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Measuring visual outcomes in children with uveitis using the "Effects of Youngsters' Eyesight on Quality of Life" questionnaire

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Abstract

Objective—The Effects of Youngsters' Eyesight on Quality of Life (EYE-Q) is a novel measure of vision-related quality of life (QOL) and function in children. We aim to determine the validity of EYE-Q in childhood uveitis.

Methods—We abstracted medical record data on arthritis and uveitis in a convenience sample of children with juvenile idiopathic arthritis (JIA) and/or uveitis. In addition to the EYE-Q, parents and patients completed questionnaires on overall QOL (Pediatric QOL Inventory - PedsQL), and physical functioning (Childhood Health Assessment Questionnaire - CHAQ).

Results—Among 57 children (8 JIA, 24 JIA and uveitis, 25 uveitis alone), 102 ocular examinations were performed within 1 month of completing questionnaires. Uveitis patients had bilateral disease (69%), anterior involvement (78%), synechiae (51%) and cataracts (49%). Children with vision loss in their better eye (visual acuity (VA) 20/50 or worse) had worse EYE-Q ($p = 0.006$), and PedsQL ($p = 0.028$), but not CHAQ scores. The EYE-Q moderately correlated with logMAR VA ($r_s = -0.43$), PedsQL ($r_s = 0.43$) and CHAQ ($r_s = -0.45$), but was not correlated with anterior chamber cells or intraocular pressure. The PedsQL and CHAQ did not correlate with VA or cells. There were strong correlations between the parent and child EYE-Q ($r_s = 0.62$). Cronbach's α for the child report was 0.91. The EYE-Q had strong test-retest reliability ($r_s=0.75$).

Conclusion—The EYE-Q may be an important tool in the assessment of visual outcomes in childhood uveitis and an improvement over general measures in detecting changes in vision-related function.

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Uveitis is an inflammatory ocular disease that can affect children and lead to ocular complications and vision loss. It most commonly presents without associated systemic illness (i.e. idiopathic uveitis), but it can be related with autoimmune diseases, including juvenile idiopathic arthritis (JIA), sarcoidosis and Behcet's disease. JIA is the most common systemic disease associated with uveitis, reportedly affecting 10-20% of North American children with JIA[1]. Although visual outcomes of JIA patients have improved due to better screening and improved collaboration between ophthalmology and rheumatology, many children still suffer from vision-related sequelae.

Common measures to assess the clinical status of children with JIA and uveitis include: 1) ophthalmologic examination, including visual acuity (VA) and the slit lamp examination to grade inflammation (i.e. anterior chamber cells and flare) as recommended by the Standardization of Uveitis Nomenclature (SUN) criteria; 2) joint examination quantifying arthritis (e.g. number of tender and swollen joints); 3) questionnaires assessing patient-reported outcomes, including quality of life (QOL) and physical function; 4) questionnaires assessing adult visual function[2-5]. However, none of these measures are pediatric vision-specific nor consider the child's perspective on the impact of uveitis and visual impairment on daily functioning. Measuring QOL will enable us to understand the patient's perspective on disease burden and, ultimately, to evaluate health improvement secondary to treatment.

There is a paucity of pediatric vision focused patient-reported outcome instruments, none specific to uveitis, and fewer for children <7 years old[6-12]. Increasing awareness regarding the importance of the patient's perspective in measuring outcomes led us to develop a novel instrument, the “Effects of Youngsters’ Eyesight on Quality of Life (EYE-Q).” We previously described the initial validation for children with normal vision and varied ocular disorders by: 1) Item generation, 2) Operationalism, 3) Pre-testing, and 4) Validation that conforms to the recommendations of the Classification and Response Criteria Subcommittee of the ACR Committee on Quality Measures[13-15]. Our objective is to validate the EYE-Q for childhood uveitis.

Subjects and Methods

This validation study was approved by the Emory University Institutional Review Board, which conformed to the US Health Insurance Portability and Privacy Act requirements. Informed consent/assent was appropriately obtained.

Focus Groups

After initial validation described in earlier studies, we conducted two focus groups for children with uveitis (8 to 14 years and 15 to 19 years of age; 3 patients per group) recruited from our pediatric rheumatology clinic. Ideally, 3-5 pediatric focus groups consisting of 4-6 children is optimal, but due to the need for small group detailed discussion, we chose a smaller number of subjects[16]. The goal was to create items specific for uveitis. The moderator led the discussion utilizing a standard questionnaire. The sessions were recorded and transcribed. The moderator began each session by describing our group's interest in learning more about how uveitis affects one's life and in developing a questionnaire to assess QOL and function. We asked each child to introduce him/herself and talk about something

they did for fun. The following standard rules were then presented: 1) There are no right or wrong answers, 2) One person will speak at a time, 3) There are no side conversations, 4) All participants should contribute equally. Each child relayed the most significant way that uveitis has affected his/her life. We presented each item to the group and obtained their feedback regarding its relevance to their lives and comprehensibility. To create new items, we asked about different ways that uveitis affected their daily lives in school, home, and other common childhood environments. We queried children about their ocular symptoms (i.e. pain, eye redness, photophobia, and blurry vision), medication use (drops, oral meds, and injections), frequency of doctor visits and feelings about having uveitis. Following this, we reworded existing items and added questions related to uveitis -symptoms, daily life and medically-related activities including: photophobia, sports activities participation, writing, attending doctor visits, medication use, phlebotomy, school absences, and others knowing about their eye disease.

We then conducted two separate focus groups with four pediatric ophthalmologists and three pediatric rheumatologists at Emory University to discuss the additional uveitis-specific items developed from the children's focus groups. We reviewed the relevance and comprehensibility of each question. The EYE-Q was then revised based on these findings.

Subjects

Children with JIA alone, JIA-associated uveitis (JIA-U) and other forms of uveitis (U) were invited to participate during their Emory Children's Center pediatric rheumatology clinic visit from September 2011- September 2014. Potential subjects were approached consecutively during their regular appointment. Inclusion criteria included: 1) a diagnosis of JIA (International League of Associations for Rheumatology (ILAR) classification)[17, 18], or uveitis regardless of etiology, 2) age <18 years at diagnosis, 3) English speaking. Exclusion criteria included: 1) significant co-morbidity unrelated to uveitis (i.e. sickle cell anemia) affecting QOL and function, 2) major developmental disorders (i.e. cerebral palsy, mental retardation). We only included children who had an ocular examination within one month of completing the EYE-Q.

Data Collection

1. Baseline and Follow-up Data—We conducted systematic medical record reviews and administered parent- and patient-based questionnaires at enrollment and every 3-6 months. Collected data included date of birth, gender, self-described race and ethnicity, date of visit, arthritis characteristics (onset, diagnosis date, JIA subtype, joints with tenderness, swelling and/or limitation), uveitis characteristics (onset, diagnosis date, laterality, location, ocular complications, surgeries), ocular exam (best corrected visual acuity (BCVA), intraocular pressure (IOP), anterior chamber cells), labs (antinuclear antibody (ANA), rheumatoid factor (RF), erythrocyte sedimentation rate (ESR), angiotensin converting enzyme (ACE), HLA-B27, and anti-cyclic citrullinated peptide (anti-CCP)) and medications. We obtained the most recent ophthalmology visit note to record visual acuity (VA) in the *better* eye if bilateral disease or the un*affected* eye if unilateral disease, uveitis activity (anterior chamber and vitreous inflammation) based on the SUN criteria, intraocular

pressure, and ocular complications[3]. VA was transformed to logMAR VA for statistical purposes.

2. Questionnaires—Parents and children, when age appropriate and depending on the specific instrument, completed questionnaires about overall QOL (Pediatric Quality of Life Inventory - PedsQL), physical function (Childhood Health Assessment Questionnaire - CHAQ) and vision-related function and QOL (EYE-Q).

a. Vision-Related QOL and Function Assessment: The EYE-Q consists of parent reports and patient self-reports for children ≥8 years of age. It is written in large print, consists of 26 items and takes approximately 10 minutes to complete. It uses a five-point Likert scale with no visual analogue scale to remain sensitive to children with visual difficulties. The following response format is used to assess difficulty performing tasks with response options including: 1 (Not hard/Never), 2 (A little hard/Rarely), 3 (Hard/Sometimes), 4 (Very hard/Often), and 5 (Cannot do).

Nineteen items measure near, far, color and night vision, photosensitivity, and functionality. Four QOL items inquire about feelings regarding the use of medications, missing school for doctor visits, and lab draws. One question queries about the presence of common uveitis symptoms (eye redness, blurry vision, eye pain, and photosensitivity). Additionally, there is an item that inquires about visual aids (special lamps, magnifying glass and large print material) and allows the child to specify other aids used. A subjective assessment of vision severity allows the child to rate their eyesight as: 1 (excellent), 2 (good), 3 (fair), 4 (poor), 5 (very poor), or 6 (blind).

The instrument is scored as the sum of the items (minus 2 points for each aid used, up to a maximum of 4 aids) divided by the number of items answered. Items were rescaled; scores range from 0 to 4 with higher scores indicating better QOL and/or function. We calculated a total vision score (EYE-Q Total) consisting of all items, a visual function score (EYE-Q VF) (19 items), and a vision related QOL score (EYE-Q VRQL) (4 items). Scores would not be computed if the respondents did not complete, missed, or marked “does not apply” for more than 50% of items.

To determine test re-test reliability or consistency of the measure, the EYE-Q was completed during the clinic visit and at home after 7-10 days.

b. Physical Function Assessment: The CHAQ is a valid measure that evaluates functional disability and contains parent and patient self-reports[4]. It comprises 20 questions within 8 functional components: 1) dressing and grooming, 2) arising, 3) eating, 4) walking, 5) hygiene, 6) reach, 7) grip, 8) activities. There are three parameters within each area: 1) difficulty in performing daily functions, 2) use of special aids or devices, 3) activities that require assistance from another person. Scores range from 0-3; higher scores indicate worse physical function.

c. Quality of Life Assessment: The PedsQL is a valid measure of general health-related QOL in patients 2 to 18 years of age and consists of 4 core scales: 1) physical functioning,

2) emotional functioning, 3) social functioning, 4) school functioning[2]. Scores range from 0-100; higher scores indicate better QOL.

Statistical Methods

Statistical analyses were performed using SAS v. 9.3 (Cary, NC, USA) and statistical significance was assessed at the $\alpha = 0.05$ level unless otherwise noted. Descriptive statistics were calculated for demographics and clinical characteristics using means and standard deviations, medians and interquartile ranges, or counts and percentages when appropriate. For continuous outcomes, disease groups and other clinical subgroups were compared using Kruskal-Wallis oneway analysis of variance models when three groups were compared or Mann-Whitney-U tests or Kolmogorov-Smirnov tests when two groups were compared. For categorical outcomes, Chi-square tests were used. In instances of small expected cell counts, a Fisher's exact p-value was reported.

Associations between measures of vision, overall QOL, and ophthalmologic examinations were determined using Spearman's rank order correlation coefficient. Correlations were further quantified using 95% confidence intervals based on a Fisher's Z-transformation. Correlations < 0.3 were considered weak, 0.3 to 0.7 were moderate, and > 0.7 were strong. Internal consistency reliability (Cronbach's alpha) was calculated and used to identify redundancy in items. A Cronbach's alpha greater than 0.8 indicated high internal reliability; however, a level too high (≥ 0.95) indicated possible item redundancy. Construct validity was assessed by correlating the EYE-Q with other measure of QOL and ocular disease. For test-retest reliability, we examined correlations between EYE-Q scores at a study visit and 10 days after. Additionally, a paired t-test was used to examine change in EYE-Q scores. Multivariable regression models were used to identify predictors of EYE-Q scores. Variables included demonstrated an association with EYE-Q during univariate analyses or were known to be associated with vision related function and/or QOL.

Results

Patient Characteristics

Demographics and Disease Characteristics—Among 314 children (227 with JIA, 50 with JIA-U and 37 with U) enrolled, 70 completed the EYE-Q within one month of a slit lamp examination. On further discussion with parents of non-school aged children, we determined that most items were not applicable to children <5 years of age (i.e. seeing circles to shade on a bubble answer sheet, writing on lined notebook paper). Thus, 13 children <5 years of age at the time of questionnaire administration were excluded. There were 8 children with JIA and 49 with uveitis (24 with JIA-U and 25 with U) who contributed to 102 ocular examinations (Table 1). Of these examinations, 94 were in children with uveitis and 8 in children with JIA alone.

Children were primarily female (74%) and Caucasian (58%). Of these, 57% had a diagnosis of JIA with a median (IQR) age of 3.1 years (2.1 – 7.1), and were mainly of the oligoarticular JIA subtype (84%). Almost half had been on oral (53%) and/or subcutaneous (61%) methotrexate.

Uveitis Characteristics—The 49 children with uveitis had a median (IQR) age at diagnosis of 6.7 (4.7 – 10.6). Most had bilateral (67%) and anterior involvement (78%) with complications (Table 1). Less common complications included amblyopia (n=6), retinal neovascularization (n=4) and macular scarring (n=2).

There were 94 ocular examinations in 49 children with uveitis. We included the better eye in bilateral disease and the unaffected eye in unilateral disease. Mean intraocular pressure was 15.5 ± 5.9 and mean logMAR VA was 0.18 ± 0.33. Eighty-one percent of examinations revealed a VA of 20/40 or better, 19% had a VA of 20/50 or worse. Of these, 4% had a VA of 20/200 or worse. Of 82 slit lamp examinations, 83% had <1 cell per field, 5% had 0.5+, 4% had 1+, 6% had 2+, and 2% had 3+.

Questionnaire Development

Of the 314 children enrolled in the overall study, 50 had JIA-U and 37 had U. Only 4% of EYE-Q parent reports had more than 50% of missing data that prevented scoring the questionnaire. The most common items skipped were, “How often does it bother your child to have others know about his eye disease?” (44%), and “How often does it bother your child to have to take medications for their eyes like eye drops, injections, or by mouth?” (29%). These items were skipped mostly by children without uveitis (95%). The question most frequently skipped that was not related to uveitis was, “How hard is it for your child to see the circles on a bubble answer sheet so that he can fill them in when he is taking a multiple choice test?” (17.4%). Sixty two percent were skipped by JIA patients, 7% by U and 30% by JIA-U. We think this item was omitted by because some children do not do standardized testing.

Redundancy of Items—We calculated Cronbach's alpha and noted redundancy leading to removal of 4 items. Furthermore, these items were all highly correlated with one another wherein correlation between each pair was at least 0.9. Subsequent scores were calculated after removal of the 4 items. Current Cronbach's alpha is 0.91 for the child report and 0.93 for the parent report. Correlation between parent and child EYE-Q responses was moderate, $r_s = 0.62$. When we compared the old version of the EYE-Q to our current EYE-Q which has uveitis specific items, Spearman's rank correlation was 0.87 (95% CI: [0.81 – 0.92]; $p < 0.001$) for the child report and 0.88 (95% CI: [0.82 – 0.92]; $p < 0.001$) for the parent report. Test-retest reliability on a subset of participants were consistent over the 10 day period ($r_s = 0.75$); paired t-test on the two sets of EYE-Q scores showed no significant changes ($p= 0.921$). All subsequent sections describing the EYE-Q used the uveitis specific version.

Comparing Quality of Life and Function—There were 98 examinations with VA data. We compared children with and without vision loss in their better/unaffected eye (VA 20/50 or worse) and noted that those with vision loss had significantly worse EYE-Q Total scores (2.52 vs. 3.36, p=0.006), EYE- VF scores (2.48 vs. 3.45, p=0.002), and PedsQL scores (68.5 vs. 81.5, p = 0.028) in the child report (Table 2). There were no differences in the EYE-Q VRQL or CHAQ scores based on vision loss. Similar differences were observed on the parent reported measures between the two VA groups.

Correlation with standard measures of vision, physical function and overall QOL—When comparing EYE-Q with the ophthalmology exam in the better/unaffected eye, EYE-Q Total child and parent scores had moderate correlations with LogMAR VA respectively, (r_s = −0.43 95% CI: [−0.59 - (−0.22)], p<0.001; r_s = −0.43, 95% CI [−0.58 - (−0.24)], p<0.001) (Table 3). This was similar to the EYE-Q VF scores. The EYE-Q Total child and parent scores were uncorrelated with anterior chamber cell grade or intraocular pressure. Although not shown, the PedsQL and CHAQ did not correlate with LogMAR VA, anterior chamber cells or intraocular pressure.

When examining correlations between EYE-Q child report with standard measures of overall QOL and physical function, the EYE-Q had moderate correlations with PedsQL Total (r_s = 0.43; 95% CI: [0.22 – 0.59]) and CHAQ (r_s = −0.45; 95% CI:(−0.61 – (−0.25)). There were similar moderate correlations to the PedsQL physical and psychosocial reports.

Factors predictive of visual outcome—After adjusting for multiple visits from the same patient, VA was predictive of EYE-Q scores in children (p < 0.01) with a pseudo-R^2 of 0.35 and parents (p < 0.001) R^2= 0.33.

Discussion

The modified version of the EYE-Q, with uveitis-specific items, appears to be a valid and reliable measure of vision related-function in pediatric uveitis. It has significant correlations with VA, and measures of overall QOL and physical function. Poor vision reflected by worse VA predicted worse vision. Thus, the EYE-Q may complement current methods in the assessment of the impact of inflammatory eye disease.

Uveitis and its' sequelae can adversely affect a child's daily function and ability to perform visual tasks in the home and school. Additionally, children need frequent ophthalmology and rheumatology physician visits, phlebotomy, ophthalmic drops, and systemic immunosuppressive therapy consisting of oral medications, injections and infusions. Studies in adults with uveitis incorporate vision specific instruments in addition to general measures in their assessment of outcomes[5, 19-2122]. Adults have significantly decreased visual functioning and general health compared to the normal population, often reflecting the severity of uveitis[19, 23]. Our study showed similar results since children with severe uveitis (ocular complications and vision loss) had worse vision-related function and QOL as reflected by the EYE-Q Total and VF scores. Additionally, the EYE-Q's ability to detect changes in VA was reflected in the moderate correlation with logMAR VA. Thus, vision-specific measures may provide distinct complementary information in the outcomes of childhood uveitis.

There is a lack of instruments that measure vision-related function and QOL in children overall[24]. There is no questionnaire specifically for pediatric uveitis despite the well-established need for disease-focused instruments. Existing vision questionnaires can differentiate between children with and without ocular disorders, but they may not distinguish between varied degrees of disease severity or clinically significant changes in vision over time in pediatric uveitis. As reviewed elsewhere, many focus on the impact of

function but do not consider health-related QOL that includes physical, emotional and social domains[25, 26]. Further support for the need for vision-specific instruments is that the EYE-Q correlated with VA, whereas the measures for general QOL and physical function (PedsQL and CHAQ) did not. We also describe that poor vision as determined by VA is predictive of worse vision related functioning. Hence, the EYE-Q may provide additional insight into visual disability secondary to uveitis that is not detected by general vision questionnaires.

Of interest is how arthritis and uveitis jointly contribute to QOL and function in children with both JIA and uveitis compared to those with JIA or uveitis alone. Our study did not show correlations between standard measures of vision and EYE-Q VRQL items. The vision related QOL items queried on feelings on medication use, lab draws and missing school which are relevant to all children with JIA, JIA-U and other forms of uveitis, but may not be reflective of vision loss. Those with both JIA and uveitis may have worse general QOL due to having two diseases affecting two systems. It is possible that any diagnosis of a chronic autoimmune disease, regardless of the number of illnesses, affects QOL equally since care and treatment are similar, regardless of diagnosis and disease activity. Conversely, in adults with vitreoretinal disease and associated comorbidities, QOL was determined primarily by the ocular disease; it appears that the single disease that most adversely affected QOL had the greatest impact in adults.[27] Hence, it may not be possible to detect whether there is a difference in general QOL versus vision-specific QOL.

The importance of child self-reports is well known, as there have been well described discrepancies compared to parents' proxy reports[28, 29]. The EYE-Q showed mild concordance between parent and child reports. In fact, parents reported worse visual outcomes and vision related function. This is potentially due to differences in the perception of disease effects and the general adaptability of children. Hence, a child-centered approach is crucial. Our results suggest that both parent and child perspectives on the burden of ocular disease are important and may be valid contributors in the assessment of visual outcomes.

Measurement of the outcomes of children with uveitis can be difficult due to the paucity of vision-specific instruments for those younger than 8 years of age. This is especially relevant in a uveitis population, as these children are at highest risk for developing eye disease. We discovered that several items in the EYE-Q were inapplicable to children less than 5 years of age since many tasks were school specific or required independent skills. Thus, we may need to develop a module for non-school aged children. Meanwhile, we are piloting the validated Children's Visual Function Questionnaire (CVFQ) for our younger children with uveitis[6, 12]. The CVFQ is an instrument that measures visual function through parent reports in children ≤7 years of age but is not disease specific.

There are several challenges in developing pediatric instruments, one of which is the creation of developmentally appropriate items. For example, the PedsQL has parent and child modules for ages 5-7, 8-12 and 13-18, with an additional parent proxy-report for 2-4 year old children[2]. We initially developed modules for children <15 years of age, and teenagers 16-18 years of age. However, based on our analysis, there was no need for age specific modules since the items geared towards 16-18 year olds did not add validity to the instrument (i.e. driving). Likewise, not all states allow solo driving until 18 years of age.

Hence, the current EYE-Q version appears valid for patients 5 years of age and above and takes a minimum time to complete and administer.

A major limitation of this study is the need for further validation in a larger cohort of children with uveitis with varied disease activity in other centers. However, our instrument has been validated previously in smaller uveitis populations and in children with other ocular diseases. We continue to administer the questionnaire in our uveitis population and plan to validate in a multi-center approach. We also need to assess whether the EYE-Q has dynamic associations with the components of the clinical ocular exam related to changes in disease activity and response to treatment. Similar to our earlier studies, we plan to administer the EYEQ to children with uveitis during their ophthalmology examination.

The EYE-Q VRQL items may not be specific to vision loss as they apply to children with chronic autoimmune diseases in general. However, the questions may still be important to better understand how ocular disease affects QOL. Likewise, the completion of the EYE-Q up to 4 weeks after the ocular exam may not accurately reflect QOL at the time of examination. The EYE-Q Total score contains both vision specific QOL and function items and appeared valid. We may consider removing vision related QOL items in the future if these prove to be irrelevant.

We had a limited number of children with JIA without uveitis who completed questionnaires within one month of their ophthalmology examination. These children may have had more active arthritis; hence were being seen more frequently and able to complete study related questionnaires close to the time of their ocular examination.

The EYE-Q appears to be a valid and reliable uveitis specific measure of vision in children 5-18 years of age. It may serve as an important addition to the global assessment of childhood uveitis, as well as complement generic measures and the ophthalmologic examination by incorporating all aspects of disability. This could enable the use of this measure as a treatment end point in clinic settings and clinical trials. As noted by Pasadhika, et al., “Visual acuity itself may not always reflect the quality of vision, as many patients may experience various degrees of decreased visual field, decreased contrast sensitivity, alteration of depth and color perception, increased light sensitivity, glares, and floaters.“ [30]. We need to better assess and understand the long standing effects of uveitis which can greatly impact a child's life.

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The instrument used in this study, the Effects of Youngsters' Eyesight on Quality of Life (EYE Q), can be licensed through Emory University but no royalties have been received by the authors.

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Significance and Innovation

- Uveitis can have a significant impact on a child's vision-related quality of life and function.
- The EYE-Q is the first validated instrument to measure vision-related quality of life and function in childhood uveitis.
- It is a promising vision-specific instrument that complements the ophthalmic exam, arthritis specific measures, and general quality of life measures in assessing visual outcomes in children with uveitis.

Table 1

Characteristics of children with juvenile idiopathic arthritis and uveitis at study enrollment

Characteristics ***Median (25th – 75th), unless otherwise specified***	**Overall N = 57**	**JIA N = 8**	**JIA-U N = 24**	**U N = 25**
Age at Enrollment, (yrs)	11.4 (8.2 – 14.5)	11.4 (7.9 – 15.4)	9.1 (7.0 – 14.8)	12.4 (9.2 – 13.7)
Gender, female, *N (%)*	42 (73.7%)	6 (75.0%)	22 (91.7%)	14 (56.0%)
Hispanic, *N (%)*	8 (14.0%)	1 (12.5%)	6 (25.0%)	1 (4.0%)
Race, *N (%)*				
Caucasian	33 (57.9%)	6 (75.0%)	16 (66.7%)	11 (44.0%)
African American	19 (33.3%)	1 (12.5%)	5 (20.8%)	13 (52.0%)
Disease Characteristics				
Age at JIA diagnosis, (yrs)	3.1 (2.1 – 7.1)	5.9 (3.1 – 10.8)	2.7 (2.0 – 4.2)	--
Duration of JIA, (yrs)	4.8 (2.2 – 8.7)	2.5 (1.6 – 8.6)	5.3 (3.1 – 9.2)	--
JIA Subtype, *N (%)*				--
Oligoarticular persistent	23 (71.9%)	3 (37.5%)	20 (83.3%)	--
Oligoarticular extended	4 (12.5%)	3 (37.5%)	1 (4.2%)	--
Polyarticular rheumatoid factor (-)	3 (9.4%)	1 (12.5%)	2 (8.3%)	--
Enthesitis related arthritis	2 (6.3%)	1 (12.5%)	1 (4.2%)	--
Labs, N (%)[1]				
ANA positive	17 (41.5%)	2 (33.3%)	10 (58.8%)	5 (27.8%)
HLA-B27 positive	8 (24.2%)	0 (0%)	2 (18.2%)	6 (33.3%)
Medication History, ***N (%)***				
Methotrexate oral	30 (53.6%)	3 (37.5%)	15 (65.2%)	12 (48.0%)
Methotrexate subcutaneous injections	34 (60.7%)	5 (62.5%)	15 (65.2%)	14 (56.0%)
Infliximab	15 (26.8%)	2 (25.0%)	9 (39.1%)	4 (16.0%)
Etanercept	2 (3.6%)	1 (12.5%)	1 (4.4%)	0 (0%)
Adalimumab	8 (14.3%)	2 (25.0%)	3 (13.0%)	3 (12.0%)
Abatacept	2 (3.6%)	0 (0%)	1 (4.4%)	0 (0%)
Uveitis Disease Characteristics	**Uveitis N = 49**			--
Age at uveitis diagnosis, (yrs)	6.7 (4.7 – 10.6)	--	4.8 (3.5 – 7.4)	9.3 (6.4 – 10.6)
Duration of Uveitis, (yrs)	2.7 (1.3 – 4.5)	--	3.5 (1.4 – 6.6)	2.5 (1.2 – 3.3)
Duration between Uveitis and Arthritis Dx, (yrs)	1.3 (0 – 3.3)	--	1.3 (0 – 3.3)	--
Location, N (%)[1]				
Anterior	38 (77.6%)	--	22 (91.7%)	16 (64.0%)
Intermediate	5 (10.2%)		1 (4.2%)	4 (16.0%)
Panuveitis	3 (6.1%)		0 (0%)	3 (12.0%)
Unknown	3 (6.1%)	--	1 (4.2%)	2 (8.0%)
Bilateral Involvement, N (%)[1]	33 (67.4%)	--	16 (66.7%)	17 (68.0%)
Type of Ocular Complications, ***N (%)***	**Uveitis Only**			
Cataracts	24 (49.0%)	--	10 (41.7%)	14 (56.0%)
Glaucoma/ Ocular Hypertension	18 (36.7%)	--	8 (33.3%)	10 (40.0%)
Synechiae	25 (51.0%)	--	10 (41.7%)	15 (60.0%)
Band keratopathy	16 (32.7%)	--	8 (33.3%)	8 (32.0%)

Characteristics ***Median (25th – 75th), unless otherwise specified***	**Overall N = 57**	**JIA N = 8**	**JIA-U N = 24**	**U N = 25**
Cystoid macular edema	16 (32.7%)	--	5 (20.8%)	11 (44.0%)
Other Complications	12 (24.4%)	--	2 (8.3%)	10 (40.0%)
Ocular Surgeries, ***N (%)***	**Uveitis Only**			
Cataract Extraction	5 (10.2%)	--	2 (8.3%)	1 (12.0%)
Steroid ocular injection	15 (30.6%)	--	7 (29.2%)	8 (32.0%)

Table 2

Comparison of function and quality of life in children with and without vision loss in the better seeing or unaffected eye**

Measurement, *Median (25th – 75th)*	VA 20/40 or better (N = 75)	VA 20/50 or worse (N = 23)	P-value
Child Report			
EYE-Q[a] Total	3.36 (2.96 – 3.68)	2.52 (1.48 – 3.00)	0.006*
EYE-Q[a] VF[b]	3.45 (3.00 – 3.62)	2.48 (1.25 – 3.32)	0.002*
EYE-Q[a] VRQL[c]	2.60 (1.80 – 3.60)	2.00 (1.20 – 3.00)	0.115
PedsQL[d] Total	81.5 (60.2 – 94.6)	68.5 (50.0 – 78.3)	0.028*
CHAQ[e]	0 (0 – 0.25)	0.25 (0.06 – 0.50)	0.335
Parent Report			
EYE-Q[a] Total	3.40 (3.14 – 3.64)	2.88 (1.29 – 3.24)	< 0.001*
EYE-Q[a] VF[b]	3.50 (3.24 – 3.69)	2.86 (1.62 – 3.52)	< 0.001*
EYE-Q[a] VRQL[c]	2.40 (1.80 – 3.00)	2.00 (1.60 – 3.00)	0.063
PedsQL[d] Total	83.7 (63.0 – 93.5)	77.2 (53.3 – 87.0)	0.160
CHAQ[e]	0 (0 – 0.25)	0.13 (0- 0.5)	0.339

*p = <0.05

**N = 98 visual acuity examinations

[a]Effects of Children's Eyesight on Quality of Life

[b]Visual Function

[c]Vision Related Quality of Life

[d]Pediatric Quality of Life Inventory

[e]Childhood Health Assessment Questionnaire

Table 3

Correlation of the EYE-Q with standard measures of quality life and function

Instrument	R_s [95% CI]**	P value
EYE-Q[a] Child Reports		
Ocular exam		
LogMAR VA[b]	−0.43 (−0.59 – (−0.22))	< 0.001
Cells	−0.10 (−0.33 – 0.13)	0.393
IOP	0.05 (−0.20 – 0.31)	0.672
Overall QOL		
PedsQL[c] Total	0.43 (0.22 – 0.59)	< 0.001*
PedsQL[c] Physical	0.33 (0.11 – 0.52)	0.004*
PedsQL[c] Psychosocial	0.42 (0.21 – 0.59)	< 0.001*
Physical function		
CHAQ[d] Child	−0.45 (−0.61 – (−0.25))	< 0.001*
EYE-Q[a] Parent Reports		
Ocular exam		
Logmar VA[b]	−0.43 (−0.58 – (−0.24))	< 0.001*
Cells	−0.15 (−0.35 – 0.06)	0.167
IOP	0.22 (−0.01 – 0.43)	0.064
Overall QOL		
PedsQL[c] Total	0.37 (0.17 – 0.53)	< 0.001*
PedsQL[c] Physical	0.11 (−0.10 – 0.31)	0.281
PedsQL[c] Psychosocial	0.42 (0.25 – 0.58)	< 0.001*
Physical function		
CHAQ[d]	−0.28 (−0.45 – (−0.08))	0.006*

Spearman's correlation coefficients

* p-value <0.05

** Mild correlations: R <0.3; Moderate correlations: R = 0.3 - 0.7; Strong correlation: R = >0.7l

[a] Effects of Youngsters Eyesight on QOL

[b] Logmar visual acuity

[c] Pediatric Quality of Life Inventory

[d] Childhood Health Assessment Questionnaire