Journal of Psychosomatic Research 74 (2013) 260–264

Contents lists available at SciVerse ScienceDirect

Journal of Psychosomatic Research

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

Gabriëlle M.N. Daleboudt [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.

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: gmndaleboudt@gmail.com (G.M.N. Daleboudt).

0022-3999/$ – see front matter © 2012 Elsevier Inc. All rights reserved.
http://dx.doi.org/10.1016/j.jpsychores.2012.11.004

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 ($\text{SLEDAI} = 0$), 2) mild activity ($\text{SLEDAI} = 1–5$), 3) moderate activity ($\text{SLEDAI} = 6–10$), 4) high activity ($\text{SLEDAI} = 11–19$), and 5) very high activity ($\text{SLEDAI} \geq 20$).

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 characteristics and SLEDAI scores. In these analyses, the involved socio-demographic characteristics were scored as follows: religion as a dichotomous variable (0 = no religion, 1 = religion), education as an ordinal variable with 5 categories (1 = primary education, 2 = secondary education, 3 = bachelor's degree, 4 = master's degree, and 5 = doctoral degree). Five separate analyses were performed for sexual functioning in general (i.e., total score on the PDSBE), the three subscales of the PDSBE (i.e., sexual esteem, body esteem, and attractiveness), and the impact of treatment on sexual functioning. The stepwise method was used to select the most important predictor variables. An alpha level of .05 was used for all statistical tests.

Results

Participants

The mean age of the patients was 43.34 years ($SD = 14.96$). 94.3% of the patients were female, which can be explained by the higher prevalence of SLE in females. The largest ethnic group consisted of New Zealand Europeans (39.6%). Table 1 gives an overview of socio-demographic characteristics.

The patients had a mean disease duration of 10.2 years ($SD = 9.1$). Half of the patients (54.7%) had experienced one or more organ involvements. Nearly three quarters of patients (71.7%) had one or more comorbidities. An overview of disease characteristics is provided in Table 2.

Physical Disability and Sexual and Body Esteem (PDSBE)

A hundred and one patients completed the PDSBE. Two patients did not want to complete the questionnaires, one patient had never been sexually active, and two patients thought the majority of the questions were not applicable to their situation. 49.1% of the patients agreed that having SLE had a negative influence on their sexual functioning. This influence consisted of a lower sexual esteem and body esteem for 38.4% and 46.1% of the patients, respectively, and feelings of a lower attractiveness for 25.8% of the patients. In comparison with patients with other chronic illnesses [27], SLE patients appear to have a lower sexual esteem ($M = 10.11$, $SD = 3.91$ vs. $M = 12.58$, $SD = 4.25$; $t = -6.28$, df = 98, $p < .001$) and feel less attractive ($M = 7.25$, $SD = 3.0$ vs. $M = 9.63$, $SD = 3.2$; $t = -7.33$, df = 92, $p < .001$).

Table 1
Socio-demographic variables of the total participant group (N = 106)

Female to male ratio	100:6
Age, mean (*SD*)	43.34 (14.96)
Ethnicity	
New Zealand European	42 (39.6%)
Pacific Islands	15 (14.2%)
Maori	13 (12.3%)
Middle Eastern/Latin American/African	3 (7.5%)
Other	3 (6.6%)
Employment	
Fulltime	34 (32.1%)
Part time	23 (21.7%)
Sickness benefit	20 (18.9%)
Housewife	9 (8.5%)
Retired	9 (8.5%)
Student	8 (7.5%)
Unemployed	7 (6.6%)
Marital status	
Unmarried	31 (31.2%)
Married or living together	55 (51.9%)
Divorced	11 (10.4%)
Widow/widower	7 (6.6%)
Education	
Primary education	5 (4.7%)
Secondary education	63 (59.4%)
Bachelor's degree	31 (29.2%)
Master's degree	5 (4.7%)
Doctoral degree	2 (1.9%)
Children (one or more)	65 (61.3%)
Religion	
None	60 (56.6%)
Christianity	37 (34.9%)
Other	9 (8.5%)

Table 2
Disease characteristics of total participant group (N = 106)

Disease duration, mean (*SD*) in years	10.2 (9.1)
SLEDAI[a] score, mean (*SD*) (range 0–105)	10.2 (6.2)
Organ involvement	
None	48 (45.3%)
Lupus nephritis	31 (29.2%)
NPSLE[b]	17 (16.0%)
Pleuritis	13 (12.3%)
Pericarditis	10 (9.4%)
Hepatitis	7 (6.6%)
Eyes	8 (7.5%)
Co-morbidity	
None	30 (28.3%)
Other auto-immune diseases	18 (17.0%)
Hypertension	18 (17.0%)
Fibromyalgia	12 (11.3%)
Antiphospholipid antibody syndrome	12 (11.3%)
Secondary Sjögren's syndrome	11 (10.4%)
Dyslipidemia	10 (9.4%)
Medication	
Hydroxychloroquine	89 (84.0%)
Prednisone	56 (52.8%)
Azathioprine	42 (39.6%)
Other immunosuppressants	15 (14.2%)
Psychopharmaceuticals	26 (24.5%)
Analgesics	30 (28.3%)

[a] Systemic Lupus Erythematosus Disease Activity Index.
[b] Neuropsychiatric systemic lupus erythematosus.

Medical Impact Scale (MIS)

The impact of treatment on sexual functioning was assessed for 87 patients. Nineteen patients could not complete the questionnaire because they were either not sexually active at the time of assessment or they had not had sexual contact yet before they were diagnosed with SLE. The mean score on the SFQ Medical Impact Scale ($M = 2.27$, $SD = .97$) differed significantly from 0, i.e., there is no effect of treatment on sexual functioning ($t = 21.8$, df = 86, $p < .001$). SLE patients appear to report a greater negative influence of treatment on their sexual functioning than patients who have been treated with bone marrow transplantation for different types of cancer ($M = 2.27$, $SD = .97$ vs. $M = 2.92$, $SD = .96$; $t = -4.97$, df = 86, $p < .001$) [22]. In conclusion, SLE patients' sexual functioning was negatively affected by their treatment.

Brief Illness Perception Questionnaire (B-IPQ)

Patients' illness perception scores in general clustered around the midrange of the items (see Table 3). Two exceptions are the items Timeline with the highest mean score ($M = 8.43$, $SD = 2.53$) and Treatment Control with the lowest mean score ($M = 2.71$, $SD = 2.23$). This indicates that patients held chronic perceptions of their SLE and felt that treatment could not help them much. The first most important reported causes were grouped into 5 broad categories: psychosocial causes (33.3%), genetics (32.0%), environmental causes (10.7%), previous bacterial or viral infections (13.3%), and pregnancy (10.7%). Causal perceptions showed no relationship with measures of sexual functioning.

Regression analyses

Table 4 summarizes the results for the five separate regression analyses. With sexual functioning in general as the dependent variable, a significant model emerged in which emotion and religion explained 16.7% of the variance ($F\,(2, 100) = 11.20$, $p < .001$). Emotion was the strongest predictor accounting for 11.3% of the explained

Table 3
Means and standard deviations for the Brief Illness Perception Questionnaire (B-IPQ)

	SLE patients
	(N = 106)
Identity	6.14 (2.58)
Consequences	5.45 (2.71)
Timeline	8.44 (2.49)
Personal Control	4.88 (3.00)
Treatment Control	2.71 (2.23)
Coherence	3.29 (2.47)
Emotion	5.50 (3.03)
Concern	6.90 (2.83)

variance. Religion added a further 5.4% to the proportion of explained variance. The subscale Attractiveness was best predicted by Emotion (adjusted $R^2 = 0.95$) and Coherence (adjusted $R^2 = 0.73$), which together explained 16.8% of the variance (F (2, 90) = 10.32, $p < .001$). A model with Sexual Esteem as the dependent variable explained 14.2% of the variance and included the variables Emotion (adjusted $R^2 = 0.11$) and Identity (adjusted $R^2 = 0.32$; F (2, 94) = 8.94, $p < .001$). The variables Personal Control, Emotion, Religion, and Education were important predictors of Body Esteem and explained 22.3% of the variance (F (4, 97) = 8.24, $p < .001$). Personal Control was the strongest predictor accounting for 8.2% of the explained variance. Emotion, Religion, and Education added a further 6.4%, 4.7%, and 3.2% to the proportion of the explained variance, respectively. With the impact of treatment on sexual functioning as dependent variable, a significant model emerged with Consequences, Coherence, SLEDAI, and Treatment Control as significant predictors (F (5, 92) = 4.97, $p < .000$). The model explained 31.3% of the variance in sexual functioning. Coherence was the strongest predictor accounting for 12.6% of the explained variance. Consequences, Treatment Control, and SLEDAI added a further 10.8%, 4.3%, and 3.6% to the proportion of explained variance, respectively.

Altogether these analyses suggest that illness perceptions are stronger predictors of sexual functioning than medical or socio-demographic characteristics.

Discussion

The present study assessed the influence of SLE and its treatment on patients' sexual functioning. The results showed that half of the patients experienced negative effects of SLE in general on their sexual functioning, especially on their sexual esteem and body esteem. In addition, treatment for SLE specifically seemed to play an important role in the negative influence on sexual functioning. Patients' illness perceptions were more important predictors of sexual functioning than socio-demographic and medical characteristics. The influence of SLE on sexual functioning appears to be disease specific as SLE patients seem to report a lower sexual functioning than patients with other chronic illnesses.

Problems with sexual functioning are common among patients with chronic illnesses [28]. Between one and two thirds of patients with rheumatic diseases experience sexual problems [5]. However, sexual functioning in rheumatic patients, and specifically in patients with SLE, has not been frequently studied [5]. The few previous studies that have addressed sexual functioning in SLE patients in general found a negative effect [10–15]. This was also demonstrated in the present study, with nearly 50% of patients reporting a lower sexual functioning because of their SLE. The high prevalence of sexual problems in SLE patients highlights the need to address this subject during regular check-ups. Patients may feel reluctant to introduce the topic themselves, but if the physician inquires about sexual functioning this will make it more likely that patients will report problems at that time and in the future [29].

Previous studies have found medical and socio-demographic factors to be important predictors of sexual functioning in SLE patients [12,14,15]. Although the present study also found an association between sexual functioning and disease activity, age, and education, patients' illness perceptions were stronger predictors of sexual functioning than medical and socio-demographic characteristics. In particular, patients who were more emotionally affected by their SLE reported a lower sexual functioning. In addition, patients reported a lower sexual functioning when they perceived that SLE had a large impact on their lives, felt they did not understand their SLE, and believed that treatment could not help them much. Of interest is the finding that patients' emotional representations were associated with the PDSBE subscales Attractiveness, Body Esteem, and Sexual Esteem, whereas patients' cognitive perceptions showed a relationship with the influence of treatment on SLE as measured by the Medical Impact Scale. Hence, in assessing sexual functioning in SLE patients it is important to differentiate between what patients feel and think because the impact on sexual functioning may differ. Sexual functioning may be enhanced by interventions that are directed towards illness perception modification. Previous research with SLE patients has shown positive changes in the perceptions of Identity, Treatment Control, and Emotion and related improvements in distress after a onetime two-hour CBT intervention [30].

Although patients' illness perceptions appear to be important predictors of the influence of illness on sexual functioning, the results suggest that other factors not included in the present study also play a role. For instance, it is likely that coping strategies are involved since coping acts as a mediator between illness perceptions and outcomes, as described by self-regulation theory [16]. In addition, a recent model of coping with sexual dysfunction in chronic illness claims that flexibility in coping with sexual dysfunction can be increased by enhancing the flexibility in patients' definitions of sexual functioning within their self-concept [31]. A preliminary application of the model in cancer survivors with sexual problems has shown good results [32]. The effectiveness of such an intervention to improve sexual functioning in SLE patients should be explored.

Determinants of problems with sexual functioning have been shown to be multifactorial and disease specific [5]. The present study illustrates this disease specificity by showing that SLE patients appear to experience a lower sexual functioning in general and as a result of treatment, compared with patients with other chronic illnesses. These comparison groups were derived from two separate studies. One study investigated sexual satisfaction and sexual self-image among men (N = 95) and women (N = 65) with one of seven different chronic medical conditions (e.g., arthritis related conditions, muscular illnesses, neurological related illnesses) [27]. The second study looked at sexual problems in 161 women and 118 men who have been successfully treated with blood or bone marrow transplants for leukemia or other types of cancer [22]. Patients from both studies were comparable on socio-demographic characteristics such as age, education and marital

Table 4

Summary of regression analyses to predict sexual functioning (Physical Disability Sexual and Body Esteem (PDSBE) overall score, subscales and the Medical Impact Scale)

Predictor variables	PDSBE total		Sexual Esteem		Body Esteem		Attractiveness		Medical Impact Scale	
	Beta	*p*	Beta	*p*	Beta	*p*	Beta	*p*	Beta	*p*
Socio/demographic										
Religion[a]	−.249	.007	N/A		−.245	.008	N/A		N/A	
Education	N/A		N/A		−.198	.028	N/A		N/A	
Disease-related										
SLEDAI	N/A		N/A		N/A		N/A		.239	.015
Illness perceptions										
Emotion	.362	.000	.251	.019	.252	.006	.333	.001	N/A	
Coherence	N/A		N/A		N/A		.286	.003	.326	.001
Treatment Control	N/A		N/A		N/A		N/A		.225	.016
Consequences	N/A		N/A		N/A		N/A		321	.001
Identity	N/A	.222		.037	N/A		N/A		N/A	
Personal Control	N/A		N/A		.232	.012	N/A		N/A	

High scores correspond with low sexual functioning.

[a] Religion was coded as 0 = not religious, 1 = religious.

status. The difference in sexual functioning between SLE patients and patients with other chronic illnesses could indicate that SLE has a greater impact on sexual functioning than other illnesses, which would be in line with the finding that HRQoL is lower in SLE patients than in patients with other chronic illnesses [1,2]. Sexual functioning is one of the domains of quality of life and because research has shown that disease specific measures are essential for an optimal measure of HRQoL in SLE patients [33], future studies should be dedicated to the development of disease specific measures of sexual functioning in SLE patients.

An important limitation of the present study is that it was cross-sectional and correlational, which limit interpretations about causality. In addition, regression analyses indicated that important factors in the prediction of sexual functioning were not included in the present study. Apart from a possible association with coping behavior, previous research has shown that sexual functioning was strongly related to premorbid sexual adjustment and relationship quality [14]. These psychosocial characteristics were not assessed in the present study.

In conclusion, SLE in general and 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. SLE patients with sexual problems could benefit from methods such as illness perception modification and coping style interventions to reduce their sexual problems. The high prevalence of sexual problems highlights the need to more frequently address and aim to improve sexual functioning in SLE patients.

Conflict of interest

The authors have no conflict of interest.

Acknowledgments

This research received no specific grant from any funding agency in the public, commercial, or not for profit sectors.

References

[1] Jolly M. How does quality of life of patients with systemic lupus erythematosus compare with that of other common chronic illnesses? Journal of Rheumatology September 2005;32:1706-8.

[2] Daleboudt GM, Berger SP, Broadbent E, Kaptein AA. Health-related quality of life in patients with systemic lupus erythematosus and proliferative lupus nephritis. Psychology, Health & Medicine August 2011;16:393-404.

[3] Grootscholten C, Snoek FJ, Bijl M, van Houwelingen HC, Derksen RH, Berden JH. Health-related quality of life and treatment burden in patients with proliferative lupus nephritis treated with cyclophosphamide or azathioprine/methylprednisolone in a randomized controlled trial. Journal of Rheumatology August 2007;34:1699-707.

[4] Hennessy CH, Moriarty DG, Zack MM, Scherr PA, Brackbill R. Measuring health-related quality of life for public health surveillance. Public Health Reports September 1994;109:665-72.

[5] Tristano AG. The impact of rheumatic diseases on sexual function. Rheumatology International January 2009;29:853-60.

[6] Ostensen M. New insights into sexual functioning and fertility in rheumatic diseases. Best Practice & Research Clinical Rheumatology April 2004;18:219-32.

[7] Sowers KM, Rowe WS, McCarter AK. Sexual dysfunction. In: Dulmust CNR-PLA, editor. Handbook of preventive interventions for adults. Hoboken, New Jersey: John Wiley & Sons, Inc; 2005. p. 125-40.

[8] Christie D, Viner R. Adolescent development. BMJ February 5 2005;330:301-4.

[9] Andrade R, Sanchez ML, Alarcon GS, Fessler BJ, Fernandez M, Bertoli AM, et al. Adverse pregnancy outcomes in women with systemic lupus erythematosus from a multiethnic US cohort: LUMINA (LVI). [corrected]Clinical and Experimental Rheumatology March 2008;26:268-74.

[10] Stein H, Walters K, Dillon A, Schulzer M. Systemic lupus erythematosus—a medical and social profile. Journal of Rheumatology June 1986;13:570-6.

[11] Curry SL, Levine SB, Corty E, Jones PK, Kurit DM. The impact of systemic lupus erythematosus on women's sexual functioning. Journal of Rheumatology December 1994;21:2254-60.

[12] Seawell AH, Danoff-Burg S. Body image and sexuality in women with and without systemic lupus erythematosus. Sex Roles December 2005;53:865-76.

[13] Karlen A. Positive sexual effects of chronic illness: case studies of women with lupus (SLE). Sexuality and Disability September 2002;20:191-208.

[14] Curry SL, Levine SB, Jones PK, Kurit DM. Medical and psychosocial predictors of sexual outcome among women with systemic lupus erythematosus. Arthritis Care and Research March 1993;6:23-30.

[15] Tseng JC, Lu LY, Hu JC, Wang LF, Yen LJ, Wu HC, et al. The impact of systemic lupus erythematosus on women's sexual functioning. The Journal of Sexual Medicine December 2011;8:3389-97.

[16] Leventhal H, Meyer D, Nerenz DR. The common sense representation of illness danger. In: Rachman S, editor. Medical psychology. New York: Pergamon; 1980. p. 7–30.

[17] Kaptein AA, van Klink RC, De Kok F, Scharloo M, Snoei L, Broadbent E, et al. Sexuality in patients with asthma and COPD. Respiratory Medicine February 2008;102:198-204.

[18] Daleboudt GMN, Broadbent E, McQueen F, Kaptein AA. Intentional and unintentional treatment non-adherence in patients with systemic lupus erythematosus. Arthritis Care and Research March 2011;63:342-50.

[19] Tan EM, Cohen AS, Fries JF, Masi AT, McShane DJ, Rothfield NF, et al. The 1982 revised criteria for the classification of systemic lupus erythematosus. Arthritis and Rheumatism November 1982;25:1271-7.

[20] Bombardier C, Gladman DD, Urowitz MB, Caron D, Chang CH. Derivation of the SLEDAI. A disease activity index for lupus patients. The Committee on Prognosis Studies in SLE. Arthritis and Rheumatism June 1992;35:630-40.

[21] Taleporos G, Dip G, McCabe MP. Development and validation of the Physical Disability Sexual and Body Esteem Scale. Sexuality and Disability September 2002;20:159-76.

[22] Syrjala KL, Schroeder TC, Abrams JR, Atkins TZ, Brown WS, Sanders JE, et al. Sexual function measurement and outcomes in cancer survivors and matched controls. Journal of Sex Research March 2000;37:213-25.

[23] Broadbent E, Petrie KJ, Main J, Weinman J. The Brief Illness Perception Questionnaire. Journal of Psychosomatic Research June 2006;60:631-7.

[24] Petri M, Hellmann D, Hochberg M. Validity and reliability of lupus activity measures in the routine clinic setting. Journal of Rheumatology January 1992;19:53-9.

[25] Guzman J, Cardiel MH, Arce-Salinas A, Sanchez-Guerrero J, Alarcon-Segovia D. Measurement of disease activity in systemic lupus erythematosus. Prospective validation of 3 clinical indices. Journal of Rheumatology October 1992;19:1551-8.

[26] Hawker G, Gabriel S, Bombardier C, Goldsmith C, Caron D, Gladman D. A reliability study of SLEDAI: a disease activity index for systemic lupus erythematosus. Journal of Rheumatology April 1993;20:657-60.

[27] Kedde H, Van Berlo W. Sexual satisfaction and sexual self images of people with physical disabilities in the Netherlands. Sexuality and Disability March 2006;24:53-68.

[28] Nusbaum MR, Hamilton C, Lenahan P. Chronic illness and sexual functioning. American Family Physician January 15 2003;67:347-54.

[29] Taylor B, Davis S. The extended PLISSIT model for addressing the sexual wellbeing of individuals with an acquired disability or chronic illness. Sexuality and Disability September 2007;25:135-9.

[30] Goodman D, Morrissey S, Graham D, Bossingham D. The application of cognitive behaviour therapy in altering illness representations of systemic lupus erythematosus. Behaviour Change June 2005;22:156-71.

[31] Barsky JL, Friedman MA, Rosen RC. Sexual dysfunction and chronic illness: the role of flexibility in coping. Journal of Sex & Marital Therapy September 2006;32:235-53.

[32] Reese JB, Keefe FJ, Somers TJ, Abernethy AP. Coping with sexual concerns after cancer: the use of flexible coping. Supportive Care in Cancer February 2010;18:785-800.

[33] Thumboo J, Strand V. Health-related quality of life in patients with systemic lupus erythematosus: an update. Annals of the Academy of Medicine, Singapore February 2007;36:115-22.