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ORIGINAL ARTICLE

Factors influencing the quality of life of Moroccan patients with juvenile idiopathic arthritis

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Abstract The aim of our study is to investigate the factors influencing the quality of life, assessed by the Pediatric Quality of Life Inventory 4.0 (PedsQL4) Generic Score Scales, in Moroccan patients with juvenile idiopathic arthritis. This is a cross-sectional study conducted between January and June 2012, covering children with juvenile idiopathic arthritis (JIA) seen at the consultations of El Ayachi Hospital and Children's Hospital of the University Hospital of Rabat. Quality of life is assessed by the PedsQL4 which is a questionnaire composed of 23 items, completed by the child and the parent; the response to each item ranges from 0 to 100, so that higher scores indicate a better quality of life. The functional impact is assessed by the Childhood Health Assessment Questionnaire (CHAQ), and the disease activity by the number of tender and swollen joints, visual analogue scale (VAS) activity, erythrocyte sedimentation rate (ESR), and C-reactive protein. Forty-seven patients are included; the average age of the patients is 11±3.35 years, and 40.4 % are females, with a median disease duration of 4 (2; 6) years. The oligoarticular form presents 26.7 %, the systemic form 24.4 %, and the enthesic form 22.2 %. The median of PedsQL4 is 80.43 (63.19; 92.93), and the median of the CHAQ is 0 (0; 1). Our study shows that some clinical and biological characteristics have significant effects on PedsQL by both parent and child reports. This study suggests that the achievement of the quality of life of our patients with JIA depends on the disease activity measured by swollen joints, the number of awakenings, parent VAS, physician VAS, patient VAS, and the ESR.

Keywords Disease activity · Juvenile idiopathic arthritis · PedsQL4 · Quality of life

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Introduction

Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease of childhood. It affects approximately 1 in 1,000 children under the age of 16 years. It can result in significant pain and physical disability [1, 2]. JIA can influence all aspects of a child's and his or her family's life. It has also been established that children with JIA report lower health-related quality of life (HRQOL) as compared to their healthy peers [3, 4]. So clinicians and researchers now recognize that improved HRQOL is a key treatment goal for JIA [5].

Quality of life has been defined by the World Health Organization as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns [6]. Instruments used to measure HRQOL can be condition specific, generic, or chronic generic. The condition-specific instruments address aspects related to a specific condition and can be used to compare data from children and adolescents with the same chronic medical condition. Generic instruments are usable for assessment in all

Table 1 Clinical and demographic characteristics

Characteristics	Total number (n=47)	Girls=19 (40.4 %)	Boys=28 (59.57 %)	p value[a]
Mean age in years (SD)	11.5±3.35	10.8±3.04	12.1±3.5	0.13
Articular forms, number (%)				
Systemic arthritis	10 (21.2)	5 (26.3)	5 (17.9)	0.44
Polyarticular RF positive	2 (4.2)	0 (0.0)	2 (7.4)	
Polyarticular RF negative	6 (12.7)	2 (11.1)	4 (14.8)	
Oligoarticular persistent	12 (25.5)	7 (38.9)	5 (18.5)	
Oligoarticular extended	2 (4.2)	1 (5.6)	1 (3.7)	
Enthesitis and arthritis	11 (23.4)	2 (10.5)	9 (32)	
Psoriatic arthritis	0 (0.0)	0 (0.0)	0 (0.0)	
Unclassified arthritis	4 (8.5)	2 (10.5)	2 (7.1)	
Arthritis characteristics, median (range)				
Tender joints	1 (0; 16)	0 (0; 10)	2 (0; 16)	0.39
Swollen joints	0 (0; 18)	0 (0; 13)	0 (0; 18)	0.20
Patient VAS	20 (0; 100)	30 (0; 80)	27.5 (0; 70)	0.19
CHAQ	0 (0; 2.75)	0 (0; 2.75)	0 (0; 2)	0.73
ESR	21 (2; 97)	14 (2; 97)	28 (2; 80)	0.41
CRP	24 (0.2; 224)	5 (0.24; 96)	46 (2; 224)	0.01
Medication use, number (%)				
NSAID	29 (63)	11 (57.9)	18 (66.7)	0.84
Aspirin	2 (4.4)	2 (11.1)	0	0.18
Prednisone	14 (31.1)	8 (42.1)	6 (22.2)	0.24
Bolus of corticosteroids	9 (19.6)	4 (21.1)	5 (18.5)	0.74
Methotrexate	10 (21.3)	6 (31.6)	4 (14.3)	0.16
Biotherapy	2 (4.3)	1 (5.3)	1 (3.7)	0.80

[a] Mann–Whitney U test

children, whether they are healthy or suffering from a medical condition [7].

HRQOL is known to be associated with medical variables in children with JIA. Recent studies show that better self-report and parent proxy report of child HRQOL are associated with better parent ratings of child functional ability, pain intensity, physician rating of disease activity, and erythrocyte sedimentation rate (ESR) [4, 8, 9].

The aim of our study is to investigate the clinical and biological factors influencing the quality of life, assessed by the Pediatric Quality of Life Inventory 4.0 (PedsQL4) Generic Score Scales, in Moroccan patients with juvenile idiopathic arthritis.

Methods

Study design

This is a cross-sectional study conducted between January and June 2012, covering children with JIA according to the International League of Associations for Rheumatology (ILAR) classification [10], seen at the consultations of El Ayachi Hospital and Children's Hospital of the University Hospital of Rabat.

Our establishment is a third-level public university hospital, receiving patients from across the country for tertiary care, with access to csDMARDS, biological DMARDS, symptomatic treatment, and functional rehabilitation. These services are free for the poor patients belonging to the RAMED health organization or with coverage by public and military medical organizations such as the CNOPS and Royal Armed Forces of Morocco. Other patients just pay a portion of their care, the other part being paid by private insurance. Patients not belonging to any care organization pay in full. JIA patients represent approximately 0.08 % of all patients seen in the consultations of our institution.

Table 2 Reliability of the Moroccan version of the PedsQL

	Child report	Parent report
Health and activities	0.937	0.965
Emotional functioning	0.874	0.855
Social functioning	0.835	0.840
School functioning	0.805	0.843

Table 3 Correlation between total PedsQL 4.0 Generic Core Scales and the parameters of disease activity by the child report

	Health and activities	Emotional functioning	Social functioning	School functioning	Total PedsQL score
Awakenings	−0.44¥	−0.20	−0.25	−0.11	−0.33*
Morning stiffness	−0.21	0.10	−0.15	−0.29	−0.12
Tender joints	−0.22	−0.07	−0.12	0.41	−0.17
Swollen joints	−0.36	−0.15	−0.34	−0.23	−0.28
Parent VAS	−0.40¥	−0.25	−0.39¥	−0.26	−0.40¥
Physician VAS	−0.40¥	−0.24	−0.31*	−0.17	−0.43¥
Patient VAS	−0.37¥	−0.15	−0.26	−0.14	−0.37¥
ESR	−0.15¥	0.39	−0.06	−0.09	−0.06¥
CRP	−0.17	0.10	−0.06	−0.12	−0.02
CHAQ	−0.38¥	−0.30*	−0.36	−0.29	−0.38

Values shown represent Spearman nonparametric correlation coefficients

*$p<0.05$; ¥ $p<0.01$

Participants

Children and their parents agreed to participate in the study. The eligibility criteria are as follows:

1. Child age 8 to 18 years at time of study and age <16 years at time of JIA diagnosis
2. JIA diagnosis as defined by the ILAR classification criteria [10]

The exclusion criteria are represented by major developmental disorders of the child, making him unable to complete the questionnaires.

Measures

HRQOL is assessed by the PedsQL4 translated into the Arabic dialect [11]. It is a generic questionnaire which consists of 23 items combined into physical, emotional, social, and school functioning scales. Mean values are computed for each scale. The parent report forms assess the parent's perception of HRQOL of their children and are constructed to directly parallel the self-report forms. Options range from 0=never a problem to 4=almost always a problem [12].

Scoring Items are reverse coded and linearly transformed to a 0–100 scale (e.g., 0=100 to 4=0). Each scale score equals the average of the transformed items answered in a given scale. For scales with more than 50 % missing data, one does not compute a scale score. However, research suggests that little missing data occur. High scores correspond to better quality of life [12]. Suboptimal HRQOL is defined as a PedsQL total mean scale score of <78.6 [1].

Reliability of translation of the questionnaire PedsQL Internal consistency is an indication of how the items within a scale are interrelated. Cronbach α is one method of assessing internal consistency. A high Cronbach α value reflects high internal consistency. Generally, a value larger than 0.7 is regarded as satisfactory [13].

Assessment of physical function Physical function is measured by the Moroccan validated version of the Childhood Health Assessment Questionnaire (CHAQ) [14], which is an instrument for evaluating functional disability in juvenile arthritis. The scores for each of the eight functional areas were averaged to calculate a disability index (DI), ranging from 0 (no disability) to 3 (disabled) [15]. The cutoff levels for mild, mild-to-moderate, and moderate disabilities have been suggested at medians 0.13, 0.63, and 1.75, respectively [16].

Disease activity is assessed in each patient by the attending physician: number of joints with swelling, number of joints with tenderness/pain on passive motion, number of joints with limited range of motion, number of joints with active arthritis, and physician's global assessment of the overall disease activity on a double-anchored 10-cm visual analogue scale (VAS) (with anchors of 0 [inactive] and 10 [very severe]). The laboratory

Table 4 Correlation between total PedsQL 4.0 Generic Core Scales and the parameters of disease activity by the parent report

	Health and activities	Emotional functioning	Social functioning	School functioning
Awakenings	−0.33*	−0.01	−0.33*	−0.01
Morning stiffness	−0.18	0.22	−0.22	0.06
Tender joints	−0.10	0.09	−0.12	0.10
Swollen joints	−0.31*	−0.04	−0.40¥	−0.04
Parent VAS	−0.32*	−0.06	−0.42¥	−0.04
Physician VAS	−0.33*	−0.05	−0.32*	−0.02
Patient VAS	−0.28	−0.03	−0.30*	−0.04
ESR	−0.20	0.28	−0.23	−0.04
CRP	−0.10	0.31	−0.17	0.11
CHAQ	−0.37*	−0.07	−0.30*	−0.38*

Values shown represent Spearman nonparametric correlation coefficients

*$p<0.05$; ¥ $p<0.01$

Table 5 Health-related quality of life measured by PedsQL 4.0 Generic Core Scales in children with JIA in self- and parent reports

	Girls, median (range)	Girls' parent report, median (range)	*p* value	Boys, median (range)	Boys' parent report, median (range)	*p* value
Health and activities	78.12 (31.25; 100)	78.12 (25; 100)	0.956	78.12 (40.63; 100)	75 (3.25; 100)	0.386
Emotional functioning	90 (50; 100)	95 (45; 100)	0.452	70 (50; 100)	85 (50; 100)	0.297
Social functioning	100 (40; 100)	100 (35; 100)	0.646	90 (50; 100)	95 (50; 100)	0.709
School functioning	80 (30; 100)	70 (35; 100)	0.431	75 (50; 100)	70 (45; 100)	0.143

indicators of systemic inflammation are erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP).

Statistics

Data from girls and boys are analyzed separately. Results of the descriptive analysis are presented as median and range or numbers and percentages. Results concerning HRQOL are presented by median and range. Reliability of translation of the questionnaire PedsQL is assessed by the Cronbach α. Mann–Whitney *U* test is used to analyze gender differences and differences between self- and parent reports. The analysis is performed by use of the Statistical Package for the Social Sciences (SPSS) version 17. Statistical significance is defined at $p<0.05$.

Results

Forty-seven patients are included; the mean age of the patients is 11±3.35 years, and 40.4 % are females, with a median disease duration of 4 (2; 6) years. Girls and boys did not show a significant difference in any of the assessed characteristics (Table 1). The oligoarticular form presents 26.7 %, the systemic form 24.4 %, the enthesic form 22.2 %, and the polyarticular form 17.7 %.

Reliability of translation of the PedsQL questionnaire

The Cronbach α is good for all domains of the PedsQL questionnaire with a value larger than 0.7, reflecting a high internal consistency (Table 2).

Disease activity and health-related quality of life

Our study shows that some clinical and biological characteristics have significant effects on PedsQL by both parent and child reports. Except the emotional functioning in the child report, all subscale scores for the PedsQL are significantly associated with the parameters of activity of the disease including the number of awakenings, swollen joints, parent VAS, physician VAS, patient VAS, the ESR, and the CHAQ. The total PedsQL shows a significant relationship between the number of awakenings, parent VAS, physician VAS, patient VAS, and the ESR (Tables 3 and 4).

Health-related quality of life

In our study, suboptimal HRQOL is reported by 23 of the children (48.9 %). The median of PedsQL4 is 80.43 (35.87; 100), with a physical median score of 78.12 (31.25; 100), an emotional median score of 85 (50; 100), a psychosocial median score of 95 (40; 100), and a school median score of 80 (30; 100) in the child report. In the parent report, the physical median score is 75 (25; 100), the emotional median score is 90 (45; 100), the psychosocial median score is 100 (35; 100), and the school median score is 70 (35; 100). No differences are found between self- and parent reports (Table 5) nor for the gender in the children's self-reports (Table 6).

Discussion

Our study shows that 23 of the children (48.9 %) experienced suboptimal HRQOL, based on self-reports. In a study of Moroccan patients with JIA, the analysis of HRQOL measured by the JAQQ shows that children and adolescents with JIA have poorer HRQOL [17]. Lundberg et al., in a study of 53 children and adolescents with JIA describing their HRQOL using the PedsQL, find that suboptimal HRQOL is reported by 29 of the children (55 %) [18].

Table 6 Differences between girls and boys self-reports of PedsQL 4.0 Generic Core Scales

	Girls, median (range)	Boys, median (range)	*p* value
Health and activities	78.12 (31.25; 100)	78.12 (40.63; 100)	0.99
Emotional functioning	90 (50; 100)	70 (50; 100)	0.06
Social functioning	100 (40; 100)	90 (50; 100)	0.34
School functioning	80 (30; 100)	75 (50; 100)	0.14

Our results showing that children and parents rate physical, school, and emotional functioning the worst and social functioning the best are similar to results reported by both Varni et al. and Lundberg et al. in their psychometric studies [12, 18].

Concerning parent–child agreement, we do not find any significant differences between the parent and self-reports. This is in accordance with a study of children with JIA, when the authors report no significant differences between the parents and their children's evaluation of the child's quality of life [19]. In contrast, a review study concludes that parents of healthy children report higher scores of HRQOL than the children themselves. On the other hand, parents of children with different health conditions tend to underestimate the child's HRQOL [20]. Lundberg et al. report that among girls, the parent reports of HRQOL are lower compared to corresponding self-reports, and the parents of the boys tend to report higher scores than their sons with regard to physical health, social functioning, psychosocial health, and total HRQOL. These differences are not statistically significant except in the social functioning subscale. This is also found in another study among children with JIA [1, 18].

The results of earlier studies on health ratings in children with JIA are diverse. Shaw et al., in one sample of 303 adolescent–parent dyads with JIA, report a wide variation in agreement for health-related variables including pain, general health, functional ability, and HRQOL. Agreement is evidently better when the disease-related variables are recognizably mild or severe. In contrast, variation is greatest for more midrange outcomes. Thus, it would appear that parents are able to recognize disease outcomes when they are absent, very mild, or severe but may have difficulties interpreting them when less pronounced. In these cases, agreement is likely to be influenced by the communication and coping styles of the adolescent and parent, as well as other individual differences [21].

Previous findings show that physical health is particularly important in rheumatic diseases, and the parent–child agreement on this subscale seems to be high [22, 23]. In our study, no significant differences are found in physical health between child and parent reports among the girls and the boys.

Our study shows that except the emotional functioning in the child report, all subscale scores for the PedsQL are significantly associated with the parameters of activity of the disease including the number of awakenings, parent VAS, physician VAS, patient VAS, the ESR, and the CHAQ. The total PedsQL shows a significant relationship between the number of awakenings, parent VAS, physician VAS, patient VAS, and the ESR. Seid et al. relied on a retrospective analysis of existing data and had access only to PedsQL total scores for the generic core scales and the rheumatology module. They were unable to examine the relationship between symptoms and subscale scores for the PedsQL with the existing data set [1]. Sawyer et al. who investigated the relationship between HRQOL, experience of pain, and pain coping strategies in children with juvenile idiopathic arthritis report that for parent reports, there is a significant negative relationship between the pain intensity score and the PedsQL physical functioning, emotional functioning, and social functioning scores. The pain intensity score also has a significant negative relationship with the PedsQL treatment scale score and a significant positive relationship with the CHAQ score. Child-reported scores also show a significant negative relationship between the pain intensity score and the PedsQL physical functioning, emotional functioning, social functioning, and treatment scale scores. For child-reported scores, there is also a significant negative relationship between the pain intensity score and the PedsQL worry and communication scale scores [20]. One study examining the association between caregiver-perceived financial hardship, psychological distress, children's disease activity, and the HRQOL of children with JIA shows that higher caregiver-perceived economic hardship, psychological distress, and higher children's disease activity are associated with worse children's HRQOL. Furthermore, higher disease activity may reduce the impact of economic hardship on HRQOL, thus highlighting the importance of disease activity on HRQOL [24].

Conclusion

This study suggests that achieving the quality of life of our patients with JIA depends on disease activity assessed by the swollen joints, number of awakenings, parent VAS, physician VAS, patient VAS, the ESR, and the CHAQ. Improving the quality of life would increase by early diagnosis and more effective treatment.

Disclosures None

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