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Experiences of Sexuality Six Years After Stroke: A Qualitative Study

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ABSTRACT

Background: Little is known about the long-term consequences of stroke on sexuality, and studies on how individuals with stroke communicate with health care professionals about information and/or interventions on sexuality are even sparser.

Aim: To explore experiences of sexuality 6 years after stroke, including communication with health care professionals concerning sexuality.

Methods: This qualitative study was based on data collected by semistructured interviews with 12 informants 43 to 81 years old 6 years after stroke. Interviews were recorded and transcribed verbatim and thematic analysis was performed.

Results: The analysis resulted in the following three themes. Not exclusively negative experiences in sexuality after stroke: Most informants experienced some change in their sexual life from before their stroke. Decreased sexual interest and function were ascribed to decreased sensibility, post-stroke pain, or fatigue. Some informants reported positive changes in sexuality, which were attributed to feelings of increased intimacy. Individual differences and variability on how to handle sexuality after stroke: Different strategies were used to manage unwanted negative changes such as actively trying to adapt by planning time with the partner and decreasing pressure or stress. Open communication about sexuality with one's partner also was described as important. Strikingly, most informants with negative experiences of sexual life attributed these to age or a stage in life and not to the stroke or health issues. Furthermore, they compared themselves with others without stroke but with changes in sexuality, thus achieving a sense of normality. Communication and counseling concerning sexuality—many unmet needs: Experiences of communication with health care professionals varied. Very few informants had received any information or discussed sexuality with health care professionals during the 6 years since the stroke, although such needs were identified by most informants.

Clinical Translation: When encountering individuals with previous stroke, there is a need for vigilance concerning individual experiences of stroke on sexuality to avoid under- or overestimating the impact and to raise the subject, which currently might be seldom.

Strengths and Limitations: Individuals with long-term diverse consequences of stroke and with different sociodemographic backgrounds were interviewed. Because most individuals in the present study had retained functioning, this could decrease transferability to populations with more severe sequelae after stroke.

Conclusions and Implications: The individuals in the present study had different experiences of sexuality after stroke. The results point to the importance of acknowledging sexual rehabilitation as part of holistic person-centered stroke rehabilitation. **Nilsson MI, Fugl-Meyer K, von Koch L, Ytterberg C. Experiences of Sexuality Six Years After Stroke: A Qualitative Study. J Sex Med 2017;14:797−803.**

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Key Words: Sexuality; Stroke; Counseling and Communication; Sexual Rehabilitation Needs

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INTRODUCTION

There is a knowledge gap concerning the relation between stroke and sexuality from the perspective of the patient and partner and the perspective of the health care professional. This might be somewhat surprising because, worldwide, a first stroke will affect approximately 17 million people per year.[1] Lifelong impairments and disabilities of varying degrees, from mild to severe, often follow. The effects can influence physical, psychological, and social aspects of life, including participation in work, leisure, and society, and can affect relationships with partners, families, and surrounding networks.[2–4] Thus, the barriers against a fulfilling sexual life can be multifaceted and can be caused by patients' physiologic, psychological, and social sequelae and spousal fear of sexual activities.[5,6] However, there are few scientific studies on this subject; descriptive studies have found decreased sexual function, sexual activity, and satisfaction are common after stroke.[6–9] Qualitative research has indicated that altered body image and being dependent on a partner can underlie negative changes in sexuality.[10–12] It has been suggested that sexual dysfunction is one of the more under-recognized disabilities after stroke,[6,10] and more knowledge is needed. Furthermore, there is a lack of studies on long-time stroke survivors and their experiences of sexuality and intimacy.

When patients with stroke ask for information or about interventions on sexuality, most health care professionals believe they lack the knowledge and experience to discuss these issues and instead refer patients to patient organizations.[13] Knowledge about stroke survivors' rehabilitation needs and preferences for interventions on sexual life is very limited.[14,15] Although little is known about the subject, studies on how individuals with stroke communicate with health care professionals on information and/or interventions regarding sexuality are even sparser. Health care professionals in stroke rehabilitation have been found to be reluctant to raise the issue of sexuality[16] and very few patients bring up the subject. As a consequence of this lack of information, individuals with stroke and their partners might turn to information on the internet. However, the information available on the internet has been seriously questioned concerning quality and direction (ie, with a focus on the problem rather than the solution).[17]

AIMS

This study explored the experiences of sexuality 6 years after stroke, including communication with health care professionals concerning sexuality.

METHODS

Participants and Sampling

The sampling frame was a 6-year follow-up of the Life After Stroke Phase 1 (LAS-1) study, a prospective cohort study of the rehabilitation process after stroke. A detailed description of the study has been reported elsewhere.[18] The original LAS-1 study included 349 patients diagnosed with stroke who were admitted to stroke units at the Karolinska University Hospital (Stockholm, Sweden) in 2006 and 2007. At the 6-year follow-up, data were collected through tests and questionnaires from 121 individuals. A purposive sampling of 15 individuals was performed to include male and female informants of different ages and marital statuses and with varying degrees of disability and self-rated recovery as assessed by the Stroke Impact Scale, the Katz Index of Independence in Activities of Daily Life, and the Life Satisfaction Checklists.[18] Three declined because of illness or another reason and 12 accepted participation in the interview study. No reimbursement was offered to the informants.

The study received ethical approval from the regional ethics committee in Stockholm and informed consent was obtained from all participants before being included in the present study.

Data Collection and Analysis

An interview guide on rehabilitation needs after stroke was developed in an interdisciplinary research group, which included an expert in sexual medicine and stroke rehabilitation. The interview guide included questions related to stroke survivors' experiences of sexuality after stroke. The interviews started with questions related to life in general after stroke and proceeded to more specific questions on sexuality: Can you tell me about your sexual life at present? Have you experienced any changes in your sexual life since your stroke and, if so, what changes? If you have experienced any changes in sexuality and, if so, how have you handled these? Could you describe what kind of information, guidance, or interventions you have received from health care professionals concerning sexuality after stroke? What would your preferences, if any, be concerning information, guidance, or interventions on sexuality? The interview guide was tested in five interviews and the guide was evaluated and changed slightly to gain more in-depth information about the topic. Terms regarding sexuality can have different meanings for different people. In this study, the patients self-defined sexual desire, interest, and orgasm and the authors did not offer definitions from diagnostic tools or instruments. This approach was chosen because sexuality can be a sensitive topic, although the interviewers could ask follow-up questions and allowed the informants use their own terms for sexual desire, interest, practices, and behavior. Therefore, during analysis and the writing of article, the authors closely adhered to the participants' accounts.

The interviews, which were 30 to 120 minutes long, were conducted at a site of the informants' choosing (in their home, at their workplace, or at the university hospital). The length of the interview depended on the informants' narratives; on average, the interviews lasted approximately 1 hour. The locations were strictly chosen by the informants, so they would feel secure discussing the matter at hand. Ten interviews were conducted by the first author (M.I.N.; an experienced medical social worker with experience in sexology) and two interviews were performed

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