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ORIGINAL RESEARCH

Multicenter Study of Sexual Functioning in Spouses/Partners of Persons With Traumatic Brain Injury

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Abstract

Objective: To investigate sexual functioning and its predictors in spouses/partners of persons with traumatic brain injury (TBI). **Design:** Inception cohort survey.

Setting: Community.

Participants: Persons (N=70) with complicated mild to severe TBI admitted to 1 of 6 participating TBI Model Systems inpatient rehabilitation units and their spouses/partners who were both living in the community and assessed 1 year after injury.

Interventions: Not applicable.

Main Outcome Measures: Derogatis Interview for Sexual Functioning Self-Report; Global Sexual Satisfaction Index.

Results: Twenty percent of spouses/partners of persons with TBI reported sexual dysfunction, and 44% reported dissatisfaction with sexual functioning. Sixty-two percent of spouses/partners reported a decrease in sexual activity during the year postinjury, 34% reported a decrease in sexual drive or desire, and 34% indicated that sexuality was less important in comparison to preinjury. The sexual functioning of spouses/partners of persons with TBI was highly associated with the sexual functioning of the person with TBI. Age of spouses/partners and sexual functioning in persons with the TBI were significant predictors of spouses'/partners' sexual functioning, even after controlling for sex of partners and the physical, cognitive, participation, and sexual functioning of the persons with injury.

Conclusions: Greater sexual dysfunction in spouses/partners was associated with older age and with poorer sexual functioning in the person with injury. Rehabilitation professionals should provide education on the potential impact of TBI on sexual functioning for both persons with TBI and their spouses/partners, and integrate the assessment of sexual functioning into their clinical assessment, making appropriate referrals for therapy. Archives of Physical Medicine and Rehabilitation 2016; \blacksquare : \blacksquare \blacksquare \blacksquare \blacksquare

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Spouses/partners of persons with traumatic brain injury (TBI) face substantial challenges, both as an individual and as a partner. These include coping with emotional and behavioral changes in the person with injury,¹⁻⁴ and changing, often multiplying, roles within the relationship and the context of daily life.⁵ Given these challenges, it is not surprising that emotional distress occurs in a substantial portion of spouses/ partners of persons with TBI.⁶⁻⁸ This distress is often paralleled

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The NIDILRR Traumatic Brain Injury Model Systems Module Project on Sexuality After TBI was a collaborative effort between TIRR (principal investigator [PI]: Angelle M. Sander), Carolinas Rehabilitation Hospital (site PI: Flora M. Hammond), Craig Hospital (site PI: David Ripley), Mayo Clinic (site PI: Anne Moessner), Rehabilitation Institute of Chicago (site PI: Felise Zollman), and Wayne State University (site PI: Robin A. Hanks).

by marital dissatisfaction, 5,9 reduced relationship quality, or both. 2,10,11

Studies^{2,12-14} have documented decreased sexual functioning in a large percentage of individuals with TBI. Sexual problems have been determined to be a major treatment need for veterans with TBI returning from the Afghanistan and Iraq wars.¹⁵ Decreased sexual functioning in the person with TBI, along with other relationship and role changes, has the potential to result in decreased sexual functioning for spouses/partners. Documentation of such changes could lead to appropriate assessment and treatment for spouses/partners.

A few preliminary studies have indicated sexual problems among spouses/partners of persons with TBI. In a study investigating changes in sexual functioning among married couples after TBI, Garden et al¹⁶ reported reduced frequency of intercourse in over half of the couples, dissatisfaction with frequency of sex in 47% of couples, and decreased ability to reach orgasm in 64% of female spouses. Using the Golombok Rust Inventory of Sexual Satisfaction, O'Carroll et al¹⁷ reported sexual dysfunction in 9% of 14 female partners of men with TBI. In a qualitative study,¹⁸ spouses/partners of persons with injury described negative changes in their sexual relationship, including decreased desire and performance on the part of the person with injury, or conversely, sexual disinhibition or lack of consideration during lovemaking, or both. Many spouses/partners expressed frustration regarding unmet sexual needs, while others discussed that they had lost interest in sex with their partner. Many described feeling that the sexual style of their partner with injury was different, as if they were sleeping with another person.

While prior studies have provided preliminary information about the impact of TBI on spouses'/partners' sexual functioning, conclusions are limited by lack of standardized measures of sexual functioning in some studies and small sample sizes in others. The primary aim of the current study was to investigate sexual functioning in a larger sample of spouses/partners of persons with TBI, using a standardized measure of sexual functioning as well as a structured interview. Secondary aims were to determine correlates of sexual functioning in the spouses/partners and to compare their sexual functioning to that of persons with injury.

Methods

Design and procedure

These data were part of a multicenter study on sexuality after TBI, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research's Traumatic Brain Injury Model Systems (TBIMS) program. Data were collected from 2007 to 2010. Persons with TBI and their partners were recruited from among those enrolled in the TBIMS national database. The study was approved by the institutional review board at each of the 6

List of abbreviations: DISF-SR Derogatis Interview for Sexual Functioning Self-Report GCS Glasgow Coma Scale GSSI Global Sexual Satisfaction Index PART-O Participation Assessment with Recombined Tools-Objective TBI traumatic brain injury TBIMS Traumatic Brain Injury Model Systems participating sites. Informed consent was obtained from the persons with TBI and their spouses/partners, who independently completed self-report measures on sexual functioning and satisfaction and an examiner-administered structured interview at approximately 1 year postinjury (mean ± SD, 13±1.5mo; range, 10-16mo). A spouse/partner was identified by persons with injury as someone with whom they shared a sexual relationship. As part of the TBIMS national database year 1 follow-up interview, measures of general outcomes were completed at 12 months after injury with a window of 10 to 14 months. Most participants (n=63) completed the questionnaires via a telephone interview, with the participant following along on a mail-out form. The staff member recorded responses to the structured interview, but participants recorded their responses to the sexual functioning measure and returned it using self-addressed stamped envelopes. This procedure was based on focus group feedback that oral responding to the sexually explicit questions may be uncomfortable or embarrassing. The remainder completed their interview and questionnaires in person at their respective research centers. Participants were paid \$20 for completing the interview and questionnaires.

Participants

All persons with TBI enrolled in the sexuality study met the following criteria: (1) medical documentation of complicated mild, moderate, or severe TBI based on an emergency department Glasgow Coma Scale (GCS)¹⁹ score <13, loss of consciousness >30 minutes, posttraumatic amnesia duration >24 hours, or abnormalities on intracranial neuroimaging; (2) admission to a TBIMS trauma facility within 72 hours of injury; (3) received inpatient rehabilitation at a TBIMS facility; and (4) age ≥ 18 years at the time of participation in the study. Attempts were made to contact all persons from the TBIMS database who met these initial criteria to determine eligibility for the sexuality study, which included the additional criteria of (1) being fluent in English; (2) having no preinjury history of psychiatric or neurologic disorder; and (3) being cognitively able to respond to the self-report sexuality measures. Persons with TBI were not required to have a partner to participate in the larger sexuality study, which included 255 persons with TBI who met the above criteria and were followed up at 1 year after injury. More detailed information on the derivation of the larger sample can be found in a prior article by Sander et al.²⁰ Of the 255 persons in the original study, 146 reported that they were married or in a relationship. Of these 146, 70 had partners who were available and willing to complete questionnaires on sexual functioning.

Measures

Sexual functioning

The Derogatis Interview for Sexual Functioning Self-Report (DISF-SR)^{21,22} is a self-report questionnaire on sexual functioning with separate forms for men and women, with accompanying normative data from 277 healthy community controls. Twenty-five Likert scale items assess the quality of a person's sexual functioning in 5 domains: sexual cognition/fantasy, sexual arousal, sexual behavior/experience, orgasm, and sexual drive/relationship. Internal reliability is adequate, with alpha coefficients ranging from .74 (sexual drive/relationship domain) to .80 (orgasm domain). Test-retest reliability coefficients are between .80 and .90.²¹ Criterion validity has been demonstrated by

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