

# Psychological Effects and Parent Quality of Life in Children of Vision Loss for Uveitis

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## Research Article

**Keywords:** Juvenile idiopathic arthritis, Uveitis, Quality of life, Parent Stress, Coping, Resilience

**Posted Date:** November 17th, 2021

**DOI:** <https://doi.org/10.21203/rs.3.rs-1007547/v1>

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# Abstract

**Purpose:** Juvenile idiopathic arthritis (JIA) is a chronic inflammatory disease common in children and young adults. Uveitis is most frequent serious extra-articular JIA manifestation and can lead to severe ocular complications, vision loss and permanent blindness. The aim of this study is to evaluate the quality of life and the psychological effects of JIA associated with uveitis (JIA-U) on these children and to explore the effect of a child's chronic illness on parents.

**Materials and Methods:** 30 children and adolescents with active uveitis referred to Unit of Ophthalmology, Giovanni XXIII Hospital of Bari and 30 subjects of control group were enrolled with their parents. Informed consent was signed by the subjects and four questionnaires were administered: Child Behaviour Checklist (CBCL), Parent Stress Index in short form (PSI), Pediatric Quality of Life Inventory (PedsQL) and Coping Inventory for Stressful Situations (CISS). Data were collected from February 2020 to December 2020.

**Results:** The analysis of the emotional and behavioral problems of children (CBCL) with JIA associated with uveitis, the rate of parent's stress (PSI) and the strategies of coping with the stress (CISS) of their families did not show statistically significant differences between the clinical sample and the control group. Significant differences were observed in quality of life between the two groups. In particular, significant differences ( $p < 0,05$ ) were found in all domains of PedsQL: physical functioning (PF), emotional functioning (EF), social functioning (SF) and school functioning (ScF).

**Conclusions:** This study shows a worse quality of life in children with JIA-U. Several ocular complications, eye examinations and the rigor of long-term treatment influence health-related quality of life in these children. This study suggests the importance of helping children with uveitis cope with chronic disease and may improve outcome. Inclusion of a screening related quality of life should be considered in management of children with JIA-U. Further studies are needed to evaluate the long-term impact on psychological health in these children.

## 1. Introduction

Juvenile idiopathic arthritis (JIA) is a chronic inflammatory disease common in children and young adults.<sup>1</sup> The supported etiology is an immunogenic mechanism, and genetic and environment factors are also involved.<sup>2</sup> The uveitis is most frequent serious extra-articular manifestation.<sup>3</sup> Although the eye is known as an immune-privileged organ, when the breakdown of the blood-aqueous humour barrier is made, the non-infectious uvea inflammation is done.<sup>4</sup>

The oligoarticular (four or fewer joints involved) and polyarticular (affects five or more joints) JIA are the most common types associated with uveitis. Especially, the oligoarticular type develops uveitis at a higher rate (20%) than polyarticular (5%) one.<sup>5</sup>

According to Standardization of Uveitis Nomenclature (SUN) Criteria, uveitis features associated with JIA include anterior chamber cells, anterior chamber flare, vitreous cells, and haze.<sup>6</sup> Other clinical findings are

band keratopathy, posterior synechiae, cataract, glaucoma, and macular edema.<sup>7</sup>

JIA is strongly associated with psychosocial distress especially when associated with uveitis.<sup>8-10</sup>

The sudden or insidious symptoms onset, trend of remission and recrudescence, visual loss, chronic therapy (topical, systemic, or biological molecules), short or medium-long term eye complications of uveitis have a strong psychological impact on the quality of life of children and their families.

The significance to investigate psychological changes in patients with chronic diseases is well-acknowledged.<sup>11,12</sup>

Similarly, parenting stress in pediatric chronic physical illnesses is well known. For instance, diabetes,<sup>13</sup> cystic fibrosis,<sup>14</sup> asthma, cancer, epilepsy, sickle cell disease<sup>15,16</sup> are some of the chronic health conditions previously described in literature.

Understanding the measure of parents' stress and strategies used as an adaptation can direct towards an improvement in the therapeutic and family support approach.

The study aims to investigate: 1) the quality of life of children and adolescent with JIA-U (PedsQL), 2) young patients with JIA associated with uveitis behavior from parents' point of view (CBCL Test), 3) the rate of parents' stress (PSI-SF stairs), 4) the strategies applied by their family to cope with stress (CISS scale), and comparing them with children without chronic diseases and their families. The research hypothesis of this study is that the JIA-U worsened the quality of life and the emotional and behavioral problems of these children and increased stress levels in the parents of these patients. The period in which we checked these families and administered the tests coincided with the pandemic period SARS-CoV2. Therefore, all data collected will refer to this period.

## 2. Methods

The clinical sample consisted of 30 children and adolescents with active uveitis referred to Unit of Ophthalmology, Giovanni XXIII Hospital of Bari and their parents. The study was carried during the period February-December 2020. Eligibility criteria were active uveitis, having no other systemic or ocular disease that could potentially affect vision and being under aged 18 years. We administrated validated questionnaires such as Child Behaviour Checklist (CBCL),<sup>17</sup> Parent stress Index in short form (PSI),<sup>18</sup> Pediatric Quality of Life Inventory (PedsQL),<sup>19</sup> and Coping Inventory for Stressful Situations (CISS).<sup>20,21</sup> Parent and patient-based questionnaires were completed in person after the ophthalmic examination at the clinic. A member of the research team was available to read the questions to subjects who requested it. The control group consisted of 30 children and adolescents that was random recruited, based on the availability of parents and subjects to participate in the study, from school located in Bari and Foggia.

The study was approved by the local Ethics Committee. An informed consent was obtained from all patients who agreed to participate in the study.

## 2.1 Assessment

The assessment was carried out by administering standardized scales, the "PSI", the "CBCL", the "PedsQL" and the "CISS":

the PSI Short Form (PSI / SF) is a reliable questionnaire designed to measure parental stress and difficulties about the parenting role. It is a summary form of the Parenting Stress Index (PSI) full-length test.<sup>18</sup> All 36 items on The Short Form are contained on the Long Form and are written at a 5th-grade reading level. Each item requires the parent to respond with a statement on a five-point Likert scale (1=Strongly Agree, 2=Agree, 3=Not Sure, 4=Disagree, and 5=Strongly Disagree). The PSI consists of the three subscales: parenting distress (PD) scale, dysfunctional interaction parent-child (P-CDI) scale, difficult child (DC) scale. The PD scales define the level of distress that a parent perceives in his parenting role. The P-CDI scale expresses the parent's perception of a child who does not respond to his or her expectations and therefore of a non-gratifying interaction with the child. The DC scale values how much the parent perceives his child as easy/difficult to manage. The PSI-SF produces subscales raw scores ranging from 12 to 60 and an overall parenting stress total score that ranges from 36 to 180; a higher score indicates a greater level of stress. A score above the 90th percentile indicates clinically significant level of parenting stress. The total stress (TS) scores, obtained by the sum of the scores of the 3 subscales, is an index of total parenting stress. The test includes also a Defensive Responding (DF) scale that indicates the parent tends to give a better self-image, minimizing the problems and the perceived stress in the relationship with the child.

The CBCL is a common questionnaire used to assess emotional and behavioral problems in children,<sup>17</sup> as rated by parents and include CBCL/6-18 and CBCL/1 ½-5 for different ages.

The first section of the scale includes 20 items related to child's participation in sports, hobbies, games, activities, organizations, jobs, chores, friendships, social interactions during play, independent work, and school functioning. The second section consists of 120 items on behavior or emotional problems during the past 6 months. The main areas investigated are aggression, hyperactivity, bullying, conduct problems, defiance, and violence. Responses are recorded on a Likert scale: 0=Not true, 1=Somewhat or Sometimes true, 2=very true or often true. Lower scores indicate lower functioning on the academic performance and adaptive functioning scales. Higher scores indicate higher levels of maladaptive behavior on the syndrome, total problems, externalizing, and internalizing scales.

The PedsQL is a validated measure of general health-related QOL in children and adolescent from 2 to 18 years of age.<sup>19</sup> It consists of four scales measured on a 5-point-scale: 1: physical functioning (PF) 8 items, 2: emotional functioning (EF) 5 items, 3: social functioning (SF) 5 items and 4: school functioning (ScF) 5 items. The questions investigate how many problems children has had in the past month Score range from 0 to 100; higher scores indicate better QoL. Child self-report includes ages 5 to 7, 8 to 12 and 13 to 18 years. Parent-report includes ages 2 to 4 (toddler), 5 to 7 (young child), 8 to 12 (child), 13 to 18 (adolescent). A 5-point response scale is utilized: 0 (never a problem), 1 (almost never a problem), 2

(sometimes a problem), 3 (often a problem), 4 (almost always a problem). To further increase the ease of use for the young child self-report (ages 5-7), the response scale is simplified to a 3-point scale: 0 (not at all a problem, 2 (sometimes a problem), 3 (a lot of a problem). Parent-report includes toddler age range, which does not include self-report form and only 3 items for the school functioning scale. Items are reverse-scored and transformed 0 to 100 (0=100, 1=75,2=50, 3=25, 4=0). Higher score indicates a better Health related-QoL (HRQoL).

The CISS measures the following three type of coping styles: Task-Oriented Coping (dealing with the problem at hand), Emotion-Oriented Coping (focus on consequent emotions) and Avoidance – Oriented Coping (Distraction and Social Diversion).<sup>20,21</sup> The CISS includes adolescent and adult forms. They include 48 items and use a five-point response format. The adolescent version of the CISS is suitable for individuals between the ages of 13 and 18. The adult version of the CISS is suitable for individuals who are 18 years of age and older. For this study we used only the adult version.

## 2.2 Statistical analysis

Descriptive statistics were used to summarize the variables studied and the characteristics of the subjects. Differences among demographic variables were evaluated by the chi-squared test (sex). Non-parametric tests (Mann–Whitney) were used to examine the differences in age, PSI / SF, CBCL, CISS, PedsQL between group. A *P* value of less than .05 was considered as statistically significant. For statistical processing, we used the data processing program the Statistical Package for Social Science, Version 20.0.

## 3. Results

The socio-demographic characteristics of the sample and control group are summarized in Table 1. The analysis of the emotional and behavioral problems of the patients included in the study did not show significant statistical differences in two groups as shown in table 2.

No statistically significant differences were found in variables analyzed in the PSI and CISS questionnaire, as shown in tables 3 and 4.

The analysis conducted to evaluate differences in the quality of life (QoL) highlights statistically significant differences in all variables of the PedsQL questionnaire. In particular, significant data were found in the variables: PF ( $p < 0.05$ ), EF ( $p < 0.05$ ), SF ( $p < 0.05$ ) and ScF ( $p < 0.05$ ). They are summarized in Table 5.

Table 1. Social demographic characteristics of patients and their parents of Clinical Sample and Control group. Data are given in Mean, Standard Deviation.

	CS	CG
<b>Number</b>	30	30
<b>Gender</b>		
M	13	14
F	17	26
<b>Mean age, years (SD)</b>	9,77±3,57	9,33±4,498
<b>Mother (N)</b>	26	27
<b>Father (N)</b>	4	3

Table 2. No significant differences scores between groups found in CBCL. † (p<0,05)

	CS	CG	Mann-Whitney U	Wilcoxon W	Z	†p
age	9,77±3,57	9,33±4,50	403,500	868,500	-,690	,490
Anxious/depressed	56,73±9,95	53,43±6,28	382,500	847,500	-1,210	,226
Withdrawn	52,87±5,32	52,20±5,12	409,000	874,000	-,798	,425
Somatic complaints	55,10±9,59	52,47±5,46	407,500	872,500	-,777	,437
Attention problems	51,17±4,09	53,37±7,23	388,500	853,500	-1,401	,161
Aggressive behaviour	51,73±4,29	52,23±5,20	435,000	900,000	-,329	,742
Affective problems	53,50±7,71	53,97±7,38	427,500	892,500	-,449	,654
Anxiety problems	55,00±9,54	53,60±6,93	446,500	911,500	-,068	,946
adhd	51,67±5,14	53,17±6,70	405,000	870,000	-,986	,324
Oppositional Defiant Problems	51,57±4,26	53,60±7,23	411,000	876,000	-,826	,409
Internalizing problems	55,37±9,93	52,90±5,83	417,000	882,000	-,642	,521
Externalizing Problems	52,00±4,28	52,13±4,78	447,000	912,000	-,064	,949
Total problems	54,07±8,37	52,90±5,58	449,000	914,000	-,019	,984

Table 3. No significant differences scores between groups found in PSI. † (p<0,05)

	CS	CG	Mann-Whitney U	Wilcoxon W	Z	† p
Parenting distress	24,90±7,43	27,50±10,17	393,500	858,500	-,837	,403
Dysfunctional interaction parent-child	21,50±6,28	19,97±6,89	373,000	838,000	-1,141	,254
Difficult child	24,77±8,07	23,70±7,88	413,500	878,500	-,540	,589
Defensive responding	15,93±5,61	17,50±6,31	379,000	844,000	-1,053	,292
Total Stress	70,93±20,53	70,30±19,47	441,500	906,500	-,126	,900

Table 4. No significant differences scores between groups found in CISS. † (p<0,05)

	CS	CG	Mann-Whitney U	Wilcoxon W	Z	† p
Task	48,03±10,80	46,90±10,04	406,000	871,000	-,651	,515
Emotion	49,07±11,74	47,47±12,18	432,500	897,500	-,259	,796
Avoidance	49,37±8,86	52,83±10,11	362,500	827,500	-1,295	,195
Distraction	50,80±9,01	50,60±10,04	433,000	898,000	-,252	,801
Social diversion	46,80±8,77	50,03±11,86	355,500	820,500	-1,401	,161

Table 5. Significant differences scores between groups in PedsQL. † (p<0,05)

	CS	CG	Mann-Whitney U	Wilcoxon W	Z	† p
Physical functioning†	80,17±14,86	89,53±12,57	269,500	734,500	-2,703	,007
Emotional functioning†	77,83±12,98	89,33±16,07	207,000	672,000	-3,635	,000
Social functioning†	89,67±14,08	96,00±12,55	285,500	750,500	-2,858	,004
School functioning†	79,37±17,36	88,67±17,90	311,500	776,500	-2,151	,032
TOTped†	81,55±9,97	90,60±11,38	204,000	639,000	-3,509	,000

## 4. Discussion

A poor number of studies examined the impact of QoL in patients with JIA-U.

It is not infrequent that the uveitis appears as asymptomatic or the child does not perceive it, while it being in an advanced stage. Therefore, we are faced already with visual loss, or ocular complications to be managed and sometimes we have to resort to surgery.<sup>22</sup>

Most recent studies concern solely adult patients,<sup>8,23,24</sup> contrary very few about children and teens and their parents. Our study is one of them and, to our knowledge, it is the only one to have a control group.

Analyzing the responses to the PedsQL questionnaire significant results emerged in all domains: PF, EF, SF, ScF. These results highlight that uveitis has a major impact on the quality of life and affects every aspect of the children's life. Our results agree with most of other studies.<sup>10,25-28</sup>

In particular a study reviewed groups of children (and their parents) with visual impairment due to ocular conditions apart from the uveitis (and their parents) and found comments from 510 (44%) of 1163 children and 1078 (55%) of 1952 parents related with the QoL, such as psychosocial, impact on the school, expectations and frustrations, dependency, and participation.<sup>25</sup> An other study conducted a semi-structured interview on 10 children and adolescents aged between 6 and their parents; impact on the school, social factors, and emotional reactions were investigated, considering clinical evidence and therapeutic strategies were practiced.<sup>26</sup>

A recent study had proven a worsening of overall parameters of the QoL among children with a visual impairment, as measured by the PedsQL, version 4.0.6.<sup>27</sup>

A series of factors JIA-U-related were contemplated how strongly impactful on the QoL in these patients.

These studies show that indeed uveitis is associated with worse physical and mental health-related quality of life in children because of additional important medical stressors in this population.<sup>10,28</sup> Management of uveitis consists in complicated examinations, which can be frightening for children, and complex regimens of topical and systemic medications, which can be difficult to follow. Parents in fact report that children have difficulty understanding treatment regimens. Furthermore, children with uveitis may need to miss numerous school days for eye treatments and often may miss school for long periods because of complications. Many children report difficulty compensating for missed course work and this obviously has a negative impact on their academic performance. Absences from school result also in less opportunities to socialize with peers and loss of friends. These children have less time to spent with other children for eye examinations and treatments and often changes in vision affects the ability to play some sports and to take part in play and leisure activities. Furthermore, children find embarrassing to talk about their eye conditions with their peers and this contributes to the deterioration of interpersonal relationships. Uveitis and generally chronic illness of childhood can also lead to a slower development of autonomy, close relationships with parents and high levels of parental involvement. These children are



vulnerable to being unable to manage their disease enough to ask for the help of parents even in adulthood. For all these reasons children with uveitis experience negative emotions as sadness, anxiety and anger for the future, according to the results of our study.

The American Academy of Pediatrics Section on Rheumatology and Section on Ophthalmology recommended then ophthalmology screenings every 3–4 months until 7 years of age to monitor the disease development, considering in the childhood the higher risk to develop uveitis for youngest with JIA.<sup>29</sup>

For the correct adherence to the therapy, attention and care of the family is fundamental.<sup>28</sup>

The chronic disease so had a strong impact on the child's parents. A study showed a greater total stress score of mothers of children with JIA as measured by the PSI (235.4; 95% CI 218.5-252.3) than the mean total stress scores for mothers of normal children (222.8; 95% CI 221.4-224.2).<sup>30</sup>

Instead in our study, no significant results emerged on parenting distress by the PSI. Our hypothesis is that the SARS-Cov-2 pandemic may have impacted parental stress. In fact, several studies show an increase in parenting distress in the pandemic period.<sup>31-33</sup> The main stressors for parents were having to reconcile work with family routine. Many parents worked from home, with related logistical problems and at the same time, due to the closure of schools, managing their children in the context of personal autonomy, management of meals, school activities, and free time. Further causes of stress were in many cases the loss of work and a direct experience with Covid-19. This would explain why from our data, parenting stress is high but comparable to those parents of the control sample.

The statistical analysis of the CBCL questionnaire did not show significant results. It appears from our data that a chronic disease such as JIA-U does not cause emotional and behavioral problems in children. To the best of our knowledge, there are no other studies that focused on CBCL in children with JIA-U. A coping with anxiety was reported instead in adolescents.<sup>34</sup>

The importance to screen psychological challenges in even younger children origin from the possibility that chronic disease might develop in anxiety and depression in adulthood.<sup>35-38</sup> For this reason, we believe it is important to evaluate the psychological health of these children through frequent screening.

Our study is also the only one that studied the adaptation of the parents on the child's clinical conditions (CISS Test). In this perspective, parents' adaptative skills may be crucial to manage the clinical condition, depending on this even the child's behavior. However, no significant results emerged from the CISS. Several studies show instead that the use of positive coping strategies is considered a necessary step in achieving resiliency and successful adaptation to stress.<sup>39,40</sup>

Agree with other study, our impression is that parents help their children when they focus coping efforts on altering controllable factors.<sup>28</sup> In all these cases we have observed various examples of resilience in children and their parents.

Some limitations of our study should be noted. The number of the sample is limited and the interview took place with a single parent, mainly mothers with a low number of fathers recruited. Finally, we collected data in the first and second wave of the pandemic. We believe this may have affected the stress levels of the general population and acted as a confounding factor on our data.

## 5. Conclusion

Children with JIA-U have decreased quality of life and visual functioning which worsens with severe disease. Several ocular complications, eye examinations and the rigor of long-term treatment influence health-related quality of life in these children. Our findings support the need of a screening related quality of life and further evaluation on the long-term psychological health in this patient group and the establishment of interdisciplinary collaboration including psychological counselling.

## Abbreviations

- CBCL: Child Behaviour Checklist
- CISS: Coping Inventory for Stressful Situations
- DC: Difficult Child
- DF: Defensive Responding
- EF: Emotional Functioning
- HRQoL: Health related- Quality of life
- JIA: Juvenile Idiopathic Arthritis
- JIA: Juvenile Idiopathic Arthritis associated with Uveitis (JIA-U)
- P-CDI: Dysfunctional Interaction Parent-Child
- PD: Parenting Distress
- PedsQL: Pediatric Quality of Life Inventory
- PF: Physical Functioning
- PSI: Parent Stress Index
- PSI-SF: Parent Stress Index (PSI / SF)
- QoL: Quality of life
- SARS Cov-2: Severe Acute Respiratory Syndrome- Coronavirus 2
- ScF: School Functioning
- SF: Social Functioning
- SUN: Standardization of Uveitis Nomenclature
- TS: Total Stress

## Declarations

## **Ethical Approval and Consent to participate**

This case study was performed in the Department of Basic Medical Sciences, Neurology and Sensory Organs, Eye Clinic, Bari University, Bari, Italy. It adhered to the tenets of the Declaration of Helsinki. This paper is a retrospective study and is approved by the Independent Ethical Committee – IEC, Policlinico of Bari. Written informed consent was obtained from all subjects.

## **Consent for publication**

Not applicable.

## **Availability of supporting data and materials**

The datasets during and/or analysed during the current study available from the corresponding author on reasonable request.

## **Competing interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## **Funding**

None.

## **Authors' contributions**

All authors attest that they meet the current ICMJE criteria for Authorship.

S.G., R.P., F.C., V.A., P.L., A.D.G. conceptualization.

S.G., R.P., V.A. wrote the main manuscript text.

S.G., R.P., F.C., F.L.T., V.A., G.A., P. L., A. D. G. data curation.

S.G., R.P., F.C., F.L.T., G.A., P. L., A. D. G. formal analysis.

S.G., R.P., F.C., F.L.T., V.A., G.A., P. L., A. D. G. investigation.

S.G., R.P., F.C., V.A., P. L., A. D. G. methodology.

S.G., FC, G.A., A. D. G. supervision.

S.G., R.P., F.C., V.A., A. D. G. validation.

All authors reviewed the manuscript.

## Acknowledgements

None.

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