Sex and relationship dysfunction in neurological disability

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Abstract
Objectives—(1) to ascertain how many people with neurological disability experience sexual or relationship problems; (2) to examine the interplay of neurological disability and sexual function within the context of the dyadic relationship; (3) to consider the implications of the results for service provision.

Methods—A survey of outpatients attending Hunters Moor Regional Rehabilitation Centre, Newcastle upon Tyne over a 6 month period. Standardised measures of sexual function and concern, relationship satisfaction, disability, and mental health were used.

Results—Seventy people were interviewed (18% of the potential study population). Prevalence figures therefore refer to this self selected sample. Fifty one per cent had experienced a change in sexual function and 27% were concerned about this change. Of those in cohabiting relationships 25% were experiencing difficulties. Gender was significantly associated with concern about sexual function, men being more concerned. A high score on the marital adjustment scale indicating relationship dissatisfaction was the best predictor of change in and concern about sexual function. Change in sexual function and duration of illness were the most powerful predictors of relationship dissatisfaction.

Conclusion—If concern is taken as an indication of a desire for help more than one in four of this sample required help for sexual dysfunction. Sexual and relationship functioning were very closely associated and dysfunction in either of these areas was the best predictor of dysfunction in the other area. The dyadic relationship is an important institution in the management of disability. Sexual dysfunction can be predictive of difficulties within a relationship. Any service designed to address sexual health should also address relationship issues.

Keywords: sexual dysfunction; relationship satisfaction; neurological disability

Sexuality is one of the most complex aspects of human life. Sexual expression is dependent on functioning anatomical and physiological systems, which are influenced by cognitive and emotional processes. Other than in masturbation and fantasy, sexual expression occurs within the context of a dyadic relationship. To assess and treat problems in this area knowledge of those factors influencing both the dynamics of the relationship and the physical and psychological aspects of sexual functioning is necessary.

Neurological disease and trauma have long been recognised as causing sexual dysfunction. Detailed studies of sexual functioning among various diagnostic groups with neurological disability have disclosed a high prevalence of sexual dysfunction.1–12 For example, in multiple sclerosis over two thirds of men may have an unsatisfactory or inactive sex life, after traumatic brain injury 50% of men may experience sexual dysfunction, and in Parkinson’s disease 50% of men and women may have sexual problems.13–15 However, the incidence of problems presented in routine consultations remains low. Szasz et al16 in a study of people with multiple sclerosis distinguished clearly between the presence of dysfunction and concern about the change.16 Although this research identified about half the study group as sexually less active or abstinent only 27% of the total group were concerned about the change. It was proposed that the concerned group represented those who would wish for treatment.

The intensely personal and private nature of sex produces a reticence on the part of patients in presenting sexual problems and in screening for such problems on the part of healthcare professionals.17–20 The associated lack of training in sexual medicine has not helped in developing services for this group of patients.21 22

This study examined sexual dysfunction within the context of the dyadic relationship and assessed the following issues.

- The prevalence of sexual or relationship problems among a population with neurological disability
- The interplay of neurological disability and sexual function within the context of the dyadic relationship
- The implications for service provision of sexual dysfunction of whatever cause or character in terms of the concern which participants in the study experienced in relation to their sex lives.

Method

STUDY POPULATION
Over a 6 month period all patients aged 16 to 64 years attending Hunters Moor Regional Rehabilitation Centre (RRC) as outpatients were invited by letter to take part in the study. Hunters Moor RRC, based in Newcastle upon Tyne, offers rehabilitation to patients in the 16 to 64 age group who have experienced neurological disease or trauma.
**Study Plan**

The project was conducted in two phases. Phase 1 (reported in this paper) was an interview based survey with neurologically disabled subjects. Interviews were conducted by a research psychologist (SB) at the RRC unless the subject had indicated a wish to be interviewed at home. Phase 2 encompassed in depth focused interviews with a few subjects and their partners. The interviews were recorded, transcribed, and coded for analysis (reported separately).

Having gathered general demographic information, specific measures were used.

**Modified Mini Mental State Examination**

The modified mini mental state examination was used as a brief screen for severe impairment of cognitive functioning which would preclude a person from understanding the study questions. Those scoring less than 3 were excluded from the study. Less severe cognitive problems were accepted as part of the range of neurological disability and were identified on the subscale of the OPCS disability screening questionnaire.

**General Health Questionnaire 12 Item Version**

Psychological distress is well recognised as a contributor to sexual or relationship dissatisfaction. The GHQ 12 provided a brief well validated screening tool for detecting general psychiatric morbidity. A score of 2 or more distinguished between psychologically distressed and non-distressed cases.

**OPCS Disability Scale**

The OPCS disability scale gave an overall disability score as well as subscale scores for specific areas of disability. It has been validated in population based studies and has more recently been used as an alternative to the Kurtzke scale and the Golombok Rust Inventory of marital state.

**Golombok Rust Inventory of Marital State**

The Golombok Rust Inventory of marital state was used as an alternative to the Kurtzke scale in a study of people with multiple sclerosis. It consists of five points indicating a most meaningful measure of sexual expression. It was designed and validated for use among heterosexual people in cohabiting relationships.

The questionnaire comprises 28 items covering shared interests, independence, communication, decision making, warmth and love, trust and respect, role expectations and goals, commitment, extent of agreement, and attitudes to relationships.

**Sexual Function Scale**

The sexual function scale was originally designed for use in a population with multiple sclerosis. It consists of five points indicating a change in sexual function or concern about that change. It provides a subjective assessment of sexual satisfaction, which is arguably the most meaningful measure of sexual expression. A sixth category was used in this study to incorporate those subjects who were not in a current sexual relationship and therefore were not aware of altered sexual functioning.

**Subjects**

The total number of potential respondents was 398, of whom 44% were male and 56% were female, with a mean age of 46 years. Ninety two people agreed to take part in the study. Twenty two subjects were subsequently excluded; three because of cognitive problems and 19 who lived too far from the RRC to allow a home visit, which was their preference for the interview.

**Results**

**Demographic Details**

Seventy people were interviewed (18% of the potential study population), 31 were men and 39 were women, with a mean age of 47 (SD 10) years. This was not significantly different from the age and sex distribution of the study population. The diagnoses included multiple sclerosis (33%), focal dystonia (33%), stroke (14%), head injury (6%), and various other conditions including generalised dystonia and spinal injury (14%). Most of the sample was mild to moderately disabled with a mean score of 3.5 on the OPCS scale. Twenty subjects scored zero (no disability) and three scored 10 (very severely disabled). Forty two people scored two or more on the GHQ, implying psychiatric morbidity.

**Relationships**

Sixty seven per cent (n=48) of the sample were married or cohabiting. Of those living alone 10% (n=7) had a stable relationship.

Of those in cohabiting relationships 30 subjects scored in the above average range of the GRIMS suggesting a high level of satisfaction with their relationship. Six had an average score. Seven scored in the range “poor” or “bad” and five had scores indicating severe relationship problems. In total 25% of those in a cohabiting relationship had problems of a sufficient magnitude to cause concern.

The influence of gender and diagnosis on relationship satisfaction was examined using a Mann-Whitney U test. There was no significant difference in relationship satisfaction between men and women (p=0.37). Examination of the two principal diagnostic groups showed that subjects with a diagnosis of multiple sclerosis or dystonia did not differ significantly in relationship satisfaction from other diagnostic groups (p=0.28 and 0.52 respectively).

A significant correlation between higher GRIMS scores (indicating poor relationship satisfaction) and increasing severity of disability was found (Spearman’s r=0.29, p<0.05). Duration of illness did not significantly influence relationship satisfaction (Spearman’s r test, p=0.29).

There was no significant difference in relationship satisfaction between those who were and were not psychologically distressed as measured by the GHQ (χ² squared p=0.48).

**Sexual Functioning**

Fifty one per cent (n=36) of the sample had experienced a change in sexual function, sexual activity, or had become abstemious. Of these...


**Table 1**  Results using the Szasz sexual functioning scale

<table>
<thead>
<tr>
<th>Raw scores</th>
<th>Interpretation</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No change in sexual function</td>
<td>28</td>
</tr>
<tr>
<td>1</td>
<td>Sexually less active/some sexual changes/not concerned</td>
<td>7</td>
</tr>
<tr>
<td>2</td>
<td>Sexually less active/ some changes/concerned</td>
<td>12</td>
</tr>
<tr>
<td>3</td>
<td>Sexually inactive (absent) concerned</td>
<td>7</td>
</tr>
<tr>
<td>4</td>
<td>Sexually inactive (abstinent) not concerned</td>
<td>10</td>
</tr>
<tr>
<td>5</td>
<td>Not in a sexual relationship/not aware of change</td>
<td>6</td>
</tr>
</tbody>
</table>

Sexual function and relationship satisfaction were explored for association using a Mann-Whitney U test. Scores on the GRIMS scale of marital satisfaction were significantly associated with change in sexual function (p<0.01), concern about the change (p<0.01), and abstinence (p<0.01). People who were less satisfied with their relationship were more likely to have experienced altered sexual functioning and concern about this.

**Table 2** Distribution of cases by sexual function and relationship satisfaction

<table>
<thead>
<tr>
<th>No change in sexual function/activity or not aware of any change</th>
<th>No relationship problems GRIMS &lt;34</th>
<th>Relationship problems GRIMS ≥34</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some change in sexual function and/or activity or given up sex and concerned about the change</td>
<td>21</td>
<td>1</td>
</tr>
<tr>
<td>Some change in sexual function and/or activity or given up sex and not concerned about the change</td>
<td>7</td>
<td>8</td>
</tr>
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</table>
is often multifactorial in origin incorporating an interplay of psychosocial and physical factors. Assessment and treatment of those factors, which are accessible, should provide a better therapeutic outcome and this is certainly an area to be further researched. Offering an assessment by a couple’s therapist to those seeking help with sexual problems is a possible model and this has been successfully applied in a multidisciplinary diabetic clinic. There is evidence that combining marital therapy with psychosexual therapy results in a better outcome than either therapy alone.

This study has demonstrated the close association between sexual and relationship dysfunction among people with neurological disability. Further research is needed to explore the most effective means of treating these common problems.

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30 Collier JL. The use of the GHQ and the GRISS in the assessment and outcome of sexual problems: are questionnaires of more value than a clinical interview? Sexual and Marital Therapy 1989;4:11–16.