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Quality of life and functional vision across pediatric eye conditions assessed using the PedEyeQ

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Abstract

Purpose—To evaluate eye-related quality of life (ER-QOL) and functional vision across a wide range of pediatric eye conditions, using the Pediatric Eye Questionnaires (PedEyeQ).

Methods—A total of 1,037 children with an eye condition and 254 visually normal controls, across 0–4, 5–11, and 12–17 years age groups, completed the following questionnaires: Child PedEyeQ (Functional Vision, Bothered by Eyes/Vision, Social, Frustration/Worry domains), Proxy PedEyeQ (same domains plus Eye Care), and Parent PedEyeQ (Impact on Parent and Family, Worry about Child's Eye Condition, Worry about Child's Self-perception and Interactions, and Worry about Functional Vision domains). The primary eye condition was classified as amblyopia (n = 171), cataract (n = 99), cerebral visual impairment (CVI; n = 50), cornea (n = 20), eyelid (n = 35), glaucoma (n = 24), nystagmus (n = 57), orbital (n = 19), pupil/iris (n = 7), refractive error (n = 119), retina (n = 82), strabismus (n = 332), and uveitis (n = 22).

Results—PedEyeQ domain scores (scaled 0–100) were significantly worse across eye conditions, compared with controls. Child PedEyeQ greatest differences were on the Bothered by Eyes/Vision domain (nystagmus 5–11 years, −26 points [95% CI, −39 to −12]; nystagmus 12–17 years, −45 [95% CI, −61 to −28]). Proxy PedEyeQ differences were greatest on Functional Vision (CVI 0–4 years, −45 [95% CI, −56 to −34]; CVI 5–11 years, −58 [95% CI, −72 to −43]; nystagmus 12–17 years, −50 [95% CI, −69 to −31]). Parent PedEyeQ differences were greatest on Worry about Child's Functional Vision (CVI 0–4 years, −64; 95% CI −77 to −50).

Conclusions—The PedEyeQ detects reduced ER-QOL and functional vision across pediatric eye conditions, and across age groups, indicating its utility for clinical practice and clinical trials.

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We previously reported the development of the Pediatric Eye Questionnaire (PedEyeQ) to assess functional vision (by subjective report) and eye-related quality of life (ER-QOL; subjective report of the effects of eye conditions on quality of life) in children across a wide spectrum of eye conditions.[1] In previous reports, the PedEyeQ detected reduced functional vision and ER-QOL in patients with bilateral visual impairment,[2] strabismus,[3] residual amblyopia,[4] and refractive error.[5] Although these previous studies provided valuable information regarding the effect of those specific conditions, the impact of other common eye disorders has not yet been evaluated. Therefore, the current study was designed to assess functional vision and ER-QOL in children with a diverse range of external, anterior segment, posterior segment, and neurologic eye conditions, using the PedEyeQ. We hypothesized that PedEyeQ scores would be lower in these clinical populations compared with visually normal controls.

Subjects and Methods

Institutional Review Board approval was obtained from Mayo Clinic, Rochester, Minnesota, and University of Texas Southwestern Medical Center, Dallas; written informed consent and assent were obtained. All procedures and data collection were conducted in a manner compliant with the US Health Insurance Portability and Accountability Act of 1996. All research procedures adhered to the tenets of the Declaration of Helsinki. Subjects were prospectively enrolled at Mayo Clinic, Rochester, Minnesota, and Retina Foundation of the Southwest, Dallas, Texas, between November 2017 and June 2020.

A total of 1,037 children aged 0–17 years of age were prospectively enrolled: 346 aged 0–4 years, 440 aged 5–11 years, and 251 aged 12–17 years (Table 1). Of these, 152 have been reported previously.[2–5] Based on review of the medical record, children were assigned to one of the following diagnostic categories, reflecting their primary eye condition: amblyopia, cataract/lens, cerebral visual impairment (CVI)/visual field, cornea, eyelid, glaucoma, nystagmus, orbital, pupil/iris, refractive error (wearing either glasses or contact lens correction, at least part time, prescribed at the discretion of the care-provider), retina/optic nerve, strabismus, and uveitis (Table 2). Of the 1,037 children, 167 (16%) were undergoing active treatment at the time of completing the questionnaires.

The control group comprised 254 children with normal-for-age uncorrected visual acuity,[6,7] and without glasses or other refractive correction, no other current or previous eye condition or treatment, and no current diagnosis of learning disability, anxiety, or depression: 89 aged 0–4 years, 105, 5–11 years and 60, 12–17 years (Table 1). Of these, 171 have been reported in previous studies.[2–5]

All included children and parents were required to be conversant in either English or Spanish. Fifteen (1%) of Proxy and Parent questionnaires were completed in Spanish.

The Pediatric Eye Questionnaire (PedEyeQ)

All children aged ≥5 years (if able) completed the Child 5–11 or 12–17 years PedEyeQ (one functional vision domain, and three ER-QOL domains: Bothered by Eyes/Vision, Social, Frustration/Worry[1]). Fifty-three of 691 children ≥5 years of age with an eye condition were

unable to complete Child questionnaires due to developmental delay; all 165 controls aged ≥5 years completed Child questionnaires. One parent or legal guardian per child completed the 0–4, 5–11, or 12–17 years Proxy PedEyeQ (Functional vision, Bothered by Eyes/Vision, Social, Frustration/Worry, and Eye Care domains[1]; 5 incomplete questionnaires for eye conditions and 2 incomplete for controls). Parents also completed the Parent PedEyeQ (Impact on Parent and Family, Worry about Child's Eye Condition, Worry about Child's Self-perception and Interactions, and Worry about Child's Functional Vision domains[1]; 5 incomplete questionnaires for eye conditions). Each questionnaire uses a 3-point frequency scale for responses: "never," "sometimes," "all of the time" (questionnaires in English and Spanish, scoring algorithms, and look-up tables are freely available at: https://public.jaeb.org/pedig/view/Other_Forms).

Analysis

For each subject, Rasch-calibrated domain scores were calculated using look-up tables and converted to 0 (worst) to 100 for interpretation. For each age group, domain score distributions were compared between diagnostic categories and visually normal controls using Wilcoxon rank-sum tests (data were not normally distributed). Multiplicity was addressed by using a linear step-up method to adjust *P* values and control for a false discovery rate of 5%[8] across domains and conditions, with comparisons for Child, Proxy, and Parent questionnaires analyzed independently for each age group. To aid interpretation, mean differences with a 95% confidence interval around the mean difference were also calculated. Reported *P* values relate to nonparametric comparison of distributions of scores, which in some cases were significantly different despite the medians of the two distributions being the same or similar. The 95% confidence intervals on the mean differences provide interpretation of the precision of estimates. In rare cases there are discrepancies between parametric and nonparametric comparisons. Data were not analyzed in diagnostic categories with fewer than 5 subjects. SAS software version 9.4 (SAS Institute. Cary, NC) was used for all statistical analyses.

Results

Patient demographics are shown in Table 1; and subjects in each diagnostic category are shown in Table 2.

PedEyeQ in 0-to 4-year-olds

Proxy PedEyeQ domain scores were lower for children with eye conditions than for visually normal controls across all diagnostic categories ($P \leq 0.002$ for each; eSupplement 1, available at jaapos.org) except the Social domain for corneal and orbital conditions. The greatest mean difference for those with an eye condition versus controls was for CVI on Functional Vision (−45; 95% CI, −56 to −34; $P < 0.001$). Parent PedEyeQ domain scores were lower across all diagnostic categories ($P < 0.001$ for each; eSupplement 2, available at jaapos.org) with the greatest mean difference for CVI on Worry about Child's Functional Vision (−64, 95% CI, −77 to −50; $P < 0.001$).

PedEyeQ in 5- to 11-year-olds

Child PedEyeQ scores for each domain and diagnostic category are shown in eSupplement 3 (available at jaapos.org). Scores were significantly lower across domains compared with visually normal controls ($P \leq 0.04$ for each), excepting uveitis on Functional Vision (mean difference, −10; 95% CI, −19 to −1; $P = 0.06$), and cornea on Social (−7; 95% CI, −17 to 2; $P = 0.052$). The greatest mean difference was for nystagmus on Bothered by Eyes/Vision (−26; 95% CI, −39 to −12; $P < 0.001$). Proxy PedEyeQ scores were significantly lower for each diagnostic category on each domain compared with visually normal controls ($P \leq 0.008$ for each; eSupplement 4, available at jaapos.org). The greatest mean difference was for CVI on Functional Vision (−58; 95% CI, −72 to −43; $P < 0.001$). Parent PedEyeQ scores were also lower across domains and diagnostic categories ($P < 0.001$ for each; eSupplement 5, available at jaapos.org). The greatest mean differences were on Worry about Child's Eye Condition for glaucoma (−59; 95% CI, −77 to −42; $P < 0.001$) and uveitis (−5; 95% CI, −70 to −47; $P < 0.001$).

PedEyeQ in 12- to 17-year-olds

Child 12–17 PedEyeQ scores were significantly lower across diagnostic categories and domains compared with visually normal controls ($P \leq 0.047$ for each, eSupplement 6, available at jaapos.org). The greatest mean difference was for nystagmus on Bothered by Eyes/Vision (−45; 95% CI, −61 to −28; $P < 0.001$). Proxy 12–17 PedEyeQ scores were also significantly lower for each diagnostic category on each domain ($P \leq 0.01$ for each; eSupplement 7, available at jaapos.org). The greatest mean difference was for nystagmus on Functional Vision (−50; 95% CI, −69 to −31; $P < 0.001$). Parent PedEyeQ scores were lower for each diagnostic category on each domain ($P \leq 0.004$ for each; eSupplement 8, available at jaapos.org). The greatest mean difference was for nystagmus on Worry about Child's Functional Vision (−56; 95% CI, −76 to −36; $P < 0.001$).

Discussion

In this large, prospective study, we found significantly lower PedEyeQ scores across age groups in children with a broad range of eye conditions compared with visually normal control subjects, by both child and proxy report. We also found significantly lower scores for parents of children with eye conditions compared with parents of visually normal controls, using the Parent PedEyeQ.

Few instruments have been developed to evaluate eye- or vision-related concerns without limiting the scope to specific eye conditions. Available vision-specific instruments only allow child self-report for school-age children,[9–13] or proxy report,[14] and evaluate either quality of life or functional vision but not both (as distinct domains). In addition, while evaluation of the impact of a child's eye condition on the parent/family has been previously assessed using generic[15,16] or condition-specific instruments,[17] we are unaware of any developed specifically to assess parental quality of life as related to pediatric eye conditions. The PedEyeQ incorporates both child and proxy components, both ER-QOL and functional vision domains, and has age-appropriate versions as well as a parent component. Data from the present study confirm the utility of the Child, Proxy, and Parent PedEyeQ across age

groups and sensitivity to functional vision and ER-QOL concerns across a wide spectrum of mild to severe eye conditions.

Although the present study was not designed to provide a detailed understanding of the differential effects of specific conditions on functional vision and ER-QOL, our data highlight the presence of such overall deficits and could be helpful for generating hypotheses for future studies. For example, the severity of parental Worry about Eye Condition in 5- to 11-year-olds with glaucoma and uveitis might lead to a hypothesis that educational interventions can help to address these concerns.

There are some limitations to our study. Although we included a wide range of different pediatric eye conditions, further work remains to be done exploring associations with clinical factors in specific eye conditions, overall associations with visual acuity, and evaluating change over time and in response to treatment. We did not separately analyze children who were receiving versus not receiving treatment, but with only 167 (16%) of 1,037 in active treatment, the data we report most likely represent the effect of the underlying condition. In addition, findings may differ by race/ethnicity and by other demographic factors, and such associations deserve further study in large, diverse populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Hatt SR, Leske DA, Castañeda YS, et al. Development of pediatric eye questionnaires for children with eye disease. Am J Ophthalmol 2019;200:201–17. [PubMed: 30653960]
2. Leske DA, Hatt SR, Castañeda YS, et al. Validation of the Pediatric Eye Questionnaire (PedEyeQ) in children with visual impairment. Am J Ophthalmol 2019;208:124–32. [PubMed: 31377286]
3. Hatt SR, Leske DA, Castañeda YS, et al. Association of strabismus with functional vision and eye-related quality of life in children. JAMA Ophthalmol 2020;138:528–35. [PubMed: 32215586]
4. Hatt SR, Leske DA, Castañeda YS, Wernimont SM, Liebermann L, Cheng-Patel CS, et al. Understanding the impact of residual amblyopia on functional vision and eye-related quality of life using the PedEyeQ. Am J Ophthalmol 2020;218:173–81. [PubMed: 32511967]
5. Leske DA, Hatt SR, Castañeda YS, et al. Eye-related quality of life and functional vision in children wearing glasses. J AAPOS 2020;24:91.e1–6. [PubMed: 32113988]
6. Drover JR, Felius J, Cheng CS, Morale SE, Wyatt L, Birch EE. Normative pediatric visual acuity using single surrounded HOTV optotypes on the Electronic Visual Acuity Tester following the Amblyopia Treatment Study protocol. J AAPOS 2008;12:145–9. [PubMed: 18155943]
7. Pan Y, Tarczy-Hornoch K, Cotter SA, et al. Visual acuity norms in pre-school children: the Multi-Ethnic Pediatric Eye Disease Study. Optom Vis Sci 2009;86:607–12. [PubMed: 19430325]
8. Benjamini Y, Hochberg Y. Controlling the false discovery rate: a practical and powerful approach to multiple testing. J R Stat Soc B 1995;57:289–300.

9. Cochrane GM, Marella M, Keeffe JE, Lamoureux EL. The impact of vision impairment for children (IVI_C): validation of a vision-specific pediatric quality-of-life questionnaire using Rasch analysis. Invest Ophthalmol Vis Sci 2011;52:1632–40. [PubMed: 21178144]
10. Tadic V, Robertson AO, Cortina-Borja M, Rahi JS. An age- and stage-appropriate patient-reported outcome measure of vision-related quality of life of children and young people with visual impairment. Ophthalmology 2020;127:249–60. [PubMed: 31623869]
11. Gothwal VK, Sumalini R, Bharani S, Reddy SP, Bagga DK. The second version of the L. V. Prasad-functional vision questionnaire. Optom Vis Sci 2012;89:1601–10. [PubMed: 23069725]
12. Khadka J, Ryan B, Margrain TH, Court H, Woodhouse JM. Development of the 25-item Cardiff Visual Ability Questionnaire for Children (CVAQC). Br J Ophthalmol 2010;94:730–35. [PubMed: 20508047]
13. Tadic V, Cooper A, Cumberland P, Lewando-Hundt G, Rahi JS. Development of the functional vision questionnaire for children and young people with visual impairment: the FVQ_CYP. Ophthalmology 2013;120:2725–32. [PubMed: 24120327]
14. Birch EE, Cheng CS, Felius J. Validity and reliability of the Childrens Visual Function Questionnaire (CVFQ). J AAPOS 2007;11:473–9. [PubMed: 17512228]
15. Celano M, Hartmann EE, Drews-Botsch CD. Parenting stress in the infant aphakia treatment study. J Pediatr Psychol 2013;38:484–93. [PubMed: 23475835]
16. Tailor VK, Abou-Rayyah Y, Brookes J, Khaw PT, Papadopoulos M, Adams GGW, et al. Quality of life and functional vision in children treated for cataract-a cross-sectional study. Eye (Lond) 2017;31:856–64. [PubMed: 28128793]
17. Hatt SR, Leske DA, Yamada T, Bradley EA, Cole SR, Holmes JM. Development and initial validation of quality of life questionnaires for intermittent exotropia. Ophthalmology 2010;117:163–8. [PubMed: 19896195]

Table 1.

Demographics of children and their parents

Subject characteristic	Age 0–4 years		Age 5–11 years		Age 12–17 years	
	Eye conditions (n = 346), no. (%)	Controls (n = 89), no. (%)	Eye conditions (n = 440), no. (%)	Controls (n = 105), no. (%)	Eye conditions (n = 251), no. (%)	Controls (n = 60), no. (%)
Sex of child						
Female	163 (47)	49 (55)	218 (50)	52 (50)	126 (50)	26 (43)
Race/ethnicity						
Non-Hispanic white	223 (64)	57 (64)	314 (71)	72 (69)	186 (74)	42 (70)
Hispanic	46 (13)	9 (10)	39 (9)	5 (5)	12 (5)	3 (5)
Other	25 (7)	8 (9)	30 (7)	9 (9)	18 (7)	2 (3)
Black/African American	23 (7)	2 (2)	13 (3)	4 (4)	13 (5)	4 (7)
Asian	15 (4)	10 (11)	30 (7)	9 (9)	17 (7)	7 (12)
More than 1	14 (4)	3 (3)	14 (3)	6 (6)	5 (2)	2 (3)
Parent / legal guardian completing questionnaires						
Mother	281 (81)	77 (87)	353 (80)	92 (88)	192 (77)	52 (87)
Father	63 (18)	12 (13)	82 (19)	13 (12)	53 (21)	8 (13)
Legal guardian	2 (1)	0 (0)	5 (1)	0 (0)	6 (2)	0 (0)
Age						
Median (interquartile range)	2 (1–3)	2 (1–3)	8 (6–9)	7 (6–9)	14 (13–16)	13 (12–15)

Table 2.

Diagnostic categories and specific subcategories

Primary diagnostic category & specific subtypes[a,b]	Age 0–4 years, no. (%)	Age 5–11 years, no. (%)	Age 12–17 years, no. (%)
Amblyopia, allowing strabismus <10 PD	37 (100)	103 (100)	31 (100)
Anisometropic	22 (59)	49 (48)	13 (42)
Strabismic	7 (19)	13 (13)	1 (3)
Combined mechanism	8 (22)	38 (37)	16 (52)
Bilateral	0 (0)	3 (3)	1 (3)
Cataract/lens, allowing secondary glaucoma, strabismus, amblyopia, and nystagmus	42 (100)	44 (100)	13 (100)
Cataract	17 (40)	7 (16)	5 (38)
Pseudophakic/aphakic	22 (52)	36 (82)	7 (54)
Subluxated (Marfan)	3 (7)	1 (2)	1 (8)
Cornea/conjunctiva,[c] allowing coexistent strabismus, amblyopia, sensory nystagmus, and mild ptosis	6 (100)	7 (100)	7 (100)
Cerebral visual impairment/visual field loss, allowing coexistent nystagmus, strabismus, optic atrophy, retinopathy of prematurity, and ptosis	21 (100)	17 (100)	12 (100)
Eyelid, allowing coexistent amblyopia (strabismus, orbital conditions excluded)	16 (100)	12 (100)	7 (100)
Ptosis	12 (75)	8 (67)	2 (29)
Lid-other[d]	4 (25)	4 (33)	5 (71)
Glaucoma, allowing secondary cataract, strabismus, amblyopia, and mild ptosis	6 (100)	10 (100)	8 (100)
Nystagmus, allowing coexistent strabismus, amblyopia, mild optic nerve hypoplasia, mild cataract and regressed retinopathy of prematurity	23 (100)	21 (100)	13 (100)
Orbital,[e] allowing secondary strabismus, amblyopia, and sequelae of microphthalmia.	7 (100)	6 (100)	6 (100)
Pupil / iris,[f] allowing secondary amblyopia.	7 (100)	0	0
Refractive error, no other diagnoses allowed (no amblyopia or strabismus)	16 (100)	55 (100)	48 (100)
Retina/optic nerve, allowing coexistent strabismus, amblyopia, nystagmus, cataract, and glaucoma	28 (100)	26 (100)	28 (100)
Acquired	9 (32)	6 (23)	10 (36)
Congenital	12 (43)	11 (42)	2 (7)
Inherited retinal dystrophy	7 (25)	9 (35)	16 (57)
Strabismus	137 (100)	133 (100)	62 (100)
Allowing coexistent amblyopia if angle >10 PD			
Esotropia	87 (64)	65 (49)	26 (42)
Exotropia	39 (28)	46 (35)	23 (37)
Hypertropia	11 (8)	22 (17)	13 (21)
Uveitis, allowing coexistent strabismus, amblyopia, uveitic cataract, and uveitic alaucoma	0	6 (100)	16 (100)

PD, prism diopter.

[a] Assigned based on review of the medical record to reflect primary (original) eye condition.

[b] Coexistent refractive error allowed for all diagnostic categories.

[c] Specific diagnoses for cornea were: corneal opacity/scar (5), corneal ulcer (1), epithelial defect (1), keratoconus (1), megalocornea (1), Peter's anomaly (5), posterior polymorphous dystrophy (1), Schnyder's corneal dystrophy (1), sclerocornea (2), pigmented caruncular lesion (1), and severe conjuntivitis (1).

[d] Specific other lid diagnoses were: chronic chalazia (4), cleft lid (1), dermoid cyst (1), epiblepharon (1), herpes simplex virus (1), lagophthalmos (2), lid nodule (1), and staphyloma (2).

[e] Specific orbital diagnoses were: cherubism (1), craniosynostosis (2), hemangioma (6), microphthalmos (3), orbital floor fracture (1), orbital mass (3), and ocular prothesis (3).

[f] Specific pupil / iris diagnoses were: ectopic pupil (2), iris coloboma (1), iris flocculi (1), and pupillary membrane (3).