КЛІНІЧНА ПРАКТИКА

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THE ROLE OF THE "CHILD WITH GLAUCOMA PASSPORT" IN IMPROVING AWARENESS AND TREATMENT ADHERENCE AMONG PARENTS OF CHILDREN WITH CONGENITAL GLAUCOMA

Abstract.

Congenital glaucoma is a leading cause of irreversible visual impairment and disability in children, requiring early detection, timely surgical intervention, and long-term follow-up. Treatment effectiveness depends substantially on parental awareness and adherence to medical recommendations, which is particularly critical in the context of a chronic disease course.

Objective. *To evaluate the effectiveness of the «Child with Glaucoma Passport» as an educational and informational tool aimed at improving parental awareness and compliance, and at optimizing the monitoring and treatment of children with congenital glaucoma.*

Materials and Methods. *The study enrolled parents of children with newly diagnosed congenital glaucoma admitted to the ophthalmology department of the clinic of Tashkent Pediatric Medical Institute. Participants were allocated to the intervention group (n = 40), who received the passport prior to hospitalization, and the control group (n = 42), who did not use this tool. Parental compliance was assessed using a mobile application questionnaire and supplemented by the assessments of attending ophthalmologists and anesthesiologists. The study was conducted in accordance with the principles of the World Medical Association Declaration of Helsinki (2013). The study protocol was approved by the Ethics Committee of the Ministry of Health of the Republic of Uzbekistan (Protocol No. 9, dated 25 September 2025). All parents (legal representatives of the children) provided written informed voluntary consent to participate in the study and to the processing of personal data. Statistical analysis was performed using standard methods of descriptive and inferential statistics; differences were considered statistically significant at $p < 0.05$. This article derives from a doctoral dissertation entitled «A Differentiated Approach to the Management of Children with Glaucoma,» defended on 18 December 2025.*

Results. *Use of the «Child with Glaucoma Passport» significantly improved parental awareness, readiness for surgical treatment, adherence to medical recommendations, and regularity of follow-up visits ($p < 0.05$). High compliance was observed in 65% of parents in the intervention group compared with 38% in the control group. The sensitivity of the method was 96% and the specificity was 85%. Statistically significant differences between the groups were maintained at the 6-month follow-up assessment.*

Conclusions. *The «Child with Glaucoma Passport» is an effective and accessible tool for enhancing parental compliance and optimizing long-term monitoring of children with congenital glaucoma. Its implementation improves physician-family communication, increases treatment efficacy, and is recommended for broad adoption in pediatric ophthalmological practice.*

Keywords: *Congenital Glaucoma; Parental Compliance; Patient Awareness; Patient Passport; Pediatric Ophthalmology.*

Introduction

Congenital (pediatric) glaucoma is among the leading causes of irreversible visual impairment and disability in children, exerting a profound impact on patients' quality of life and that of their families [1, 3, 24]. The disease is characterized by impaired aqueous humor outflow, resulting in elevated intraocular pressure and progressive optic nerve damage. In the absence of timely diagnosis and adequate treatment, permanent and often irreversible visual loss ensues [1, 8, 10, 17, 20-22].

Contemporary advances in ophthalmology provide a range of surgical and pharmacological approaches for managing congenital glaucoma [2, 4, 7, 11, 14]. However, treatment outcomes are determined not only by the technical aspects of the intervention but also by the level of parental or guardian awareness, their active engagement in the therapeutic process, and strict adherence to the physician's recommendations [12, 13, 18]. Non-compliance with the prescribed regimen, missed instillations, and delayed follow-up visits substantially diminish therapeutic efficacy, increase the risk of disease progression, and may lead to premature disability [18, 19, 25].

Among the most promising strategies for improving parental compliance is the implementation of structured educational tools specifically adapted for families raising children with chronic diseases [9, 15, 16]. Such tools may encompass both informational materials and interactive educational programs aimed at developing sustainable self-monitoring skills, correct instillation technique, and timely help-seeking behavior.

Despite the recognized efficacy of such approaches, their use in clinical practice remains limited worldwide [5, 18]. The insufficient availability of educational programs tailored to the specific needs of parents of children with congenital glaucoma underscores the relevance of developing and clinically evaluating novel tools to improve compliance and, consequently, treatment outcomes. Incorporating such programs into comprehensive therapy would not only increase parental knowledge but also create conditions for safer and more successful management of children with chronic ophthalmic conditions [9, 12, 23].

Study objective

To evaluate the effectiveness of the «Child with Glaucoma Passport» as a tool for improving parental awareness and compliance, and for enhancing the quality of monitoring and treatment of children with congenital glaucoma..

Materials and methods

The study was conducted in the ophthalmology department of the clinic of Tashkent Pediatric Medical Institute. Eligible participants were parents of children presenting for the first time with a diagnosis of glaucoma.

Participants were allocated to two groups: Intervention group – 40 parents who received the «Child with Glaucoma Passport» prior to the child's hospitalization; Control group – 42 parents who did not use the passport. The mean age of mothers in the intervention group was 33.5 ± 2.3 years and in the control group 35.2 ± 3.1 years. Educational level and place of residence were comparable between groups.

Parental compliance was assessed using a mobile application questionnaire [5] comprising items on disease awareness, adherence to medical recommendations, regularity of follow-up visits, and readiness for surgical treatment. Additionally, the opinions of attending ophthalmologists and anesthesiologists regarding quality of communication with parents were recorded.

The «Child with Glaucoma Passport» was available in two languages and comprised:

An informational section for parents – including disease overview, treatment stages, pre- and post-operative care algorithms, and instructions for administering eye drops;

A monitoring section for clinicians – containing structured tables for recording dynamic changes in axial length and its growth rate, visual acuity, corneal diameter, degree of corneal opacity, tonometry, tonography, and optic disc cupping.

The study was conducted in accordance with the principles of the World Medical Association Declaration of Helsinki (2013). The study protocol was approved by the Ethics Committee of the Ministry of Health of the Republic of Uzbekistan (Protocol No. 9, dated 25 September 2025). All parents (legal representatives of the children) provided written informed voluntary consent to participate in the study and to the processing of personal data. The authors declare no conflicts of interest.

Statistical analysis was performed using standard methods of descriptive and inferential statistics; differences were considered statistically significant at $p < 0.05$.

This article derives from a doctoral dissertation entitled «A Differentiated Approach to the Management of Children with Glaucoma,» defended on 18 December 2025.

Results and discussion

Use of the «Child with Glaucoma Passport» was associated with a significant improvement in parental awareness and compliance. Immediate consent to surgical treatment was obtained from 90% of parents in the intervention group compared with 71.4% in the control group; in the control group, 28.6% of parents expressed uncertainty when making a decision.

Complete disease awareness was reported by 100% of parents in the intervention group. In the control group, complete awareness was noted in 48% of parents, partial awareness in 24%, and 28% lacked sufficient knowledge about the disease.

Strict adherence to the attending physician's recommendations was recorded in 95% of parents in the intervention group versus 76% in the control group; missed instillations were documented in 24% of parents in the control group. Regular post-operative follow-up visits were maintained by 85% of parents in the intervention group and 67% in the control group.

An overall compliance assessment revealed that high adherence to treatment was observed in 65% of parents in the intervention group, moderate adherence in 20%, and low adherence in 15%. The corresponding figures in the control group were 38%, 33%, and 29%, respectively. Differences between groups were statistically significant ($p < 0.05$) and persisted through the 6-month follow-up assessment. The sensitivity of the method was 96% and the specificity was 85%.

These findings confirm the high effectiveness of the «Child with Glaucoma Passport» as an educational and informational tool. Improved parental awareness fosters a responsible attitude toward the disease, enhances interaction with healthcare professionals, and increases treatment adherence [6].

The structured monitoring section also facilitates clinical workflow, supports systematic follow-up, and provides an accessible means of tracking changes in clinical parameters over time – a feature of particular importance given the chronic nature of congenital glaucoma. Beyond its registration function, the monitoring section serves a motivational role: parents can directly observe changes in key indicators (axial length, corneal diameter, tonometry data, optic disc status), thereby strengthening their engagement in the therapeutic process.

The persistence of statistically significant differences at 6 months indicates a sustained effect of the intervention – an especially relevant finding in congenital glaucoma, which requires long-term dispensary follow-up and repeated interventions. Organizational advantages of passport implementation should also be noted: data collection standardization facilitates multidisciplinary collaboration among ophthalmologists, anesthesiologists, and pediatricians, improves continuity of care, and reduces the risk of loss of clinically significant information.

Limitations of the study include the relatively small sample size and single-center design. Future research should involve expanded samples, multicenter trials, and evaluation of long-term outcomes (beyond 12 months) of passport use.

Conclusion

The «Child with Glaucoma Passport» is an effective tool for enhancing parental awareness and compliance in the management of children with congenital glaucoma. Its use promotes stricter adherence to medical recommendations, regular ophthalmological follow-up, and improved quality of clinical monitoring. The findings support the recommendation for widespread implementation of this passport in pediatric ophthalmological practice.

Prospects for further research. Further multicenter studies with larger sample sizes and long-term follow-up are planned to evaluate the sustained effectiveness of the «Child with Glaucoma Passport» in improving parental compliance and treatment outcomes in children with congenital glaucoma.

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РОЛЬ «ПАСПОРТА ДИТИНИ З ГЛАУКОМОЮ» У ПІДВИЩЕННІ ІНФОРМОВАНОСТІ ТА ДОТРИМАННІ ЛІКУВАЛЬНОГО РЕЖИМУ БАТЬКАМИ ДІТЕЙ З ВРОДЖЕНОЮ ГЛАУКОМОЮ

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Резюме.

Вроджена глаукома є провідною причиною незворотного порушення зору та інвалідності у дітей, що вимагає раннього виявлення, своєчасного хірургічного втручання та довгострокового спостереження. Ефективність лікування значною мірою залежить від обізнаності батьків та дотримання ними медичних рекомендацій, що є особливо важливим у контексті хронічного перебігу захворювання.

Мета. Оцінити ефективність «Паспорта дитини з глаукомою» як освітнього та інформаційного інструменту, спрямованого на підвищення обізнаності та дотримання рекомендацій батьками, а також на оптимізацію спостереження та лікування дітей із вродженою глаукомою.

Матеріали та методи. До дослідження були залучені батьки дітей з нещодавно діагностованою вродженою глаукомою, госпіталізованих до офтальмологічного відділення клініки Ташкентського педіатричного медичного інституту. Учасників розподілили на групу втручання (n = 40), яка отримала інформаційний паспорт до госпіталізації, та контрольну групу (n = 42), яка не використовувала цей інструмент. Дотримання батьками рекомендацій оцінювали за допомогою анкети в мобільному додатку та доповнювали оцінками лікуючих офтальмологів та анестезіологів. Дослідження проводили відповідно до принципів Гельсінської декларації Всесвітньої медичної асоціації (2013). Протокол дослідження був затверджений Етичним комітетом Міністерства охорони здоров’я Республіки Узбекистан (Протокол № 9 від 25 вересня 2025 р.). Усі батьки (законні представники дітей) надали письмову інформовану добровільну згоду на участь у дослідженні та на обробку персональних даних. Статистичний аналіз проводився з використанням стандартних методів описової та інференційної статистики; відмінності вважалися статистично значущими при $p < 0,05$. Ця стаття базується на докторській дисертації на тему «Диференційований підхід до лікування дітей з глаукомою», захищеній 18 грудня 2025 року.

Результати. Використання «Паспорта дитини з глаукомою» значно покращило обізнаність батьків, їхню готовність до хірургічного лікування, дотримання медичних рекомендацій та регулярність контрольних візитів ($p < 0,05$). Високий рівень дотримання рекомендацій спостерігався у 65% батьків в інтервенційній групі порівняно з 38% у контрольній групі. Чутливість методу становила 96%, а специфічність – 85%. Статистично значущі відмінності між групами зберігалися під час оцінки через 6 місяців спостереження.

Висновки. «Паспорт дитини з глаукомою» є ефективним та доступним інструментом для підвищення дотримання рекомендацій батьками та оптимізації довгострокового спостереження за дітьми з вродженою глаукомою. Його впровадження покращує комунікацію між лікарем та родиною, підвищує ефективність лікування та рекомендується для широкого застосування в дитячій офтальмологічній практиці.

Ключові слова: вроджена глаукома; дотримання рекомендацій батьками; обізнаність пацієнта; паспорт пацієнта; дитяча офтальмологія.

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