Sexuality After Stroke: Patient counseling preferences

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Introduction

Stroke affects almost 800,000 individuals annually in the United States, with many survivors experiencing substantial disability. Often these impairments restrict independence in functional tasks such as incontinence and activities of daily living (ADLs). Rehabilitation typically emphasizes regaining mobility and achieving functional independence. Intimate relationships are a major component of quality of life for most adults, irrespective of age. Despite recognition that sexual dysfunction is common after stroke,1-11 most post-stroke rehabilitation programs do not include a consistent approach for addressing sexuality post-stroke. Physicians and other healthcare professionals vary considerably in their approach to discussing sexuality after stroke, ranging from routine discussions early in the course of care to addressing these issues only when specifically raised by a patient or family member.1 The assessment tools typically utilized in the post-stroke rehabilitation setting focus primarily on functional ability rather than quality of life issues, such as sexuality. Additionally, factors such as lack of training, personal beliefs, embarrassment and fear of offending the patient may act as barriers to initiating discussions of quality of life issues, such as sexuality. Additionally, factors such as lack of training, personal beliefs, embarrassment and fear of offending the patient may act as barriers to initiating discussions of sexual dysfunction with stroke patients.1 These factors may contribute to the paucity of research regarding sexual dysfunction after stroke.

While some data is available on the frequency of sexual dysfunction after stroke,1-12 and on the limited counseling and education typically provided by healthcare providers, there is no information about actual patient preferences for counseling about sexuality after stroke. This study was therefore intended to explore patient preferences for receiving information and counseling regarding sexuality post-stroke.

Methods

• 285 stroke survivors from our stroke registry were contacted and sent survey materials.
• Questions were developed about sexual dysfunction (CSFQ-14), fatigue level (FAS), depression (BDI), ADL independence (BI) and questions specific to receiving information about sexual dysfunction post-stroke.
• 36 patients responded to the survey.

Results

Sexual Function (CSFQ)

- 100% of men and 58% of women met standard criteria for sexual dysfunction.11

Depression (BDI)

- 3% of respondents met criteria for minimal depression
- 54.4% for mild depression
- 36.4% for moderate depression
- 0.0% for severe depression

Independence (BI)

- 78.8% met criteria for full independence with ADLs
- 18.2% required minimal assistance
- 3% are categorized as very dependent

Fatigue (FAS)

- A score >22 is considered significant fatigue; 55% of women and 35% of men surveyed met this criterion.13-15

How would you rate the importance of sexual issues in the context of your overall stroke recovery?

- 15% of respondents rated this as unimportant, 25% as important, 30% as very important, and 20% as critical.

Has your sexual functioning changed as a result of your stroke?

- 12% of respondents indicated this question was unchanged, 36% worse, 54% better.

Who would you prefer to talk to about sexual issues?

- 30% of respondents chose physician, 25% chose nurse, 20% chose physical therapist.

If you received information about sexuality after your stroke, who or what was the source of information?

- 100% of men and 58% of women met standard criteria for sexual dysfunction.

Discussion

A primary concern for stroke survivors is maximizing their quality of life. Intimate relationships and sexuality are important factors that contribute to quality of life post-stroke. Topics such as sexuality and intimacy are often left unaddressed in the post-stroke rehabilitation process.

To our knowledge this is the first study examining patient preferences regarding counseling on sexuality post-stroke. Our results suggest that addressing sexual dysfunction is an important part of stroke rehabilitation, and that the majority of study patients felt that they did not receive sufficient information on this topic.

Our data indicates that patients wish to receive information about sexuality from a variety of sources, including printed material, health care practitioners, and DVDs. For patients who wish to discuss issues of sexuality post-stroke with a health care practitioner, a majority would prefer to have this conversation with a physician. The explanation for why this interaction does not typically take place is likely multifactorial. Participants also indicated that they would like to receive information in print on sexual dysfunction. This preference for written educational materials has been found in other patient populations as well.

The proper timing of providing this information appears to vary from person to person, and therefore an individualized strategy may be necessary. In prior studies, patients indicated that receiving this information in the early acute phase of hospitalization might be overwhelming given the focus on survival and physical functioning.2 We advocate physicians raising this topic periodically over the course of a patient’s recovery.

The results of this data indicate a high prevalence of depression and fatigue in this population, and most patients were on multiple medications to treat these conditions. These factors are known to be independently associated with sexual dysfunction16-17 however we were unable to determine the relative contributions of these factors given our small sample size.

Conclusions

• There is a need for integration of counseling related to sexual dysfunction post-stroke into our current rehabilitation model.
• Currently, there exists a mismatch between patient preferences and provider delivery of information related sexual issues following stroke.
• Awareness of this discrepancy provides an opportunity for rehabilitation programs to develop training programs on this topic.
• Deploying effective patient education tools to assist in the dissemination of information on sexual dysfunction post-stroke is paramount.