



The impact of illness perceptions on sexual functioning in patients with systemic lupus erythematosus

Gabriëlle M.N. Dalebout^{a,*}, Elizabeth Broadbent^b, Fiona McQueen^c, Ad A. Kaptein^a

^a Department of Medical Psychology, Leiden University Medical Center, Leiden, The Netherlands

^b Department of Psychological Medicine, Faculty of Medical and Health Sciences, University of Auckland, Auckland, New Zealand

^c Department of Rheumatology, Auckland District Health Board, Auckland, New Zealand

ARTICLE INFO

Article history:

Received 5 April 2012

Received in revised form 4 November 2012

Accepted 6 November 2012

Keywords:

Chronic illness

Disease activity

Illness perceptions

Immunosuppressive treatment

Psychosocial factors

Sexual functioning

Systemic lupus erythematosus

ABSTRACT

Objective: Sexual problems are common in patients with chronic illnesses. However, few studies have investigated problems with sexual functioning in patients with systemic lupus erythematosus (SLE). The present cross-sectional study assessed the influence of SLE on sexual functioning and its associations with illness perceptions and medical and socio-demographic characteristics.

Method: The study included 106 SLE patients who used at least one immunosuppressive agent to control their SLE. Sexual functioning was measured using the Physical Disability Sexual and Body Esteem and the Medical Impact Scale from the Sexual Functioning Questionnaire. Patients' illness perceptions were assessed using the Brief Illness Perception Questionnaire.

Results: 49.1% of patients agreed that their SLE had a negative influence on their sexual functioning. In addition, treatment for SLE seemed to play an important role in the negative impact on sexual functioning. Patients' illness perceptions were more important predictors of sexual functioning than medical and socio-demographic characteristics. SLE patients appear to report a lower sexual functioning than patients with other chronic illnesses.

Conclusion: SLE in general and immunosuppressive treatment for SLE specifically have a negative influence on sexual functioning. Patients' illness perceptions appear to play a more important role in the negative impact on sexual functioning than medical characteristics such as disease activity. The high prevalence of sexual problems highlights the need to more frequently address and aim to improve sexual functioning in patients with SLE. Patients may benefit from methods such as illness perception modification and coping style interventions to reduce their sexual problems.

© 2012 Elsevier Inc. All rights reserved.

Introduction

The impact of the chronic, rheumatic, autoimmune disease systemic lupus erythematosus (SLE) on health-related quality of life (HRQoL) has been addressed by several studies [1–3]. HRQoL aims to assess both the extent to which illness and its treatment influences functioning on several domains (e.g., physical, mental, social, and role) and patients' emotional responses to these influences [4]. The effect of SLE on the domain of sexual functioning specifically has been less studied [5,6]. There is no universal definition of sexual functioning and it is used interchangeably with other terms such as sexual well-being and sexual satisfaction [7]. In the present study, sexual functioning will refer to the extent to which illness interferes with one's sexual identity (e.g., feelings of sexual attractiveness, sexual expression, preferences) and sex life (e.g., arousal, orgasm, intercourse) and patients' emotional responses to these interferences. Sexual

functioning may be disturbed by a variety of factors, including pain, fatigue, stiffness, functional impairment, depression, anxiety, negative body image, reduced libido, hormonal imbalance, and drug treatment [6].

Several disease characteristics specific for SLE may have a negative impact on sexual functioning. First, disease onset is commonly in the adolescent years, which is an important period for the development of body-image and sexual identity [8]. Second, the clinical manifestations of SLE (e.g., skin rashes, vitiligo, painful joints) may have an adverse effect on interest, desire, and body-image. Third, common side effects of immunosuppressive agents such as weight gain, hair loss, and infertility, may also negatively affect body image. Fourth, active SLE is associated with an increased likelihood of adverse pregnancy outcomes [9], which could have an additional negative impact on sexual functioning.

Although few previous studies have investigated sexual functioning in SLE patients, the results in general indicate a negative impact [10–15]. In comparison with healthy women, SLE patients report lower sexual functioning and poorer body image [11]. Among SLE patients a lower sexual functioning has been found to be associated with high levels of fatigue [12], depressive symptoms [12], disease

* Corresponding author at: Department of Medical Psychology, Leiden University Medical Center (LUMC), P.O. Box 9600, 2300 RC Leiden, The Netherlands. Tel.: +31 71 526 2905; fax: +31 71 524 8123.

E-mail address: gmnalebout@gmail.com (G.M.N. Dalebout).

activity or severity [14], menstrual cycle disturbances [15], and the presence of vascular disease (i.e., coronary or peripheral artery disease) [15].

Apart from the association between sexual functioning and medical and a few psychosocial factors, no research with SLE patients has investigated the relationship with psychological constructs such as illness perceptions. Illness perceptions consist of emotional and cognitive responses to illness and can be grouped into different dimensions: perceived identity (illness name and symptoms), illness cause, timeline, consequences, how much personal control the patient has, how much treatment can help, how much the illness makes sense to the patient (coherence), whether the illness concerns the patient, and emotional responses [16].

Research with other chronic illness patients has suggested that such psychological parameters may be more important determinants of sexual functioning than medical factors [17]. Therefore, the purpose of the present study was not only to expand the knowledge of the influence of SLE on sexual functioning, but also to investigate whether sexuality in these patients was more strongly associated with patients' illness perceptions than medical or socio-demographic characteristics. In addition, SLE patients were compared with patients with other chronic illnesses on measures of sexual functioning to assess the presence of a disease specific influence.

Methods

This cross-sectional study was conducted at Auckland City Hospital, Auckland, New Zealand and was approved by the Northern X Ethics Committee.

Participants

Patients were recruited from the rheumatology clinic at Greenlane Clinical Centre (the outpatient clinic of Auckland City Hospital,) and from two lupus patients' associations in New Zealand. This study was coupled with one investigating the association between treatment non-adherence and psychosocial and medical characteristics [18]. Therefore, inclusion criteria were not only a diagnosis of SLE according to the revised American College Rheumatology (ACR) criteria for SLE [19], but also current treatment with corticosteroids and/or another immunosuppressive agent. Two weeks after sending out invitation letters to potential participants, patients were contacted by telephone. Out of the 141 patients who were approached, 106 patients were willing to participate (75% participation rate). Twenty-two patients showed no interest in joining the study, four patients did not attend the scheduled appointment, and nine patients stated that they were too busy or didn't want to participate because of language barriers.

Participants provided informed consent and completed four self-administered, paper-and-pencil questionnaires. After completion of the questionnaires, the principal investigator (GMND, MD and MSc in psychology) assessed disease activity according to the SLE Disease Activity Index (SLEDAI) [20]. The assessment took place in a private room at the clinical center or at the patient's home if that was more convenient for the patient.

Instruments

Socio-demographic and medical characteristics were recorded through a separate questionnaire and included the following parameters: age, gender, ethnic group, marital status, number of children (no distinction between biological or adopted), employment status, highest educational level achieved, religion, year of diagnosis of SLE, past and present organ involvement(s), and current medication use.

Sexual functioning was measured using the Physical Disability and Sexual and Body Esteem scale (PDSBE) [21] and the Medical Impact Scale of the Sexual Functioning Questionnaire (SFQ) [22]. Because

there is no questionnaire specifically developed to measure sexual functioning in SLE patients, these two scales were chosen because of their good psychometric characteristics and because they were developed for or tested in several patient groups with diverse medical conditions [21,22]. Both questionnaires measure level of sexual functioning at the time of assessment. The PDSBE has been shown to be a psychometrically sound instrument to assess body esteem and sexual esteem in patients with physical disabilities [21]. The questionnaire consists of 10 items that are rated on a 5-point scale from strongly disagree to strongly agree. The items can be subdivided in three subscales: 1) attractiveness, 2) sexual esteem and 3) body esteem. Examples of items of the PDSBE are "I feel that my illness interferes with my sexual enjoyment" (subscale Sexual Esteem), "I feel that people are not sexually interested in me because of my illness" (subscale Attractiveness) and "I envy people with 'normal' bodies" (subscale Body Esteem). Mean scores are calculated for the three subscales separately and all together. In addition, sum scores of the three subscales were dichotomized at the scale midpoint to assess the strength of patients' body and sexual esteem and feelings of attractiveness.

The Sexual Functioning Questionnaire (SFQ) was originally developed to assess sexual functioning in patients with cancer, but is thought to result in equally reliable and valid outcome measures in patients with other medical conditions as well [22]. The Medical Impact Scale assesses the impact of treatment on sexual functioning and contains 5 items: one rating scale item and four 5-point scale items. The rating scale item asks patients to rate how well they think they have adjusted to changes in their sex life since their treatment for SLE. An example of a 5-point scale item is "What impact has your treatment had on your interest or desire for sex?". A total score is calculated as the mean score on all 5 items.

The Brief Illness Perception Questionnaire (B-IPQ) was used to measure illness perceptions. The B-IPQ contains 8 items scored on a scale from 0 to 10 and one open-ended question where the participants state what they think are the three most important causes of their disease. The scale items measure patients' cognitive and emotional representations of their illness and correspond to 8 different domains: Identity, Consequences, Timeline, Personal Control, Treatment Control, Coherence, Concern, and Emotion. The reported causes in the open-ended question were grouped into categories on the basis of common themes. The B-IPQ has been shown to be a valid and reliable measure to assess illness perceptions in ill populations [23].

The Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) was used to measure disease activity at the time of assessment [20]. The SLEDAI is a reliable, valid and widely used instrument to assess disease activity in patients with SLE [24–26]. Disease activity scores can range from 0 to 105. Five activity categories have been defined: 1) no activity (SLEDAI = 0), 2) mild activity (SLEDAI = 1–5), 3) moderate activity (SLEDAI = 6–10), 4) high activity (SLEDAI = 11–19), and 5) very high activity (SLEDAI ≥ 20).

Statistical analysis

Data were analyzed using SPSS 17.0 software. Descriptive statistics and frequencies were obtained for the socio-demographic and disease related characteristics. One sample t-tests were used to test differences in PDSBE scores between SLE patients and patients with other chronic illnesses (derived from Kedde and Van Berlo [27]) and to assess whether scores on the Medical Impact Scale were significantly different from 0. Scores on the Medical Impact Scale for the SLE group were compared with those for a group of cancer patients (derived from Syrjala et al. [22]).

Associations between sexual functioning and socio-demographic and disease related characteristics and illness perceptions were explored with correlational analysis. Significant relationships were investigated with multiple linear regression analyses to further explore the predictive associations between variables, while controlling for socio-demographic

Download English Version:

<https://daneshyari.com/en/article/10469633>

Download Persian Version:

<https://daneshyari.com/article/10469633>

[Daneshyari.com](https://daneshyari.com)