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# In their eyes: parental experiences navigating pediatric glaucoma diagnosis, treatment, and care in Turkey — a qualitative study

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## Abstract

**Background** Pediatric glaucoma is a rare but vision-threatening condition requiring complex, lifelong management. While clinical outcomes have been well-documented, little is known about the lived experiences of families navigating this condition, particularly in middle-income countries. This study aimed to explore how parents in Turkey experience and navigate the diagnosis, treatment, and ongoing care of a child with pediatric glaucoma.

**Methods** We conducted a qualitative exploratory study using semi-structured interviews with parents of children diagnosed with pediatric glaucoma in Turkey. Twenty-two parents (17 mothers, 5 fathers) representing 20 children with various forms of pediatric glaucoma participated. Participants were recruited through pediatric ophthalmology clinics, social media, and snowball sampling. Interviews were conducted remotely, audio-recorded, transcribed verbatim, and analyzed using thematic analysis.

**Results** Six major themes emerged: (1) Diagnosis Journey: Shock, Confusion, and the Search for Answers; (2) Treatment Burden: Managing Complex Care Regimens; (3) Navigating the Healthcare System: Structural Barriers and Facilitators; (4) Impact on Family Life: Adjustments, Limitations, and Emotional Tolls; (5) Coping and Resilience: Finding Strength Amid Challenges; and (6) Unmet Needs and Recommendations for System Improvement. Parents reported significant geographical disparities in access to specialist care, substantial financial burdens despite universal health coverage, and lack of psychological support and Turkish-language information resources. Parents demonstrated remarkable resilience through peer support networks, religious faith, and sophisticated medication management strategies, but identified critical gaps in the healthcare system that impeded optimal care.

**Conclusions** Pediatric glaucoma affects not only vision but all aspects of family life, including finances, sibling relationships, and parental wellbeing. Findings highlight the need for family-centered care models that address both clinical and psychosocial dimensions of pediatric glaucoma. Implementing teleophthalmology services, developing regional expertise through hub-and-spoke models, integrating psychological support, and creating accessible educational resources in Turkish could significantly improve family experiences. This first qualitative study from Turkey provides insights relevant to other middle-income countries with similar healthcare systems.

**Keywords** Pediatric glaucoma, Parental experience, Qualitative study, Health disparities, Turkey

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## Introduction

Pediatric glaucoma represents a heterogeneous group of vision-threatening conditions characterized by elevated intraocular pressure (IOP) that can lead to optic nerve damage and irreversible blindness if not properly managed. Unlike adult-onset forms, pediatric glaucoma presents unique diagnostic and management challenges due to its rarity, diverse etiology, and the developmental considerations of treating young patients. Primary congenital glaucoma (PCG), the most common form, affects approximately 1 in 10,000 live births globally, with higher prevalence observed in regions with greater consanguinity rates, including parts of the Middle East and Turkey. Other variants include juvenile open-angle glaucoma (JOAG) and secondary glaucomas associated with anterior segment dysgenesis, trauma, uveitis, or following cataract surgery.

The pathophysiology of pediatric glaucoma typically involves structural abnormalities in the anterior chamber angle, leading to aqueous humor outflow obstruction. In PCG, abnormal development of the trabecular meshwork and anterior chamber angle during gestation results in increased resistance to aqueous outflow. Clinical manifestations often present within the first year of life and include classic signs such as epiphora (excessive tearing), photophobia, blepharospasm, corneal enlargement, corneal edema, and buphthalmos ("ox eye"—enlarged eyeball). Later presentations may be more subtle, with gradual corneal enlargement, myopia progression, or asymptomatic elevation of intraocular pressure detected during routine examinations.

The prognosis for childhood glaucoma has improved dramatically over recent decades due to advances in surgical techniques, microsurgery, anesthesia protocols, and enhanced diagnostic capabilities. Studies demonstrate that early detection and prompt intervention are critical determinants of visual outcomes. Moschos et al. [1] reported that children diagnosed and treated within the first three months of life achieve significantly better visual outcomes than those with delayed diagnosis, emphasizing the time-sensitive nature of this condition. Despite these advances, pediatric glaucoma remains a lifelong condition requiring vigilant monitoring and often multiple interventions over the patient's lifetime.

While primary surgical management through goniotomy or trabeculotomy remains the gold standard for PCG, treatment paradigms vary based on glaucoma type, age at presentation, corneal clarity, and available surgical expertise. The treatment burden extends beyond the initial intervention, frequently requiring adjunctive topical medications, additional surgeries, and long-term monitoring of vision, refractive status, intraocular pressure, and amblyopia prevention. This creates a complex care trajectory that families must navigate for years or decades following diagnosis.

The rarity of pediatric glaucoma belies its substantial impact on affected children and their families. The condition carries significant morbidity, with risk of amblyopia, anisometropia, refractive errors, corneal scarring, and progressive vision loss despite intervention. Khitri and colleagues [2] documented that approximately 30% of children with PCG achieve visual acuity of 20/50 or better, while 20% progress to severe visual impairment or blindness despite optimal management. These statistics underscore the devastating potential of this condition and the critical importance of comprehensive clinical and psychosocial care for affected families.

The existing literature on pediatric glaucoma predominantly focuses on surgical techniques, clinical outcomes, and disease mechanisms. A comprehensive review by Papadopoulos and colleagues [3] cataloged over 200 publications on PCG since 2000, with more than 80% addressing surgical techniques or reporting surgical outcomes. This emphasis on clinical management, while essential for advancing treatment protocols, leaves significant gaps in our understanding of how families experience and navigate this condition.

The limited research examining the impact of pediatric glaucoma on quality of life and family functioning suggests significant challenges. Dahlmann-Noor et al. [4] reported that families of children with glaucoma experience disruptions in daily routines, financial strain, parental anxiety, and social isolation—burdens that often receive minimal attention in clinical settings. However, these studies predominantly originate from high-resource settings with well-established healthcare systems and may not capture the unique challenges faced in middle-income countries or regions with different cultural contexts.

Turkey represents an interesting context for examining pediatric glaucoma care experiences. As a nation bridging Europe and Asia with a developing healthcare system, Turkey has made significant advances in healthcare access through universal health insurance coverage. Yet, Coban et al. [5] noted persistent disparities in specialized care access, particularly for rural populations and those of lower socioeconomic status. The country's public health system faces challenges in providing highly specialized services such as pediatric ophthalmology equitably across all regions, potentially creating barriers for families seeking timely diagnosis and treatment of complex conditions like pediatric glaucoma.

Despite the rich potential for understanding care disparities and family experiences in this context, no qualitative studies have examined how Turkish families navigate the complex journey of pediatric glaucoma

care. This represents a significant knowledge gap, as understanding the lived experiences of these families could inform targeted interventions to improve care delivery, reduce treatment burden, and enhance psychosocial support. Moreover, insights from the Turkish context may provide valuable lessons for other middle-income countries with similar healthcare system challenges.

The rationale for this study emerges from the recognition that effective care for pediatric glaucoma extends beyond surgical and medical interventions to encompass the broader experience of affected families. Understanding parental perspectives on diagnosis processes, treatment burdens, healthcare navigation, and psychosocial impacts is essential for developing family-centered care models that address the multifaceted challenges of this condition.

Turkish families managing pediatric glaucoma face a unique constellation of challenges shaped by the country's healthcare system structure, cultural attitudes toward childhood disability, geographical variations in specialist access, and financial considerations despite universal health coverage. By exploring these experiences through qualitative inquiry, this study aims to illuminate the lived realities of these families and identify opportunities for systematic improvements in care delivery and support.

The primary objective of this study is to explore how parents of children with pediatric glaucoma in Turkey experience and navigate their children's condition across multiple domains: the diagnostic journey, treatment implementation and adherence, interactions with the healthcare system, psychosocial and financial impacts, and access to formal and informal support systems. By elucidating these experiences, we seek to identify critical junctures where interventions might reduce treatment burden, enhance family coping, improve communication, and ultimately optimize both clinical and quality-of-life outcomes for affected children and their families.

Secondary objectives include identifying variations in experience based on geographical location (urban vs. rural), socioeconomic status, severity of the child's condition, and time since diagnosis. These contextual factors may significantly influence how families experience pediatric glaucoma care and highlight specific vulnerabilities requiring targeted support. By documenting unmet needs and parent-identified solutions, this research aims to generate actionable insights for clinicians, healthcare administrators, and patient advocacy organizations seeking to improve the ecosystem of care for this vulnerable population.

## Methods

This study employed a qualitative exploratory design using in-depth, semi-structured interviews to investigate the lived experiences of parents navigating pediatric glaucoma care in Turkey. We selected this methodology because qualitative approaches are particularly valuable when exploring complex phenomena that cannot be adequately captured through quantitative measures alone, especially when examining experiences within healthcare systems [6]. The study was grounded in an interpretivist paradigm, acknowledging that parental experiences are shaped by social, cultural, and systemic contexts unique to Turkey's healthcare environment. This approach enabled us to explore the subjective meanings parents attribute to their experiences while recognizing the researchers' role in co-constructing knowledge through the interview and analysis process.

Eligible participants included parents or primary caregivers of children under 18 years of age diagnosed with any form of pediatric glaucoma (primary congenital glaucoma, juvenile open-angle glaucoma, or secondary glaucomas) who were receiving or had received treatment within the Turkish healthcare system. We sought diversity in our sample regarding the child's age, disease severity, time since diagnosis, treatment modalities experienced, and geographical location within Turkey to capture a comprehensive range of experiences. Parents were required to be conversant in Turkish, as this was the primary language of the research team and represented the dominant language of healthcare delivery in the research setting. We excluded potential participants who could not provide informed consent or participate in an audio-recorded interview. In cases where both parents wished to participate, they were interviewed separately to capture potentially different perspectives on the care experience.

We employed multiple recruitment strategies to assemble a diverse sample. Primary recruitment occurred through pediatric glaucoma clinics at Istanbul University-Cerrahpaşa Faculty of Medicine, representing one of Turkey's major referral centers for pediatric ophthalmology. Clinic ophthalmologists identified eligible families and provided information about the study during routine appointments. With permission, the research team then contacted interested parents to provide detailed information about the study procedures.

Additionally, we implemented snowball sampling by asking participating parents to refer other families they knew through support networks. To reach families from different geographical regions and socioeconomic backgrounds, we extended recruitment through social media platforms, particularly closed Facebook groups and WhatsApp communities dedicated to

families affected by pediatric eye conditions in Turkey. Digital recruitment materials included study information and contact details for the research team, allowing interested parents to self-refer to the study. This multipronged approach enabled us to reach families with varied experiences across Turkey's diverse healthcare landscape, including those in rural areas who might travel to Istanbul only occasionally for specialized care.

Data collection occurred through individual, semi-structured interviews conducted between March and August 2024. Interviews were conducted remotely via secure videoconferencing platforms (primarily Zoom and WhatsApp video calls) due to both geographical dispersion of participants and ongoing public health considerations. This approach also minimized burden on families already navigating complex care schedules. When video interviews were not feasible due to connectivity issues or participant preference, telephone interviews were conducted as an alternative.

The interviews, lasting between 30 and 60 min, were guided by a semi-structured interview protocol developed based on existing literature, clinical expertise from pediatric ophthalmologists, and input from two parent advisors with lived experience of caring for children with glaucoma. The interview guide consisted of open-ended questions exploring: (1) the diagnostic journey, (2) treatment experiences and burden, (3) interactions with the healthcare system, (4) psychosocial impacts on the child and family, (5) financial implications, (6) support systems, and (7) recommendations for improving care. The semi-structured format allowed for consistent exploration of key topics while providing flexibility to pursue emerging themes and individual narratives.

All interviews were conducted in Turkish by trained researchers with backgrounds in qualitative health research. Interviews were audio-recorded with participant consent and transcribed verbatim. Contextual observations about emotional responses, hesitations, or emphases were noted by interviewers immediately following each interview. Participants were invited to review their interview transcripts for accuracy and to add clarifications if desired, enhancing the trustworthiness of the data.

We planned to recruit 15–25 participants, with the final sample size determined by thematic saturation—the point at which additional interviews yield no substantively new themes or insights. Saturation was assessed through an iterative process in which the research team reviewed emerging themes after each set of 3–4 interviews. Data collection continued until team consensus determined that saturation had been achieved across major thematic areas. This approach aligns with established qualitative research principles that prioritize depth and richness of data over predetermined sample sizes [7].

We analyzed the data using thematic analysis following the six-phase approach outlined by Braun and Clarke [8]. Initial coding was conducted in Turkish to preserve linguistic nuances and cultural contexts, with the final themes and illustrative quotes translated to English for reporting purposes. The analysis process proceeded as follows: (1) familiarization with the data through repeated reading of transcripts; (2) generating initial codes using a combination of inductive and deductive approaches; (3) searching for potential themes by clustering related codes; (4) reviewing themes against the coded data and entire dataset; (5) defining and naming themes; and (6) producing the report with illustrative quotes.

Two researchers independently coded a subset of interviews to develop an initial coding framework, which was then refined through discussion and consensus. NVivo software (version 13, QSR International) facilitated the organization and analysis of the qualitative data. To enhance analytical rigor, we employed member checking by sharing preliminary findings with a subset of participants, incorporated researcher reflexivity through regular team discussions about positionality and interpretations, and maintained an audit trail documenting analytical decisions.

The study received ethical approval from the American University in Bulgaria Human Subjects Review Commitee (Protocol no: 20240104YEL). All participants provided informed consent prior to participation, with options for either written consent (via email) or verbal consent (recorded at the interview start) to accommodate different participation modalities. Participants were informed about study aims, procedures, potential risks and benefits, voluntary participation, and their right to withdraw without affecting their child's care.

To protect confidentiality, all identifying information was removed during transcription, and pseudonyms were assigned for reporting purposes. Data were stored on encrypted, password-protected devices accessible only to the research team. Given the potentially sensitive and emotional nature of the interviews, researchers received training in responding to distress and had referral information available for psychological support services if needed.

## Results

### Participant characteristics

A total of 22 parents participated in the study, representing the experiences of 20 children with pediatric glaucoma. Demographic characteristics and clinical details of the children are presented in Table 1. The majority

**Table 1** Demographic and clinical characteristics of study participants and their children

| Characteristic | n (%) or Mean ± SD |
|---|---|
| Parent Characteristics | |
| Relationship to child | |
| Mother | 17 (77.3%) |
| Father | 5 (22.7%) |
| Age (years) | 36.4 ± 5.7 |
| Educational level | |
| Primary/secondary | 7 (31.8%) |
| High school | 8 (36.4%) |
| University or higher | 7 (31.8%) |
| Geographic location | |
| Metropolitan cities (Istanbul, Ankara, Izmir) | 12 (54.5%) |
| Other cities | 6 (27.3%) |
| Rural areas | 4 (18.2%) |
| Child Characteristics | |
| Age (years) | 7.3 ± 4.6 |
| Sex | |
| Male | 13 (65.0%) |
| Female | 7 (35.0%) |
| Type of glaucoma | |
| Primary congenital glaucoma | 14 (70.0%) |
| Juvenile open-angle glaucoma | 3 (15.0%) |
| Secondary glaucoma | 3 (15.0%) |
| Time since diagnosis (years) | 5.8 ± 4.2 |
| Number of surgeries | |
| None | 5 (25.0%) |
| 1–2 surgeries | 8 (40.0%) |
| 3 or more surgeries | 7 (35.0%) |
| Visual acuity in better eye | |
| Good (> 20/40) | 9 (45.0%) |
| Moderate (20/40–20/200) | 7 (35.0%) |
| Poor (< 20/200) | 4 (20.0%) |

of participants ($n=17$) were mothers, while five were fathers. The children's ages ranged from 8 months to 16 years (mean age: 7.3 years), with varying forms of pediatric glaucoma. Time since diagnosis ranged from 4 months to 15 years, with most children ($n=15$) having undergone at least one surgical intervention. Participants resided across diverse geographical regions of Turkey, with approximately half ($n=12$) living in metropolitan areas (Istanbul, Ankara, Izmir) and the remainder in smaller cities or rural areas, necessitating travel for specialized care.

### Thematic analysis

Analysis of the interview data revealed six major themes with corresponding subthemes, as presented in Table 2. These themes encompass the complex and multifaceted experience of raising a child with pediatric glaucoma in Turkey, from initial diagnosis through ongoing management and its impact on family life.

#### *Theme 1: diagnosis journey: shock, confusion, and the search for answers*

*Subtheme 1.1: Initial Recognition of Symptoms and Delayed Diagnosis*

Most participants described noticing unusual features in their child's eyes, including cloudiness, excessive tearing, light sensitivity, or unusual eye appearance. For many, this initiated a challenging journey through the healthcare system before receiving a definitive diagnosis. Parents from non-metropolitan areas reported especially prolonged diagnostic journeys, often involving multiple referrals through various levels of the healthcare system.

> *"I noticed his eyes were very sensitive to light when he was about 3 months old. He would cry when we went outside. The local doctor said it was normal, but I felt something was wrong. It took three more doctors and nearly 2 months before someone mentioned glaucoma and referred us to Istanbul." (Mother of 6-year-old boy, rural Eastern Turkey)*

> *"The first doctor we saw in our town said that the cloudiness in her eyes would disappear on its own. We lost precious time—nearly 5 months—before we finally saw a specialist in Ankara who diagnosed her immediately and told us surgery was urgently needed." (Father of 4-year-old girl, Anatolian town)*

In contrast, participants living in major cities with specialist pediatric ophthalmology services typically reported more straightforward diagnostic experiences, though the emotional impact remained significant regardless of timeline.

> *"We were fortunate that our pediatrician recognized the signs immediately. Within three days, we had seen a specialist at Cerrahpaşa who confirmed congenital glaucoma and scheduled surgery for the following week. Even with this quick response, those were the most terrifying days of our lives." (Mother of 3-year-old boy, Istanbul)*

*Subtheme 1.2: Emotional Turmoil and Information Gaps*

All participants described intense emotional reactions to their child's diagnosis, characterized by shock, fear, guilt, and overwhelming concern about their child's visual future. Many parents reported receiving insufficient information at diagnosis, leaving them with unanswered

**Table 2** Themes and subthemes from thematic analysis of parental experiences

| Themes | Subthemes | Representative Quote |
|---|---|---|
| 1. Diagnosis Journey: Shock, Confusion, and the Search for Answers | 1.1 Initial Recognition of Symptoms and Delayed Diagnosis | "I noticed his eyes were very sensitive to light when he was about 3 months old. He would cry when we went outside. The local doctor said it was normal, but I felt something was wrong. It took three more doctors and nearly 2 months before someone mentioned glaucoma and referred us to Istanbul." |
| | 1.2 Emotional Turmoil and Information Gaps | "When the doctor said 'glaucoma,' I had no idea what it meant for a baby. He explained it's high pressure in the eye, but what does that mean for her future? Will she go blind? Can it be cured? I left with a surgery date but so many questions." |
| 2. Treatment Burden: Managing Complex Care Regimens | 2.1 Surgical Experiences and Decision-Making | "He's had four surgeries already, and he's only five. Each time, I hand him over to the surgical team and then wait, praying. The surgeries saved his sight, but I'll never get used to seeing my baby wheeled away to an operating room." |
| | 2.2 Medication Management Challenges | "He needs three different eye drops, each on a different schedule. One is four times daily, another three times, and the last is twice daily. I set alarms on my phone, but it's still overwhelming, especially with a toddler who fights every drop." |
| | 2.3 Follow-up and Monitoring Challenges | "Every three months, we travel 600 km to Istanbul for a 15-min appointment. We stay overnight because appointments are early, which means missing work, arranging care for our other children, and spending money we don't really have on hotels. But what choice do we have?" |
| 3. Navigating the Healthcare System: Structural Barriers and Facilitators | 3.1 Geographical and Specialist Access Disparities | "When his pressure spiked and his eye was red and hard, our local hospital couldn't help. They said we needed to go to Istanbul, but that's an 8-h drive. Those hours on the road, with him in pain, were excruciating. We need more specialists in the eastern regions." |
| | 3.2 Financial Burden Despite Universal Coverage | "The surgeries and most medications are covered, yes. But some of the newer drops aren't fully covered, and those can cost 300–400 lira per bottle. Then there's transportation to Istanbul, hotels, meals, and lost wages from missing work." |
| | 3.3 Coordination and Continuity of Care Challenges | "Besides glaucoma, she has developmental delays. We see ophthalmologists, neurologists, physiotherapists, and developmental specialists. None of these departments communicate with each other. I'm the one carrying information between them, explaining everything repeatedly." |
| 4. Impact on Family Life: Adjustments, Limitations, and Emotional Tolls | 4.1 Educational and Social Integration Challenges | "Her teacher has been amazing, arranging for special lighting, enlarged materials, and seating at the front. But the physical education teacher excludes her from activities 'for her protection,' which is unnecessary and makes her feel different." |
| | 4.2 Sibling Dynamics and Family Relationships | "Our older daughter, who's 10, has become like a third parent. She helps with the eye drops and remembers medication schedules. While I'm proud of her compassion, I worry she's losing her childhood." |

**Table 2** (continued)

| Themes | Subthemes | Representative Quote |
|---|---|---|
| 5. Coping and Resilience: Finding Strength Amid Challenges | 5.1 Religious Faith and Spiritual Practices | "Every surgery, every setback, I find strength in prayer. Our mosque community has been incredibly supportive, organizing transportation to Istanbul for appointments and helping with our other children when we travel." |
| | 5.2 Peer Support and Information Networks | "The WhatsApp group of glaucoma parents has been more valuable than any medical resource. They guided us to the best specialists, advised on medication techniques for uncooperative toddlers, and most importantly, understood our fears without judgment." |
| | 5.3 Doctor-Patient Relationships as Support | "Our doctor gives us his personal phone number for emergencies. Once, he called at 10 PM to check how our son was responding to a new medication. This kind of care makes a world of difference." |
| 6. Unmet Needs and Recommendations for System Improvement | 6.1 Psychological Support Gaps | "No one ever asked how I was coping emotionally with all of this. When I mentioned feeling depressed and overwhelmed to our ophthalmologist, he acknowledged it was normal but had no resources to offer. Mental health should be part of glaucoma care." |
| | 6.2 Information and Communication Needs | "Most of the reliable information online is in English. We need Turkish resources written for parents, explaining everything from the basics of the condition to what each surgical option means." |
| | 6.3 Structural and System Recommendations | "Turkey needs a hub-and-spoke model for pediatric glaucoma. Specialists from centers like Istanbul should regularly visit regional hospitals to build capacity and reduce the need for families to travel." |

questions and driving them to seek information online or through patient groups.

*"When the doctor said 'glaucoma,' I had no idea what it meant for a baby. He explained it's high pressure in the eye, but what does that mean for her future? Will she go blind? Can it be cured? I left with a surgery date but so many questions. I spent all night searching online, which only scared me more." (Mother of 10-month-old girl, Izmir)*

*"I blamed myself. During my pregnancy, I had taken some medication for a severe infection before knowing I was pregnant. For months, I was convinced I had caused my son's condition. Only later, when connecting with other parents and learning more, did I understand this wasn't my fault." (Mother of 9-year-old boy, Ankara)*

### *Theme 2: treatment burden: managing complex care regimens*

*Subtheme 2.1: Surgical Experiences and Decision-Making*

Most children in the study had undergone at least one surgical intervention, with several experiencing multiple procedures. Parents described the emotional weight of consenting to eye surgery for their young child and the anxiety of waiting during procedures.

*"He's had four surgeries already, and he's only five. Each time, I hand him over to the surgical team and then wait, praying. The surgeries saved his sight, but I'll never get used to seeing my baby wheeled away to an operating room." (Mother of 5-year-old boy, Istanbul)*

Parents also reported varying levels of involvement in surgical decision-making, with some feeling fully informed and included, while others described more paternalistic approaches from healthcare providers.

*"Our doctor in Istanbul explained every option, the risks, the benefits. He showed us diagrams and even introduced us to another family whose child had undergone the same procedure. We felt empowered to make an informed choice." (Father of 7-year-old girl, Bursa)*

*"There wasn't really a discussion. The doctor said this surgery was necessary, and if we waited, our son could lose his vision. What choice did we have? We trusted the doctor, but I wish there had been more explanation about alternatives or what to expect afterward." (Mother of 4-year-old boy, Trabzon)*

*Subtheme 2.2: Medication Management Challenges*

Daily administration of eye drops emerged as a significant burden for nearly all families, with particular challenges for those managing multiple medications or treating very young children. Table 3 presents the medication management strategies reported by parents.

*"He needs three different eye drops, each on a different schedule. One is four times daily, another three times, and the last is twice daily. I set alarms on my phone, but it's still overwhelming, especially with a toddler who fights every drop." (Mother of 2-year-old boy, Adana)*

*"We created a family schedule. His grandmother administers the morning doses, I handle afternoon and dinner time, and my husband does the bedtime medication. It takes a village, literally." (Mother of 4-year-old boy, Istanbul)*

*"The hardest part is knowing that if I miss doses, his pressure could rise, and he could lose more vision. That responsibility weighs on me every day. Sometimes I wake up panicking, wondering if I gave the night dose or just dreamed I did." (Mother of 8-year-old girl, Ankara)*

*Subtheme 2.3: Follow-up and Monitoring Challenges*

Regular monitoring appointments posed significant logistical and financial challenges, particularly for families traveling from distant regions.

*"Every three months, we travel 600 km to Istanbul for a 15-min appointment. We stay overnight because appointments are early, which means missing work, arranging care for our other children, and spending money we don't really have on hotels. But what choice do we have?" (Father of 11-year-old boy, Van)*

*"The appointments themselves are stressful because measuring pressure in young children is difficult. Sometimes we make this long journey only to be told they couldn't get an accurate reading and we should come back in a few weeks. It's frustrating but necessary." (Mother of 3-year-old girl, Antalya)*

### *Theme 3: navigating the healthcare system: structural barriers and facilitators*

*Subtheme 3.1: Geographical and Specialist Access Disparities*

A stark contrast emerged between families in major urban centers and those in more remote areas regarding access to specialist care. While Turkey's health system provides universal coverage, the concentration of pediatric glaucoma expertise in a few major centers created significant access barriers.

*"In Istanbul, we're fortunate. We can reach our glaucoma specialist within 45 min. When we had an emergency—his eye was very red and painful—we received care immediately." (Mother of 6-year-old boy, Istanbul)*

*"When his pressure spiked and his eye was red and hard, our local hospital couldn't help. They said we needed to go to Istanbul, but that's an 8-h drive. Those hours on the road, with him in pain, were excruciating. We need more specialists in the eastern regions." (Mother of 5-year-old boy, Diyarbakır)*

*Subtheme 3.2: Financial Burden Despite Universal Coverage*

**Table 3** Medication management strategies reported by parents

| Strategy | Description | Number of Parents Reporting ($n = 22$) |
|---|---|---|
| Technology-assisted reminders | Using smartphone alarms, medication tracking apps, or electronic calendars to schedule doses | 16 (72.7%) |
| Visual aids and charts | Creating visual schedules, charts with stickers, or color-coded systems to track administration | 12 (54.5%) |
| Distraction techniques | Using toys, videos, or games to distract child during administration | 14 (63.6%) |
| Physical restraint methods | Swaddling, "burrito method," or having one parent hold while other administers drops | 9 (40.9%) |
| Reward systems | Sticker charts, small treats, or privileges following successful administration | 11 (50.0%) |
| Family involvement | Distributing responsibility among multiple family members | 8 (36.4%) |
| Teaching self-administration | Training older children to administer their own medications | 5 (22.7%) |
| Environmental adaptations | Creating consistent medication "stations" or routines | 10 (45.5%) |

While Turkey's universal health insurance covers most direct medical costs, parents reported significant out-of-pocket expenses and indirect costs that strained family finances.

> *"The surgeries and most medications are covered, yes. But some of the newer drops aren't fully covered, and those can cost 300–400 lira per bottle. Then there's transportation to Istanbul, hotels, meals, and lost wages from missing work. Each specialist visit costs us around 2,000 lira beyond what insurance covers." (Father of 13-year-old girl, Kayseri)*

> *"I had to reduce my working hours to manage his care, which means less income. His father works extra shifts to compensate. The financial stress compounds the emotional stress." (Mother of 8-year-old boy, Samsun)*

*Subtheme 3.3: Coordination and Continuity of Care Challenges*

Parents described difficulties navigating fragmented care systems, particularly when their children needed multidisciplinary support beyond ophthalmology.

> *"Besides glaucoma, she has developmental delays. We see ophthalmologists, neurologists, physiotherapists, and developmental specialists. None of these departments communicate with each other. I'm the one carrying information between them, explaining everything repeatedly." (Mother of 4-year-old girl, Eskişehir)*

> *"We've seen four different glaucoma specialists in three years because doctors keep moving between hospitals. Each new doctor wants to change the treatment approach, which is confusing and frustrating. There's no continuity." (Father of 9-year-old boy, Ankara)*

#### *Theme 4: impact on family life: adjustments, limitations, and emotional tolls*

*Subtheme 4.1: Educational and Social Integration Challenges*

Parents of school-aged children reported varying experiences with educational accommodations and social integration, often dependent on school resources and administrative support.

> *"Her teacher has been amazing, arranging for special lighting, enlarged materials, and seating at the front. But the physical education teacher excludes her from activities 'for her protection,' which is unnecessary and makes her feel different." (Mother of 12-year-old girl, Istanbul)*

> *"We moved from our village to Ankara specifically for better schools that could accommodate his visual needs. It meant leaving our support network behind, but his education had to come first." (Father of 10-year-old boy, formerly from rural Central Anatolia)*

Several parents described the social stigma their children faced, particularly in communities with limited exposure to childhood disability.

> *"Children can be cruel. They called him 'strange eyes' because of his enlarged corneas. The school did nothing until we escalated to the district education office. Now they have disability awareness programs, but the damage to his confidence was already done." (Mother of 11-year-old boy, mid-sized Aegean city)*

#### *Theme 5: coping and resilience: finding strength amid challenges*

Parents employed various coping strategies to manage the ongoing challenges of their child's condition. The frequency of different coping mechanisms reported by parents is presented in Table 4.

#### *Theme 6: Unmet needs and recommendations for system improvement*

Parents identified several critical gaps in the current care system and offered recommendations for improvements based on their experiences. These centered around psychological support, information resources, and structural changes to the healthcare system.

> *"No one ever asked how I was coping emotionally with all of this. When I mentioned feeling depressed and overwhelmed to our ophthalmologist, he acknowledged it was normal but had no resources to offer. Mental health should be part of glaucoma care." (Mother of 6-year-old girl, Istanbul)*

> *"Most of the reliable information online is in English. We need Turkish resources written for parents, explaining everything from the basics of the condition to what each surgical option means." (Mother of 9-month-old baby, Ankara)*

> *"Turkey needs a hub-and-spoke model for pediatric glaucoma. Specialists from centers like Istanbul should regularly visit regional hospitals to build capacity and reduce the need for families to travel." (Mother of 11-year-old boy, Gaziantep)*

> *"For routine pressure checks, we should be able to use telehealth. There's technology to measure eye*

**Table 4** Coping mechanisms reported by parents

| Coping Mechanism | Description | Number of Parents Reporting ($n=22$) | Representative Quote |
|---|---|---|---|
| Religious faith and practices | Prayer, scripture reading, religious community support | 18 (81.8%) | "Every surgery, every setback, I find strength in prayer. Our mosque community has been incredibly supportive." |
| Peer support networks | Online support groups, parent-to-parent mentoring | 17 (77.3%) | "The WhatsApp group of glaucoma parents has been more valuable than any medical resource." |
| Information seeking | Researching condition, treatments, and resources | 15 (68.2%) | "I've become an expert on glaucoma. Knowledge gives me a sense of control in an uncontrollable situation." |
| Focusing on positives | Gratitude practices, celebrating small victories | 14 (63.6%) | "We celebrate every stable pressure reading, every successful day at school. You learn to find joy in what others take for granted." |
| Professional psychological support | Therapy, counseling, psychiatry | 5 (22.7%) | "I started therapy last year. It's helped me process the grief and anxiety that comes with this journey." |
| Advocacy activities | Participating in awareness campaigns, support group leadership | 7 (31.8%) | "Advocating for better glaucoma care gives purpose to our struggles. My pain becomes meaningful when it helps other families." |
| Compartmentalization | Creating mental and temporal boundaries around glaucoma care | 10 (45.5%) | "We have 'glaucoma days' for appointments and 'normal family days' when we try not to talk about the condition." |
| Maintaining normalcy | Ensuring child participates in regular activities despite condition | 16 (72.7%) | "We've adapted his activities, but we never use his eyes as an excuse to limit his life. He plays sports, goes to camp—just with some modifications." |

*pressure at home now. Turkey should invest in this to reduce the travel burden on families." (Father of 7-year-old girl, Trabzon)*

*"There should be a special allowance for families managing chronic childhood conditions like glaucoma—something that recognizes the ongoing transportation costs, accommodations for appointments, and lost work time." (Mother of 4-year-old boy, rural Western Turkey)*

## Discussion

The study highlights several key findings from the experiences of parents navigating the complex terrain of pediatric glaucoma care in Turkey. One of the most striking aspects was the significant diagnostic delay and emotional burden faced by families. Many parents reported long diagnostic journeys, particularly those in rural areas, where delays in diagnosis compounded emotional distress. As these parents navigated the uncertainty of their child's condition, they frequently encountered gaps in available information and support. This finding mirrors previous studies where delayed diagnoses of pediatric glaucoma have been linked to worse visual outcomes [2].

The challenges within Turkey's healthcare system also emerged prominently. Despite universal health coverage, families faced barriers in accessing specialized care, particularly in rural areas. This lack of access was compounded by logistical and financial barriers, including the high cost of medications not covered by insurance and the significant travel required for specialist visits. These issues reflect similar challenges identified in other middle-income countries, where healthcare access is often uneven [5].

Family-centered care also emerged as a key theme. Parents emphasized the need for greater emotional and psychological support throughout their child's journey, both at diagnosis and during treatment. Despite the resilience and coping strategies demonstrated by parents, such as peer support groups and religious practices, the lack of systemic psychological support was a significant gap in the healthcare experience. These findings align with those of Dahlmann-Noor et al. [4], who documented the emotional toll of pediatric glaucoma on families, underscoring the necessity of integrating psychological care into glaucoma management.

Lastly, the resilience of parents in the face of these challenges was evident throughout the study. Parents showed remarkable strength and adaptability, drawing on a range of coping mechanisms including peer support, religious faith, and maintaining a semblance of normalcy in their children's lives. However, these coping strategies were

often not enough to mitigate the systemic issues that hampered their children's care, highlighting a need for structural improvements within the healthcare system.

Our findings resonate with existing literature on pediatric glaucoma, particularly in terms of the emotional toll and treatment burdens experienced by families. Khitri et al. [2] found that families of children with glaucoma experience significant challenges in managing complex care regimens, a theme echoed in our study, where medication management and the emotional strain of repeated surgeries were common concerns. Furthermore, Moschos et al. [1] identified the importance of early detection in improving visual outcomes, a concept also reflected in the parental narratives in our study, where diagnostic delays were linked to worsened prognoses.

When comparing our results to adult glaucoma literature, there are distinct differences. The adult glaucoma experience is often more focused on individual management of the disease, with less emphasis on the broader family impact. In contrast, pediatric glaucoma is a family-centered condition, where the parent's emotional burden, financial strain, and logistical challenges are central to the disease trajectory. This distinction highlights the need for a more nuanced approach to managing pediatric glaucoma that accounts for the psychological and social dimensions of care [4].

Globally, studies on pediatric glaucoma experiences have been limited, with most focusing on high-income countries with more established healthcare systems. A study by Alrasheed [9] found that in Africa, families similarly faced challenges related to delayed diagnosis, limited access to treatment, and a lack of psychological support, further underscoring the universality of these issues in low-resource settings. This is the first study of its kind in Turkey, offering a unique perspective from a middle-income country. The findings are particularly relevant for other low- and middle-income countries (LMICs) with similar healthcare challenges, where access to specialized care is often constrained by financial and geographic barriers [5].

The findings of this study have several important implications for the clinical management of pediatric glaucoma. First, the need for multidisciplinary pediatric glaucoma care teams is critical. As parents often navigate multiple specialists and healthcare providers, coordinated care is essential to streamline the diagnostic and treatment processes. In addition, family-centered care models should be prioritized, ensuring that psychological support and parent education are integral components of the care plan. The provision of clear, accessible information at the time of diagnosis, coupled with ongoing education, would help mitigate some of the emotional distress parents face [4].

Teleophthalmology could also play a crucial role in alleviating the burden of travel for rural families. With technological advancements, remote monitoring tools for intraocular pressure measurement could reduce the need for frequent travel to specialized centers, improving access to care while lowering financial and logistical barriers. The integration of telemedicine for routine follow-up appointments could significantly improve the quality of life for families, as suggested by the recommendations of several parents in our study.

Furthermore, psychological support programs for parents should be developed and integrated into pediatric glaucoma care. Given the significant emotional toll highlighted in our findings, providing parents with access to mental health resources, peer support groups, and counseling services could help reduce the burden of care and improve overall family well-being. Previous studies have highlighted the positive impact of psychological support for parents of children with chronic conditions [10], suggesting its potential value in pediatric glaucoma care.

Structured peer mentorship programs represent another promising intervention that could address multiple challenges identified in our study. Such programs, which have been successfully implemented in some pediatric glaucoma centers in high-income countries, systematically connect newly diagnosed families with experienced parents who have navigated similar journeys. These programs could be particularly valuable in the Turkish context, where our findings show that informal peer support through WhatsApp groups and social media already plays a crucial role in parental coping. Formalizing these connections through structured mentorship could ensure that all families, regardless of their access to technology or social networks, receive peer support. Mentorship programs could be organized based on factors such as the child's age, glaucoma type, geographic region, and language preferences, ensuring relevant and culturally appropriate support. The implementation of such programs in Turkey could build upon existing parent networks while addressing the isolation and information gaps that many families experience, particularly during the initial diagnosis period.

This study provides important insights into the experiences of families managing pediatric glaucoma in Turkey, offering a rich and diverse dataset from both urban and rural areas. One of the key strengths of the study is its qualitative approach, which allows for a nuanced understanding of the challenges faced by parents. The inclusion of participants from various geographical regions and socioeconomic backgrounds enhances the generalizability of the findings within Turkey.

However, the study also has several limitations. First, the single-country context limits the ability to generalize

the findings to other settings, particularly those with different healthcare systems. Additionally, while the study aimed for diversity in participant selection, there may be sampling biases related to the voluntary nature of participation, as those with greater access to technology or support networks may have been more likely to participate. Finally, the use of online interviews, while practical and necessary given the geographical dispersion of participants, may have limited the depth of emotional expression compared to in-person interviews.

## Conclusion

This qualitative study provides the first in-depth exploration of how parents in Turkey experience and navigate the complex challenges of caring for a child with pediatric glaucoma. Our findings reveal that pediatric glaucoma impacts families far beyond the clinical management of the condition itself, affecting family dynamics, financial stability, emotional wellbeing, and social functioning. Parents demonstrate remarkable resilience in the face of significant healthcare system barriers, developing sophisticated coping strategies and support networks to manage their children's care.

The study highlights several critical gaps in the current care model for pediatric glaucoma in Turkey. Geographic disparities in access to specialized care create significant barriers for families in rural and eastern regions, often resulting in diagnostic delays and treatment challenges. Despite universal health coverage, the substantial indirect costs associated with specialized care—including transportation, accommodation, and lost wages—place considerable financial strain on families. Furthermore, the absence of integrated psychological support and Turkish-language information resources leaves many parents struggling to manage the emotional burden of their child's condition without adequate guidance or assistance.

These findings call for a comprehensive, family-centered approach to pediatric glaucoma care that addresses both clinical and psychosocial dimensions. Implementing teleophthalmology services for routine monitoring, developing regional expertise through hub-and-spoke models, integrating psychological support into standard care protocols, creating accessible educational resources in Turkish, and establishing structured peer mentorship programs could significantly improve the experience of affected families. Peer mentorship programs, which connect newly diagnosed families with experienced parents, could help address the social isolation and information needs identified in this study while building upon the informal support networks that parents already value highly. Additionally, policy considerations should include financial support mechanisms that acknowledge the ongoing indirect costs borne by families managing chronic childhood conditions.

Pediatric glaucoma affects not only vision but the entire fabric of family life. By listening to parental voices and responding to their identified needs, healthcare providers and policymakers have an opportunity to develop care models that better support families throughout their challenging journey. Future research should explore the experiences of the affected children themselves and evaluate interventions designed to address the systemic challenges identified in this study. Through such efforts, we can work toward a healthcare system that truly addresses the multifaceted impact of pediatric glaucoma and supports the resilience already demonstrated by these remarkable families.

## Supplementary Information

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Supplementary Material 1.

### Authors' contributions

CYE: Conceptualization, Methodology, Validation, Investigation, Resources, Data Curation, Writing – Initial Draft, Supervision, Visualization. CE: Methodology, Formal analysis, Writing - Review & Editing.

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### Data availability

Qualitative data is available upon request from the corresponding author.

## Declarations

### Ethics approval and consent to participate

We confirmed that informed consent was obtained from all participants' legal guardians. All the families had been informed that participation in the study was voluntary and anonymous, the researcher would keep the study confidential, and the final report of the study would only contain analysis of the data with de-identifiable information. This study has been approved by the AUBG Human Subjects Review Committee (Protocol no: 20240104YEL). And all methods were carried out in accordance with relevant guidelines and regulations including the Declaration of Helsinki.

### Consent for publication

All authors and participants who took part in the study give consent to publication of the study.

### Competing interests

The authors declare no competing interests.

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