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Original Article (Pages: 8795-8803)

Assessment of Health Related Quality of Life (HRQL) in Egyptian Children with Rheumatic Diseases; Its Relation to Disease Activity and Functional Disability

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Abstract

Background
Many pediatric rheumatic diseases persist into adulthood, with negative squeal from the disease or its treatment. We aimed to assess health related quality of life in a group of children with rheumatic diseases and its relation to disease activity and functional disability.

Materials and Methods
Fifty one patients were divided into three groups: Group 1 includes 27 patients diagnosed as juvenile idiopathic arthritis (JIA), Group 2 includes 15 patients diagnosed as juvenile onset systemic lupus erythematosus (SLE) and Group 3 includes nine patients; three diagnosed as Juvenile Dermatomyositis, three diagnosed as Familial Mediterranean Fever and three female's patients diagnosed as Juvenile Scleroderma. Childhood Health Assessment Questionnaire (CHAQ), Pediatric Quality of Life generic core scale version 4.0, Visual analogue scale for pain and Visual analogue scale (VAS) for global assessment were recorded. The activity index was assessed in each patient according to the nature of the disease.

Results
In JIA patients, the mean PedsQL score was 73.6+ 15.4, the mean CHAQ score was 0.7+ 0.7, the mean DAS28 was 3.5+ 0.9, with a significant negative correlation between PedsQL and CHAQ (p=0.48), VAS pain (p=0.001), and DAS 28 activity index (p=0.017). In SLE patients, the mean PedsQL was 66.4 + 20.3, mean CHAQ score was 0.7 + 0.67 and mean SLEDAI-2K was 24.2 + 14.6 with no significant correlation between functional disability and SLEDAI-2K (p=0.539). PedsQL showed a significant negative correlation with SLEDAI-2k (p=0.001), and positive correlation between CHAQ (p=0.022).

Conclusion
Health related quality of life in patients with juvenile rheumatic diseases is correlated with disease activity and functional disability and should be assessed in regular basis.

Key Words: Children, Egypt, Juvenile idiopathic arthritis, Health related quality of life.

*Please cite this article as: Maher SE, Abdel-Magid RA. Assessment of Health Related Quality of Life (HRQL) in Egyptian Children with Rheumatic Diseases; Its Relation to Disease Activity and Functional Disability. Int J Pediatr 2019; 7(1): 8795-8803. DOI: **10.22038/ijp.2018.34033.2999**

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Received date: Jul.12, 2018; Accepted date: Aug. 12, 2018

1- INTRODUCTION

Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease in childhood with the risk of disability in children (1-4). Long-term studies report that 40 to 68% of patients with Juvenile idiopathic arthritis are in remission after 17 to 30 years of follow-up and those patients can suffer significant functional limitations and decreased health-related quality of life (6, 7). Childhood-onset Systemic Lupus Erythematosus (cSLE) is typically more severe than adult-onset SLE and was found to be an independent predictor of increased mortality (5). Patients with cSLE also have decreased health-related quality of life, including limitations in social capacities and restricted life goals (8). Juvenile Dermatomyositis (JDM) leads to calcinosis in approximately one-third of patients (9). Most recently, there has been an increased focus on parent- and child-reported outcomes (PCROs) (10). The assessment of HRQL is necessary because its results reflect individual and/or observer perspectives about the impact that has health or disease, disorder, disability on his/her mental, physical, psychological, and social functioning (1). We aimed to assess the health related quality of life in a group of children with rheumatic diseases and its relation to disease activity and functional disability.

2- MATERIALS AND METHODS

2-1. Method

This cross-sectional descriptive study carried out on 51 consecutive patients with different juvenile onset rheumatologic diseases who attendants to the Pediatric Department and the Rheumatology and Rehabilitation outpatient clinic at Minia University hospital (Minia city, Egypt) from September 2016 to March 2017. Verbal informed consent/assent was obtained as for local requirements. Patients who had infective, traumatic, rheumatic arthritis or inflammatory joint disease were excluded from the study. Patients were divided into three groups according the nature their disease. *Group 1* includes 27 patients (9 males and 18 females) diagnosed as juvenile idiopathic arthritis according to the International League of Associations for Rheumatology (ILAR) classification criteria (11); *Group 2* includes 15 patients (3 males and 12 females) diagnosed as pediatric onset systemic lupus erythematosus who fulfilled the American College of Rheumatology (ACR) 1997, SLE classification (12), and the onset of the disease before the age of 16 years old and *Group 3* includes nine patients; three patients (Two female and one male) diagnosed as Juvenile Dermatomyositis by the criteria described by Bohan and Peter (13), three patients (two females and one male) diagnosed as Familial Meditirian Fever by the Tel Hashomer criteria (14), and three female's patients diagnosed as Juvenile Scleroderma according to 2013 systemic sclerosis classification criteria (15). All patients were subjected to complete history taking.

Assessment of functional disability using Childhood Health Assessment Questionnaire (CHAQ) (16), assessment of psychological and emotional health using Pediatric Quality of Life generic core scale version 4.0 (PedsQL) (17), assessment of pain using visual analogue scale for pain (VAS pain) (18, 19), and assessment of well-being using visual analogue scale for global assessment (VAS well-being) (20); all these were completed by every patient or his/her parents. Activity index was assessed in each patient according to the nature of the disease, in Juvenile idiopathic arthritis by DAS-28 (disease activity score 28) (21, 22), Pediatric systemic lupus erythematosus by SLEDAI-2K (systemic lupus erythematosus activity index 2000) (23) which is reliable , valid, sensitive, and responsive to change over time (24), in Juvenile Dermatomyositis by PRINTO

core set measures for dermatomyositis (Pediatric Rheumatology International Trials Organization) (25) which is partially validated tool measures the global evaluation by the treating physician of the overall disease activity and muscle strength of the patient, Juvenile Scleroderma by EULAR SCLEROID (The European League Against Rheumatism Scleroderma Impact of disease Score) (26), and finally Familial meditation fever was assessed by AIDAI (Auto Inflammatory Disease Activity Index) (25). The AIDAI score is a valid and simple tool for assessing disease activity in FMF/MKD/TRAPS/CAPS. This tool is easy to use in clinical practice (27).

2-2. Statistical analysis

The collected data were coded, and statistically analyzed using SPSS program (Statistical Package for Social Sciences) software version 20.0. Descriptive statistics were done for numerical data by mean, standard deviation (SD), and the range; while categorical data were done by number and percentage. Analyses were done for parametric variables using one-way ANOVA test for comparison between three groups and post Hoc Tukey's correction between each two groups. Analyses were done for non-parametric variables using Kruskal Wallis test for comparison between three groups and Mann Whitney test for comparison between each two groups. Analyses were done for quantitative variables using independent sample t test for parametric data between the two groups. Chi- square test was used for qualitative data between groups. Correlation between two quantitative variables was done by using Pearson's correlation coefficient. Correlation coefficient ranges from (0-1), weak (r=0-0.24), fair (r=0.25-0.49), moderate (r=0.5-0.74), strong (r=0.75-1). The level of significance was taken at p value ≤ 0.05.

3- RESULTS

Regarding demographic data, first group included 27 patients diagnosed with juvenile idiopathic arthritis their age ranged (6-18 years), disease duration (0.5-6 years), gender (male 33.3% and female 66.7%), onset subtype (59.3% oligoarticular-33.3% polyarticular-7.4% systemic onset), residence (70.4% rural and 29.6 urban). Second group included 15 patients diagnosed with systemic lupus erythematosus their age ranged (7-21 years), disease duration (1-7 years), gender (20% male and 80% female), residence (80% rural and 20% urban).Third group included other rheumatologic diseases their age ranged (6-15 years), disease duration (0.5-5 years), gender (22.2% male and 77.8% female), residence (88.9 % rural and 11.1% urban) (**Table.1**).

The mean of erythrocyte sedimentation rate (ESR) was highest in SLE patients (56.7 $\pm$ 25.7); while in children with other rheumatologic diseases it was 53.2 $\pm$ 37.6 and in JIA patients it was 39.1 $\pm$ 25.7. The mean of CHAQ score in JIA patients, SLE patients, and children with other rheumatologic diseases was 0.7$\pm$ 0.7, 0.7 $\pm$ 0.67 and 1.4 $\pm$ 0.9, respectively. The mean of PedsQL in JIA patients, SLE patients, and children with other rheumatologic diseases was 73.6 $\pm$ 15.4, 66.4 $\pm$ 20.3 and 52.7 $\pm$ 15.6, respectively (**Table.2**).

DAS28 in JIA patients ranged from 1.79-5.07, DAS28 activity score was 18.5% remission, 22.2% low activity, 59.3% moderate activity. The mean of SLEDAI-2K in SLE patients was 24.2$\pm$14.6. The activity index mean for scleroderma, dermatomyositis and Familial Mediterranean fever (FMF) were (54.3$\pm$ 9.1, 26.7$\pm$ 8.7, 8.3 $\pm$ 2.5, respectively) (**Table.3**).

Table-1: Baseline Characteristics among the studied patients.

Variables	JIA patients (n=27)	SLE patients (n=15)	Other rheumatologic diseases (n=9)	P- value
Age of the patient (years) Range Mean ± SD	 6-18 11.9±3.9	 7-21 14.7±3.7	 6-15 11.3±2.9	0.027
Disease duration (years) Range Mean ± SD	 0.5-6 2.8±1.5	 1-7 3.7±1.7	 0.5-5 2.6±1.4	0.065
Gender Number (%) Male Female	 9 (33.3%) 18 (66.7%)	 3 (20%) 12 (80%)	 2 (22.2%) 7 (77.8%)	0.603
Onset subtype for JIA, number (%) Oligoarticular Polyarticular Systemic onset	 16 (59.3%) 9 (33.3%) 2 (7.4%)	----------	----------	-------
Residence n (%) Rural Urban	 19 (70.4%) 8 (29.6%)	 12 (80%) 3 (20%)	 8 (88.9%) 1 (11.1%)	0.488

SD: standard deviation; JIA: juvenile idiopathic arthritis; SLE: systemic lupus erythematosus.

Table-2: Functional disability and quality of life among studied patients.

Variables	JIA patients, (n=27)	SLE patients, (n=15)	Other rheumatologic disease (n=9)	P- value
CHAQ Range Mean ± SD	 0.0-2.375 0.7± 0.7	 0.0-2 0.7±0.67	 0.125-2.625 1.4± 0.9	0.918
PedsQL Range Mean ± SD	 (38-91) 73.6± 15.4	 (23-89) 66.4±20.3	 (34-81) 52.7± 15.6	0.222
VAS pain Range Mean ± SD	 0-8 2.4± 1.9	 0-9 3.4± 2.5	 1-9 4. 9± 2.9	0.024
VAS global Range Mean ± SD	 0-7 2.7± 1.9	 1-10 3.5± 2.4	 2-10 5.4± 3.6	0.017

SD: standard deviation; CHAQ: childhood health assessment questionnaire; PedsQL: pediatric quality of life questionnaire; VAS global: visual assessment score for global assessment; VAS pain: visual assessment score for pain; JIA: juvenile idiopathic arthritis; SLE: systemic lupus erythematosus.

Table-3: Disease activity in JLA patients and pSLE patients and patients with other rheumatic diseases.

Disease activity index	Range (mean± SD)
DAS28 (for JIA)	1.79-5.07 (3.5± 0.9)
DAS28activity N (%) Remission Low activity Moderate activity	 5 (18.5%) 6 (22.2%) 16 (59.3%)
SLEDAI2K (for SLE)	0-57 (24.2± 14.6)
Autoinflammatory (for FMF)	6-11 (8.3± 2.5)
Printodermatomyositis (for dermatomyositis)	17-34 (26. 7± 8.7)
EULAR (for scleroderma)	44-61 (54.3±9.1)

SD: standard deviation; DAS28: disease activity score 28 for juvenile idiopathic arthritis; DAS28 activity: disease activity score28 activity for juvenile idiopathic arthritis; SLEDAIk2: systemic lupus erythematous activity index 2; FMF: familial mediterranean fever; EULAR: The European League Against Rheumatism.

In JIA patients; CHAQ was statistically positively correlated with DAS28 (r= 0.458, p=0.018), VAS pain (r=0.643, p<0.0001), VAS global (r=0.609, p=0.001), and negatively correlated with PedsQL (r=-0.578, p=0.048) (**Table.4**). DAS28 was statistically positively correlated with VAS pain (r=0.596, p=0.001), VAS global (r=0.448, p=0.019), and negatively correlated with PedsQL (r=0.456, p=0.017) (**Table.5**). PedsQL were statistically negatively correlated with VAS pain (r=-0.587, p=0.001), but not correlated with VAS well-being (r=-0.366, p=0.061).

In SLE patients; CHAQ was statistically positively correlated with VAS pain (r=0.705, p=0.003), and VAS global (r=0.708, p=0.003), and negatively correlated with PedsQL (r=-0.585, p=0.022) (**Table.4**). SLEDAI2K was statistically positively correlated with VAS pain (r=0.556, p=0.049), and statistically negatively correlated with PedsQL (r=-0.776, p=0.001) (**Table.5**). PedsQL was statistically negatively correlated with VAS pain (r=-0.746, p=0.001), and statistically negatively correlated with VAS well-being (r=-624, p=0.013).

Table-4: Correlation between functional disability, disease activity and different HRQL tools in our JIA and SLE patients.

Variables	CHAQ for JIA		CHAQ for SLE	
	r	P value	r	P- value
DAS28 / SLEDAI-2K	0.458	0.018	0.172	0.539
PedsQL	-0.578	0.048	-0.585	0.022
VAS pain	0.643	0.0001	0.705	0.003
VAS global	0.609	0.001	0.708	0.003

CHAQ: childhood health assessment questionnaire; PedsQL: pediatric quality of life questionnaire; VAS pain: visual assessment score for pain; VAS global: visual assessment score for global assessment; DAS28 number: disease activity score 28 number for juvenile idiopathic arthritis; SLEDAI2: systemic lupus erythematous activity index 2; r: Pearson's correlation.

Table-5: Correlation between disease activity and HRQL tool in JIA and SLE patients.

Variables	DAS 28 for JIA		SLEDAI-2K for SLE	
	r	P-value	r	P-value
PedsQL	-.456	0.017	-0.776	0.001
VAS pain	0.596	0.001	0.556	0.049
VAS global	0.448	0.019	0.425	0.114

PedsQL: pediatric quality of life questionnaire; VAS pain: visual assessment score for pain; VAS global: visual assessment score for global assessment; DAS28 number: disease activity score 28 number for juvenile idiopathic arthritis; SLEDAI2: systemic lupus erythematous activity index 2; r: Pearson's correlation.

4- DISCUSSION

Rheumatologic diseases have the ability to influence many aspects of the child's life including; physical, social, emotional, intellectual and economic aspects. The active disease can cause pain, disability and permanent damage to several organs unless it is regularly checked (28). There has been an increased focus on parent- and child-reported outcomes (PCROs) to improve the quality of care (10, 29). The mean of the CHAQ score in our JIA patients was 0.7 which was in concordance with Kwon et al., (30) as the average

CHAQ score in their study was 0.6 representing a slightly serious level of difficulty. A study by Spiegel et al. conducted in Canada on systemic onset JIA reported that the mean of CHAQ score of their patients was 0.125 and this differ from our results. In the current study, the mean PedsQL score in JIA patients was 73.6 reflecting suboptimal HRQL. That was in agreement with Lundberg et al., (33) who detected that more than half of the JIA children experienced suboptimal HRQL. In our JIA patients, there was a significant negative correlation between health related quality of life by PedsQL and pain by VAS pain (p=0.001), which was in concordance with Kwon et al., (28) who stated that pain is an important key variables indicative of a degrading health-related quality of life.

Also, noted that pain result in an initial reduction in physical activity will subsequently affect the physical strength and the quality of life in patients. In our JIA patients, there was a significant positive correlation between CHAQ and pain measured by VAS pain (p<0.0001), which was in concordance with Gueddari et al., (35) who detect a significant correlation between CHAQ and pain describing that the active disease with pain and discomfort during physical activity. Moreover, Sällfors et al., (33) noted a strong influence of pain on well-being which in turn detects the importance of preventing physical disability and controlling pain to preserve HRQOL of children with JIA. The HRQOL of our JIA measured by PedsQl was significantly negatively correlated with disease activity measured by DAS28 activity index (p=0.017) which was in concordance with Arkela-Kautiainen et al., (34) who found a lower HRQOL in all physical components in patients with active disease in comparison to those in remission. In our JIA patients, there was a significant positive correlation between CHAQ and pain measured by VAS pain (p<0.001), which was in concordance with Gueddari et al., (35) who detect a significant correlation between CHAQ and pain describing that the active disease with pain and discomfort during physical activity. We demonstrated that the mean of CHAQ score of cSLE patients was 0.7 compared with a study by Moorthy et al., (36) who found that the mean of CHAQ score was 0.35 reflecting better functional abilities in their patients than in ours. In our pSLE patients, the mean of PedsQL was 66.4 which were in concordance with a study by Jones et al., (37) in which the mean of PedsQl in their patients was 70.4 reflecting a suboptimal HRQL. The overall disease activity of our pSLE patients measured by SLEDAI2K was high.

This result was against Levy et al., (38) who found a low disease activity among their pSLE patients. The cause of this difference may be due to the small number of our studied group of pSLE patients compared to their multiethnic multicenter research. The mean SLEDAI-2K score in our pSLE patients was 24.2, however in a study made by Jones et al., (37) the mean of SLEDAI2K in their pSLE patients was 5.9. Our pSLE patients did not show a significant correlation between functional disability and SLEDAI-2K score (p=0.539). This was in concordance with Moorthy et al., (39) who did not find a strong correlation between physical function and disease activity. On the contrary, Levy et al., (38) found negative correlation between disease activity and functional disabilities among their pSLE patients that was weak to moderate. HRQOL in our SLE patients measured by PedsQl showed a significant negative correlation with SLEDAI-2k score (p=0.001). Our results were in concordance with Levy et al., (38) who found that higher disease activity is associated with significantly lower HRQOL. On the other hand Jones et al.,

(37) could not detect a significant relation between disease activity and damage with patient quality of life. The mean of VAS pain in our pSLE patients was 2.4 which were in concordance of the results detected by Jones et al., (37) in which the mean of VAS pain in their pSLE patients was 2.9. Pain in our SLE patients had a significant negative correlation with PedsQL (p=0.001) which was in concordance with a study by Jones et al., (37) in which they proved that pain had a significant negative impact on HRQOL. In our pSLE patients, we could not detect significant correlation between the duration of the disease and CHAQ or PedsQL (p=0.343) (p=0.122), respectively. This was in agreement with Moorthy et al., (36) as in their study the disease duration didn't correlate with either CHAQ or PedsQL. In our study, a significant correlation in pSLE patients between CHAQ and PedsQL (p=0.022) was detected. However, Moorthy et al., (39) didn't found a strong correlation between CHAQ and PedsQL. We failed to establish any statistically significant data or correlation between HRQL and other tools in our study. This is explained by the limited number of the patients studied due to the seldom nature of their disease and the limitation of our study only at Minia University hospital.

4-1. Strengths and Limitation of study

Strengths of our study are the use of reports from parents and children obtained using valid and reliable measures. Limitations of our study are the relatively small number of patients due to geographic reasons and the social weirdness of such questionnaires and attention addressed to the children or their parents.

5- CONCLUSION

We conclude that children have a significantly lower HRQL across both physical and psychosocial domains compared to their normal peers. Disease activity correlated negatively with functional disability which denotes the impact of controlling the disease on leading a better quality of life.

6- CONFLICT OF INTEREST: None.

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