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Quality of Life and Functional Vision in Children with Glaucoma

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Purpose: To evaluate the effect of glaucoma on functional vision and on vision-related (VR) and health-related (HR) quality of life (QoL) in children up to 16 years of age.

Design: Cross-sectional observational study.

Participants: One hundred nineteen children 2 to 16 years of age (mean age, 9.4 years; standard deviation [SD], 4.56 years) with glaucoma and their parents.

Methods: Completion of 3 validated instruments for children to assess (1) functional visual ability (FVA) with the Cardiff Visual Ability Questionnaire for Children (CVAQC), (2) VR QoL with the Impact of Vision Impairment for Children (IVI-C), and (3) HR QoL with the Pediatric Quality of Life Inventory (PedsQL) version 4.0.

Main Outcome Measures: Cardiff Visual Ability Questionnaire for Children, IVI-C, and PedsQL scores.

Results: Scores for FVA, VR QoL, and HR QoL were reduced in children with glaucoma: median CVAQC score, −1.24 (interquartile range [IQR], −2.2 to −0.11; range, −3.00 higher visual ability to +2.80 lower visual ability); mean IVI-C score, 67.3 (SD, 14.4; normal VR QoL, 96); median PedsQL self-report, 78.8 (IQR, 67.4−90.2); parent report, 71.2 (IQR, 55.7−85.8); and family impact score, 74.3 (IQR, 56.9−88.5; normal HR QoL, 100). Psychosocial subscores were lower than physical subscores on the PedsQL. Older children reported less impairment on CVAQC, IVI-C, and PedsQL than younger children. Parents reported greater impact on their child's HR QoL than children reported themselves.

Conclusions: Glaucoma and its management have a marked impact on a child's FVA and QoL. Children with glaucoma report HR QoL scores similar to those described by children with severe congenital cardiac defects, who have undergone liver transplants, or who have acute lymphoblastic leukemia. *Ophthalmology 2017;■:1−8 © 2017 by the American Academy of Ophthalmology*

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Childhood glaucoma is a rare but significant and potentially sight-threatening condition associated with elevated intraocular pressure (IOP).[1,2] Common causes of childhood glaucoma are primary developmental defects of the aqueous drainage pathways, leading to primary congenital glaucoma and more extensive ocular maldevelopment or systemic disease, or both, such as Axenfeld-Rieger anomaly, aniridia, and phakomatoses, along with acquired glaucoma after lensectomy for congenital cataract. Childhood glaucoma poses significant management challenges, and visual outcomes may be disappointing.[3−5] Primary treatment for primary congenital glaucoma is surgical, but secondary glaucomas also often require surgical intervention to control IOP should topical medications fail to do so.[6] Surgical success often is compromised by aggressive postoperative inflammation and scarring, potentially leading to multiple surgical interventions.[6] Children often require topical medication to control IOP before and after surgery, which may cause discomfort and be a burden to families. Correction of ametropia and amblyopia in young children requires additional monitoring and treatment. Furthermore, examinations under anesthesia (EUAs) may be necessary in infants and young children for accurate assessment.

The diagnosis of glaucoma in a child can be very stressful for the child and for the parents or caregivers (henceforth referred to as "parents"), siblings, and extended family members for many reasons. Glaucoma is a chronic, sight-threatening condition with an uncertain prognosis that requires lifelong treatment and follow-up. Associated visual impairment may have a significant impact on the child's development, education, social integration, and independence. Treatment may involve multiple operations, often when the patient is a neonate or infant. A decision to proceed to incisional or laser surgery may be made during an EUA, so children and parents face the anxiety of not knowing whether the child will wake up in discomfort or pain. The challenges associated with assessing and controlling glaucoma in children also result in numerous hospital appointments, requiring parents to take time off work and the child to be absent from school as the child grows older, affecting education. Secondary glaucoma may be associated with systemic disease requiring treatment,

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which may compound these absences further. Additionally, buphthalmos, a physical manifestation of glaucoma in infancy, may exacerbate a child's difference from his peers, especially if unilateral, as may a port wine stain. Finally, the potential financial burden on the family should not be underestimated. In some countries, medical expenses may have to be paid for by the family. Loss of earnings resulting from hospital visits affects families everywhere.

Published data on the impact of glaucoma on children and their families is scarce partly because of a paucity of suitable instruments to measure a child's functional visual ability (FVA; i.e., an individual's use of his given vision in activities of daily living) and quality of life (QoL; i.e., an individual's subjective impression of various aspects of life, such as physical, emotional, and social factors as well as schooling) as it relates to their vision (vision-related [VR] QoL) and health (health-related [HR] QoL). Three previous studies have used validated tools to explore QoL in children with glaucoma and their parents. Children with glaucoma report lower VR QoL scores than healthy children,[7] and better visual acuity is associated with higher VR QoL.[8] Glaucoma surgery in children is associated with an improvement in the QoL of their parents.[9] No study has assessed HR QoL or FVA in children with glaucoma. Our main objective, therefore, was to explore FVA, VR QoL, and HR QoL in children with glaucoma and their parents.

Methods

This work presents an analysis of children with glaucoma who took part in a larger cross-sectional, observational study of QoL in children with developmental eye defects, approved by the National Research Ethics Committee South Central—Oxford A (14/SC/1052). It adhered to the tenets of the Declaration of Helsinki.

Between June 25, 2014, and June 3, 2015, we enrolled children 2 to 16 years of age with primary or secondary glaucoma who attended clinics at Moorfields Eye Hospital, London, United Kingdom. Exclusion criteria were inability to communicate in English and surgical intervention (incisional or laser) within 1 month of the date of completing questionnaires (before or after). We screened the notes of all children attending our pediatric glaucoma clinics in advance to identify those who met the inclusion criteria. These children then were approached consecutively for inclusion in the study. For those who did not wish to take part, we noted the reasons given. Age-appropriate written informational material was provided; we addressed any questions before obtaining written consent and assent.

We recorded age at study participation, gender, and racial or ethnic background. From the medical notes, we recorded ocular and systemic diagnoses, age at diagnosis of the eye condition (primary glaucoma or eye defect causing secondary glaucoma), and best-corrected visual acuity (BCVA) with both eyes open in logarithm of the minimum angle of resolution (logMAR) units on the day of study participation. Where visual acuity was recorded as counting fingers, we noted a BCVA of 2.1 logMAR, for hand movements only we noted 2.4 logMAR, for light perception we noted 2.7 logMAR, and for no light perception or for ocular prosthesis or artificial eye we noted 3 logMAR.[10] Details of previous and current treatments were recorded. The number of previous glaucoma-related surgical interventions performed in the operating room only was noted; these were considered more significant than clinic procedures because of factors such as the potential traumatic experience of hospital admission, anesthesia, and postoperative pain. The sum of interventions to the right and left eyes included incisional surgery (angle surgery, trabeculectomy, and glaucoma drainage device surgery); laser treatment; bleb needling; and removal of sutures or subconjunctival injections or both, performed under EUA. The number of general anesthetics for both surgical procedures and EUAs, and the number of current topical medications (sum of eyedrop applications per day in the right and left eyes) also were noted.

Main Outcome Measures

To evaluate functional vision, children 5 years of age and older completed the Cardiff Visual Ability Questionnaire for Children (CVAQC).[11] The CVAQC was developed to assess the difficulty in performing activities in children's daily lives in the developed world after extensive work with focus groups of children with and without impaired sight to determine the relevant questions. The tool was validated in children with visual impairment. It is a self-report tool consisting of 25 questions, with answers selected on a 4-point scale (very easy to very difficult), that cover the areas of education, near and distance vision, getting around, social interaction, entertainment, and sports.[11] For example, children were asked, "Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to walk in a crowded place?" or "Because of your eyesight and with your glasses and low vision aids if you use them, how difficult do you find it to watch television?" Using a Rasch conversion calculator provided by the developers of the CVAQC tool, we transformed the raw CVAQC scores into logarithmic scores. The resulting scores ranged from −3.00 (higher visual ability) to +2.80 (lower visual ability).

To assess VR QoL, a subgroup of children 8 years of age and older enrolled after August 1, 2014, when required agreements and permissions were granted, completed the Impact of Vision Impairment for Children (IVI-C) tool.[12] The IVI-C tool was validated in visually impaired and normally sighted children. It entails 24 questions with 5 possible answers plus an additional option of "no, for other reasons." We scored the IVI-C responses using the relevant scoring sheet that allocates values between 0 and 4 to the responses from "never" to "always" for questions covering areas of school (aspects of school life and classroom activity), mobility (travel and access to the environment), interaction (with non-vision-impaired peer group and people in the broader community), and emotion (the emotional impact of visual impairment on day-to-day life). For example, children were instructed to give an answer that best described what they did and felt most of the time in response to questions such as, "Do you find it difficult to go down stairs or to step off the footpath?" or "Are you confident in places you don't know?" or "Can you find your friends in the playground at lunch and play time?" We did not allocate a score when the response "no, for other reasons" was selected. Because the tool comprises 24 items, the resulting raw scores range from 0 to 96, with the highest score indicating normal VR QoL. No Rasch conversion table is available for this tool yet, and we did not carry out a Rasch transformation of our data because the sample size was small.

For HR QoL, age-specific versions of the Pediatric Quality of Life Inventory (PedsQL) enable children 5 to 18 years of age to express their views on different aspects of their physical and emotional states and their social and school life.[13,14] Parents completed 2 questionnaires, one about the child (parental report) and another about the impact on the family (family report). The parental report is specific to the age of the child and usually consists of 23 questions covering children 2 to 4 (21 questions), 5 to 7, 8 to 12, and 13 to 18 years of age. The family report contains 36