Effect of Musculoskeletal Pain on Sexuality of Male Adolescents and Adults with Juvenile Idiopathic Arthritis

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ABSTRACT. ***Objective.*** To develop a questionnaire for the evaluation of sexuality of male patients with juvenile idiopathic arthritis (JIA).

Methods. A cohort of male patients with rheumatoid factor (RF)-negative polyarticular JIA according to the 2004 revised ILAR criteria and inactive disease was studied. The Health Assessment Questionnaire (HAQ) was applied to all patients. As a control group, 120 age-matched males of the same socioeconomic status were evaluated. A self-administered structured instrument, the Male Sexual Evaluation Questionnaire (MSEQ), was developed by multiprofessional experts to assess sexual life, including satisfaction, practice, and related functional aspects.

Results. Thirty-two male patients with RF-negative polyarticular JIA [mean age 20.8 ± 3.8 yrs (range 16–26), mean disease duration 15.4 ± 3.6 yrs (range 13–20)] were studied. Mean HAQ score was 1.25 ± 0.67 (range 0.1–2.1). Masturbation was practiced similarly by patients and controls (87.5% vs 91%; $p > 0.999$), although joint pain was observed in only 2 (7%) patients. Regular sexual intercourse (≥ once/week) was reported by 78% of patients and 62% of controls ($p = 0.86$). Joint pain during intercourse was more frequent in patients (48% vs 3% in controls; $p < 0.001$). The mean HAQ score was higher in the 12 patients with joint pain (hips = 3, knees = 5, and hips + knees = 4) during intercourse compared to the 13 patients without joint pain (1.82 ± 0.27 vs 1.43 ± 0.32; $p < 0.05$). Preserved desire and satisfaction were universal findings for all JIA patients and controls.

Conclusion. The MSEQ was applicable to this cohort of male patients with RF-negative polyarticular JIA and showed that sexual life is preserved despite longterm disease, morbidity/functional dysfunction, and joint pain. (First Release May 1 2009; J Rheumatol 2009;36:1337–42; doi:10.3899/jrheum.080867)

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Human sexual function, which starts in childhood and extends through puberty and adolescence into adulthood, is essential for a full and satisfying life but is vulnerable to interference from chronic diseases, including those that directly affect the skeletal muscle system such as juvenile idiopathic arthritis (JIA)[1]. During adolescence, reproductive capability is achieved and sexuality is developed. In general, sexual satisfaction by self-actualization, libido, emotional link with a partner, or complete sexual intercourse are considered to be essential for the life of a human being[2,3].

In JIA, the presence of chronic arthritis and functional impairment may affect the patient throughout life by interfering with daily life activities. Similarly, sexuality may also be compromised[4-8], since pain, fatigue, stiffness, impaired function, and deformities may influence behavior and the practice of adequate sexual positions. Together, difficulties and discomfort during intercourse may reduce a patient's interest and activity and thereby influence his sexual performance and frequency[9].

In males, sexual function can be divided into 5 different items: erection, orgasmic function, sexual libido (desire), and satisfaction with intercourse and with his sexual life as a whole[10,11]. Disturbance in any of these components may result in possible dysfunctions, potentially characterizing a specific sexual disease[10,11].

Few questionnaires are available to assess sexual function in humans[10,12,13]. The Liver Disease Quality of Life Instrument[10], the self-administered Brief Male Sexual

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Function Inventory[13], and the International Index of Erectile Function[14] evaluate sexual performance, ejaculation, erection, satisfaction, and perception of male sexual problems[10,11,13-15]. In contrast, the Questionnaire of Satisfaction with Sexual Relationship and the International Consultation on Incontinence Questionnaire-Short Form assesses urinary incontinence in females[12,16]. For patients with arthritis, the Sexuality Questionnaire was developed; however, this instrument is very ambiguous and consists of only 11 questions related to patient-partner relationship, sexual relationship and activity, influence of disease symptoms, drug therapy, and communication[17]. However, none of these questionnaires was specifically designed to evaluate the influence of musculoskeletal pain on sexual activity in males. Therefore, our aim was to develop and apply a self-administered questionnaire for assessment of sexual life in a homogeneous population of male patients with rheumatoid factor (RF)-negative polyarticular JIA.

MATERIALS AND METHODS

Patients. Thirty-two male patients with RF-negative polyarticular JIA according to the criteria of the International League of Associations for Rheumatology[6] were studied. All patients were recruited from 2 pediatric rheumatology outpatient clinics of the University of Sao Paulo Medical School. Patients were eligible for study if they ranged in age from 16 to 26 years and had inactive JIA defined as the absence of any synovitis associated with a low erythrocyte sedimentation rate for at least 3 months. As a control group, 120 healthy males, students from 2 public schools, matched for age and of the same socioeconomic status according to the Economic Classification Criterion of Brazil[18] were interviewed. All patients and controls were sexually active, literate, capable of reading and writing in a spontaneous, free manner and without help, and had sufficient knowledge of the Portuguese language to complete a self-report questionnaire. All subjects signed the consent form approved by the Institutional Review Board of the University of Sao Paulo Medical School.

Elaboration of the Male Sexual Evaluation Questionnaire (MSEQ). A self-administered questionnaire regarding male sexuality was specifically developed for patients with JIA based on previous studies[17,19-23] and according to general agreement among 6 specialists. This group of experts consisted of 3 physicians — one rheumatologist, one epidemiologist, and one psychiatrist — with expertise in human sexuality, 2 physiotherapists, and one Portuguese-language teacher. Information about marital status, masturbation, intercourse, and intercourse limited by pain, position or fatigue was collected. Before establishment of the final model of the questionnaire, 3 successive pilot versions were initially developed and consecutively reanalyzed in order to guarantee full understanding by the patients and to adapt them to the proposed idea. All questionnaires were tested in 10 different patients in order to evaluate their applicability. The definitive version of the MSEQ consisted of 34 questions and required roughly 13 minutes to be completed. A visual analog scale ranging from 0 (totally unsatisfied) to 10 (totally satisfied) was developed to quantify the level of sexual life satisfaction.

Application of the pilot and definitive versions of the MSEQ. Each patient filled out his respective questionnaire alone in a room, maintaining his privacy and anonymity in order to guarantee total discretion and to avoid factors such as embarrassment and inhibition. All questionnaires were identified with a number and kept inside a sealed envelope until the time of analysis in order to assure better reliability of the answers.

Application of the Health Assessment Questionnaire (HAQ). To evaluate the functional capacity of patients with JIA, the validated Brazilian version of the HAQ[24,25] instead of the childhood HAQ[26,27] was applied because all subjects were age 16 years or older.

Statistical analysis. The unpaired Student t test was used to compare age. The chi-square test of homogeneity was applied to the comparison of social classes, initiation of sexual life, presence of pain during masturbation and sexual intercourse, sexual position, and sexual satisfaction between patients and controls. Fisher's exact test was used for comparison of erection related to attraction among groups, whereas the chi-square and Fisher's exact tests were applied for doubts regarding sex and function of sex. The relationship between HAQ scores and pain during masturbation and sexual intercourse was determined by the nonparametric Mann-Whitney test. A level of significance of $p < 0.05$ was adopted for all tests[28-30].

RESULTS

Sample characteristics. Twenty-eight of the 32 male patients with RF-negative polyarticular JIA were from the rheumatology outpatient clinic of Hospital das Clinicas, and 4 were followed up at Instituto da Criança. The control group consisted of 120 healthy subjects. All participants were heterosexual. The mean age was similar in patients and controls (20.8 ± 3.8 and 19.6 ± 3.7 yrs, respectively; range 16–26; $p = 0.1$). The mean duration of JIA was 15.4 ± 3.6 years (range 13–20). The same proportion of patients and controls belonged to socioeconomic class B1 (6.3% vs 11.7%), B2 (18.6% vs 16.3%), C (68.8% vs 60.3%), and D (6.3% vs 11.7%) ($p = 0.566$).

Applicability of the MSEQ. The MSEQ consisted of questions related to male sexuality, including erection, masturbation, intercourse, libido, and sexual satisfaction. The instrument demonstrated good quality of the terms used, and good applicability and understanding on the part of the subjects who answered the questionnaire and by the investigator.

General aspects of sexuality. As shown in Table 1, there were no differences in the answers given by patients and controls regarding their doubts about sex, function of sex for the human being, initiation of sexual life, or erection related to physical attraction. In contrast, the proportions of subjects who did not know whether they had nocturnal emissions was higher in the control group (20%) compared to patients (3.2%) ($p = 0.001$).

Masturbation. The frequency of masturbation at least once a week was similar in the patient and control groups (28/32, 87.5%; and 109/120, 91%, respectively). Similarly, pain during masturbation was reported by 3/28 (11%) patients and 5/120 (5%) controls ($p = 0.36$): 2 patients reported tenderness in hips and feet, while the other reported genital pain (all 3 patients associated their pain with the primary disease). In contrast, all 5 control subjects reported genital pain due to excess movement in that region.

Intercourse. Complete intercourse was regularly practiced by 78% (25/32) of patients and 62% (75/120) of controls ($p = 0.09$). Mean age at first intercourse was 15.5 ± 2.7 years (range 14–20) in the patient group and 15.8 ± 3.1 years (range 12–18) in the controls, with no difference between the groups ($p = 0.763$). Twenty-two percent of patients

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Table 1. General aspects of male sexuality in patients with juvenile idiopathic arthritis (JIA) and controls.

Questions	JIA (n = 32) n (%)	Controls (n = 120) n (%)	p
1. Queries or questions about sex			
Parents	5 (15.7)	24 (20)	0.648*
Brothers	3 (9.4)	13 (10.8)	> 0.999†
Cousins	2 (6.2)	6 (5)	> 0.999†
Teachers	1 (3.1)	3 (2.5)	0.108*
Friends	7 (21.9)	36 (30)	0.7*
Health professional	3 (9.4)	10 (8.3)	0.521†
Magazines	2 (6.2)	8 (6.7)	0.7*
Internet	8 (25)	14 (11.7)	0.411†
Nobody	1 (3.1)	6 (5)	0.283†
2. Functions of sex			
Love	16 (50)	58 (48.3)	0.538*
Pleasure	12 (37.5)	43 (35.9)	0.638*
Pregnancy	4 (12.5)	10 (8.3)	0.605*
Intimacy	—	9 (7.5)	0.071†
3. Initiation of sexual life			
According to age	6 (18.7)	27 (22.5)	0.522*
Feeling physical attraction	10 (31.2)	45 (37.5)	0.612*
Falling in love	9 (28.2)	28 (23.3)	0.342*
I don't know	7 (21.9)	20 (16.7)	0.211*
Other	—	—	—
4. Nocturnal emission			
Yes	15 (46.9)	72 (60)	
No	16 (50)	24 (20)	0.001
I don't know	1 (3.1)	24 (20)	
5. Erection related to attraction			
Yes	27 (84.3)	105 (87.5)	0.768†
No	5 (15.7)	15 (12.5)	

* Chi-square test. † Fisher's exact test.

(7/32) and 37% (45/120) of controls had never had sexual intercourse (p = 0.098). All sexually active subjects (25 patients and 75 controls) had at least one sexual intercourse per week, with a similar weekly frequency of sexual intercourse in the 2 groups (p = 0.314): once/week = 8 (31%) versus 15 (20%), 2–3 times/week = 16 (61%) versus 35 (47%), and 4–5 times/week = 1 (8%) versus 25 (33%). One patient (4%) and 5/75 (11%) controls reported difficulties in achieving erection during intercourse in about 10%–20% of attempts (p > 0.999).

Contraception methods were regularly used by 24/25 (96%) patients and by 73/75 (97.3%) controls (p > 0.999), although more control subjects (94.5%) than patients (88%) used condoms (p = 0.005). Interrupted coitus was performed by 3 patients and oral contraceptives were used by the partners of 4 control subjects. Most patients and controls used condoms for the prevention of sexually transmitted diseases, except 1 patient and 2 controls (all 3 married). Three subjects of the control group (4%) had a history of syphilis.

Pain during intercourse was reported by 13 patients (52%), including genital pain in one and joint pain in 12. Among the patients with joint pain, the hips were involved in 3 (25%), knees in 5 (42%), and hips and knees in 4 (33%). All 13 patients attributed their pain during intercourse to the presence of arthritis, and one patient adopted a specific position (with his partner on top) for relief. Only one patient reported that his partner's pleasure was affected by his pain. Table 2 shows the intensity of joint pain reported by the 12 patients with JIA according to the different sexual positions during intercourse. Ten patients experienced less pain in the "woman on top" position, 10 experienced more pain in the "man on top" position, and more than 40% of patients were unable to perform "side-by-side" and "lap dance" positions. On the other hand, only 2 control subjects reported right wrist pain during intercourse related to previous injury and both reported the use of analgesics before coitus for pain relief. Similar to patients, the position "unable to perform" by these 2 controls was "woman on armchair with man standing" (p = 0.099). In contrast to patients, "lap dance" and "side-by-side" positions caused "less" and "more" joint pain, respectively (p = 0.002).

As shown in Table 3, more pleasure was achieved during intercourse by the same proportion of patients and controls irrespective of sexual position (p = 0.059).

Association between HAQ scores and joint pain during masturbation and intercourse. Table 4 shows significantly higher HAQ scores for patients with joint pain compared to those without pain, indicating more functional disability during both masturbation (p = 0.019) and intercourse (p = 0.007).

Table 2. Intensity of joint pain according to intercourse position reported by 12 patients with juvenile idiopathic arthritis.

Position	Less Pain, n (%)	More Pain, n (%)	Unable to Perform, n (%)
Man on top	—	10 (83)	—
Woman on top	10 (83)	—	—
Side by side	—	—	5 (41.5)
Lap dance	2 (17)	—	5 (41.5)
Woman on armchair with man standing	—	—	2 (17)
Rear entry	—	2 (17)	—

Table 3. Position providing more pleasure during sexual intercourse achieved by patients with juvenile idiopathic arthritis (JIA) and controls.

Position	JIA, (n = 25), n (%)	Controls, (n = 75), n (%)
Man on top	—	4 (5.3)
Woman on top	5 (20)	16 (21.3)
Side by side	3 (12)	14 (18.7)
Lap dance	1 (4)	12 (16)
Woman on armchair with man standing	—	3 (4)
Rear entry	16 (64)	26 (34.7)

Chi-square test, p = 0.059.

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Table 4. HAQ scores of patients with juvenile idiopathic arthritis with and without joint pain during masturbation and intercourse.

	HAQ Score	
	Mean ± SD	Median (range)
Masturbation, n = 28		
With pain (n = 3)	2 ± 0.17	2.1 (1.8–2.1)
Without pain (n = 25)	1.58 ± 0.3	1.5 (1.1–2.1)
Intercourse, n = 25		
With pain (n = 12)	1.82 ± 0.27	1.8 (1.3–2.1)
Without pain (n = 13)	1.43 ± 0.32	1.3 (1.1–2.1)

Mann-Whitney test: p = 0.019 patients with pain vs without pain during masturbation; p = 0.007 patients with pain vs without pain during intercourse.

Level of sexual life satisfaction. All patients and controls considered themselves to be satisfied with their sexual life, with mean scores of 8.0 ± 0.6 for patients and 8.3 ± 0.7 for controls (p = 0.250).

DISCUSSION

A board of specialists has developed, for the first time and according to consensus, a questionnaire, the Male Sexual Evaluation Questionnaire, aimed at evaluating the sexual life of male patients with JIA. The MSEQ was found to be applicable and good quality responses were obtained, which were objective, direct, and related to the questions regarding sexuality.

Of note, all issues except one (nocturnal emission, which was less recognized by controls) related to male sexuality were similar in patients and controls. Masturbation and intercourse were practiced equally by both groups of subjects, although joint pain during intercourse was significantly more frequent among patients. Moreover, although some patients experienced joint pain associated with greater functional disability as indicated by higher HAQ scores, overall sexual pleasure and satisfaction were preserved.

Alterations in sexual function have been described in several chronic diseases, including rheumatic diseases such as rheumatoid arthritis (RA), systemic lupus erythematosus, osteoarthritis, and ankylosing spondylitis[31-35]. A variety of problems related to pain and sexual interest, activity, and satisfaction have been reported[36] in patients with chronic pain diseases. Similarly, chronic childhood diseases may also influence functional abilities that interfere with sexual behavior. Indeed, pain, fatigue, and stiffness may affect the sexuality of patients with chronic diseases such as JIA[37,38].

All patients included in our study were heterosexual young adults and most were sexually active. Despite the long duration of joint disease and longterm joint involvement, morbidity, functional dysfunction, and pain, the sexual life of the patients with JIA we studied was preserved. Mean age at first intercourse was 15.5 years, and was similar to that of controls and healthy Brazilian adolescents[39]. These findings are in agreement with the study by Packham, *et al*[21], in which 83% of patients with JIA were sexually active, although the mean age at first sexual experience was 19.3 years. In addition, 58% of the patients of that study experienced difficulties related to JIA, mainly linked to the effects of arthritis, pain, and physical restriction on their whole-body image. Intriguingly, some studies have found sexual activity and behavior in young males with juvenile chronic arthritis to be comparable to that of their peers in the general population[23,36], whereas others have reported differences between patients and controls in sexual activity, which was less frequent in males with juvenile chronic arthritis[22]. Moreover, a higher proportion of men with JIA were singles and did not date anyone[22].

Contraceptives were used equally, although more controls than patients preferred condoms over other alternatives, a common method used by youngsters in Brazil[40]. Most control subjects used condoms regardless of marital status, whereas all 3 married patients did not, a finding suggesting that the latter may think that a more stable relationship with their partners would protect them from infections and sexually transmitted diseases. However, it is important to highlight the need for condom use not only by healthy males, but especially by patients with JIA, who are more susceptible to infections in general due to their immunosuppressed state secondary to disease activity or therapy[41,42].

Compared to adult patients, our observations are in contrast to the high prevalence of sexual difficulties among patients with chronic pain demonstrated by Ambler, *et al*[36]. Further, in the study by Hill, *et al*[17] more than half the patients with RA reported that their arthritis limited sexual intercourse, mainly because of fatigue and pain. Similarly, Elst, *et al*[35] found that about 50% of patients with RA reduce their sexual frequency due to muscle contractures, deformities, and difficulties in performing some movements. These differences between young and adult patients might be explained by the fact that JIA manifests in childhood before the establishment of definite links, relationships, and complete growth. Thus, the limited child is able and has the opportunity and possibility to learn and build up new strategies and developmental mechanisms, such as alternative movements, gestures, and sexual positions, to adapt himself, indicating better adaptive skills related to his new reality and life aspects, including sexual functioning. Further, our patients were young men in whom sexuality was still being developed and explored.

In our study, both patients with JIA and controls searched the Internet and asked friends, parents, brothers, and health professionals for sexual counselling. This agrees with findings from Shaw, *et al*[43], who found that the presence of parents during the medical visit was a cause of embarrassment of adolescents with JIA who were willing to talk about sex with their doctors. However, Ambler, *et al*[36] observed that adults with chronic joint diseases did not talk about sex with their physicians because they thought that this topic could be

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ignored. Indeed, Ostensen[44] concluded that sexuality is an often-neglected area of quality of life among patients with rheumatic diseases. This indicates the need to include sex talks in routine patient care. Thus, establishment of a well defined and validated questionnaire for evaluation of male sexuality as proposed here will further permit specific professional sex counseling. This might be particularly relevant in patients with chronic musculoskeletal diseases because of the interference of these conditions with aspects of reproductive behavior and health.

As expected, the sexual positions that caused less joint pain to the patients were those that required a more passive performance and fewer movements. In contrast, the "position of more joint pain" was the one that required more physical energy and greater range of motion, whereas the "impossible to perform position" was that requiring more joint mobility and isotonic plus isometric muscle strength. Although we did not ask whether masturbation or intercourse relieved joint pain, it should be clarified that the difficulties in executing some movements during sexual intercourse did not prevent our patients with JIA from having an active and satisfying sexual life. Although some patients experienced joint pain during masturbation and sexual intercourse associated with more functional disability, as demonstrated by the higher HAQ score, sexual satisfaction and libido were preserved, indicating adequate sexual development.

Our study has some limitations, such as the small sample size and the lack of a qualitative approach before the implementation of the questionnaire. The next step for a more precise assessment of measurement properties would be inclusion of a wide variety of patients with different economic conditions and clinical disability and to incorporate questions derived from a qualitative study.

A broad general sex education of patients with JIA should include not only emotional, behavioral, and psychological aspects, but particularly physical aspects. Instructions are extremely important and physiotherapeutic interventions should be proposed in order to restore and preserve functional capacity for autonomy for daily life activities, including sex. Teaching strategies and specific techniques that will avoid overload will develop and maintain the patient's physical skills to achieve more comfortable and pleasurable sexual positions. Stretching exercises, joint mobilization, and enhancement of muscle strength may relieve pain during intercourse and improve sexual performance. Further, the MSEQ developed here was efficient in assessing the behavior and functional aspects of sexuality of males with JIA. In addition, this questionnaire might be a useful tool to guide (1) further studies evaluating the sexual life of healthy men and of patients with other musculoskeletal diseases, and (2) the development of a questionnaire for females with JIA.

Our findings highlight the importance of establishing specific intervention programs and sexual counseling for patients with JIA in order (1) to clarify and explain that the disease will not impair their sexuality despite possible physical restrictions; 2) to emphasize the need and importance of condom use to prevent sexually transmitted diseases; and (3) to provide information regarding adequate sexual positions for better sexual performance and satisfaction.

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