Functional Visual Ability and Quality of Life in Children With Glaucoma

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• PURPOSE: To evaluate the effect of glaucoma and its management on the functional visual ability (FVA) and the vision-related quality of life (VR QoL) in children 8-18 years of age.

• DESIGN: Cross-sectional study.

• METHODS: FVA was assessed using the Cardiff Visual Ability Questionnaire for Children (CVAQC) and VR QoL was assessed using the Impact of Vision Impairment for Children (IVI_C) tool.

• RESULTS: Eighty-five children 8-18 years of age were interviewed at King Khaled Eye Specialist Hospital (KKESH), Riyadh, Saudi Arabia. Scores for FVA and VR QoL were decreased in children with glaucoma: median of CVAQC scores, -0.68 (interquartile range [IQR], -1.27 to 0.19; range, -3.00 higher visual ability to +2.80 lower visual ability); IVI_C mean score, 55.3 (standard deviation, 13.0; normal VR QoL, 96). Factors associated with significantly lower FVA and VR QoL included, lower best-corrected visual acuity (BCVA) ($P < .0001$ for both FVA and VR QoL), bilateral glaucoma ($P = .04$ for in FVA and $P = .009$ in VR QoL), and 3 or more glaucoma surgeries ($P < .001$ for both FVA and VR QoL).

• CONCLUSION: FVA and VR QoL as perceived by children with glaucoma are reduced. Children with lower BCVA, those with bilateral glaucoma, and those who had undergone 3 or more glaucoma surgeries had significantly lower FVA and VR QoL. Improving the QoL with psychosocial involvement and visual rehabilitation by the use of low-vision aids among children with glaucoma should be included in the treatment plan in addition to medical and surgical treatment. (Am J Ophthalmol 2019;200:95–99. © 2019 Elsevier Inc. All rights reserved.)

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CHILDHOOD GLAUCOMA IS A MAJOR CAUSE OF childhood blindness in developing countries including the Kingdom of Saudi Arabia (KSA).[1,2] Although treatment is mainly surgical,[3-5] adjuvant medical management is frequently required for maintaining the intraocular pressure at an acceptable level for prolonged periods. Adherence to medication is often a challenge for children and their families.[6] Furthermore, these patients require treatment and monitoring of amblyopia, requiring additional visits to the hospital. Many of these examinations in early life include examination under anesthesia (EUA) or sedation, which adds an additional burden to the child and the family. Furthermore, the complexity of the disease that is often associated with visual impairment may have a significant impact on the child's psychological behavior, education, social integration, and independence. Childhood glaucoma in 1 child or multiple children in a family might also affect the parents and the siblings.

Financially, treatments and follow-up visits may result in additional expenses to the family. Many patients in the KSA live in villages and smaller cities and have to regularly travel long distances to maintain the follow-up schedule. In the KSA, pediatric glaucoma presents with a unique set of challenges because in some families multiple members are affected. Additionally, the social structure and transportation issues may also affect the quality of life differently than in Western societies.

Previous studies have used validated tools to assess quality of life (QoL) in children with glaucoma. These studies have reported a lower vision-related quality of life (VR QoL) score in children with glaucoma compared to healthy children[7] and better visual acuity was associated with higher vision-related quality of life.[8] Glaucoma and its management have a marked impact on a child's functional visual ability (FVA) and QoL.[9] Saudi Arabia has among the highest rates of childhood glaucoma globally.[10] To the best of our knowledge, there is limited information on the QoL issues among children with glaucoma in Saudi Arabia. The main objective of the current study was to evaluate the effect of glaucoma and its management on the FVA and the VR QoL in Saudi children with glaucoma.

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METHODS

THIS CROSS-SECTIONAL STUDY EVALUATED CHILDREN aged 8 18 years (children older than 18 years of age were not included) diagnosed and managed for glaucoma at KKESH, Riyadh, Saudi Arabia. The children/parents were requested to participate in the survey. Parental written informed consent was obtained in all cases. The institutional ethics committee approved this study and the study was in adherence to the tenets of the Declaration of Helsinki.

The sample size was calculated using Epiinfo.[11] To achieve 95% confidence interval (CI) with 10% error margin and a design effect of 1.5, we needed to enroll 85 children with glaucoma.

The study sample was composed of 85 children with primary or secondary glaucoma who presented to the hospital from April 2017 to December 2017. Exclusion criteria were the inability to communicate in Arabic or other sensory, physical, or intellectual comorbidities that prevented the child from responding to the questionnaire. In addition, the questionnaire was not administered to children who were scheduled to undergo or had undergone surgical intervention (incisional and laser) within 1 month of the questionnaire's being administered. Children with traumatic glaucoma were also excluded.

Consecutive children with glaucoma within the recruitment age range were identified and screened from the glaucoma and pediatric clinics of the hospital. Data were collected on the age of the child at the time of the study, time since diagnosis, sex, laterality of glaucoma, age of the parent, education level and occupation of the parent, and the residential location of the child. Data were also collected on the ocular and systemic diagnoses, age at diagnosis (primary glaucoma or secondary glaucoma), and best-corrected visual acuity (BCVA) with both eyes open. The use of low-vision aids, whether optical, nonoptical, or both, was also noted. Details of previous and current treatments were recorded. The sum of interventions in the right and left eyes were noted, including incisional surgery (angle surgery, trabeculectomy, and glaucoma drainage device surgery), laser treatment, and bleb needling, performed under anesthesia. Data were collected on the number of times the child had received general anesthesia for surgical procedures and EUA, the number of current topical medications (sum of eye drop applications per day in the right and left eyes), and the number of ophthalmologists who had evaluated the child.

Two sets of questionnaires were filled out by the interviewer after listening to the child's responses in the presence of the child's guardian. The interviewers were trained in a way such that the questionnaires were clearly explained and comprehensible to the child and administered uniformly among the participants (Appendices A and B; Supplemental Material available at AJO.com).

The first questionnaire (in Arabic) was prepared and tested to evaluate FVA. The survey instrument was the Cardiff Visual Ability Questionnaire for Children (CVAQC).[12] This is a self-reporting tool consisting of 25 questions and was validated in visually impaired children; questions cover education, near and distance vision, getting around, social interaction, entertainment, and sports. The responses were selected on a 4-point scale (very easy to very difficult).[12]

The experienced certified translators at KKESH forward-translated the English questionnaires to Arabic. They were then reverse-translated by 2 Arabic-speaking health professionals in the glaucoma department. These individuals checked and confirmed that the intent and content of the questions were not altered during translation. The questionnaire was then piloted on 5 patients not included in the main study. The responses were reviewed by the investigators to ensure that the questionnaire was understood by the participants.

The raw CVAQC scores were transformed into logarithmic scores using a Rasch conversion calculator provided by the developers of the CVAQC tool. Rasch analysis was used by the developers to identify the optimum number of response categories that participants could discriminate reliably between and was used to fit statistics to identify any items that did not contribute to the underlying unidimensional scale and therefore should be removed.[12] The resulting scores ranged from -3.00 (higher visual ability) to +2.80 (lower visual ability).

A second questionnaire was used to evaluate VR QoL and was adopted on the basis of the Impact of Vision Impairment for Children (IVI_C) tool, which was also translated into Arabic.[13] The IVI_C tool is a self-reporting tool of 24 questions covering aspects of school life, travel and access to the environment, interaction with people in the broader community, and the emotional impact of visual impairment on day-to-day life. It was validated in normally sighted children and children with visual impairment.[13] The responses were graded on a 5-point Likert scale: "always," 4; "almost always," 3; "sometimes," 2; "almost never," 1; and "never," 0. Six of the items were reverse scored (0, 1, 2, 3, and 4) to prevent response bias. The resulting scores for this tool ranged from 0 to 96 (24 questions with a maximum of 4 points for each question), with the highest score indicating normal VR QoL. Rasch transformation of the data for this tool was not performed to make it easier for comparison with other reports,[8,9] since they did not use Rasch analysis for this tool. Some questions were slightly modified to make them more understandable and suitable to the Saudi culture. For example, in item 3 in the CVAQC ("how difficult do you find geography lessons?") "geography lessons" was changed to "geography or social sciences lessons"; CVAQC item 12, "How difficult do you find watching film at a cinema?" was changed to "How

TABLE. Demographics, Ocular Characteristics, and Ophthalmic History of Children With Glaucoma

Mean (SD) age at participation (years)	14 (3.2)	
Median (IQR) of time since diagnosis (years)	11 (8.5, 15.5)	
	Number	%
Age at diagnosis		
At birth	55	64.7%
<1 year	8	9.4%
>1 year	22	25.8%
Sex		
Male	34	40
Female	51	60
Parent education level		
Illiterate	10	11.8
School graduate	28	32.9
University graduate	43	50.6
Higher education	4	4.7
Laterality of glaucoma		
Unilateral	11	12.9
Bilateral	74	87.1
Type of glaucoma		
1) Primary childhood glaucoma	69	81.2
• Primary congenital glaucoma	63	74.1
• Juvenile open-angle glaucoma	6	7.1
2) Secondary childhood glaucoma:	16	18.8
a) Glaucoma associated with nonacquired ocular anomalies	6	7.1
• Axenfeld-Rieger anomaly	1	1.2
• Peters anomaly	2	2.3
• Aniridia	3	3.5
b) Glaucoma associated with nonacquired systemic anomalies	2	2.3
• Sturge-Weber syndrome	2	2.3
c) Glaucoma associated with acquired condition	3	3.5
• Uveitic glaucoma	1	1.2
• Retinopathy of prematurity	2	2.3
d) Glaucoma following cataract surgery	5	5.9
Glaucoma surgeries		
None	8	9.4
1	15	17.6
2	11	12.9
3 or more	59	60.1
Number of drops instilled in both eyes per day		
0	5	5.9
1-5	38	44.7
6-10	33	38.8
More than 10	9	10.6
Vision in the better eye		
20/20 to 20/50	39	45.7
20/60 to 20/200	21	24.8
<20/200 to 20/400	11	12.9
<20/400	14	16.5

difficult do you find watching a video on a large screen?" (Appendices A and B).

If 33% or more of the items were left blank, the patient's questionnaire was excluded from analysis. For data analysis, the responses in Arabic were translated into English and stored in a database. A clinical research coordinator entered the data for each patient into an Access spreadsheet (Microsoft Corp, Redmond, Washington, USA). This data sheet was checked for consistency and then transferred to the Statistical Package for Social Sciences (SPSS version 23; (IBM, Armonk, New York, USA). The IVI_C and CVAQC scores are continuous variables and were checked for a normal or nonnormal distribution. If the data were not normally distributed, the median and interquartile ranges (IQR) were calculated. The score was correlated to different independent variables including age, sex, duration of glaucoma, laterality of glaucoma, number of previous surgeries, and number of current glaucoma medications. The subgroups were also analyzed to compare the influence of glaucoma on these subgroups. A P value less than .05 was considered statistically significant.

RESULTS

THE STUDY SAMPLE COMPRISED 85 SUBJECTS. THE MEAN AGE was 14 ± 3.2 years. There were 51 (60%) female and 34 (40%) male subjects ($P = .63$). The Table presents the patient demographics, ophthalmic features, and history.

All the subjects (n = 85) completed the CVAQC for FVA and the IVI_C for VR QoL.

• **FUNCTIONAL VISUAL ABILITY:** Eighty-five children, 8-18 years of age, completed the CVAQC for FVA. The median of Rasch-transformed scores for the dataset was -0.68 (IQR, -1.27 to 0.19; range, -3.00 [higher visual ability] to +2.80 [lower visual ability]). The CVAQC correlated with BCVA ($P < .0001$), with lower BCVA associated with lower FVA score. Also, bilateral glaucoma ($P = .04$), patients who had 3 or more glaucoma surgeries ($P < .001$), and children with increased number of glaucoma daily eye drops bilaterally ($P < .001$) had lower Rasch scores. However, Rasch score for FVA did not correlate with age at participation in the survey ($P = .1$), time since diagnosis ($P = .3$), sex ($P = .32$), type of glaucoma ($P = .54$), parental education level ($P = .59$), or number of children with glaucoma in the family ($P = .29$).

The median score of FVA for children with primary congenital glaucoma (n = 62) was -11.7 (IQR, -31.2 to 7.2). The median score of FVA for children with other types of glaucoma (n = 22) was -23.4 (IQR, -33.4 to 6.4);

the difference in Rasch score for FVA among these 2 glaucoma groups was not significant ($P = .18$).

• **VISION-RELATED QUALITY OF LIFE:** All 85 children completed IVI_C questionnaires for VR QoL and the mean score was 55.3 ± 13.0 (normal VR QoL, 96[9,13]). The IVI_C score was divided as follows: 75-96 was an "excellent" score, 50-74 was a "good" score, 25-49 was a "poor" score, and <25 was a "very poor" score. Three (3.5%) children had an excellent VR QoL, 55 (64.0%) children had a good score and 27 (31.4%) had a poor score. There were statistically significant associations with lower IVI_C scores and lower BCVA ($P < .0001$), bilateral disease ($P = .009$), 3 or more glaucoma surgeries ($P < .001$), and children with illiterate parents ($P = .025$). Age at participation ($P = .08$), time since diagnosis ($P = .1$), sex ($P = .69$), type of glaucoma ($P = .4$), and number of glaucoma eye drops instilled in both eyes daily ($P = .7$) were not significantly associated with lower VR QoL.

DISCUSSION

CHILDHOOD GLAUCOMA IS A MAJOR CAUSE OF CHILDHOOD blindness in developing countries including the KSA.[1,2,10] The high prevalence warrants greater attention and special consideration for childhood glaucoma in the KSA, including socially, emotionally, and psychologically. Some of these aspects can be evaluated with tools such as the CVAQC and IVI_C.[12,13] To the best of our knowledge, this is the first study in the Middle East and in the KSA to evaluate the effect of childhood glaucoma on FVA and VR QoL as perceived by children. This study demonstrated that most children with glaucoma presented with bilateral disease (87.1%), higher than previously reported,[10] which reflected the severity of the disease in the KSA and, similar to other studies globally, was associated with significantly lower FVA and lower VR QoL.[8,9]

In our study, for the CVAQC, the median Rasch-transformed score was -0.68 (IQR, -1.27 to 0.19) for functional visual ability compared to -1.24 (IQR, -2.2 to -0.11) in the study by Dahlmann-Noor and associates.[9]

The significantly reduced FVA scores in our study was reflected negatively on VR QoL in almost one third of our participants (31.4%) who had "poor" VR QoL.

The functional vision and QoL in children with glaucoma in the KSA were in general worse than in children with glaucoma in the United States[8] and the United Kingdom.[9] The poor VR QoL in our subjects was likely influenced by several factors, some of which might have been different from those reported in childhood glaucoma seen in the West.

In this study, lower BCVA was significantly associated with lower FVA and VR QoL scores, and unfortunately, 54.3% of the participants had a BCVA of 20/60 or worse. BCVA was the most significant association with both FVA and VR QoL, suggesting that efforts to improve vision in these children may play a major role in improving the functional vision and QoL of children with glaucoma in the KSA. It is also possible that more comprehensive management for children with glaucoma in industrialized countries, with more resources for psychosocial involvement and visual rehabilitation, contributed to better VR QOL scores.

Other factors that negatively affected the FVA and VR QoL in children with glaucoma and placed an additional burden on the families included the number of eye drops instilled per day in both eyes, which specifically affected the FVA, and the number of glaucoma surgeries, which affected both the FVA and VR QoL. These findings are not surprising, since they likely indirectly reflect disease severity but are factors that would help clinicians become aware of how these factors influence FVA and VR QoL and use this information to guide patients and families in treatment plans for this complex disease.

A comparison of visual scores in our study with others needs explanation, as comparison with some studies can be difficult. In the study by Freedman and associates,[8] VR QoL in children was reported in children with glaucoma aged 5-17 and the mean score for IVI_C in their study was 24, with 0 being assigned as the highest score. Also of note is that this study included children younger than the age for which the tool was validated (the tool was validated for children 8-18 years of age). In Dalhmann-Noor and associates' study from the UK,[9] discussed below, a score of 96 was used as the highest score (similar to what we used in our study) and the study had children in the same age range as in this report. The mean score for IVI_C (for VR QoL) in our study was lower (score 55.3, SD, 13.0[9,13]) than the scores from normal subjects in Dahlmann-Noor and associates' study (normal score 96) and children with glaucoma (score 67.3, SD, 14.4).[9] Freedman and associates[8] studied VR QoL in children with glaucoma aged 5-17 years and the mean IVI_C score in their study was 24. Since the numerical scoring system in the Freedman paper was different from that used in our study, it was difficult to directly compare our results to those in the Freedman study other than stating that in general the QoL measures were better in their study when compared to the children in our study.

Gothwal and associates[14] assessed parent-child agreement regarding the child's health-related quality of life (HR QoL) in children operated for congenital glaucoma using the Kidscreen-27 questionnaire and found that the level of agreement varied according to the HR QoL level, and there was a statistically significant difference between mean HR QoL scores of children with congenital glaucoma and their parents. Furthermore, the range of child-parent

agreement was wide and bidirectional; parents tended to underestimate and overestimate their child's HR QoL. However, HR QoL was beyond the scope of our study and we cannot compare our results to those obtained by Gothwal and associates.

Haddad and associates[15] found that the use of low-vision aids had an important place in the management of childhood glaucoma, suggesting that such aids would assist in the child's global development, improve their daily life activities, and promote social and educational inclusion. Also, others[16] have reported a highly significant improvement of vision with the use of visual aids in a pediatric low-vision population. In the current study, we added a few questions on the use of vision aids and recommendations on how to use them. Sixty-seven percent of the participants responded that they were "never" or "rarely" advised to use visual aids and 72 of 85 (84.7%) had "never" used a low-vision aid. These results indicate that low-vision aids were not used efficiently in the KSA and open an opportunity to encourage ophthalmologists in the country to include vision aids in the treatment plan for childhood glaucoma.

Although the CVAQC and IVI_C were completed by children in the age range for which they were developed and validated, the lack of a control group for comparison is the main limitation in this study.

In conclusion, the results of the current study showed reduced functional visual ability and vision-related quality of life as perceived by children with glaucoma. Also, it indicates that in addition to the medical and surgical treatment of children with glaucoma, measures to improve their QoL should be included in the treatment plan, including psychosocial involvement and visual rehabilitation with low-vision aids.

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REFERENCES

1. Kotb AA, Hammouda EF, Tabbara KF. Childhood blindness at a school for the blind in Riyadh, Saudi Arabia. *Ophthalmic Epidemiol* 2006;13(1):1–5.
2. Haddad MA, Sei M, Sampaio MW, Kara-José N. Causes of visual impairment in children: a study of 3,210 cases. *J Pediatr Ophthalmol Strabismus* 2007;44(4):232–240.
3. Kondo N, Sawada A, Kawase K, Yamamoto T, Kitazawa Y. Outcome of goniotomy for congenital glaucoma. *J Eye* 2003;20(7):981–984.
4. Fulcher T, Chan J, Lanigan B, Bowell R, O'keefe M. Long-term follow up of primary trabeculectomy for infantile glaucoma. *Br J Ophthalmol* 1996;80(6):499–502.
5. Al-Obeidan SA, Osman EE, Dewedar AS, Kestelyn P, Mousa A. Efficacy and safety of deep sclerectomy in childhood glaucoma in Saudi Arabia. *Acta Ophthalmol* 2014;92(1):65–70.
6. Freedman RB, Jones SK, Lin A, Robin AL, Muir KW. Influence of parental health literacy and dosing responsibility on pediatric glaucoma medication adherence. *Arch Ophthalmol* 2012;130(3):306–311.
7. Zhang XL, Du SL, Ge J, et al. Quality of life in patients with primary congenital glaucoma following antiglaucoma surgical management. *Zhonghua Yan Ke Za Zhi* 2009;45(6):514–521.
8. Freedman BL, Jones SK, Lin A, Stinnett SS, Muir KW. Vision-related quality of life in children with glaucoma. *J AAPOS* 2014;18(1):95–98.
9. Dahlmann-Noor A, Tailor V, Bunce C, et al. Quality of life and functional vision in children with glaucoma. *Ophthalmology* 2017;124(7):1048–1055.
10. Alanazi FF, Song JC, Mousa A, et al. Primary and secondary congenital glaucoma: baseline features from a registry at King Khaled Eye Specialist Hospital, Riyadh, Saudi Arabia. *Am J Ophthalmol* 2013;155(5):882–889.
11. Dean AG, Sullivan KM, Soe MM. OpenEpi: Open Source Epidemiologic Statistics for Public Health, Version 3.01. Available at: www.OpenEpi.com. Accessed May 14, 2017.
12. Khadka J, Ryan B, Margrain TH, Woodhouse JM. Development of the 25-item Cardiff Visual Ability Questionnaire for Children (CVAQC). *Br J Ophthalmol* 2010;94(6):730–735.
13. 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(3):1632–1640.
14. Gothwal VK, Bharani S, Mandal AK. Parent-child agreement on health-related quality of life in congenital glaucoma. *Transl Vis Sci Technol* 2018;7(4):15.
15. Haddad MA, Sampaio MW, Oltrogge EW, Kara-José N, Betinjane AJ. Visual impairment secondary to congenital glaucoma in children: visual responses, optical correction and use of low vision AIDS. *Clinics (Sao Paulo)* 2009;64(8):725–730.
16. de Carvalho KM, Minguini N, Moreira Filho DC, Kara-José N. Characteristics of a pediatric low-vision population. *J Pediatr Ophthalmol Strabismus* 1998;35(3):162–165.