

Health-related quality of life and emotional problems in juvenile idiopathic arthritis

Dejan Stevanovic · Gordana Susic

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Abstract

Purpose Children with juvenile idiopathic arthritis (JIA) are at an increased risk of developing emotional problems. This study evaluated the associations between levels of depressive and anxiety symptoms and health-related quality of life (HRQOL) in these children.

Methods Sixty-seven children with JIA, together with one parent, participated. Anxiety symptoms were identified using the Screen for Child Anxiety Related Emotional Disorders Questionnaire (SCARED), while depressive symptoms were identified using the Mood and Feeling Questionnaire (MFQ). The Pediatric Quality of Life Inventory (PedsQL) was used for HRQOL assessments. Using hierarchical multiple-regression analysis, demographics, clinical factors, and pain were control variables, while anxiety (the SCARED score) and depressive symptoms (the MFQ score) were HRQOL (the PedsQL score) predictors.

Results The regression model emerged with specified variables explaining 63 % of the variance in the PedsQL score ($F = 11.92, p < 0.01$) among children. Among parents, the same set of variables accounted for 49 % the variance ($F = 6.99, p < 0.01$). The MFQ score, but not the SCARED, added most to the variance.

Conclusions Depressive symptoms, but not anxiety, accounted for substantial variability in levels of HRQOL when considered with demographics, clinical factors, and pain. Thus, screening for depression needs to be considered as a part of multimodal assessment and treatment approaches in JIA.

Keywords Anxiety · Depression · Quality of life

Abbreviations

JIA	Juvenile idiopathic arthritis
HRQOL	Health-related quality of life
SCARED	Screen for Child Anxiety Related Emotional Disorders Questionnaire
MFQ	Mood and Feeling Questionnaire
PedsQL TM	Pediatric Quality of Life Inventory TM version 4.0

Introduction

Health-related quality of life (HRQOL), as a multidimensional construct covering physical, emotional, mental, social, and behavioral components of well-being and functioning, has been recognized as one of the quality measures for evaluating the outcome of juvenile idiopathic arthritis (JIA) [1]. This implies that HRQOL data should be routinely collected in every child, together with other outcomes, such as laboratory findings, joints affection, mobility, and pain, as a part of multimodal assessment and treatment approaches in JIA [2].

Considering different physical, psychological, and social domains of everyday well-being and functioning, children with JIA generally report low levels of HRQOL [3, 4]. Over the past decade, various demographic and

D. Stevanovic (✉)
Department of Psychiatry, General Hospital Sombor,
Apatinski put 38, 25000 Sombor, Serbia
e-mail: dejanstevanovic@eunet.rs

G. Susic
Institute for Rheumatology, Medical School University of
Belgrade, Belgrade, Serbia

clinical risk factors were identified for poor HRQOL, like pain, levels of physical disability, and disease activity [2, 5, 6]. Together with these risk factors, studying the impact of mental health problems on HRQOL would be necessary, because children with JIA are at an increased risk of developing various psychological problems [7]. They appear to be at risk of overall adjustment problems, internalizing symptoms, poor self-concept, and/or self-esteem problems. Specifically, estimated frequency for depression was 15 %, for somatoform disorder 12.5 %, for adjustment disorder 5 %, and for mixed anxiety and depression 2.5 % [8].

Few studies evaluated how psychological functioning and manifested psychological problems relate to clinical outcomes, especially to HRQOL. In a group of children with various types of arthritis, the relationships between self-efficacy, trait anxiety, depression, clinical state of the disease, and age were found [9]. In another study, depression correlated with pain, while, together with anxiety, depression was among the best predictors for impaired HRQOL in JIA [10]. Furthermore, depression, anxiety, and behavioral problems correlated moderately with physical function, while poor psychological outcome was linked with more severe physical disability [11]. In a Polish group of children and adolescents with JIA, the relationship between high levels of experiencing pain and high levels of anxiety was revealed [12]. Recently, it was demonstrated that depression and psychological inflexibility were predictive of anxiety, overall functioning, well-being, and HRQOL [6, 13].

This brief review of the past studies showed that emotional and behavioral problems are associated with several JIA outcomes and HRQOL as well. However, it appears that only consistent finding across the studies is about negative effects of depression, while data about the associations of other psychological problems and HRQOL are scarce or lacking. Additionally, there are some limitations observed in these studies such as considering children or parents only during assessments, using less-specific measures for constructs of interest, not considering anxiety and depressive symptoms independently or concurrently as comorbid conditions, not including various clinical variables in evaluated models, or not considering regression analysis for studying predictive values of emotional symptoms. Addressing these limitations, this study was conducted in order to provide more data about the associations between levels of emotional symptoms and HRQOL in JIA. Considering emotional problems as determinants of HRQOL, the study was organized with an aim (1) to determine the independent relationship between levels of depressive and anxiety symptoms and levels of self- and parent-rated HRQOL in JIA and (2) to examine their associations considering demographic, clinical factors, and pain.

Methods

Participants

Data for this study were collected from 67 children with JIA (Table 1). Additionally, data from one parent per child were also included. These children were consecutive patients recruited from the Institute of Rheumatology, Belgrade, during the period March–August 2010. The general inclusion criteria included a confirmable diagnosis of JIA set at least 6 months prior to the study, age of 8–18 years, regular school attendance (considering that we evaluated school achievement as a predictor variable), and ability to read and write. Young people with severe mental health problems (like psychotic disorders), neurological impairments or handicaps, or other chronic pediatric disorders were not included. At the time when the questionnaires were completed, disease activity was rated as mild, moderate, or severe for each participant considering the global clinician assessment (GCA) [14].

Participation was on a voluntary basis, and children and parents signed the informed consent forms. Children and parents separately completed a set of the questionnaires during a regular clinic visit. Both children and parents were instructed how to complete the questionnaires, while the completion was supervised to the extent to ensure that all questionnaires were completed and returned. The Ethics Committee of the Clinic for Neurology and Psychiatry for Children and Youth, Belgrade, approved the study.

Table 1 General characteristics of the sample ($N = 67$)

Age (years), M (SD)	13.6 (2.9), range 8–18
Male/female	19 (28.4 %)/48 (71.6 %)
Average school mark, M (SD)	4.7 (0.5), range 3–5
Age at JIA onset (years), M (SD)	8.7 (4.5), range 0.7–17
JIA duration (years), M (SD)	5 (3.5), 0.6–14.1
JIA therapy, N (%)	
NSAIDs	35 (52.2)
Corticosteroid	1 (1.5)
Methotrexate	12 (17.9)
Anti-TNF	8 (11.9)
Corticosteroid + Anti-TNF	1 (1.5)
Methotrexate + Anti-TNF	7 (10.4)
Corticosteroid + Anti-TNF + methotrexate	3 (4.5)
JIA activity, N (%)	
Mild	32 (47.8)
Moderate	17 (25.4)
Severe	18 (26.9)

Questionnaires

Screen for Child Anxiety Related Emotional Disorders Questionnaire (SCARED)

Levels of anxiety symptoms were identified using the SCARED [15]. This questionnaire contains 41 items that cover the symptoms of the entire spectrum of childhood anxiety disorders (panic/somatic, generalized anxiety, separation anxiety, social phobia, and school avoidance). Each item is scored on a 3-point scale, and the sum of all answered items is the total SCARED score (possible range: 0–82). The higher the SCARED scores, the higher the levels of anxiety symptoms. The questionnaire was designed to have similar versions for children (SCARED-C) and parents/caregivers (SCARED-P). The Serbian translation of the SCARED possessed appropriate internal consistency, construct validity, and sound convergent validity [16]. In the present study, Cronbach's α for internal consistency was 0.95 for a child and 0.92 for a parent version.

Mood and Feeling Questionnaire (MFQ)

Levels of depressive symptoms were identified using the MFQ [17]. The MFQ is a 33-item questionnaire for the assessment of children's mood, with items reflecting the symptoms of major depression. Each item is scored on a 3-point scale, and the sum of all answered items gives the total MFQ score (possible range: 0–66 for a child and 0–68 for a parent version). The higher the MFQ score, the higher the levels of depression symptoms. The questionnaire was designed to have parallel versions for children (MFQ-C) and parents/caregivers (MFQ-P). The Serbian translation of the MFQ possessed appropriate internal consistency, construct validity, and sound convergent/discriminant validity [16]. In the present study, Cronbach's α for internal consistency was 0.94 for both versions.

Pediatric Quality of Life InventoryTM version 4.0 (PedsQLTM)

The PedsQLTM was used for HRQOL assessments [18]. This questionnaire possesses 23 items assessing physical, emotional, social, and school functioning. Items are 5-point-scaled and transformed to a 0–100 scale, with the total PedsQL score presented as the sum of all items over the number of items answered on all four scales. The higher the PedsQL scores, the better the levels of HRQOL. The PedsQL was designed to have parallel versions for children and parents/caregivers. For the purpose of the present study, only the total PedsQL score was used.

Considering that one item in the questionnaire measures the presence of pain, the item was not included in the final PedsQL score, but it was used as a controlling variable in regression analyses. The PedsQL in Serbian has sound general psychometric properties [19]. In the present study, Cronbach's α for internal consistency was 0.90 for a child and 0.89 for a parent version.

Data analysis

Mean and standard deviations for the PedsQL, SCARED, and MFQ scores were calculated for children and parents. To test for statistical differences between them, *t*-test was used.

Initially, bivariate correlations were computed to determine the relationships between levels of anxiety and depressive symptoms and HRQOL (Spearman's rho coefficient). Because of the known comorbidity between anxiety and depressive symptoms, partial correlations were computed between HRQOL, and depressive symptoms (controlling for anxiety symptoms) and anxiety symptoms (controlling for depressive symptoms) to determine unique effects.

Subsequently, data were analyzed using hierarchical multiple-regression analysis to determine to what extent levels of depressive and anxiety symptoms would predict levels of HRQOL when considered together with general demographics, clinical factors, and pain. The dependent variable was the PedsQL score. The following independent variables were entered in blocks. Age, gender, and school achievement were entered in the first block. School achievement was included in the analyses, because it could be affected significantly by a physical disability [20]. Three clinical JIA factors were entered in the second block: age at onset, duration, and activity. The PedsQL item about the presence of pain was entered in the third block. This item was considered separately, whereas the previous research demonstrated that pain strongly affects HRQOL [10, 12]. Finally, depressive (the MFQ score) and anxiety symptoms (the SCARED score) were entered in the fourth block. In the first three blocks, the variables were entered using the entry method, because they were the controlling ones in the model, while depressive and anxiety symptoms were entered using the stepwise method. Considering this approach, if adding a variable that was tested for prediction to controlling variables contributed to a model, then it was retained, but all other variables tested in the model were then retested to see whether they are still contributing to the success of the model. If they no longer contributed significantly, they were removed. Thus, this method should ensure that it was ended up with the smallest possible set of predictors.

Results

Between children and parents, no statistically significant difference was found considering the SCARED, MFQ, and PedsQL scores (Table 2).

The MFQ–PedsQL correlation was -0.72 ($p < 0.01$) and the SCARED–PedsQL -0.55 ($p < 0.01$) for the children's ratings, while they were -0.57 and -0.54 ($p < 0.01$) for the parents' ratings. Corrected for the SCARED, the MFQ–PedsQL partial correlation was -0.50 ($p < 0.01$) among children and -0.29 ($p = 0.02$) among parents. On the other hand, the SCARED–PedsQL partial correlation corrected for the MFQ score was -0.17 ($p = 0.18$) for children and -0.26 ($p = 0.04$) for parents.

From the regression method of the children's ratings (Table 3), the model emerged with gender, age, school achievement, JIA activity, age at JIA onset, JIA duration,

pain, and the MFQ score explaining 63 % of the variance of the PedsQL score ($F = 11.92$, $p < 0.01$). For the parents' ratings (Table 4), the same set of variables in the model was responsible for 49 % in the variance ($F = 6.99$ $p < 0.01$). In both models, only the MFQ score significantly predicted the PedsQL score, $\beta = -0.52$ ($p < 0.01$) among children and $\beta = -0.53$ ($p < 0.01$) among parents.

Discussion

In the present study, the associations between emotional symptoms and HRQOL in JIA were evaluated considering demographic, clinical factors, and pain.

The results of a series of simple and partial correlations revealed that the levels of HRQOL in JIA and symptoms of depression or anxiety were negatively related. However, considering comorbidity between depressive and anxiety symptoms, when controlled for depressive, symptoms of anxiety correlated significantly with HRQOL only among parents. Further analyses showed that when controlled for demographics, clinical factors, and levels of perceived pain, levels of depressive symptoms accounted for 18 % of additional variance in HRQOL as child-rated. As parent-rated, levels of depressive symptoms accounted for nearly

Table 2 SCARED, MFQ, and PedsQL scores ($N = 67$)

Scores	M (SD)		<i>t</i> -test (<i>p</i> value)
	Children	Parents	
SCARED	12.3 (10)	12.2 (11.9)	0.1 (0.96)
MFQ	9.1 (9.9)	8.7 (9.9)	0.3 (0.79)
PedsQL	82.1 (13.9)	79.1 (12.7)	1.3 (0.19)

Table 3 Multiple-regression analysis: children

Model ^a	β	<i>p</i> value	<i>F</i> (<i>p</i> value)	Model summary		
				<i>R</i> ²	Adjusted <i>R</i> ²	<i>R</i> ² change
Gender	0.03	0.72	11.92 (<0.01)	0.63	0.58	0.10
Age (years)	-0.72	0.31				
School achievement	-0.04	0.58				
JIA activity	-0.05	0.59				0.09
Age at JIA onset	0.93	0.42				
JIA duration	0.64	0.47				
Pain	0.42	<0.01				0.26
MFQ total	-0.52	<0.01				0.18

^a Dependent variable: PedsQL total

Table 4 Multiple-regression analysis: parents

Model ^a	β	<i>p</i> value	<i>F</i> (<i>p</i> value)	Model summary		
				<i>R</i> ²	Adjusted <i>R</i> ²	<i>R</i> ² change
Gender	0.01	0.98	6.99 (<0.01)	0.49	0.42	0.03
Age (years)	0.27	0.74				
School achievement	-0.18	0.06				
JIA activity	-0.25	0.02				0.10
Age at JIA onset	-0.44	0.74				
JIA duration	-0.36	0.72				
Pain	0.33	0.01				0.13
MFQ total	-0.53	<0.01				0.23

^a Dependent variable: PedsQL total

23 % of additional variance. Nevertheless, levels of anxiety symptoms did not significantly predict levels of HRQOL when considered together with demographics, clinical factors, levels of perceived pain, and depressive symptoms.

Together, these findings imply that levels of depression and anxiety symptoms were strongly associated with well-being and everyday functioning in children with JIA, but the comorbidity between the two symptoms determined the independent effect of each. In this case, only levels of depressive symptoms when controlled for comorbid anxiety symptoms had strongly affected when children and parents were evaluated together, while the opposite situation was found only for parents. However, when considered together with demographic and clinical factors and levels of perceived pain, only depressive symptoms predicted HRQOL variations to a significant degree.

The previous study assessing HRQOL and mental health in children with JIA demonstrated that depression and anxiety predicted impaired HRQOL together with functional limitations and social isolation [4]. Nevertheless, symptoms of depression and anxiety were evaluated together without considering the independent effect of each. More recently, it was found that depression and psychological inflexibility were predictive of anxiety, overall functioning, well-being, and HRQOL [6, 13]. Thus, the findings of our study clearly indicated that levels of depressive symptoms significantly predicted levels of HRQOL perceived, while anxiety symptoms did not. Strong associations between depressive symptoms and HRQOL found in this study are in line with the previous findings showing that depression was correlated significantly with other JIA outcomes, like clinical state of the disease, pain, overall functioning, and well-being [9, 10, 13, 21]. However, in general population of children and adolescents, it was demonstrated that levels of anxiety and, only to a lesser degree, depressive symptoms significantly affect self-perceived HRQOL, contrary to the findings here [22]. Possible explanations could be that depressive symptoms are the commonest psychological reaction to JIA or that these children are more prone to experience depressive than anxiety symptoms as distressing ones considering some JIA characteristics, like using immunosuppressant drugs, pain, physical disability, or immobility [10, 13]. Finally, although not of the primary interest here, it is worth mentioning that among the controlling variables studied in this study, only levels of perceived pain among children with JIA accounted for significant additional variance in HRQOL. This finding also agrees with the previously reported ones [9, 10, 13, 21].

The strengths and limitations of the study need to be acknowledged. This study considered both children and parents during assessments, using two measures for anxiety

and depression, which have prominent construct validity above other measurement properties, and the PedsQL with sound psychometrics in general. Further, in all analyses, anxiety and depressive symptoms were considered independently and as comorbid conditions, and various clinical variables were included, as well. However, using only self-reported questionnaires and not a structured psychological interview for mental health assessment may result in a clinical mismatch between the two. Additionally, using only a generic HRQOL measure could be a limitation. A JIA-specific questionnaire usually covers domains targeted to specific characteristics of the disorder; thus, different sets of mental health predictors could be found than the one in the study. This could be the case if using more individualized care approaches including JIA-specific HRQOL aspects [23]. In addition, the cross-sectional design of the study is a limitation because it was not possible to determine whether mental health had a direct effect on QOL, whether QOL influenced mental health, or whether the relationship was bidirectional. Furthermore, nearly half of the participants had low overall JIA activity, which could bias the results and further limit the generalizability of the study.

Summarizing, there were strong negative associations between emotional problems and HRQOL among children with JIA. However, when considered together with general demographics, clinical factors, and pain, only levels of depressive symptoms accounted for substantial variations in levels of HRQOL. Thus, assessments of emotional problems, but especially depressive symptoms, need to be routinely collected in every child, together with other outcomes such as laboratory findings, joints affection, mobility, and pain, as a part of multimodal assessment and treatment approaches in JIA.

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