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WHAT ARE THE BARRIERS FACED IN DISCUSSING MULTIPLE SCLEROSIS-RELATED SEXUAL DYSFUNCTION DURING CLINIC?

Hypothesis / aims of study

Sexual dysfunction (SD) in multiple sclerosis (MS) varies between 50-90% in men and 40-80% in women, and manifests as erectile dysfunction/ reduced vaginal lubrication, impaired genital sensations, difficulties in ejaculation and achieving orgasms and reduced libido. Despite having an immense impact on quality of life, sexual dysfunction is often under-reported. Previous studies in non-neurological patients have suggested that the clinic setting poses several challenges to discussing SD (1), however these have never been systematically evaluated in neurological disease. The aim of this study was to identify barriers faced by MS patients and their health care professionals (HCPs) in discussing SD during clinic.

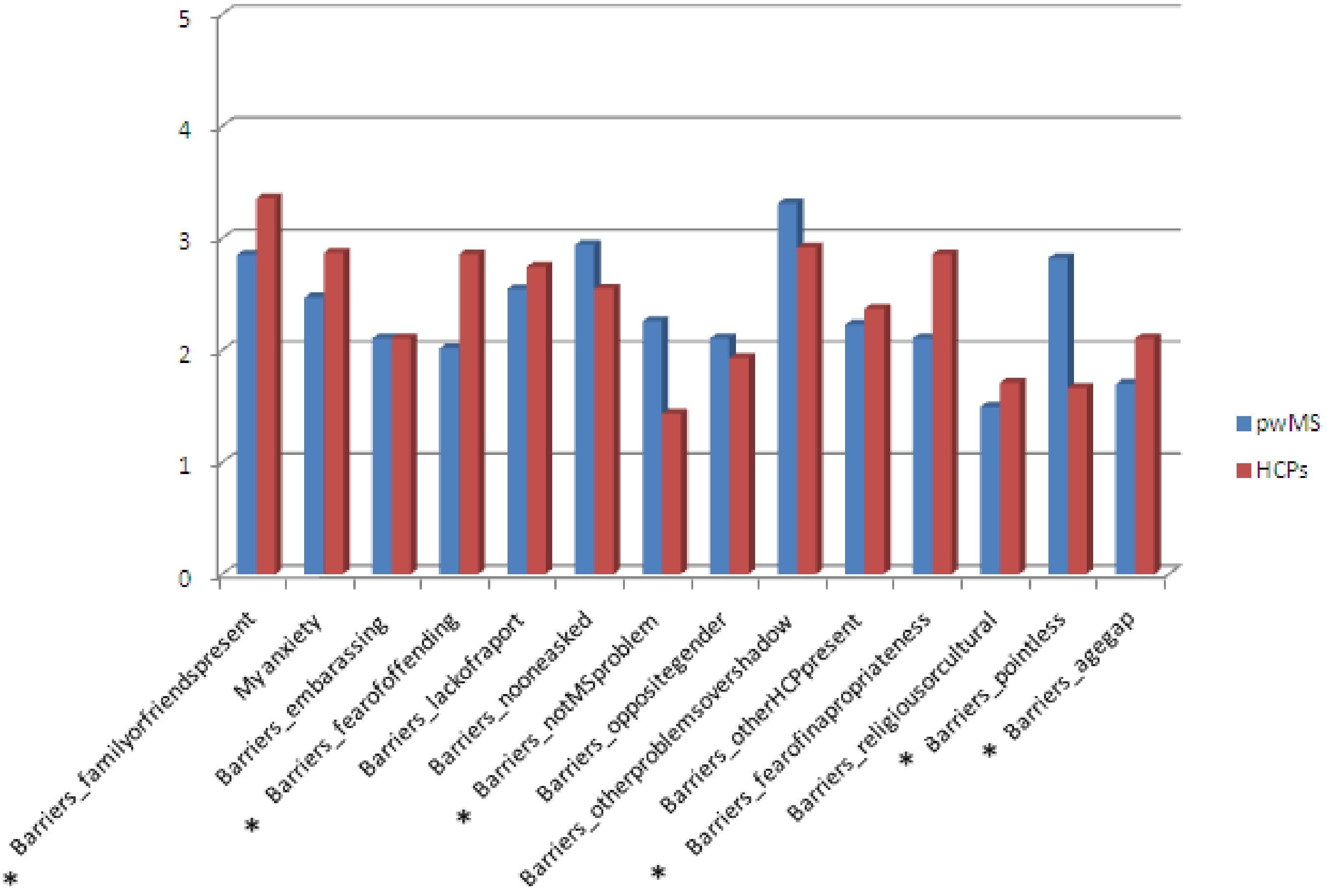
Study design, materials and methods

This was a two-part prospective study carried out at a tertiary care teaching out-patient clinic. In the absence of a validated questionnaire, known barriers to discussing sexual dysfunction in patients with medical conditions were identified through a literature search, and two questionnaires were designed (1) (2).

Part 1- survey of patients with MS: a bespoke 29-item questionnaire was designed. Sexual dysfunction was assessed using Multiple Sclerosis Intimacy and Sexuality Questionnaire (MSISQ) and Arizona Sexual Experience Scale (ASEX) and depression screened using Patient Health Questionnaire–2 (PHQ – 2). The questionnaire was reviewed by five patients attending outpatient clinics for content validity and modified according to the feedback received. Subsequently, consecutive MS patients, between the age 16 and 65, attending a specialist out-patient clinic over six months were invited to complete the anonymized questionnaire. Questionnaires were returned to the study investigators either by hand or post.

Part 2- survey of HCPs working with MS patients: a bespoke 23-item questionnaire was designed. The questionnaire was reviewed by 5 HCPs for content validity and finalized after receiving feedback. An online version of the questionnaire was designed and uploaded onto an online survey portal (SurveyMonkey.com) and was sent through email to 300 HCPs on the electronic mailing list of the Multiple Sclerosis Trust, which includes consultants, nurses, and physiotherapists.

Figure 1. Comparison of barriers between patients with MS and HCPs



* p< 0.05

Results

Part 1- survey of patients with MS: 74 patients (54 female, 20 male) participated in the questionnaire. The most common factors interfering with sexual activity according to the MSISQ questionnaire were: Lack of sexual interest (32.5%), Taking too long to orgasm or climax (31.1%), Feeling less confident about sexuality due to the MS (29.8%), Impaired genital sensations (28.4%) and Bladder or urinary symptoms (27%), Less intense or pleasurable orgasms or climaxes (24.4%), Worries about sexually satisfying the partner (23%). 32.59% (n=17.6) women report inadequate vaginal wetness or lubrication, while 94.5% (n=18.9) men reported difficulty in getting or keeping a satisfactory erection. The commonest barriers reported by patients were: prominent neurological symptoms dominating the consultation (n=30, 40.5%), presence of family or friends during the consultation (n=28, 37.8%), not being asked about sexual problems (n=25, 33.8%), sexual problems low priority (n=24, 32.5%) and lack of time (n=21, 28.4%) (figure 1).

Patients indicated that the consultant (n=43), nurse (n=39), GP (n=38), MS organisation or trust (n=28), another person with MS (n=20), physiotherapist (n=18), junior doctor (n=11), Internet (n=10) and friend or relative (n=10), were most suited for discussing management of sexual dysfunction.

Part 2- survey of HCPs working with MS patients: 98 HCPs (90 female, 8 male) participated in the questionnaire. The commonest barriers reported were presence of family or friends in the consultation room (n=34, 34.7%), lack of knowledge about sexual dysfunction (n=30, 30.6%), inadequate time during the consultation (n=27, 27.6%), perception that patient not ready to discuss the problem (n=27, 27.6%), perception that a discussion may increase patient's anxiety and discomfort (n=23, 23.4%) (figure 1). Fear of offending, fear of inappropriateness, and age gap between patient and HCP ($p<0.05$) were reported significantly more by HCPs than patients as being barriers (Figure 1.) Both patients and HCPs indicated that addressing sexual problems was a priority.

Interpretation of results

Due to the wide range of neurological symptoms that dominates MS, a discussion on SD may not always be prioritized, and therefore time should be set aside during one of the initial clinic visits to specifically enquire about SD. Bladder dysfunction was identified to interfere with intimacy and sexual activity. The presence of family or friends during clinic visits was identified as an important barrier, and a part of the clinic consultation should therefore remain private to facilitate a discussion on SD. Patients report not being asked about sexual problems as being a barrier (33.8%), suggesting that there is an expectation that HCPs should be initiating the discussion on SD. However HCPs were concerned that discussing SD may result in patient anxiety and discomfort; however a mismatch in perceptions exists and patients are prepared to discuss the problem. A lack of knowledge was identified as a barrier by HCPs.

Concluding message

The clinic consultation should be structured to allow a private discussion on SD between the patient with MS and their HCP. Training should be provided to HCPs on how to enquire about sexual dysfunction and to discuss its management.

References

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Disclosures

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