin. Psychiatry **64**, 302–307 (2003)
11. Schmitz, M.A., Finkelstein, M.: Perspectives on poststroke sexual issues and rehabilitation needs. Top. Stroke Rehabil. **17**, 204–213 (2010)
12. Moreno, J.A., Arango Lasprilla, J.C., Gan, C., McKerral, M.: Sexuality after traumatic brain injury: a critical review. NeuroRehabilitation **32**, 69–85 (2013)
13. Mitchell-Pedersen, S.L.: Impact of stroke on a couple's sexual relationship. Ed.D., University of Toronto, Canada (1994)
14. Esmail, S., Darry, K., Walter, A., Knupp, H.: Attitudes and perceptions towards disability and sexuality. Disabil. Rehabil. **32**, 1148–1155 (2010)
15. McCarthy, B., Bodnar, E.: The equity model of sexuality: navigating and negotiating the similarities and differences between men and women in sexual behaviour, roles and values. Sex. Relatsh. Ther. **20**, 225–235 (2005)
16. Baumeister, R., Tice, D.: The Social Dimension of Sex. Allyn & Bacon, Boston (2001)
17. Watson, J.: Male bodies: Health, Culture and Identity. Open University Press, Buckingham (2000)
18. Basson, R.: The female sexual response: a different model. J. Sex Marital Ther. **26**, 51–65 (2000)
19. Leiblum, S.R.: Definition and classification of female sexual disorders. Int. J. Impot. Res. **10**(Suppl 2), 102–106 (1998)

20. Merleau-Ponty, M.: Phenomenology of Perception. Routledge, London (2002)
21. Merleau-Ponty, M.: Kroppens Fenomenologi [The phenomneology of perception, 1.part, The body]. Pax Forlag A/S, Oslo (1994)
22. Ratcliffe, M.: Phenomenology, neuroscience and intersubjectivity. In: Dreyfus, L.H., Wrathall, M.A. (eds.) A Companion to Phenomenology and Existentialism, pp. 329–345. Wiley-Blackwell, United Kingdom (2009)
23. Kitzmüller, G.: The long term experience of living with stroke in a family context. Doctoral thesis, University of Tromsø, Norway (2012)
24. van Manen, M.: Researching lived experience: human science for an action sensitive pedagogy. Althouse Press, London (1997)
25. van Manen, M.: From meaning to method. Qual. Health Res. **7**, 345–369 (1997)
26. Johnson, B.K.: A correlational framework for understanding sexuality in women age 50 and older. Health Care Women Int. **19**, 553–564 (1998)
27. Gill, C.J., Sander, A.M., Robins, N., Mazzei, D.K., Struchen, M.A.: Exploring experiences of intimacy from the viewpoint of individuals with traumatic brain injury and their partners. J. Head Trauma Rehabil. **26**, 56–68 (2011)
28. Eriksson, M., Svedlund, M.: 'The intruder': spouses' narratives about life with a chronically ill partner. J. Clin. Nurs. **15**, 324–333 (2006)
29. Buschenfeld, K., Morris, R., Lockwood, S.: The experience of partners of young stroke survivors. Disabil. Rehabil. **31**, 1643–1651 (2009)
30. Westheimer, R.K., Lopater, S.: Human Sexuality: A Psychosocial Perspective. Lippincott Williams & Wilkins, Philadelpia (2005)
31. Laan, E., Both, S.: What makes women experience desire? Fem. Psychol. **18**, 505–514 (2008)
32. Trudel, G., Turgeon, L., Piche, L.: Marital and sexual aspects of old age. Sex. Marital Ther. **15**, 381–406 (2000)
33. Ervik, B., Nordoy, T., Asplund, K.: In the middle and on the sideline: the experience of spouses of men with prostate cancer. Cancer Nurs. **36**, E7–E14 (2013)
34. Farman, J., Friedman, J.D.: Sexual Function and Intimacy. In: Gillen, G., Burkhardt, A. (eds.) Stroke Rehabilitation: A Function-Based Approach, 2nd edn, pp. 533–548. Mosby, St Louis (2004)
35. Milligan, M.S., Neufeldt, A.H.: The myth of asexuality: a survey of social and empirical evidence. Sex. Disabil. **19**, 91–109 (2001)
36. Loehr, J., Verma, S., Seguin, R.: Issues of sexuality in older women. J. Women's Health **6**, 451–457 (1997)
37. HoSook, S., HyunSoo, O., HwaSoon, K., WhaSook, S.: Effects of a sexual rehabilitation intervention program on stroke patients and their spouses. NeuroRehabilitation **28**, 143–150 (2011)
38. McLaughlin, J., Cregan, A.: Sexuality in stroke care: a neglected quality of life issue in stroke rehabilitation? A pilot study. Sex. Disabil. **23**, 213–226 (2005)
39. Stein, J., Hillinger, M., Clancy, C., Bishop, L.: Sexuality after stroke: patient counseling preferences. Disabil. Rehabil. **35**, 1842–1847 (2013)
40. Calabrò, R.S., Gervasi, G., Bramanti, P.: Male sexual disorders following stroke: an overview. Int. J. Neurosci. **121**, 598–604 (2011)
41. Saunamäki, N., Andersson, M., Engström, M.: Discussing sexuality with patients: nurses' attitudes and beliefs. J. Adv. Nurs. **66**, 1308–1316 (2010)
42. Haboubi, N.H.J., Lincoln, N.: Views of health professionals on discussing sexual issues with patients. Disabil. Rehabil. **25**, 291–296 (2003)
43. Stokes, T., Mears, J.: Sexual health and the practice nurse: a survey of reported practice and attitudes. Br. J. Fam. Plan. **26**, 89–92 (2000)