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Assessment of Quality of Life of Parents of Children with Juvenile Chronic Arthritis

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Abstract: The aim of the study was to assess the quality of life (QOL) and the psychological status of parents of children with juvenile chronic arthritis (JCA). The QOL, anxiety and depression of the parents of 28 children with JCA were evaluated and compared to those of the parents of 28 healthy children. Mothers of JCA children and mothers of healthy children reported similar QOL. The reported anxiety and depression levels were similar for mothers and fathers in both groups. The parents of children with pauciarticular-type JCA reported lower QOL and higher levels of anxiety and depression than the parents of children with other types, namely polyarticular and systemic JCA. These findings may be explained by the fact that the pauciarticular patients had shorter disease duration and were less frequently seen in the outpatient clinic. The QOL of mothers of children with JCA was found to be slightly impaired in the group of children with pauciarticular JCA. Future larger studies are needed to confirm these results, as the number of subjects in the three groups was rather low.

Keywords: Children; Juvenile chronic arthritis; Parents; Quality of life

Introduction

The quality of life (QOL) of patients with rheumatic disease is increasingly recognised as an important factor in assessing health and in planning treatment and management strategies. Indeed, evidence exists that persons with systemic rheumatic disease such as rheumatoid arthritis, systemic lupus erythematosus or fibromyalgia have a decreased QOL [1–4].

Juvenile chronic arthritis (JCA) is the most common rheumatic disease in children and is an important cause of functional disability and psychosocial problems [5,6]. In the past few years several outcome measures, such as quality of life and health status, have been developed for application in children with JCA [7]. Several studies have addressed the issue of the impact of a rheumatic disorder on the QOL of the patient's family. We have shown that even relatives of fibromyalgia patients have an impaired QOL, which may be attributed to the psychological distress in families with a chronic rheumatic disease [8]. Recently, the QOL and psychological status of parents of children with familial Mediterranean fever (FMF) was assessed [9]. The QOL and psychological wellbeing of these parents were found to be slightly impaired, especially those of the mothers [9].

The impact of JCA on the mental health of mothers with JCA children has been reported in a few studies [10,11], indicating that these mothers are at risk for psychological distress.

The aim of the present study was to assess the psychological status as well as the QOL of both parents of children with JCA.

Materials and Methods

The parents (both mother and father) of 28 children with JCA and the parents of 28 healthy children participated in the study. Table 1 presents the demographic back-

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ground of the parents in both groups. There were no significant differences between the mean ages of the mothers (38.9 vs 37.7) and the fathers (41.9 vs 49.8) in the JCA and control groups, respectively. In both groups the fathers were older than the mothers, though not statistically significantly so. All the participants had similar educational levels (about 14 years of school), and the average number of children was similar in both groups (Table 1).

The JCA children were randomly chosen from a list of 62 JCA patients being followed at the paediatric rheumatic diseases clinic in Soroka Medical Center, Beer Sheva, Israel. The patients are seen regularly every 3–6 months. Their parents were previously informed about the nature of the disease, the outcome and the treatment. The control group consisted of parents of 28 healthy children of similar ages, and was recruited from hospital personnel. All the parents who were approached agreed to participate. The study was approved by the Helsinki Committee of the Soroka Medical Center; all participants gave their written consent after having received detailed information about the study.

The demographic and clinical background of the JCA children and the healthy controls are shown in Table 2. The gender and age distributions were similar in both groups. The mean duration of JCA was 4.7 ± 3.6 years. Twelve children had polyarticular-type JCA, 10 had pauciarticular and six had systemic disease. In 20 (out of 28) children the disease was active. Nine patients were treated with methotrexate (7.5–17.5 mg/week), two were treated with azathioprine (75–100 mg/day), one patient received etanercept, five were treated with prednisone (2.5–5 mg/day) and 23 patients were on non-steroidal anti-inflammatory drugs. None of the patients with pauciarticular-type JCA was treated with methotrexate.

In the past 3 months the JCA children had missed significantly more school days than the healthy children: 5.4 ± 7.9 vs 1.6 ± 2.3, respectively ($P < 0.05$).

The quality of life and the psychological status were assessed in all parents in both groups using the same questionnaires.

Table 1. Demographic background of parents with children with and without JCA (mean and standard deviations)

	JCA group $n = 28$		Control group $n = 28$	
	Mother	Father	Mother	Father
Age, years	38.9 (7.3)	41.9 (7.2)	37.7 (6.1)	49.8 (8.1)
Education, years	14.0 (2.2)	13.4 (2.8)	13.0 (3.4)	14.1 (2.3)
Number of children	3.0 (1.4)		2.6 (1.5)	

Note: None of the differences are statistically significant.

Table 2. Demographic and clinical background of children with and without JCA

Variable	JCA group $n = 28$	Control group $n = 28$
M/F ratio	8/20	10/18
Age, years (mean SD)	11.1 (4.1)	10.6 (3.7)
JCA duration, years	4.7 (3.6)	–
JCA types:		
a) polyarticular	12	–
b) pauciarticular	10	–
c) systemic	6	–
School days missed (past 3 months)	5.4* (7.9)	1.6* (2.3)
Family physician visits (last 6 months):		
a) due to JCA	1.6 (2.0)	–
b) other causes	0.6 (1.3)	0.7 (0.9)
Emergency room visits (last 6 months):		
a) due to JCA	0.6 (1.0)	–
b) other causes	0.1 (0.2)	0.2 (0.3)

*$P<0.05$

Quality of Life Assessment

Quality of life was measured using a Quality of Life Scale (QOLS) developed by Flanagan [12] from the responses of 3000 randomly selected Americans. Each of the items in the scale encompasses a domain of life that was found to be important, including health, job, independence, and relationships with family and friends. The questionnaire was used by Burkhardt et al. [13] in chronic disease patients. Subjects were asked to rate their level of satisfaction on a 7-point scale, with 1 = highly dissatisfied and 7 = highly satisfied. The scale was then aggregated and averaged across the 16 items to yield a total satisfaction score. The QOL scale was translated and validated by us in a Hebrew version [14].

Psychological Status

Psychological status was assessed by the anxiety and depression subscales of the AIMS2: Arthritis Impact Measurement Scales [15], each consisting of six questions to be answered on a 6-point scale. The final indices are the average scores normalised to range from 0 to 10, with 0 reflecting the best condition. AIMS2 was translated into Hebrew and validated by us [16]. Anxiety was also measured using a subscale of the SCL-90 psychiatric instrument [17]. This includes 10 questions to be answered on a 5-point scale. The final scores consist of the average scores, ranging from 1 to 5, with 5 reflecting the worst condition. The SCL-90 questionnaire has been translated into Hebrew and frequently used [18].

Statistical Analysis

T-tests and the Mann–Whitney test for independent samples were used to compare the study and control groups, and mothers and fathers within the same group were compared by paired *t*-tests and Wilcoxon's signed rank test. Continuous variables in the three groups were compared by analyses of variance and by Kruskal–Wallis tests.

Results

Table 3 compares the quality of life and the psychological variables for mothers and fathers within the study and the control groups, as well as for the mothers and fathers across the two groups.

The mothers and fathers of JCA children were no different from the parents of healthy children regarding life satisfaction: 5.6 ± 0.9 vs 5.9 ± 0.8 (P = 0.124). The differences remained non-significant when using non-parametric tests (Mann–Whitney). Within each group, both parents evaluated their QOL similarly (Table 3).

The anxiety levels (measured by two scales) and the depression levels were similar in both groups (Table 3).

We further addressed the question whether QOL and psychological status are associated with the type of disease. The mothers of children with pauciarticular-type JCA reported slightly lower QOL (P = 0.090) and significantly higher levels of anxiety (P = 0.023 by SCL-90; P = 0.019 by AIMS) and depression (P = 0.017) than mothers of children with polyarticular and systemic types of JCA (Table 4). This trend was less obvious for the fathers. The non-parametric analogue of analysis of variance (Kruskal–Wallis) resulted in similar findings.

Table 3. Quality of life and psychological variables of parents in the study and control groups (means and standard deviations)

Variable (range)	JCA group n = 28		Control group n = 28	
	Mother	Father	Mother	Father
Quality of life (1–7*)	5.6 (0.9)	5.5 (0.9)	5.9 (0.8)	5.5 (1.0)
Anxiety (SCL-90) (1–5**)	1.6 (0.5)	1.5 (0.4)	1.5 (0.8)	1.4 (0.5)
Anxiety (AIMS) (0–10**)	3.5 (1.9)	3.4 (1.3)	3.5 (1.2)	2.8 (1.3)
Depression (AIMS) (0–10**)	1.3 (0.8)	1.6 (1.4)	1.4 (1.6)	1.2 (1.2)

*Best possible score.
**Worst possible score.

Discussion

The QOL of patients with rheumatic disease is adversely affected to an extent comparable to that of other chronic diseases, such as chronic obstructive pulmonary disease and insulin-dependent diabetes [3]. Few studies have assessed the impact of JCA on the mental status of the mothers of children with JCA [10,11], indicating that these mothers are at risk for psychological distress.

In the present study, parents of children with JCA reported similar QOL to that of parents of healthy children. The anxiety and depression levels were similar for fathers and mothers in both groups. These findings are not quite comparable to those previously reported by us on the QOL of parents with children with FMF [9]. In that study, mothers of FMF children reported lower QOL and expressed slightly higher levels of anxiety and depression than mothers of healthy children [9]. Similarly to the present findings, no differences were observed between the fathers in the FMF study. In contrast to our results in JCA, the mothers of FMF children were more anxious and more depressed than the fathers. The fact that the QOL and the psychological status of parents of children with JCA and of parents of children with FMF were similar is interesting, because JCA is a chronic disabling condition whereas FMF is an episodic disorder. Thus, one could speculate that the QOL of parents of children with JCA would be even worse than in the case of children with FMF. However, it should be emphasised that although JCA is a chronic disabling condition, it has ups and downs, sometimes very different in the various episodes.

The lack of adverse effect on parents' psychological wellbeing, and consequently on their QOL, might be explained by the improved therapeutic approach in JCA and FMF and better education of the parents regarding the course and outcome of disease. Interestingly, the parents of children with pauciarticular-type JCA reported lower QOL and higher levels of anxiety and depression than the parents of children with other types of JCA. However, these results should be interpreted carefully, as the number of subjects in the three groups was rather low. In addition, the disease duration of the pauciarticular children was significantly shorter than that

Table 4. Quality of life and psychological variables of parents of 28 children with JCA by disease type[1] (means and standard deviations)

Variable	Mothers				Fathers			
	poly n = 12	pauci n = 10	syst n = 6	P	poly n = 12	pauci n = 10	syst n = 6	P
Quality of life	6.0 (0.8)	5.2 (0.8)**	5.5 (0.9)	0.090	5.5 (1.0)	5.4 (0.8)	5.6 (0.9)	0.890
Anxiety (SCL-90)	1.3 (0.3)	1.9 (0.7)	1.8 (0.4)	0.023	1.5 (0.4)	1.6 (0.5)	1.4 (0.3)	0.649
Anxiety (AIMS)	2.6 (1.9)	4.7 (1.4)*	3.1 (1.3)	0.019	3.3 (1.3)	4.1 (1.3)	2.2 (0.5)	0.018
Depression (AIMS)	1.5 (1.1)	2.9 (1.4)*	1.4 (0.9)	0.017	1.3 (0.4)	2.5 (2.0)	0.8 (0.9)	0.038

[1]Types: poly = polyarticular, pauci = pauciarticular, syst = systemic.
*P<0.05 – compared to control mothers.
**P<–/–1 – compared to control mothers.

of the polyarticular JCA type (6.1 vs 4.4 years, respectively). Therefore, their parents might have had less time to adjust to their child's alarming new disorder, and this can be reflected in lower QOL. Furthermore, because the parents of systemic and polyarticular JCA children were seen more frequently in the outpatients clinic, they may express less anxiety thanks to reassurance from the physician. In order to address this hypothesis, future prospective studies should be conducted periodically to evaluate the QOL of parents of children with JCA since the onset of the disease.

Further studies should assess the QOL of parents of children suffering from other rheumatic diseases, using various QOL instruments. The recognition of the possible impact of a child with arthritis on the QOL and psychological wellbeing of his/her parents is relevant to physicians who have such patients under their care.

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