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Original article

Quality of life and visual function in children with glaucoma in Spain☆

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ABSTRACT

Objective: To evaluate the effect of glaucoma on visual function, as well as quality of life in children and quality of life perceived by caregivers in children up to 16 years of age.

Material and methods: An observational and prospective study was designed using the questionnaire GQL-15 (Glaucoma Quality of Life) and conducted on children and caregivers. The questionnaire VFQ-25 (Visual Functioning Questionnaire) was conducted on children. Different variables of the clinical history that could influence the quality of life and visual function were recorded.

Results: The study included 24 patients with a mean age of 9.13 ± 3.08 years, and included 3 with unilateral involvement, and 20 diagnosed with primary congenital glaucoma. Parents reported a worse quality of life than children. The result of the GQL-15 survey was 32.3 ± 11.56 points in children and 37.52 ± 14.59 points in caregivers ($p = 0.001$). The parameter most related to quality of life and visual function was the mean deviation (MD) of the visual field in the best eye. A statistically significant correlation was found between the result of GQL-15 and the mean deviation of the visual field (children: $R = 0.63$, $p < 0.01$, caregivers: $R = 0.81$, $p < 0.001$).

Conclusions: Functional loss has an impact on the quality of life and visual function in children with glaucoma, although the quality of life perceived by the caregivers is worse than that perceived by the child.

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Estudio de la calidad de vida y la función visual en niños con glaucoma en España

Palabras clave:
Glaucoma de la infancia
Calidad de vida
Función visual

RESUMEN

Objetivo: Evaluar el efecto del glaucoma en la función visual, la calidad de vida en los niños y la calidad de vida percibida por los cuidadores en niños de hasta 16 años.

Material y métodos: Se diseñó un estudio observacional y prospectivo. Se aplicó el cuestionario GQL-15 (Glaucoma Quality of Life) a los niños y a los cuidadores, y el cuestionario VFQ-25 (Visual Functioning Questionnarie) a los niños. Se registraron diferentes variables de la historia clínica que podrían influir en la calidad de vida y la función visual.

Resultados: Se incluyó a un total de 24 pacientes con una edad media de 9,13 ± 3,08 años, de los cuales 3 tenían afectación unilateral y 20 presentaban glaucoma congénito primario. Los padres reportaron una peor calidad de vida que los niños: el resultado de la encuesta GQL-15 fue de 32,30 ± 11,56 puntos en los niños y de 37,52 ± 14,59 puntos en los cuidadores ($p = 0{,}001$). El parámetro que más se relacionó con la calidad de vida y la función visual fue el defecto medio del campo visual en el mejor ojo. Se encontró una correlación estadísticamente significativa entre el resultado de GQL-15 y el defecto medio del campo visual (niños: $R = 0{,}63$; $p < 0{,}01$ y cuidadores: $R = 0{,}81$; $p < 0{,}001$).

Conclusiones: El daño funcional visual producido por el glaucoma tiene un impacto importante en la calidad de vida y en la función visual de los niños con glaucoma, si bien la calidad de vida percibida por los cuidadores es peor que la percibida por el niño.

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Introduction

Childhood glaucoma is an infrequent disease associated to increased intraocular pressure that could potentially lead to blindness.[1,2] The most frequent causes of childhood glaucoma include primary defects in the development of aqueous humor drainage associated to systemic diseases, and glaucoma secondary to congenital cataract surgery. Childhood glaucoma treatment is surgical but frequently patients require topical treatments to maintain intraocular pressure within normal limits.[1]

Diagnosing glaucoma in a child produces a stressful situation for the family as well as for the patient. Frequently, it involves multiple hospital visits, examinations under anesthesia, surgery and topical treatments which, glaucoma being a chronic disease, must be maintained throughout the entire life of the patient. In addition, childhood glaucoma entails a significant impact in the development of children due to the special support they need at school and to the difficulties they experience in social integration and independence.[1,3]

According to the World Health Organization, quality of life is defined as the perception an individual has of his place in existence, in the context of the environmental culture and value system in relation to his expectations, rules and interests. This is a broad concept regulated in various ways by the physical and psychological health of the individual, level of independence, social relationships as well as the relationship with the essential elements in his environment.[4]

At present, knowledge about the quality of life of children with glaucoma and their family is short. It is important to know the implications on the quality of life as it relates to the visual function in childhood glaucoma, because we must not forget that our interventions will impact the social dynamics of the family. Accordingly, studying said circumstances is a key factor to improve the approach toward glaucoma in children.

The main objective of the present study is to evaluate quality of life and subjective visual function of children with glaucoma as well as the quality of life perceived by caregivers. A secondary objective is to research the correlation between quality of life results with different secondary variables such as visual acuity (VA) or the number of eyedrops utilized every day.

Material and methods

An observational and prospective study was designed, selecting 24 patients consecutively diagnosed with glaucoma among patients in follow-up in the glaucoma unit of the San Carlos Clinic Hospital (Madrid, Spain). The study was approved by the Ethics Committee of said hospital in compliance with the guidelines of the Helsinki declaration.

The study included patients diagnosed with childhood uni/bilateral primary or secondary glaucoma, with ages comprised between 4 and 16 years. Informed consents were obtained from the parents or legal custodians as well as verbal consent of the patients to participate in the study. The adults that escorted the child filled in the *Glaucoma quality of life* test (GQL-15) independently, replying the questions therein on the basis of their perception of the child's quality of life. When both parents visited the practice, the replies were agreed between both. Patients with delayed mental development, poor cooperation or no understanding of the questions included in the questionnaires were excluded from the study.

Table 1 – Linear correlation analysis between different variables of patient clinic records and GQL-15 results in children and caregivers.

	Mean (standard deviation)	GQL-15 child		GQL-15 caregiver	
		R	p	R	p
Current age (years)	9.13 (3.08)	0.03	0.9	0.19	0.4
VA best eye	0.64 (0.34)	−0.42	0.05	−0.73	<0.001
VA worse eye	0.28 (0.32)	−0.31	0.15	−0.53	0.01
Age at diagnostic (months)	12.14 (18.58)	0.18	0.42	0.11	0.63
# of visits in pasta 2 years	7.65 (3.17)	0.37	0.08	0.04	0.84
# of surgeries	4.77 (2.52)	0.26	0.25	0.39	0.08
Months since last Qx	51.70 (39.24)	−0.42	0.07	−0.14	0.56
# of eyedrops	2.57 (2.46)	0.23	0.3	0.39	0.06
Best MD	7.67 (7.26)	0.63	<0.001	0.81	<0.001

Secondly, by means of a personal interview conducted by one of the study researchers, the children were read the questions included in the GQL-15 and *Visual functioning* (VFQ-25) questionnaires, helping them in their understanding but without inducing responses. In case a question was not understood, it was removed from the final count. The parents were present during the interview but they were not allowed to explain the questions or suggest responses to the children.

The following variables of clinic records that could influence the quality of life and visual function of patients were obtained: age at diagnostic, best eye VA, worse eye VA, number of visits in the past 2 years, number of surgeries, and time since last surgery, number of eyedrops instilled daily and mean defect (MD) in the visual field of the best eye.

Visual functioning questionnaire 25

This visual function questionnaire assesses the impact of the visual diseases on a patient's subjective quality of life perception. It comprises 25 easily understandable questions that evaluate 11 vision-dependent areas and one general health area: general health, ocular pain, near vision activities, far vision activities, social function, mental health, general vision, difficulties at work, dependency, driving, color vision and peripheral vision. Considering the age of the study patients and following questionnaire indications, questions about driving were excluded.

The questionnaire numerical values were obtained for calculating the score (higher scores for higher functionality). Subsequently, each item was converted to a scale from 0 to 100, after which the items of each subscale were averaged to develop the 11 subscale scores. When calculating the overall score of the test, the subscale scores were averaged, excluding the score on general health.

Glaucoma quality of life questionnaire 15

This quality of life questionnaire is specifically designed for studying patients with glaucoma. It comprises 15 questions in which the patient is requested to evaluate his/her skills to carry out daily tasks. The questions subjectively evaluate visual function at 4 levels: central vision, peripheral vision, adaptation to light and darkness and outdoor mobility. The patient is asked to respond on the basis of a scoring scale from 1 to 5, where 1 represents no difficulty, 2 means slight difficulty, 3 indicates some difficulty, 4 means a lot of difficulty and 5 severe difficulty. If some of the activities are not carried out for nonvisual reasons, the respondents are asked to enter 0. The final score of the test was calculated as the sum of the scores of the 15 items.

This questionnaire was applied independently to parents as well as patients.

Statistical analysis

The results of a descriptive analysis are presented as mean and standard deviation. The differences between the results of the GQL-15 questionnaire of patients and their parents were analyzed with the Wilcoxon test. The correlation between the results of the questionnaires and different variables of clinic records which could affect quality of life were studied by means of linear correlation analysis. A value of $p < 0.05$ was taken as statistically significant. All the statistical analyses were carried out using the SPSS version 15 15 application (SPSS Inc., Chicago, IL, USA).

Results

The study included 24 patients, although one who did not fill in the questionnaire, leaving a total figure of 23 patients (17 males and 6 females) with a mean age of 9.13 ± 3.08 years at the time of filling in the questionnaire.

Twenty of the 23 patients were diagnosed with primary congenital glaucoma, 2 with unilateral compromise. One patient was diagnosed with iridoendothelial syndrome, another one exhibited the Axenfeld Rieger syndrome and a further one was diagnosed with unilateral anterior segment dysgenesis.

The results of the GQL-15 questionnaire for children obtained a mean score of 32.30 ± 11.56, while the result of the GQL-15 for parents had a mean score of 37.52 ± 14.59. This difference was statistically significant with $p = 0.01$ (*W* for Wilcoxon).

The linear correlation between different variables and the results of the GQL-15 questionnaire applied to caregivers and children was analyzed. The results are shown in Table 1. Figs. 1 and 2 graphically illustrate the correlation between the

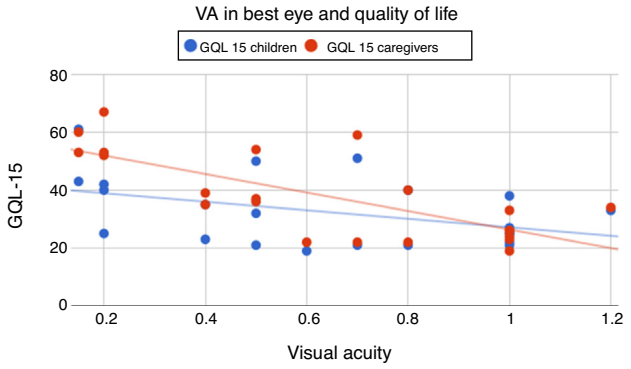

Fig. 1 – Linear correlation between visual acuity of the best eye and the GQL-15 test results in children and caregivers. There is a negative linear correlation between the result of the GQL-15 and the visual acuity of the best eye. Both patients and caregivers reported worse scores in the quality of life test in correspondence with the worsening of the best eye visual acuity.

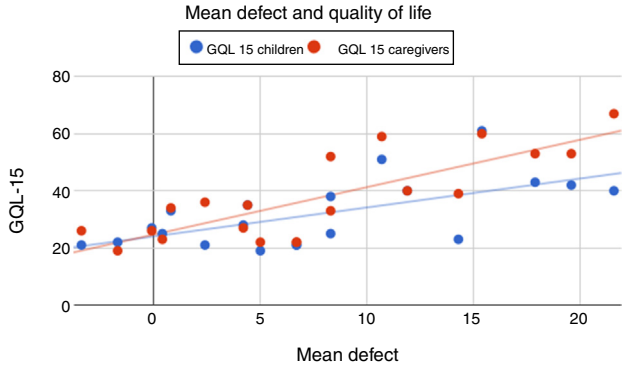

Fig. 2 – Linear correlation between visual field and mean defect and GQL-15 test results in children and caregivers. There is a positive linear correlation between the result of GQL-15 and best eye visual acuity. Both patients and caregivers reported worse scores in the quality of life test in correspondence with the increase of visual field mean defect.

VA of the best eye and the MD of the best eye with the results of the GQL-15 questionnaire filled in by children and caregivers.

Table 2 shows the results of the VFQ-25 questionnaire filled in by children. When studying the correlation between the various sections of the questionnaire and the studied variables that could affect quality of life, a statistically significant negative correlation was found between the MD of the visual field in the best eye and the score obtained in the following sections: near activities ($R=-0.64$; $p<0.001$), far activities ($R=-0.53$; $p=0.01$), social function ($R=-0.48$; $p=0.03$), dependency ($R=-0.54$; $p=0.03$) and peripheral vision ($R=-0.47$; $p=0.04$).

Table 2 – Results for each VFQ-25 domain of children.

VFQ-25	Mean	Standard deviation
General health	76.09	24.40
General vision	55.65	18.05
Ocular pain	71.43	22.06
Near activities	78.62	17.01
Far activities	77.90	12.71
Social performance	93.48	9.88
Mental health	67.86	25.56
Difficulties at work	76.19	23.02
Dependence	69.84	26.02
Chromatic vision	91.67	14.43
Peripheral vision	75.00	26.11

Discussion

Childhood glaucoma management is mainly focused on controlling clinical variables such as intraocular pressure, corneal size measurement and corneal transparency, as well as optic nerve glaucomatous damage.[5,6] However, when assessing the success of childhood glaucoma treatment, the impact caused by the disease on the quality of life of patients and caregivers should also be assessed because the repercussion of the disease on the quality of life of the latter could come to bear on the quality of the care provided to the patient.[7]

In the present study, parents reported worse quality of life than children, according to results for the GQL-15 survey of 32.30 ± 11.56 for children vs. 37.52 ± 14.59 for caregivers ($p=0.001$). The parameter that was most closely related to quality of life and visual function was visual field MD for the best eye, with a statistically significant correlation between the result of GQL-15 and visual field MD (children: $R=0.63$; $p<0.01$ and caregivers: $R=0.81$; $p<0.001$). In addition, a statistically significant negative correlation was found between visual field MD and the score for near activities ($R=-0.64$; $p<0.001$), far activities ($R=-0.53$; $p=0.01$), social function ($R=-0.48$; $p=0.03$), dependency ($R=-0.54$; $p=0.03$) and peripheral vision ($R=-0.47$; $p=0.04$).

Childhood glaucoma patients frequently receive multiple surgical treatments which must be repeated even at an early age and in all cases under general anesthesia. This means that both patient and parents, custodians or caregivers must make a high number of hospital visits which have an influence on the jobs of parents and the school activities of children. This could impact their education, particularly in the first few months after diagnostic and surgery.[1,7] In some occasions, childhood glaucoma is associated to a systemic disease that will require treatment, thus increasing the need for checkups.[8]

At present, in order to assess the impact of chronic diseases such as pediatric asthma[9] or oncological diseases,[10] the caregivers are asked to fill in quality of life questionnaire and the financial impact that said diseases can have on family resources as well as the physical stress that could influence the care given to cover the medical as well as physical and social needs of the children.[11]

Caregivers of children with primary congenital glaucoma bear a significant emotional and psychological burden. In one third of cases, studies report moderate or severe depression according to a questionnaire analyzing the emotional and psychological burden on caregivers.[12] Gothwal et al.[7] developed a questionnaire on the quality of life of caregivers of children with primary congenital glaucoma after surgery in order to assess their quality of life, reporting on the problems they faced in daily life. Said authors analyzed the results of a cohort of 119 caregivers consecutively selected with 93% participation rate.[13] The mean age of caregivers was 25.3 years and, in 95% of cases, the survey was replied by the patient's mother. In the group of patients, 24% exhibited unilateral glaucoma against 76% of bilateral cases. Caregivers or parents filled in the questionnaire prior to surgery of the child and 6 weeks later. The results demonstrated an association between improved quality of life of caregivers and surgery: quality of life improved 6–8 weeks after the operation.

Other 3 publications by Zhang et al.,[14] Freedman et al.[15] and Gothwal et al.[13] utilized validated tools to explore the quality of life in children with glaucoma and their caregivers. According to the results of these studies, children with glaucoma refer lower scores in quality of life tests related to vision when compared to healthy children. And as with the results of the present study, said authors observed that better VA is associated to better vision-related quality of life.

Recently, Dahlmann-Noor et al.[8] published a study on health-related quality of life, vision-related quality of life and VA-dependent social skills in children with glaucoma. According to the *Pediatric quality of life inventory* questionnaire, scores referring to psychosocial areas were lower than those referring to physical areas. Children with higher ages reported less impairment in the *Cardiff visual ability questionnaire for children*, *Impact of vision impairment for children* and *Pediatric quality of life inventory* questionnaire when compared to children with less age. In turn and as in the present study, parents/caregivers reported higher impact on the quality of life related to the health of the children than the impact reported by the children. The results of said study evidence a significant impact of childhood glaucoma on visual function and quality of life perceived by the patient as well as by caregivers. The results of said study evidence that the VA of the best eye is crucial for quality of life when compared to the rest of the factors, as demonstrated in the present study as well.

The limitations of the present study include the difficulty for comparing results due to the shortage of published data on the impact of glaucoma on children and their families. It is difficult to measure the visual capacity of a child, his quality of life and the subjective impression perceived related to basic aspects of life. The present series comprises a small number of cases, and the validation of the tests applied to children was not carried out in the authors' environment. It should also be pointed out that the present study has not carried out a reproducibility analysis in the children or caregivers, and that it did not include a control group of healthy children for comparative purposes.

Childhood glaucoma comprises a range of diseases such as amblyopia and refractive defects, dry eye, corneal and lens opacity as well as ocular motility alterations. And even though these diseases could have a significant impact on the quality of life of these patients, they have not been analyzed in the present study. The authors considered that new studies including said factors would be of great interest.

In accordance to the results of the present study, it can be concluded that glaucoma and its management entail a significant impact on the quality of life and visual function of children, despite the fact that the quality of life perceived by caregivers is worse than that perceived by the patients. In any case, studies with higher numbers of patients are necessary to confirm the present results.

Conflict of interests

The authors have not received financial support and have no commercial interests.

REFERENCES

1. Papadopoulos M, Cable N, Rahi J, Khaw PT, BIG Eye Study Investigators. The British Infantile and childhood Glaucoma (BIG) Eye Study. Invest Ophthalmol Vis Sci. 2007;48:4100–6.
2. Aponte EP, Diehl N, Mohney BG. Incidence and clinical characteristics of childhood glaucoma: a population-based study. Arch Ophthalmol. 2010;128:478–82.
3. Gothwall VK, Bharani S, Mandal AK. Impact of surgery in the quality of life of caregiver of children with congenital glaucoma. Ophthalmology. 2016;123:1161–2.
4. WHOQOL Group. Development of the WHOQOL: rationale and current status. Int J Mental Health. 1994;23:24–56.
5. Panicker SG, Mandal AK, Reddy AB, Gothwal VK, Hasnain SE. Correlations of genotype with phenotype in Indian patients with primary congenital glaucoma. Invest Ophthalmol Vis Sci. 2004;45:1149–56.
6. Mandal AK, Gothwal VK, Bagga H, Nutheti R, Mansoori T. Outcome of surgery on infants younger than 1 month with congenital glaucoma. Ophthalmology. 2003;110:1909–15.
7. Gothwal VK, Bharani S, Mandal AK. Quality of life of caregivers of children with congenital glaucoma: development and validation of a novel questionnaire (CarCGQoL). Invest Ophthalmol Vis Sci. 2015;56:770–7.
8. Dahlmann-Noor A, Tailor V, Bunce C, Abou-Rayyah Y, Adams G, Brookes J, et al. Quality of life and functional vision in children with glaucoma. Ophthalmology. 2017;124:1048–55.
9. Juniper EF, Guyatt GH, Feeny DH, Ferrie PJ, Griffith LE, Townsend M. Measuring quality of life in the parents of children with asthma. Qual Life Res. 1996;5:27–34.
10. Minaya P, Baumstarck K, Berbis J, Goncalves A, Barlesi F, Michel G, et al. The CareGiver Oncology Quality of Life questionnaire (CarGOQoL): development and validation of an instrument to measure the quality of life of the caregivers of patients with cancer. Eur J Cancer. 2012;48:904–11.
11. The WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. Soc Sci Med. 1998;46:1569.

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12. Dada T, Aggarwal A, Bali SJ, Wadhwani M, Tinwala S, Sagar R. Caregiver burden assessment in primary congenital glaucoma. Eur J Ophthalmol. 2013;23: 324–8.
13. Gothwal VK, Bharani S, Mandal AK. Impact of surgery on the quality of life of caregivers of children with congenital glaucoma. Ophthalmology. 2016;123:1161–2.
14. Zhang X, Du S, Ge J, Chen WR, Fan Q, Peng SX, et al. Quality of life in patients with primary congenital glaucoma following antiglaucoma surgical management. Zhonghua Yan Ke Za Zhi. 2009;45:514–21.
15. Freedman B, Jones S, Lin A, Stinnet SS, Muir KW. Vision-related quality of life in children with glaucoma. J AAPOS. 2014;18:95–8.