The sexuality and disability of males with multiple sclerosis in Poland

Seksualność i niepełnosprawność mężczyzn ze stwardnieniem rozsianym w Polsce

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Słowa kluczowe: stwardnienie rozsiane, mężczyzna, niepełnosprawność, życie seksualne, Polska.

Abstract

Introduction: Multiple sclerosis (MS) is one of the most common diseases of the central nervous system. In the world 2.1 million people suffer from MS. Usually MS is diagnosed between the ages of 20 and 50 years old and may be the cause of disability. Sexual problems are very common in male patients with MS although they are less frequent than they used to be.
Aim of the research study: To describe the level of disability and sexual life in males with MS.
Material and methods: The study was carried out on a total of 72 MS patients. MS subtypes included 30.55% (n = 22) secondary progressive; 27.77% (n = 20) relapsing-remitting; 22.22% (n = 16) primary progressive; and 16.66% (n = 12) progressive relapsing. The research tools consisted of our own questionnaires. Neurological disability was assessed by the Regional Committee for Adjudication of Disability and by the Expanded Disability Status Scale.
Results: 8.33% (n = 6) of patients reported sexual activity every day, most reported either several times a week 25% (n = 18), several times a month 33.33% (n = 24), once a month 16.66% (n = 12), a few times a year 5.55% (n = 4) or once a year 11.11% (n = 8). Our findings conclude that neurological disability, low sexual activity and frequent use of sildenafil citrate or similar were common in the patients tested.
Conclusions: These problems are permanently overlooked by medical professionals. In this aspect, cooperation between neurologists and sexologists could be important. Further research is needed for better understanding of the sexuality of this particular population.

Streszczenie

Wstęp: Stwardnienie rozsiane (*sclerosis multiplex* – SM) jest częstą chorobą ośrodkowego układu nerwowego. Na świecie blisko 2,1 mln ludzi choruje na SM. Zazwyczaj schorzenie to jest rozpoznawane między 20. a 50. rokiem życia i może być przyczyną niepełnosprawności. Problemy seksualne u mężczyzn z SM są częste.
Cel pracy: Ocena stopnia niepełnosprawności oraz życia seksualnego mężczyzn chorujących na SM.
Materiał i metody: Badaniem objęto 72 mężczyzn chorych na SM. Do badania włączono 30,55% (n = 22) pacjentów z wtórnie postępującą postacią SM, 27,77% (n = 20) z nawracająco-remitującym SM, 22,22% (n = 16) z pierwotnie postępującym SM i 16,66% (n = 12) z postępująco-nawrotowym SM. Narzędziem badawczym była ankieta własnego autorstwa. Pod uwagę wzięto orzeczenie o stopniu niepełnosprawności oraz rozszerzoną skalę niewydolności ruchowej EDSS (*Expanded Disability Status Scale*).
Wyniki: Codzienną aktywność seksualną deklarowało jedynie 8,33% pacjentów (n = 6), kilka razy w tygodniu 25% (n = 18), kilka razy w miesiącu 33,33% (n = 24), raz w miesiącu 16,66% (n = 12), kilka razy w roku 5,55% (n = 4) i raz w roku 11,11% (n = 8). Stwierdzono związek pomiędzy niepełnosprawnością a niską aktywnością seksualną oraz częstym przyjmowaniem sildanefilu i jego pochodnych u badanych.
Wnioski: Poruszony problem jest często niedostrzegany przez lekarzy, co powinno skłaniać neurologów i seksuologów do współpracy w tym zakresie. Uzyskane wyniki nakazują podjęcie szerszych badań dotyczących tej tematyki.

Introduction

Multiple sclerosis (MS) is one of the most common diseases of the central nervous system (CNS). It is a chronic inflammatory disorder of the CNS that is thought to be immune-mediated in nature [1]. The specific elements that start the inflammation of the CNS are still unknown. Studies have suggested that genetic, environmental and infectious agents may be among the factors influencing the development of MS [2]. More than 400,000 people in the United States and 2.1 million worldwide have MS. Each week, approximately 200 people are diagnosed with the disease – 1 person every hour [3]. The clinical manifestations of MS are highly variable, but most patients initially

experience a relapsing-remitting course [4]. Multiple sclerosis is characterised not only by spasticity, a common symptom that contributes to disability, but also by muscle weakness, muscle spasms, loss of sensitivity, clonus, difficulties with coordination and balance, difficulty in moving, problems with marital and sexual satisfaction, or sexual dysfunction (SD). The symptoms of MS usually appear in episodic acute periods of worsening (called relapses, exacerbations, bouts, attacks or 'flare-ups'), in a gradually progressive deterioration of neurological function, or in a combination of both [5–7]. Since there is no cure for MS, the goals of current therapy include slowing disability progression, decreasing relapse rate, reducing accumulations of lesions in the brain, managing symptoms and maintaining or improving health-related quality of life. It is known that sexual and reproductive functions are related to neurological mechanisms [3]. Neurological defects in men can cause infertility through erectile dysfunction (ED), ejaculatory dysfunction and semen abnormalities [3, 8].

Aim of the research study

The purpose of the study was to describe the sexual problems of male MS patients.

Material and methods

Seventy-two men with MS diagnosis according to the McDonald criteria were included in the study. All study group participants were members of The Polish National Multiple Sclerosis Society. The study was performed in Poland between 2011 and 2012. The inclusion criteria included: males with defined MS following at least one documented attack or insidious neurological progression suggestive of MS, current remission status, age ranging from 18 to 45 years, completed heterosexual initiation and informed consent. The exclusion criteria were: non-related neural disorder, diagnosed psychiatric disorders, sexual inactivity, and corticosteroid therapy or drug/alcohol abuse during the preceding 4 weeks. The study was approved by the research ethics committee of the Medical University of Silesia (decision number KNW/0022/KB/194/13).

The neurological status and level of disability of patients were assessed by the Expanded Disability Status Scale (EDSS), in accordance with the criteria described by Kurtzke [9], by a single researcher without access to the medical records. The EDSS is the most common scale used to assess physical function and symptoms in patients with MS.

Statistical analysis

Statistical analysis was performed using Statistica 10.0 for Windows. Differences among parameters were considered significant at the level of 0.05. Statistical analysis made use of χ^2 and logistic regression analysis.

Results

A total of 72 male MS patients participated in the study. Their mean age was 35.75 ±7.67 years. Additional parameters were assessed (Table 1).

The patients' level of education was as follows: 2.7% (n = 2) had primary education; 74.9% (n = 54) had secondary education; and 22.4% (n = 8) had higher education. Most (64%, n = 26) of the patients were from rural areas and 36% (n = 46) were from towns (≥ 20,000 people).

Multiple sclerosis subtypes included 30.55% (n = 22) secondary progressive MS (SPMS), 27.77% (n = 20) relapsing-remitting MS (RRMS), 22.22% (n = 16) primary progressive MS (PPMS) and 16.66% (n = 12) progressive relapsing MS (PRMS). The respondents' disease severity was evaluated by the decision of the Regional Committee for Adjudication of Disability. The level of disability was assessed by a group of neurologists, based on the patients' actual health state and medical documents. Most of the patients (91.66%, n = 66) were invalids. In this study, 27.77% (n = 20) of MS patients had a severe degree of disability, 47.22% (n = 34) had a moderate degree of disability and 16.66% (n = 12) had a low level of disability.

The median disease duration was 117 months (minimum 16, maximum 288), and the median number of exacerbations was 5.25 per patient (minimum 2, maximum 20). The median age of the men at sexual initiation was 18.2 years (minimum 15, maximum

Table 1. Demographic and clinical characteristics of multiple sclerosis patients (n = 72)

Parameter	Results
Age [years]	Mean: 35.75, SD: 7.67, median: 38.5, range: 20–45
Disease duration [years]	Mean: 9.25, SD: 5.86, median: 8.45, range: 1.33–24
Number of relapses	Mean: 5.19, SD: 4.41, median: 3.5, range: 1–20
EDSS	Mean: 3.61, SD: 1.93, median: 3, range: 0–10

SD – standard deviation, EDSS – Expanded Disability Status Scale

22). Most (72.22%) of the respondents were in a sexual partnership. Although 8.33% (n = 6) of patients reported sexual activity every day, most reported sexual activity several times a week (25%, n = 18) or several times a month (33.33%, n = 24); 16.66% (n = 12) reported sexual activity once a month, 5.55% (n = 4) reported sexual activity a few times a year and 11.11% (n = 8) reported sexual activity once a year. A quarter of the patients (25%, n = 18) were sexually passive, 22.22% (n = 16) were more active than their partner and 52.77% (n = 38) were as active as their partner. Fourteen (19.45%) of the males used sildenafil citrate or similar drugs to treat ED ($p < 0.05$). The median number of sexual partners in the study group was 3.30 (minimum 1, maximum 11).

Discussion

A World Health Organisation study reported that there are more than 2.5 million MS patients worldwide, accounting for 6.29% of total neurological diseases. This number is expected to increase to 6.39% in 2015 and 6.77% in 2030 [10]. Multiple sclerosis has high prevalence and the subsequent life-long disability poses a heavy care burden, both direct and indirect, to the household and community [11, 12]. Multiple sclerosis commonly affects young adults, who may be sexually active, with SD being a significant but often underestimated symptom of MS [13]. It is known that normal sexual and reproductive functions depend largely on neurological, psychologicaland emotional mechanisms, and patients accumulate disability as a result of incomplete recovery from acute exacerbations and/or gradual disease progression [4, 8, 14]. Symptoms such as fatigue, pain and SD have a great impact [15, 16].

Our findings, among male MS sufferers, of a very high prevalence and severity of sexual functional disability partly confirm the findings of earlier studies. Although 91.66% (n = 66) of the males in our study were invalids, 25% of them had been less sexually active or inactive since the onset of MS. These findings confirm those of Szasz *et al.* in 1984, in which 45% of the patients were shown to be less sexually active or inactive [17]. Such a result may have been caused by the use of the different therapeutic strategies that are available for the treatment of MS. A study of MS patients reported fewer sexual problems compared with normal values. Conversely, the MS patients' relationships seemed to be stable despite subjectively perceived lower initiative on sexual activities [18]. Persons with MS have a high prevalence of SD, up to 90% in men [19]. McCabe and Taleporos investigated the association between the severity and duration of physical disability and sexual esteem, sexual satisfaction, sexual depression and the frequency of sexual behaviour [19]. The results demonstrated that people with more severe physical impairments experienced significantly lower levels of sexual esteem and sexual satisfaction and significantly higher levels of sexual depression, and were sexually active less frequently. In our study, 16.66% (n = 12) of MS patients reported engaging in sexual activity a few times a year or once a year. These findings partly confirm Schmidt's study [20]. Of the MS patients, 71% of the men had experienced sexual changes, with 20% being sexually inactive. The men considered 'less activity' as the major cause (79% compared with 54% of women) and the women considered 'less interest' (58% compared with 37% of men) as the major cause [21]. Sometimes SD is an underestimated, common symptom of MS. It may occur in MS even in the absence of severe disability [22]. Khan *et al.* indicated that MS patients did not find sexual activities enjoyable (32%), with many failing to feel aroused (29.6%) and almost half (47.9%) reporting that they never experienced orgasm during sexual activity [23].

In our study, 19.45% of MS males used sildenafil citrate or similar drugs to treat ED ($p < 0.05$). More than 13 million patients worldwide extensively used sildenafil as a treatment for ED. Significant improvements in erectile function have been demonstrated in double-blind, placebo-controlled studies. Hatzichristou observed a significant treatment effect with sildenafil in men with ED and a history of diabetes, cardiovascular disease, minor depression, spinal cord injury, and MS [24]. Our findings confirm those of a study performed in the United States. Among men, the most prevalent sexual problems were erectile difficulties (37%). Fourteen percent of all men reported using medication or supplements to improve sexual function [25].

It is widely known that women report more SD than men [26]. Secondary SD symptoms were the most common complaints for both men and women [27]. The SD is frequent (40–74%) among women with MS, reflecting neurological dysfunction, psychological factors, depression, side effects of medications and physical manifestations of the disease, such as fatigue and muscle weakness [28].

The worldwide literature lacks studies on men suffering from MS. The findings of our study confirm that sexual problems are also serious in males. All these data suggest the presence of different sexual disabilities in MS patients. A higher prevalence of sexual disabilities in patients with MS could also be found with the use of more detailed and validated assessment methods.

Medical professionals working with patients with MS should also pay more attention to their sexual concerns. This problem is great in number and may be overlooked by physicians. Moreover, doctors working in the field of MS should be educated about the specificity of sexual life in patients with MS. This fact should be considered in a holistic look at the pa-

tient by a doctor. In this aspect, cooperation between neurologists and sexologists could be important. The assessment of sexual function should also be implemented in patients after diagnosis of MS.

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