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Participation Changes in Sexual Functioning after Mild Stroke

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Abstract

The purpose of this study was to explore the extent to which persons with mild stroke experience changes in participation in sexual activity post-stroke. A cross-sectional study was completed with adults 6-18 months post-mild stroke ($n = 13$); a brief case study was also completed with one of the participants. Participants completed an assessment battery over the phone that included the modified Quality of Sexual Function Scale (QSF), the Stroke Impact Scale (SIS), and the Patient Health Questionnaire-9 (PHQ-9). The sample reported mild problems with sexual dysfunction ($M = 10.77$, $SD = 4.09$). Sexual dysfunction post-stroke was highly correlated ($r^2 = -.372$ to $-.875$) with all the domains on the SIS. Several of the participants in this study reported that they would have liked more information about sexual functioning following stroke. These findings suggest that individuals with mild stroke are experiencing decreased participation in sexual activities post-stroke and that they would like more information from the health care community on the potential sexual changes.

Keywords

Stroke; Sexual Function; Occupational Therapy

Introduction

Stroke is a prevalent problem in the United States with the American Heart Association estimating that 795,000 adults experience a stroke each year (Roger et al., 2011). It is estimated that 40%-60% of strokes are considered mild, as defined by a score of less than six on the National Institutes of Health Stroke Scale (NIHSS) (Edwards, Hahn, Baum, & Dromerick, 2006; Rochette, Desrosiers, Bravo, St-Cyr/Tribble, & Bourget, 2007; Wolf, Baum, & Connor, 2009). The NIHSS is a common way to measure stroke severity by assessing neurological impairment with 15 items such as level of consciousness, pupillary response, facial palsy, motor arm and leg movements, and communication ability (Brott et al., 1989); a score of less than six suggests the individual with stroke is typically able to independently complete activities of daily living (ADL), such as dressing, toileting, and bathing by discharge.

Due to the lack of physical impairment and the ability to independently complete ADL, individuals with mild stroke often receive very little rehabilitation. Wolf and colleagues (2009) found that 71% of those with mild to moderate stroke went directly home from the hospital without further services, with home health services only, or with outpatient services only. However, these survivors pose unique issues because although they appear able to return to their previous life without the need for major rehabilitative efforts, important parts of their life are affected such as returning to work (Wolf et al., 2009) and driving (Edwards et al., 2006). Research has found cognitive deficits in the mild stroke population, such as attention and concentration problems (Edwards et al., 2006) and executive dysfunction (Wolf, Barbee, & White, in press). Studies also suggest that life satisfaction (Ostwald, Godwin, & Cron, 2009), interpersonal relationships (Rochette et al., 2007) and resuming spousal roles (Schmitz & Finkelstein, 2010) are additional concerns after mild stroke.

Sexual functioning after mild stroke has not been extensively studied, however research supports that sexual dysfunction is a common problem in the stroke population in general (Giaquinto, Buzzelli, Francesco, & Nolf, 2003; Jung et al., 2008; Kimura, Murata, Shimoda, & Robinson, 2001; Korpelainen, Nieminen, & Myllyla, 1999). Korpelainen and colleagues (1999) discovered that 49% (n=192) of stroke survivors and 31% (n=94) of spouses were dissatisfied with their post-stroke sexual life and 33% of stroke survivors and 27% of spouses reported completely ceasing sexual intercourse after a stroke. Furthermore, 75% of the male survivors in this study reported erectile dysfunction, while 46% of the female survivors had problems with vaginal lubrication (Korpelainen et al., 1999). Multiple studies found a significant decline in desire and satisfaction after stroke for men and women (Choi-Kwon & Kim, 2002; Kimura et al., 2001). Choi-Kwan and Kim (2002) found decreased frequency of sexual intercourse in 65% of their sample three months after the stroke occurred; this number improved only slightly to 49% two years later. Erectile function was found to be significantly decreased in male stroke survivors when compared to age-matched controls, and that frequency of intercourse and sexual desire decreased after stroke (Jung et al., 2008).

Much of the research on sexual dysfunction after stroke either does not specify the severity of the stroke, or does not include individuals with mild stroke, which is a problem due to the differences between severe, moderate and mild stroke. For example, individuals with mild stroke typically do not experience the major motor problems that impact individuals with moderate or severe stroke (Brott et al., 1989; Wolf et al., 2009). Two studies that included individuals with mild stroke in their sample suggest that sexual dysfunction may be a problem for this population as well; however, these studies did not do subgroup analysis to identify specific limitations in the mild stroke sample (Duits et al, 2009; Tamam et al., 2008).

Sexual functioning issues are important because of the negative implications that sexual dysfunction has on physical and psychological health (Davison, Bell, LaChina, Holden, & Davis, 2009; Rosen & Bachmann, 2008; Tan, Tong, & Ho, 2012), and research suggests that sexual satisfaction, a healthy marital relationship, and life satisfaction are interrelated (Ostwald et al., 2009). Individuals after stroke with sexual dysfunction report significantly higher depression scores (Kimura et al., 2001). It is important to note, however, that the

direction of the relationship between depression and sexual dysfunction is unclear – research has not established whether sexual dysfunction causes depression, or if depression causes problems with sexual functioning.

Sexual activity is considered an activity of daily living under the Occupational Therapy Practice Framework; it is also mentioned under the domain of social participation (AOTA, 2008). This implies that it is within the scope of practice of occupational therapy. Unfortunately, the lack of knowledge surrounding sexual functioning extends to rehabilitation, and few studies, if any, address sexual functioning and occupational therapy specifically.

The lack of research on sexual dysfunction after mild stroke is reflective of the lack of overall research regarding the mild stroke population. Tellier and Rochette (2009) conducted a literature review and discovered only 13 articles whose samples consist of 50% or more individuals with mild stroke. This is an important population that is often missed by research as well as rehabilitation (Wolf et al., 2009). Due to the prevalence of sexual dysfunction in the general stroke population and the lingering issues that occur with mild stroke, it is reasonable to assume that sexual problems also occur among individuals with mild stroke; however, this has not been previously studied among a sample made up exclusively of individuals with mild stroke. The purpose of this study was to investigate the extent to which persons with mild stroke experience changes in participation in sexual activity post-stroke.

Design and Methods

A cross-sectional study was completed with individuals six to eighteen months post-mild stroke; in addition, a brief case study was completed of one of the participants. The participants were recruited from the Cognitive Rehabilitation Research Group (CRRG) stroke registry at Washington University School of Medicine. Individuals who met the inclusion/exclusion criteria described below were contacted and informed consent was obtained over the phone. After consent was obtained, the participants completed the assessments described below. All data were de-identified and entered into a database for analysis and raw and scaled scores were calculated. This study was reviewed and approved by the Washington University School of Medicine Human Research Protection Office (HRPO).

Participants

Persons with mild stroke ($n = 13$) were recruited and tested for this study. All participants were admitted to the Barnes-Jewish Hospital (BJH) stroke service in St. Louis, Missouri, consented to be included in a stroke registry and gave permission to be contacted for future studies. Specific inclusion criteria for this study were: (1) individuals who experienced a mild stroke (NIHSS < 6) in the previous 6-18 months; and (2) were English speaking. Exclusion criteria for this study were: (1) history of any other neurological or mental health disorder prior to stroke; (2) had sustained more than one stroke; (3) had a history of any

other medical condition known to limit sexual activity; (4) aphasia; and (5) had not engaged in sexual activity in the past month.

Instruments

Quality of Sexual Function Scale (QSF)

The QSF is a short scale (approximately 10 minutes) that examines sexual functioning and its impact on quality of life (Heinemann et al., 2005). The four domains are: 1) psychosomatic quality of life, which are questions about general health and the impact of health on quality of life; 2) sexual activity level, or the desire for sexual activity; 3) sexual dysfunction – self-reflection, which is the participant's satisfaction with sexual activity; and 4) sexual dysfunction – partner reflection, which is the participant's perception of his/hers partner's sexual satisfaction. Composite scores for each dimension are created by summing the items, and the total score is based on the sum of the dimensions. Items are not weighted. A higher score is representative of more sexual problems or a lower quality of sexual functioning. Internal consistency was reported as acceptable except for one subscale – 0.80 for the total scale; 0.90 for psycho-somatic quality of life; 0.82 for sexual activity; 0.75 for sexual (dys)function-self-reflection and 0.57 for sexual (dys)function-partner's view (Heinemann et al., 2005). Validity of the scale is unknown due to the novelty of the assessment, however it is considered to have face validity (sexual function has an impact on quality of life) (Heinemann et al., 2005). In Heinemann and colleagues' (2005) study, the correlations between each domain and the total score were: 0.77 for psycho-somatic quality of life; 0.30 for sexual activity; 0.65 for sexual (dys)function-self-reflection and 0.33 for sexual (dys)function-partner's view (Heinemann et al., 2005). Normative scores were developed by Heinemann and colleagues (2005) and can be found in Table 1 (see Table 1).

As the QSF had not been used with individuals with stroke additional items were added, but not included in the domain scores. Six occupational therapists associated with the Program in Occupational Therapy at Washington University in St. Louis discussed topics regarding sexual functioning, stroke and important elements for the rehabilitation of sexual dysfunction in an effort to enhance the QSF for use with individuals with stroke. Additional items were added to the QSF based on these discussions in an effort to obtain information that may help increase the knowledge of rehabilitation professionals in this area.

Stroke Impact Scale (SIS)

Participants completed the SIS to determine the impact of their stroke across a multitude of dimensions, including physical functioning, participation in daily and meaningful activities, and emotional regulation (Duncan et al., 1999). The scale consists of 64 items and eight domains including strength, hand function, activities of daily living (ADL), mobility, communication, emotion, memory, and social participation. A higher score is indicative of higher functioning and less perceived limitations from stroke. It was found to be reliable and valid for determining the impact of stroke, and sensitive to changes over time (Duncan et al., 1999).

For the purposes of this study, scores on the SIS were interpreted as low, normal or high through comparison with the average domain scores reported in the study by Duncan and

colleagues (1999). The six month post-stroke scores for individuals with mild stroke ranged from 67.6 (social participation) to 89.7 (communication; Duncan et al., 1999).

Patient Health Questionnaire 9-Item (PHQ-9)

The PHQ-9 is a brief, 9-item measure of depression that consists of the criteria used to diagnose depression clinically (Kroenke, Spitzer, & Williams, 2001). It is part of a larger survey, the Patient Health Questionnaire, which assesses eight diagnoses. When used as a diagnosis tool, if five of the nine items (including depressed mood) are present “more than half of the days” or “nearly every day,” it is considered to be indicative of major depression. If two, three or four of the nine items (including depressed mood) are present “more than half of the days” or “nearly every day,” it is considered to be other depression. When used as a tool to gauge the presence and severity of depression, a higher score is indicative of more severe depression. It was found to be a reliable and valid tool to assess depression severity (Kroenke, Spitzer, & Williams, 2001), even over the telephone (Pinto-Meza, Serrano-Blanco, Penarrubia, Blanco, & Haro, 2005).

Data Analysis

All analysis was completed using IBM SPSS Statistics v. 20.0 for Windows. Descriptive analysis was completed to describe the population. To evaluate sexual dysfunction, depressive symptoms, and the impact of stroke on the participants’ lives, descriptive statistics were completed. Correlational analyses were completed to examine the relationships between sexual functioning, the impact of stroke, and depression. Finally, a descriptive analysis was completed with the additional QSF items and a brief case study was developed.

Results

Demographic data for the sample can be found in Table 2 (see Table 2). The average age of the participants was 62 years old ($SD = 15.10$) but the ages of the sample varied widely with the youngest being 36 years old and the oldest being 82 years old. The sample was predominantly male and Caucasian. The majority of the sample was either married or had a significant other at the time of their stroke. The low NIHSS scores among the participants represent mild neurological impairment. Upon discharge from their acute stay at the hospital, four participants went home without any services, four were transferred to an inpatient rehabilitation center, three went home with outpatient services, and two went home with home health services.

Descriptive statistics on the primary outcome measures are provided in Table 3 (see Table 3). The domain scores on the SIS are reported as normal because the designation of normal is based on other individuals with mild stroke not a standard score. The participants varied widely on their perception of their recovery from their stroke ($M = 77.77$, $SD = 25.59$) - one participant rated his recovery a 10, while another participant rated it a 101 because he saw it as a “wake-up call” and considers himself healthier now than before his stroke.

Correlation analyses among the main outcome variables are in Table 4 (see Table 4). The PHQ-9 was highly correlated with all of the QSF domains except the third one (sexual dysfunction – partner reflection). The correlations were all positive which suggests that a higher depression score is associated with more problems with one's psycho-somatic quality of life, issues with one's sexual activity level, and complaints of sexual dysfunction from self-reflection. Sexual dysfunction was negatively related to some of the SIS domains which suggest that more problems with sexual dysfunction are related to lower functioning in the areas of memory, emotion, communication, activities of daily living (ADL), mobility, hand function, and social participation, as well as the participant's perception of their recovery from their stroke. Sexual activity level was not significantly related to any of the SIS domains. The total QSF score was negatively related to all of the SIS domains (strength, memory, emotion, communication, ADL, mobility, hand function, social participation) and their perception of their recovery.

The additional items used to modify the QSF to better inform rehabilitation were also reviewed. In response to the question “do you feel that your stroke has changed your sexual functioning?” 38.5% of the sample replied “yes”. Some of the problems they mentioned included a lack of desire; issues reaching orgasm; and impotence. This study was also interested in whether a healthcare professional discussed sexual functioning with participants after their stroke, and if the participants wanted them to. Only four (30.8%) of the participants reported that a healthcare professional discussed sexual functioning with them at some point after their stroke (a certain amount of time was not specified in the question, however all participants were 6-18 months post-stroke during data collection). The participants reported that it was physicians who spoke with them. All of the participants who reported talking with a healthcare professional said that it was during one-on-one conversations (versus support groups or through brochures/handouts). Of those participants who reported that a healthcare professional did not speak with them about sexual functioning after their stroke, three (23.1%) stated that they would have liked them to.

One (7.7%) of the participants stated that he asked his doctor about sexual activity after his stroke, and another said that if he had questions or thought there might have a problem that he would have taken the initiative to ask the physician. Two (15.4%) of the participants stated that they would want information on the topic if there was a potential for a problem. A follow-up item to this question inquired about which healthcare professionals they would want to talk with about sexual functioning and when in the continuum of care this information would be best received. Not a single participant suggested talking about sexual functioning in the acute stage, and one participant said that “he wasn't in a good place mentally to discuss it when leaving the hospital.” One participant said they brought it up at a follow-up visit about one month after the stroke and another participant suggested talking about it after getting “back to normal life,” “maybe three months out.” At the time of the stroke, it “was one of the last things on her mind” because “at first she wanted to sleep a lot.” However, her “perspective is different now” and “now she would talk about it.”

Due to the preliminary nature of this study, a brief case study was completed of one of the participants to highlight this issue with persons with mild stroke. The participant will be referred to as “Derek”. Derek is a 55 year-old African American man who had a mild stroke,

as indicated by his NIHSS score of two. He went home without any rehabilitation and reported having a significant other at the time of his stroke. Derek is obese and has diabetes, congestive heart failure, hypertension, and a past history of smoking, drug and alcohol abuse. Derek's scores on the Stroke Impact Scale ranged from 37.50-78.57, and the majority of scales indicated lower functioning, except the areas of memory, ADL, and social participation (see Table 5). Additionally, he had mild depressive symptoms.

Derek's scores on the Quality of Sexual Functioning Scale indicated moderate problems with his general health and quality of life, similar to what his scores on the Stroke Impact Scale suggest. Interestingly, Derek did not report problems with his physical desire or ability for sexual activity, but did report moderate problems with his satisfaction with his sexual functioning. He reported feeling that his stroke changed his sexual functioning, that his desire and performance has suffered, and that he is not the man he used to be.

Discussion

Our results suggest that problems with sexual functioning occur among individuals with mild stroke based on the sexual dysfunction domain of the Quality of the Sexual Function Scale (QSF). This domain examines an individual's satisfaction with his or her sexual life from a participation focus. Deficits after mild stroke are often seen at a participation level, and this study suggests a similar mechanism with sexual dysfunction. It was anticipated that no problems would be reported in the domain of sexual dysfunction- partner reflection; this suggests that the partners of the individuals with mild stroke do not suffer from sexual dysfunction, from the participant's point of view. Lastly, the domain of psycho-somatic quality of life suggests mild problems, which is to be expected due to studies that have found persistent deficits among individuals with mild stroke (Duncan et al., 1999). These results are similar to previous studies that have found that sexual dysfunction is common among the general stroke population (Giaquinto, Buzzelli, Francesco, & Nolf, 2003; Jung et al., 2008; Kimura, Murata, Shimoda, & Robinson, 2001; Korpelainen, Nieminen, & Myllyla, 1999) but this is the first study to examine an exclusively mild stroke sample.

The Stroke Impact Scale (SIS) scores among this sample are normal compared to other mild stroke samples with the exception of the domain of emotion; this means that this sample has deficits similar to other individuals with mild stroke. The correlation between reported limitations in everyday life on the SIS and scores on the sexual dysfunction domain of the QSF further suggest that individuals with mild stroke in this study are experiencing decreased participation in sexual activities post-stroke. The lack of significant correlation between the QSF domain of sexual activity and the SIS was expected given that the focus of the sexual activity domain of the QSF is not on participation changes. The QSF domain of psycho-somatic quality of life is highly correlated with the SIS which was also expected given the similarity in focus between the two scales.

Depressive symptoms measured by the PHQ-9 are positively correlated with the QSF sexual activity and sexual dysfunction domains, and this is to be expected because of the documented relationship between depression and sexual functioning (Laurent & Simons, 2009; Kimura et al., 2001). There is also strong research suggesting depression is common

after stroke (El Hussein et al., 2012; Green & King, 2010) but the relationship between sexual functioning, depression and recovery from stroke needs to be examined further.

The additional questions developed to better inform rehabilitation professionals suggest that individuals with mild stroke would like to be informed about potential sexual functioning changes following stroke; however, only 30.8% of the participants reported a health care professional discussing sexual functioning with them. Research has shown that individuals with stroke are not satisfied with how the rehabilitation community addresses sexual dysfunction and have identified the following issues with their post-stroke rehabilitation care: 1) difficulty talking about sexual functioning with healthcare providers; 2) little to no discussion about post-stroke sexual activity in rehabilitation; 3) lack of education tailored to each couple's individual needs; 4) lack of rapport with a healthcare professional who was competent in sexual activity; and 5) appropriate timing of sexual education after stroke (Schmitz & Finkelstein, 2010). A question was posed to the sample in this study regarding the preferred time during recovery to discuss sexual functioning; the participants agreed that the discussion should not occur immediately after the stroke but were unsure of exactly when it should happen. Further research should develop standards of care for health care professionals intervening with sexual functioning after stroke.

Some limitations of this study were the small sample size and uneven amount of women and men. Further research should focus on the individual sexual needs of men and women after stroke due to the lack of knowledge on this topic. An additional limitation was the cross-sectional design, which did not allow for evaluation of how sexual functioning and rehabilitation needs related to sexual functioning change over the course of stroke recovery. Future research should investigate longitudinal changes in sexual activity after stroke. Lastly, the QSF scale was created for the general population and perhaps not appropriate for use with individuals with mild stroke; no sexual measure has been developed for individuals with stroke though, and this is another important area for future examination.

In summary, this study suggests that decreased participation in sexual activity occurs in the mild stroke population and individuals with mild stroke are interested in information from a health care professional regarding potential sexual changes. An implication for practice that can be inferred from this study is the importance for health care professionals to be knowledgeable and willing to discuss sexual functioning with their patients. There is also a need for further research in this area given the preliminary nature of this study and eventually if necessary the development of practice guidelines and standards of care for addressing this sensitive, but important, topic.

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Table 1

Normative data for Quality of Sexual Function Scale (Heinemann et al., 2005)

Score	Categories of severity
Psycho-somatic quality of life	
0-15	No or little problems
16-24	Mild problems
25-34	Moderate problems
35 +	Severe problems
Sexual activity level	
0-17	No or little problems
18-23	Mild problems
24-26	Moderate problems
27+	Severe problems
Sexual dysfunction – self-reflection	
0-9	No or little problems
10-15	Mild problems
16-19	Moderate problems
20+	Severe problems
Sexual dysfunction – partner-reflection	
0-5	No or little problems
6-8	Mild problems
9-11	Moderate problems
12+	Severe problems
Total QSF score	
0-54	No or little problems
55-68	Mild problems
69-79	Moderate problems
80+	Severe problems

Table 2*Demographic Information of the Sample (n=13)*

Variable	Mean (SD)	Range
Age	62.08 (15.10)	36-82
NIHSS score	2.38 (1.71)	0-5

	Frequency	Percent
Gender		
Male	9	69.2
Female	4	30.8
Race		
Caucasian	9	69.2
African American	4	30.8
Marital Status		
Married	8	61.5
Significant Other	2	15.4
Divorced	2	15.4
Never Married	1	7.7
Discharge Location		
Home without services	4	30.8
Home with home services	2	15.4
Home with outpatient services	3	23.1
Inpatient rehabilitation	4	30.8

Table 3*Descriptive Data for Main Construct Measures (n = 13)*

Variable	<i>M (SD)</i>	Range	Interpretation
SIS: Perception of recovery from stroke	77.77 (25.59)	20-101	Normal
SIS: Strength	75.96 (27.22)	25-100	Normal
SIS: Memory	85.99 (18.12)	39-100	Normal
SIS: Emotion	59.40 (9.11)	42-67	Low
SIS: Communication	90.11 (10.93)	64-100	Normal
SIS: ADL	91.92 (12.17)	65-100	Normal
SIS: Mobility	86.75 (19.87)	44-100	Normal
SIS: Hand Function	88.46 (19.51)	40-100	Normal
SIS: Social Participation	84.86 (19.26)	50-100	Normal
PHQ-9: Total Score	4.92 (7.24)	0-24	Mild depressive symptoms
QSF: Psycho-somatic quality of life	20.85 (8.60)	14-44	Mild problems
QSF: Sexual activity	14.77 (7.17)	7-33	No to little problems
QSF: Sexual dysfunction – self-reflection	10.77 (4.09)	7-20	Mild problems
QSF: Sexual dysfunction – partner reflection	6.62 (3.12)	2-15	No to little problems
QSF Total Score	55.00 (17.92)	34-91	Mild problems

Table 4

Correlations Among Outcome Measures

Variable	QSF: Psycho-Somatic Quality of Life	QSF: Sexual Activity Level	QSF: Sexual Dysfunction – Self-reflection	QSF: Sexual Dysfunction – Partner-reflection	Total QSF Score
SIS: Strength	-.400	-.372	-.372	-.400	-.495
SIS: Memory	-.794**	-.263	-.638*	-.030	-.637*
SIS: Emotion	-.659*	-.131	-.577*	-.121	-.479
SIS: Communication	-.958**	-.389	-.875**	-.330	-.872**
SIS: ADL	-.897**	-.477	-.778**	-.319	-.854**
SIS: Mobility	-.886**	-.397	-.768**	-.249	-.803**
SIS: Hand Function	-.806**	-.179	-.684**	-.099	-.631*
SIS: Social Participation	-.789**	-.477	-.598*	-.347	-.766**
SIS: Perception of Recovery	-.557*	-.470	-.421	-.406	-.622*
PHQ-9: Depressive Symptoms	.892**	.612*	.752**	.393	.913**

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Table 5

Scores for Case Study Participant, “Derek”

Variable	Score	Interpretation
SIS: Perception of recovery	55	Low functioning
SIS: Strength	37.50	Low functioning
SIS: Memory	78.57	Normal functioning
SIS: Emotion	41.67	Low functioning
SIS: Communication	75.00	Low functioning
SIS: ADL	70.00	Normal functioning
SIS: Mobility	44.44	Low functioning
SIS: Hand Function	40.00	Low functioning
SIS: Social Participation	56.25	Normal functioning
PHQ-9: Depressive Symptoms	9.00	Mild depressive symptoms
QSF: Psycho-somatic quality of life	32.00	Moderate problems
QSF: Sexual activity level	14.00	No to little problems
QSF: Sexual dysfunction	16.00	Moderate problems
QSF: Partner sexual dysfunction	7.00	Mild problems
QSF: Total score	69.00	Moderate problems