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# PEDIATRIC KERATOCONUS: A SCOPING REVIEW OF ITS EPIDEMIOLOGY, DIAGNOSTIC APPROACHES, THERAPEUTIC STRATEGIES, AND PSYCHOSOCIAL CONSEQUENCES

Scoping Review (ID: 1701)

**Dr. Muhammad Kashif**[1]*
[1]Assistant Professor Optometry, Ophthalmology Department, Hayatabad Medical Complex, Peshawar
**Corresponding Author:** Dr. Muhammad Kashif, drkashif@mtihmc.edu.pk, Assistant Professor Optometry, Ophthalmology Department, Hayatabad Medical Complex, Peshawar
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## ABSTRACT

**Background:** Pediatric keratoconus is a progressive corneal ectatic disorder affecting children and adolescents, with earlier onset, faster progression, and greater disease severity than adult-onset keratoconus. Advances in corneal imaging have improved detection of subclinical disease and revealed a higher disease burden than previously recognized. Although corneal collagen cross-linking has changed clinical management, evidence remains scattered across epidemiology, diagnosis, treatment, psychosocial outcomes, and economic impact.

**Objective:** This scoping review aimed to map the available evidence on pediatric keratoconus and identify major research themes, knowledge gaps, and future priorities related to epidemiology, diagnostic approaches, therapeutic strategies, and psychosocial consequences.

**Methods:** This review was conducted according to the PRISMA-ScR framework and guided by the Joanna Briggs Institute methodology for scoping reviews. Eligible studies included children and adolescents aged 18 years or younger diagnosed with keratoconus. English-language publications from January 1998 to December 2025 were searched in PubMed/MEDLINE, Scopus, and the Cochrane Database of Systematic Reviews. Studies of any design were considered if they reported epidemiological data, diagnostic methods, treatment outcomes, psychosocial findings, economic burden, or quality-of-life outcomes. Data were charted using a standardized extraction framework and synthesized narratively.

**Results:** The search identified 1,802 records. After removal of duplicates, 777 articles were screened, 97 full-text articles were assessed for eligibility, and 76 studies were included. Reported prevalence varied widely, with estimates reaching 1 in 251 confirmed cases and 1 in 72 when suspected cases were included. School-based studies reported prevalence values of 626 per 100,000 children and 3.6% in selected populations. Corneal cross-linking demonstrated disease stabilization in more than 80% of treated pediatric cases, including evidence from 2,186 eyes across 35 studies. However, progression criteria, imaging parameters, follow-up duration, and outcome measures varied substantially. Psychosocial, educational, caregiver-related, and economic outcomes were limited.

**Conclusion:** Pediatric keratoconus is an important childhood eye condition requiring early detection, standardized monitoring, timely treatment, and broader patient-centered assessment. Future research should strengthen population-based screening, harmonize progression criteria, and evaluate long-term clinical, psychosocial, and economic outcomes.

**Keywords:** Adolescent; Child; Corneal Cross-Linking; Corneal Topography; Epidemiology; Keratoconus; Quality of Life.

 

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## INTRODUCTION

Keratoconus is a bilateral, progressive, non-inflammatory ectatic disorder of the cornea characterized by stromal thinning, anterior corneal protrusion, and progressive distortion of normal corneal architecture (1–3). These structural changes commonly result in irregular astigmatism, myopic shift, higher-order optical aberrations, and gradual decline in visual acuity. Although keratoconus was previously considered an uncommon ocular disorder, its reported frequency has increased substantially with the wider use of corneal topography, tomography, pachymetry, and advanced anterior segment imaging, which allow earlier detection of subtle and subclinical disease (4). Pediatric keratoconus, defined by onset during childhood or adolescence, is now recognized as a clinically important and distinct form of the disease because it often differs from adult keratoconus in its pattern of presentation, rate of progression, severity at diagnosis, and long-term visual consequences. In children and adolescents, keratoconus tends to progress more rapidly than in adults and is frequently diagnosed at a more advanced stage. This accelerated course is clinically significant because the pediatric cornea may undergo faster biomechanical weakening, leading to increasing corneal steepening, thinning, irregular astigmatism, and reduced best-corrected visual acuity over a relatively short period. Delayed recognition may expose the child to avoidable visual disability, amblyogenic risk, repeated changes in refractive correction, contact lens intolerance, and a greater likelihood of severe complications such as acute corneal hydrops. In advanced or untreated cases, surgical intervention, including deep anterior lamellar keratoplasty or penetrating keratoplasty, may ultimately be required. Therefore, early identification, close monitoring, and timely intervention are central to preserving vision and reducing the burden of disease in pediatric patients (1–3,5).

The clinical burden of pediatric keratoconus extends beyond the cornea. Because childhood and adolescence are critical periods for visual development, education, social interaction, and psychological maturation, progressive visual impairment may interfere with school performance, reading ability, daily activities, self-confidence, social participation, and overall quality of life. Children with keratoconus may experience difficulty coping with blurred or fluctuating vision, dependence on spectacles or contact lenses, anxiety regarding disease progression, and concerns related to treatment procedures. Families may also face emotional, logistical, and financial challenges associated with repeated clinical visits, imaging assessments, optical correction, and surgical or procedural management. Despite these important consequences, psychosocial, educational, economic, and health-related quality-of-life outcomes remain less frequently investigated than clinical and anatomical outcomes. The diagnosis of pediatric keratoconus requires a high index of suspicion, particularly in children presenting with progressive myopia, increasing astigmatism, frequent changes in spectacle prescription, reduced visual acuity not fully corrected by refraction, eye rubbing, allergic eye disease, or a family history of keratoconus. Modern diagnostic approaches rely on a combination of clinical examination, retinoscopy, slit-lamp findings, corneal topography, Scheimpflug tomography, pachymetric mapping, epithelial thickness assessment, and biomechanical evaluation where available. However, diagnosis and follow-up in pediatric populations may be challenging because early disease can be subtle, cooperation during imaging may be variable, and universally accepted pediatric-specific progression criteria are still lacking. These challenges can contribute to inconsistent monitoring practices and delayed treatment decisions.

Management of pediatric keratoconus aims to improve visual function, halt or slow disease progression, and prevent irreversible corneal damage. Visual rehabilitation may include spectacles in early disease, rigid gas-permeable lenses, scleral lenses, hybrid lenses, or other specialty contact lenses in more irregular corneas. Among disease-modifying treatments, corneal collagen cross-linking has become a major therapeutic option because of its ability to strengthen corneal stromal tissue and reduce the risk of further ectatic progression. However, the pediatric population presents unique considerations, including rapid progression, younger age at treatment, corneal thickness limitations, epithelial healing, long-term stability, safety, retreatment needs, and uncertainty regarding the most appropriate timing and protocol. Although several reviews have evaluated the efficacy and safety of corneal collagen cross-linking in children, the broader evidence surrounding pediatric keratoconus remains distributed across epidemiological studies, diagnostic research, interventional studies, case series, and limited patient-centered investigations (6). A comprehensive mapping of the literature is therefore needed to clarify what is currently known about pediatric keratoconus and where important knowledge gaps remain. Existing evidence suggests variability in reported prevalence and incidence, differences in risk factor assessment, inconsistency in diagnostic and progression criteria, and limited attention to psychosocial and economic outcomes (2,7). A scoping review is particularly appropriate for this field because pediatric keratoconus involves several interconnected domains, including epidemiology, risk profiling, diagnostic evaluation, clinical monitoring, optical rehabilitation, procedural treatment, surgical management, and quality-of-life consequences. Unlike a narrowly focused systematic review, a scoping review allows the available evidence to be systematically identified, organized, and summarized across diverse methodologies and outcome measures.

This scoping review therefore aims to examine the current body of evidence on pediatric keratoconus by mapping its epidemiology, associated risk factors, diagnostic approaches, therapeutic strategies, and psychosocial consequences. Particular attention is given to the role of early detection, the challenges of monitoring disease progression in children, the effectiveness and limitations of corneal collagen cross-linking, and the underexplored impact of the condition on education, psychological well-being, family burden, and quality of life. By synthesizing evidence across these domains, the review seeks to support more informed clinical decision-making, highlight gaps requiring further investigation, and guide future research toward a more comprehensive and patient-centered understanding of pediatric keratoconus.

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## 2. METHODS

### 2.1 Protocol and Reporting Framework

This scoping review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews framework and was methodologically guided by the Joanna Briggs Institute Manual for Evidence Synthesis for scoping reviews (8). The review approach was developed before the commencement of the study to ensure methodological consistency, transparency, and reproducibility. The protocol defined the review question, eligibility criteria, search sources, study selection process, data charting procedure, and method of synthesis. As the purpose of the review was to map the breadth and nature of available evidence rather than to estimate pooled treatment effects, the methodology was designed to include diverse forms of evidence relevant to pediatric keratoconus.

### 2.2 Research Question and PCC Framework

The research question was structured using the Population–Concept–Context framework, which is recommended for scoping reviews because it allows broad and systematic exploration of evidence across complex clinical topics (8). The population of interest comprised children and adolescents aged 18 years or younger with a diagnosis of keratoconus. The concept included epidemiology, diagnostic evaluation, clinical management, therapeutic outcomes, psychosocial impact, economic burden, and health-related quality-of-life consequences. The context was intentionally broad and included all healthcare settings and geographical regions in order to capture evidence from different clinical environments and populations. The primary research question was: what evidence is currently available regarding the epidemiology, diagnosis, management strategies, and psychosocial impact of pediatric keratoconus?

### 2.3 Eligibility Criteria

Studies were considered eligible if they included pediatric participants aged 18 years or younger diagnosed with keratoconus and reported findings related to epidemiology, risk factors, diagnostic assessment, disease monitoring, treatment outcomes, psychosocial consequences, economic burden, or quality of life. A broad range of study designs was considered, including cohort studies, cross-sectional studies, case series, randomized and non-randomized clinical trials, qualitative studies, and relevant systematic reviews. Articles were included if they were published in the English language between January 1998 and December 2024 and if the full text was available for assessment. Studies were excluded if they focused exclusively on adult populations older than 18 years, did not provide pediatric-specific findings, or reported keratoconus data in mixed-age samples without separable pediatric outcomes. Case reports involving fewer than five participants were excluded to reduce the influence of isolated clinical observations. Conference abstracts without accessible full-text manuscripts, editorials, commentaries, expert opinions, correspondence, and publications lacking original or extractable research data were also excluded. These criteria were applied to ensure that the review included evidence with sufficient relevance and detail for meaningful mapping of pediatric keratoconus.

### 2.4 Search Strategy

A comprehensive literature search was undertaken to identify studies addressing the epidemiology, diagnosis, management, and psychosocial or economic impact of pediatric keratoconus. The search strategy was developed in accordance with the Population–Concept–Context (PCC) framework recommended for scoping reviews and was guided by the Joanna Briggs Institute methodology and the PRISMA Extension for Scoping Reviews (PRISMA-ScR). The following electronic databases were searched: PubMed/MEDLINE, Scopus, and the Cochrane Database of Systematic Reviews. Searches were limited to studies published in English between 1 January 1998 and 31 December 2024. No restrictions were placed on study design. Both controlled vocabulary terms, where applicable, and free-text keywords were used. Search terms included variations of keratoconus, child, adolescent, pediatric/paediatric, epidemiology, prevalence, incidence, diagnosis, corneal topography, corneal tomography, optical coherence tomography, cross-linking, contact lenses, keratoplasty, quality of life, psychosocial, and economic burden.

To maximize retrieval, the reference lists of all included studies and relevant review articles were also hand-searched for additional eligible studies. All records retrieved from the database searches were imported into a reference management system, where duplicate citations were identified and removed before screening. Two reviewers independently screened titles and abstracts against the predefined eligibility criteria. Potentially relevant studies then underwent full-text review. Disagreements at any stage of study selection were resolved through discussion and, where necessary, consultation with a third reviewer.

### 2.5 Study Selection

The study selection process followed the PRISMA-based approach and involved identification, screening, eligibility assessment, and final inclusion of studies (8). All records retrieved from database searches were first compiled, and duplicate citations were removed. The remaining records were screened by title and abstract against the predefined eligibility criteria. Articles considered potentially relevant were then retrieved in full text and assessed for final eligibility. Two reviewers independently performed the screening and

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selection process to reduce selection bias and improve consistency. Disagreements between reviewers were resolved through discussion and consensus. When consensus could not be reached, a third reviewer was consulted. Studies that fulfilled all eligibility criteria were included in the final synthesis. The selection process should be presented in the final manuscript using a PRISMA flow diagram to show the number of records identified, screened, excluded, assessed in full text, and included in the review.

### 2.6 Data Charting

Data were extracted using a predefined and standardized charting form developed in line with the objectives of the review. The charting process captured key information from each included study, including author name, year of publication, country, study design, sample size, participant age, sex distribution, ethnicity where reported, diagnostic criteria, clinical setting, and follow-up duration where applicable. Data related to epidemiology, prevalence, incidence, risk factors, diagnostic methods, disease progression, treatment interventions, clinical outcomes, complications, psychosocial impact, economic burden, and health-related quality-of-life measures were also extracted. The data charting process was performed systematically to ensure that comparable information was collected across different study designs. Extracted information was reviewed for completeness and consistency, and any uncertainty in data interpretation was resolved through discussion among reviewers. Because the review aimed to map the available evidence rather than perform a formal effectiveness comparison, the extracted data were organized descriptively according to the main domains of interest.

### 2.7 Data Synthesis

A narrative and thematic synthesis was undertaken because the included studies were expected to vary in design, population characteristics, diagnostic criteria, interventions, follow-up duration, and outcome measures. Quantitative pooling was not performed because meta-analysis was not aligned with the mapping objective of the scoping review and because methodological heterogeneity across studies was anticipated. Formal risk-of-bias appraisal was also not undertaken, as critical appraisal is not mandatory for scoping reviews unless it is specifically required by the review objective. The included evidence was grouped into major thematic areas, including epidemiology and associated risk factors, diagnostic approaches and monitoring challenges, treatment strategies and clinical outcomes, psychosocial and economic consequences, and gaps requiring future research. Findings were summarized descriptively to present the extent, nature, and distribution of available evidence on pediatric keratoconus. This approach allowed the review to identify well-studied areas, under-researched domains, inconsistencies in existing literature, and priorities for future clinical and research development.

**Table 1. Characteristics of included studies**

| Study | Country/Setting | Study design | Population/ Focus | Main domain | Key findings relevant to the review |
|---|---|---|---|---|---|
| Buzzonetti et al. (2020) | International | Literature review | Children with keratoconus | Background/clinical profile | Pediatric keratoconus was described as more aggressive than adult-onset disease, with earlier progression and greater severity at presentation. |
| Hansen et al. (2024) | International | Systematic scoping review | Pediatric keratoconus epidemiology | Epidemiology | Summarized available epidemiological evidence and highlighted variation in prevalence estimates and risk factors. |
| Mukhtar and Ambati (2018) | International | Review article | Pediatric keratoconus | Diagnosis/management | Reviewed disease characteristics, diagnostic issues, and treatment options in children. |
| Price and Larkin (2023) | International | Narrative review | Paediatric keratoconus | Diagnosis/management | Discussed current evidence for diagnosis and management in the pediatric age group. |
| Wagner et al. (2007) | United States | Longitudinal clinical study | Keratoconus patients | Epidemiology/clinical findings | Contributed background clinical and epidemiological data relevant to keratoconus assessment. |
| Mzyece et al. (2022) | Zimbabwe | School-based screening study | Schoolchildren | Epidemiology | Reported a prevalence of 626 per 100,000 children in a school-based population. |

| | | | | | |
|---|---|---|---|---|---|
| Gokhale (2013) | India | Epidemiological report | School-age population | Epidemiology | Reported population-level epidemiological observations relevant to keratoconus burden in India. |
| Assiri et al. (2005) | Saudi Arabia | Epidemiological study | General population | Epidemiology | Reported high incidence/severity patterns, supporting greater burden in Middle Eastern populations. |
| Hashemi et al. (2013) | Iran | Population-based study | General population | Epidemiology | Provided prevalence data contributing to estimates from Middle Eastern populations. |
| Sahebjada et al. (2021) | International | Systematic review and meta-analysis | Eye rubbing and keratoconus | Risk factors | Identified eye rubbing as an important and consistent risk factor in keratoconus. |
| Zehra et al. (2024) | Pakistan | Observational study | Patients with VKC | Risk factors | Reported an association between vernal keratoconjunctivitis and keratoconus. |
| Chatzis and Hafezi (2012) | Switzerland/International | Clinical study | Children and adolescents with progressive keratoconus | Treatment/CXL | Reported that corneal collagen cross-linking helped slow progression in pediatric patients. |
| Chan et al. (2015) | Hong Kong | Clinical study | Mild-to-moderate and advanced keratoconus | Treatment/CXL | Showed topographic response after accelerated CXL and noted variation by disease severity. |
| Lim and Lim (2020) | International | Review article | Contact lens management in keratoconus | Contact lenses | Reviewed current contact lens approaches and their role in visual rehabilitation. |
| Kandel et al. (2020) | International | Review article | Keratoconus and quality of life | Psychosocial/QoL | Summarized the effect of keratoconus on vision-related quality of life. |
| Rafizadeh et al. (2025)* | International | Comprehensive review | Keratoconus and quality of life | Psychosocial/QoL | Discussed the broader quality-of-life impact of keratoconus. |
| Ahmad et al. (2023) | International | Observational study | Socioeconomic correlates of keratoconus | Economic impact | Explored socioeconomic correlates of severity and progression. |
| Chan et al. (2020) | International | Economic study | Patients with keratoconus | Economic impact | Reported the economic burden of keratoconus from the patient perspective. |

**Table 2. Data-charting framework used for included studies**

| Domain | Data item | Description / coding instructions |
|---|---|---|
| Identification | Study ID | Assign a unique study number for each included study |
| Identification | Full citation | Author(s), year, title, journal |
| Bibliographic details | Year of publication | Record publication year |

| | | |
|---|---|---|
| Bibliographic details | Country/region | Country in which the study was conducted |
| Study characteristics | Study design | Cross-sectional, cohort, case-control, clinical trial, case series, qualitative study, systematic review, etc. |
| Study characteristics | Setting | Hospital-based, clinic-based, school-based, population-based, multicenter, etc. |
| Population | Sample size | Total number of participants and/or eyes studied |
| Population | Age group | Mean age, age range, confirmation that participants were ≤18 years |
| Population | Sex distribution | Male/female distribution, if reported |
| Population | Relevant comorbidities/risk factors | VKC, atopy, eye rubbing, family history, consanguinity, etc. |
| Clinical focus | Primary topic/domain | Epidemiology, diagnosis, treatment, psychosocial impact, economic burden |
| Epidemiology | Prevalence/incidence data | Record prevalence, incidence, or distribution estimates if reported |
| Epidemiology | Risk factors | Record factors associated with disease occurrence or progression |
| Diagnosis | Diagnostic modality | Topography, tomography, Pentacam, Orbscan, OCT, slit-lamp, etc. |
| Diagnosis | Diagnostic criteria/findings | Kmax, pachymetry, posterior elevation, corneal thinning, etc. |
| Treatment | Intervention type | CXL, spectacles, contact lenses, keratoplasty, ICRS, other |
| Treatment | CXL protocol | Conventional/Dresden, accelerated, transepithelial, bilateral/simultaneous, etc. |
| Treatment | Follow-up duration | Duration of follow-up after intervention |
| Treatment outcomes | Clinical outcomes | Visual acuity, Kmax, pachymetry, progression stabilization, complications |
| Psychosocial outcomes | Quality-of-life measures | Vision-related QoL, educational effects, mental well-being, social function |
| Economic outcomes | Cost/burden | Direct costs, indirect costs, caregiver burden, healthcare utilization |
| Synthesis | Key findings | Short summary of the study's most relevant findings |
| Synthesis | Authors' conclusions | Main conclusion as reported by the study authors |
| Review notes | Reviewer comments | Notes on relevance, limitations, or issues for synthesis |

## 3. RESULTS

### 3.1 Study Selection and General Characteristics of Included Evidence

The database search identified 1,802 records across PubMed/MEDLINE, Scopus, and the Cochrane Database of Systematic Reviews. After removal of 1,025 duplicate records, 777 articles were screened by title and abstract. Of these, 97 articles were considered potentially relevant and were retrieved for full-text assessment. Following full-text evaluation, 76 studies fulfilled the predefined eligibility criteria and were included in the final scoping review. The included studies represented a broad and geographically diverse body of evidence, with publications originating from North America, Europe, Asia, the Middle East, and Africa. This distribution highlighted the global relevance of pediatric keratoconus while also showing that the reported disease burden varied substantially across populations and diagnostic settings. The included evidence comprised population-based screening studies, school-based epidemiological investigations, hospital-based observational cohorts, cross-sectional studies, clinical trials, interventional studies assessing corneal collagen cross-linking, surgical case series, contact lens studies, and a smaller number of studies examining vision-related quality of life

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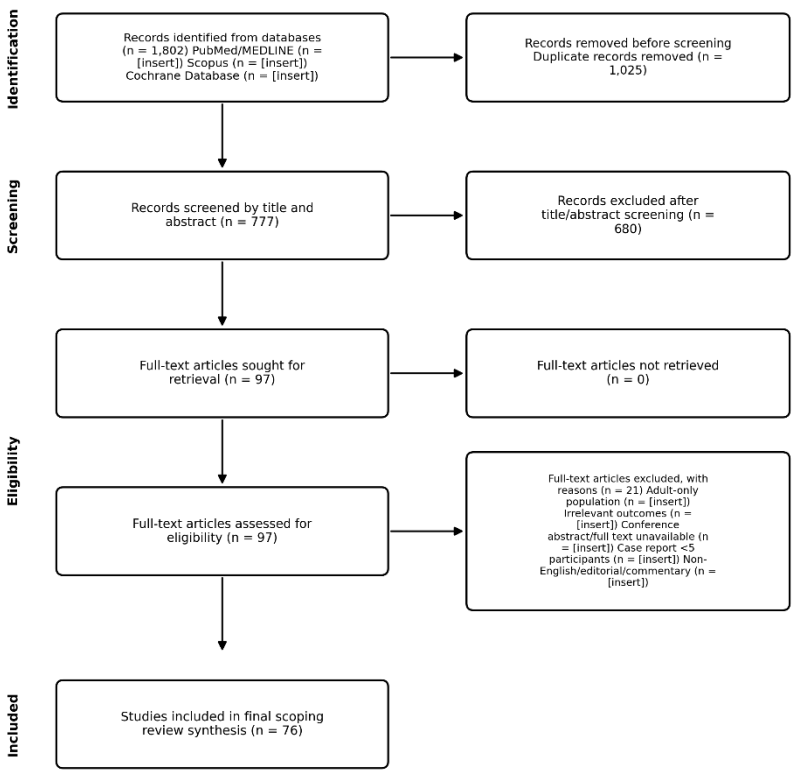
and psychosocial outcomes. Most studies focused on clinical diagnosis, disease progression, corneal imaging parameters, or treatment outcomes, whereas comparatively fewer studies addressed psychosocial burden, educational impact, caregiver challenges, or economic consequences. Overall, the evidence base was clinically rich but methodologically heterogeneous, with considerable variation in study design, population age range, diagnostic criteria, imaging modality, treatment protocol, follow-up duration, and outcome measures.

**Figure 1. PRISMA flow diagram of study selection**




### 3.2 Epidemiology and Risk Factors

The epidemiological evidence showed that pediatric keratoconus is likely more common than previously estimated, particularly when modern corneal imaging techniques are used for screening and diagnosis. Earlier estimates traditionally described keratoconus as affecting approximately 1 in 2,000 individuals in the general population (2,5,7). However, more recent studies using advanced diagnostic technologies, including corneal topography and Scheimpflug-based tomography, have reported substantially higher prevalence rates in children and adolescents (9). This shift suggests that older estimates may have underestimated the true burden of disease because early or subclinical cases were less likely to be detected using conventional clinical examination alone. Population-based and school-based studies demonstrated wide variation in prevalence across different regions. A school-age vision clinic study from Chicago reported confirmed keratoconus in approximately 1 in 251 children, while the prevalence increased to approximately 1 in 72 when suspected cases were also included (10). In Harare, Zimbabwe, school-based screening identified a prevalence of 626 cases per 100,000 children, corresponding to approximately 1 in 160 individuals (11). A school-based epidemiological survey from Mumbai, India, reported a prevalence of 3.6% among schoolchildren (12). The highest incidence rates were generally reported in Middle Eastern populations, where estimates approached approximately 1 case per 2,000 individuals annually (13–15). These findings indicate that pediatric keratoconus may be particularly frequent in certain ethnic and geographical populations and that its burden becomes more apparent when active screening strategies are used.

Several demographic and clinical risk factors were repeatedly identified across the included literature. The average age at diagnosis was most commonly reported between 12 and 14 years, although disease onset may occur earlier and may remain undiagnosed until visual symptoms become more obvious (16,17). Sex-based patterns were inconsistent. Some studies reported a male predominance, whereas others found a higher proportion of affected females, suggesting that sex distribution may vary according to study population, referral pattern, and screening method (12,18). Ethnicity appeared to be an important epidemiological factor, with higher prevalence reported among Middle Eastern, South Asian, and African populations (13,14). Among clinical risk factors, eye rubbing was one of the most consistently reported associations and was frequently linked with allergic ocular disease (19). Vernal keratoconjunctivitis was commonly observed among affected children, particularly in warmer climates where allergic eye disease is more prevalent (20). Atopic disorders were also repeatedly associated with both the development and progression of keratoconus (21). Family history and parental consanguinity were identified as important indicators of genetic susceptibility in several populations, supporting the role of inherited and familial predisposition in pediatric disease (22). Common presenting features included reduced visual acuity, progressive refractive error, ocular itching, frequent spectacle changes, and symptoms related to allergic eye disease (11).

### 3.3 Diagnostic Approaches and Challenges

The diagnostic evidence emphasized the importance of early detection because pediatric keratoconus often progresses rapidly and may already be advanced at the time of diagnosis. Multiple imaging modalities were used across the included studies, with corneal topography and tomography forming the foundation of modern diagnostic assessment. Scheimpflug corneal tomography, including Pentacam-based evaluation, was frequently reported because it provides detailed information regarding anterior and posterior corneal elevation, pachymetric distribution, corneal curvature, and ectatic progression patterns (23). Optical coherence tomography was used to assess

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corneal thickness, epithelial remodeling, and structural changes with high resolution (24). Slit-scan tomography, including Orbscan-based imaging, provided additional information regarding corneal contour and thickness distribution (25). Corneal topography remained an important diagnostic modality for identifying characteristic anterior corneal steepening and irregular astigmatic patterns associated with early keratoconus (26). Despite the availability of advanced imaging, several diagnostic challenges were identified in pediatric populations. Early disease may remain clinically silent, and children may not clearly report blurred vision, monocular visual decline, ghosting, or distortion. As a result, diagnosis may be delayed until refractive changes become more pronounced or visual acuity is no longer adequately corrected with spectacles (26). Pediatric patients also frequently present with more advanced disease than adults, which may reflect a combination of rapid progression, delayed referral, and limited routine screening (18). Obtaining reliable imaging may be difficult in younger children because of reduced attention span, poor fixation, limited cooperation, or inconsistent scan quality (10). These difficulties may affect the repeatability of corneal measurements and complicate monitoring of progression over time.

The included evidence also showed that pediatric keratoconus differs from adult disease because progression may occur more quickly and may lead to significant visual consequences during critical years of visual development (1). Progressive irregular astigmatism and corneal distortion may increase the risk of amblyopia, particularly in younger children with unilateral or asymmetric disease (21). For this reason, clinicians are advised to maintain a high level of suspicion in children with progressive myopia or astigmatism, unexplained reduction in best-corrected visual acuity, frequent changes in spectacle prescription, allergic eye disease, vernal keratoconjunctivitis, habitual eye rubbing, or a positive family history of keratoconus.

### 3.4 Clinical Management and Treatment Outcomes

The treatment evidence was dominated by studies evaluating corneal collagen cross-linking, which remains the principal disease-modifying intervention for progressive keratoconus. Cross-linking aims to increase corneal biomechanical stability by inducing additional covalent bonding within stromal collagen fibers. It is currently recognized as the only intervention with evidence for slowing or arresting keratoconus progression. Regulatory approval by the United States Food and Drug Administration has been granted for progressive keratoconus in patients aged 14 years and older (27). A systematic review including 2,186 eyes from 35 pediatric studies reported generally favorable outcomes following corneal collagen cross-linking (27). Across both conventional and accelerated protocols, disease stabilization rates exceeded 80%. Among the included studies, 15 evaluated the standard Dresden protocol, 11 assessed accelerated cross-linking techniques, and 9 directly compared different cross-linking protocols. Treatment success appeared to be influenced by several factors, including age at intervention, baseline severity of keratoconus, cone location, and cone eccentricity (27). These findings support the clinical value of timely cross-linking in children and adolescents, particularly because pediatric disease may progress rapidly after diagnosis.

Long-term studies reported sustained improvement or stabilization in visual and keratometric outcomes for up to 60 months after accelerated cross-linking (28,29). Simultaneous bilateral accelerated treatment was also described as a safe and effective approach in selected pediatric patients, with the potential advantage of reducing treatment burden and improving adherence by minimizing the number of procedural visits (28,29). Evidence also suggested that performing cross-linking soon after diagnosis may help prevent further progression and may improve long-term visual outcomes, especially in populations with a higher risk of aggressive disease (28,29). Comparative evidence indicated that both conventional Dresden and accelerated cross-linking protocols can be effective in controlling disease progression in children. However, some studies reported greater reductions in maximum keratometry and better improvement in corrected distance visual acuity following the standard Dresden protocol when compared with accelerated approaches (30–32). These findings suggest that although accelerated protocols may offer practical advantages, particularly in younger patients who may struggle with longer treatment duration, protocol selection should consider baseline disease severity, corneal thickness, patient cooperation, risk of progression, and the need for long-term stability.

Contact lenses remained an important component of visual rehabilitation, particularly in children whose visual acuity could not be adequately corrected with spectacles. The reviewed evidence described the use of rigid gas-permeable lenses, scleral lenses, hybrid lenses, and other specialty lens designs for irregular corneas. However, contact lens success in pediatric patients was influenced by adherence, handling ability, comfort, parental support, hygiene practices, ocular surface status, and the need for repeated lens adjustment as the cornea changes over time. Reported barriers included poor adherence to lens-wearing schedules, difficulty with insertion and removal, risk of corneal abrasions, microbial complications, and frequent lens replacement due to ocular growth or disease progression. Among available modalities, scleral lenses showed encouraging outcomes and were associated with meaningful improvement in visual function and quality of life for both children and caregivers (33–35). Surgical management was generally reserved for advanced keratoconus in which visual rehabilitation and disease control could not be achieved through spectacles, contact lenses, or cross-linking. Deep anterior lamellar keratoplasty was frequently described as a preferred surgical option because it preserves the host endothelium and reduces the risk of endothelial rejection (36). Penetrating keratoplasty remained one of the most commonly performed corneal transplantation procedures in advanced pediatric keratoconus, particularly when stromal scarring, severe thinning, or hydrops-related opacity was present (37). Intrastromal corneal ring segments were also reported in selected cases to improve corneal shape and visual performance (38). The available evidence did not clearly suggest inferior transplantation outcomes in pediatric patients when compared

 

with adults, although careful follow-up remains essential because younger patients may face challenges related to suture care, amblyopia risk, inflammation, trauma, and long-term graft survival.

### 3.5 Psychosocial, Educational, and Economic Impact

The included literature indicated that pediatric keratoconus has consequences extending beyond visual acuity and corneal measurements. Vision-related quality of life was consistently affected, and keratoconus was associated with substantial functional impairment when compared with several other ophthalmic conditions (39,40). In children and adolescents, these effects are particularly important because disease onset occurs during periods of education, social development, emotional maturation, and identity formation. Even relatively mild keratoconus may affect reading, classroom participation, screen use, sports, self-confidence, and daily visual tasks. Quality-of-life studies reported impairment across multiple domains, including near vision, distance vision, general visual function, mental well-being, and social functioning (39,40). Academic performance may be affected by fluctuating vision, reduced clarity, frequent prescription changes, treatment appointments, and difficulty tolerating contact lenses. Social participation may also decline when children experience blurred vision, dependence on visual aids, anxiety about progression, or embarrassment related to contact lens wear or repeated clinical visits. These findings suggest that clinical assessment of pediatric keratoconus should not be limited to tomography and visual acuity alone, but should also include functional, educational, and psychosocial dimensions.

The economic and social burden of pediatric keratoconus remained less extensively studied than clinical outcomes. Available evidence suggested that affected families may face direct costs related to consultations, imaging, spectacles, contact lenses, cross-linking, surgical procedures, medications, and follow-up care, as well as indirect costs related to travel, school absence, parental time off work, and long-term visual disability (41,42). However, few studies provided detailed cost estimates or evaluated caregiver burden in a structured manner. Similarly, limited evidence was available regarding the long-term socioeconomic consequences of pediatric keratoconus, including its impact on educational achievement, future employment opportunities, and family quality of life (41,42).

### 3.6 Evidence Gaps and Research Deficiencies

The review identified several important gaps in the current evidence base. First, there was no universally accepted definition of pediatric keratoconus progression. Studies used variable combinations of maximum keratometry, corneal thickness, refractive change, topographic indices, visual acuity, and tomography-based parameters, making comparisons across studies difficult. Second, although cross-linking outcomes were well represented, long-term prospective pediatric data remained limited, particularly beyond 5 years of follow-up and across different treatment protocols. Third, population-based and school-based screening studies were relatively scarce, despite evidence showing that active screening can identify a substantially higher disease burden than routine clinical detection. Fourth, psychosocial, educational, caregiver-related, and economic outcomes were underrepresented in the literature. While visual and keratometric outcomes were frequently measured, fewer studies assessed how keratoconus affects school performance, emotional well-being, family functioning, social participation, or healthcare affordability. Fifth, there was limited research on supportive interventions designed to improve adherence, reduce eye rubbing, manage allergic eye disease, support contact lens use, or address psychological distress in children and families. These deficiencies indicate that future research should adopt more standardized diagnostic and progression criteria, include longer follow-up periods, expand population-level screening, and incorporate patient-centered outcomes alongside clinical and anatomical measures.

**Table 3. Thematic synthesis of included evidence**

| Theme | Main areas covered | Overall evidence mapped | Knowledge gaps identified |
|---|---|---|---|
| Epidemiology and risk factors | Prevalence, incidence, risk factors | Increasing prevalence estimates; important associations with eye rubbing, VKC, atopy, and family history | Need for more population-based and school-based studies |
| Diagnostic approaches | Topography, tomography, OCT, early detection | Tomographic imaging is central to diagnosis, but early disease remains underdetected | Need for standardized pediatric diagnostic criteria |
| Treatment strategies | CXL, contact lenses, keratoplasty, ICRS | CXL appears effective in stabilizing progression in most pediatric cases | Long-term comparative data and uniform progression criteria remain limited |
| Psychosocial and economic impact | Quality of life, school functioning, family burden, costs | Evidence suggests substantial QoL burden | Economic, social, and caregiver impacts remain underexplored |

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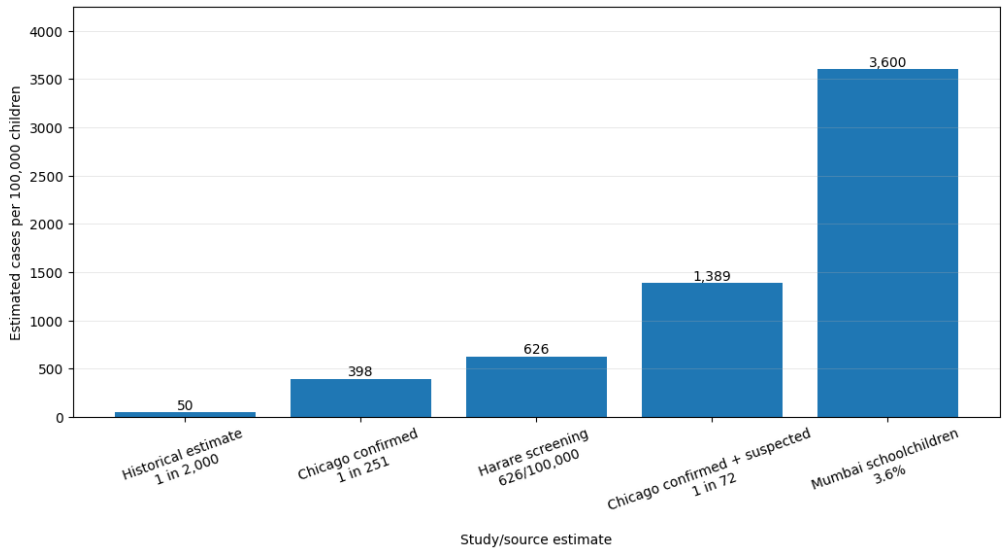
**Figure 2. Reported prevalence estimates of pediatric keratoconus**




## 4. DISCUSSION

### 4.1 Principal Findings

This scoping review mapped the available evidence on pediatric keratoconus and showed that the condition was more prevalent, clinically aggressive, and multidimensional than was traditionally recognized. The findings indicated that pediatric keratoconus should not be considered only a refractive or corneal disorder, because its impact extended across visual development, diagnosis, treatment, education, psychosocial well-being, family burden, and long-term quality of life. The review also showed that the apparent increase in reported prevalence was closely linked to the wider use of corneal topography, Scheimpflug-based tomography, and other sensitive anterior segment imaging techniques, which enabled earlier identification of subtle and subclinical disease (23). Although keratoconus had historically been described as an uncommon condition, recent pediatric studies reported substantially higher estimates, including prevalence figures approaching 1 in 72 children when confirmed and suspected cases were considered together (2). These findings suggested that earlier estimates may have underestimated the true burden of pediatric disease, particularly in populations where advanced corneal imaging had not been routinely used. The evidence also indicated that pediatric keratoconus frequently followed a more rapid course than adult-onset disease. Children often presented with advanced or asymmetric disease, and delayed recognition could result in significant visual impairment during critical years of visual maturation. This was clinically important because progressive corneal irregularity in childhood could compromise visual acuity, increase amblyopia risk, affect school performance, and increase the likelihood of requiring complex optical correction or surgical intervention. Therefore, the findings supported the need for earlier recognition, structured monitoring, and timely intervention in children and adolescents with suspected or confirmed keratoconus.

### 4.2 Interpretation of Epidemiological Findings

The epidemiological evidence suggested that pediatric keratoconus was likely underdiagnosed in many settings. Reported prevalence varied widely across regions, which reflected differences in ethnicity, genetic background, environmental exposure, screening design, diagnostic technology, and case definitions. Higher prevalence estimates reported in Middle Eastern, South Asian, and African populations were consistent with the proposed role of ethnicity, genetic susceptibility, consanguinity, and allergic eye disease in disease development. However, direct comparison across studies remained difficult because some studies used population-based screening, while others relied on clinic-based samples or referred patients. This variability may have inflated estimates in high-risk clinical cohorts and underestimated disease frequency in settings where subclinical cases were not actively screened. The findings supported targeted screening in high-risk groups rather than an unqualified recommendation for universal screening in all children. Children with progressive astigmatism, frequent spectacle changes, reduced best-corrected visual acuity, habitual eye rubbing, vernal keratoconjunctivitis, atopy, or a family history of keratoconus appeared to represent a clinically important screening population. School-based screening may be valuable in high-prevalence regions, but its implementation would require access to trained personnel, reliable imaging devices, referral pathways, treatment facilities, and follow-up systems. Without these supporting structures, screening alone may identify disease without ensuring timely management.

### 4.3 Diagnostic Considerations

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The diagnostic findings emphasized that early detection remained a major challenge in pediatric keratoconus. Early-stage disease may be minimally symptomatic, and children may not accurately describe visual distortion, monocular blur, glare, or fluctuating vision. In routine clinical practice, early keratoconus may therefore be misinterpreted as simple myopia or astigmatism, leading to repeated spectacle correction without corneal imaging. This delay was particularly concerning because pediatric disease may progress rapidly over a short period, and children may already have moderate or advanced disease at the time of first diagnosis. Modern imaging modalities improved diagnostic accuracy, but they did not eliminate all clinical difficulties. Scheimpflug tomography, corneal topography, pachymetric mapping, optical coherence tomography, and epithelial thickness assessment provided important structural information; however, reliable measurement in children could be affected by poor fixation, limited cooperation, unstable attention, and inconsistent scan quality. These challenges highlighted the need to interpret imaging results alongside clinical history, refraction trends, visual acuity, ocular allergy status, eye-rubbing behavior, and family history. A single tomographic value was not sufficient for decision-making in many pediatric cases, particularly when baseline scans were unreliable or when disease was asymmetric.

### 4.4 Therapeutic Implications

The management evidence was strongest for corneal collagen cross-linking, which remained the principal disease-modifying intervention for progressive keratoconus. Previous reviews had also reported high stabilization rates following cross-linking in pediatric populations, and the present synthesis supported its role as an effective treatment option when used appropriately (43). Both conventional and accelerated protocols demonstrated favorable outcomes, but the evidence did not allow a definitive conclusion that one protocol was superior in all pediatric patients. Differences in baseline severity, corneal thickness, cone location, patient age, definition of progression, treatment protocol, and follow-up duration limited direct comparison across studies. The choice between conventional and accelerated cross-linking remained clinically important. The standard Dresden protocol was associated in some studies with greater improvement in keratometric and visual outcomes, whereas accelerated protocols offered practical advantages by reducing procedure time and improving tolerability in younger patients. This created a balanced clinical debate rather than a simple preference for one approach. In children with poor cooperation or difficulty tolerating prolonged treatment, accelerated protocols may provide meaningful practical benefit. In contrast, children with more advanced disease or higher risk of progression may require careful consideration of whether a conventional protocol offers greater long-term stability. Overall, treatment decisions needed to be individualized according to age, disease severity, corneal thickness, progression rate, ocular surface condition, and ability to comply with follow-up.

Contact lenses remained essential for visual rehabilitation, especially when spectacles were no longer sufficient. Rigid gas-permeable lenses, scleral lenses, hybrid lenses, and other specialty designs could improve visual function in irregular corneas. However, pediatric lens use depended not only on optical suitability but also on adherence, handling ability, hygiene, comfort, parental support, cost, and access to experienced lens-fitting services. Scleral lenses appeared particularly useful in selected pediatric patients because they could improve visual function and comfort, but long-term success required careful education and follow-up (33–35). Surgical management, including deep anterior lamellar keratoplasty, penetrating keratoplasty, and intrastromal corneal ring segments, was generally reserved for advanced disease or cases that could not be managed adequately with cross-linking and contact lenses (36–38). Although pediatric transplantation outcomes were not clearly inferior to adult outcomes, children required close long-term monitoring because of amblyopia risk, suture-related complications, trauma, rejection surveillance, and the longer lifetime burden of graft care.

### 4.5 Psychosocial, Educational, and Economic Considerations

A major finding of this review was that pediatric keratoconus affected more than corneal shape and visual acuity. The disease developed during years that were critical for learning, social interaction, emotional development, and self-confidence. Vision-related quality of life was impaired across domains such as near vision, distance vision, general visual function, mental well-being, and social functioning (39,40). These findings were important because conventional clinical indicators, such as keratometry and best-corrected visual acuity, did not fully capture the lived burden of the disease. Even mild or moderate keratoconus could interfere with reading, classroom participation, screen use, sports, social confidence, and daily visual tasks. The psychosocial burden remained underexplored compared with clinical and imaging outcomes. Children may experience anxiety about disease progression, frustration with fluctuating vision, difficulty adapting to contact lenses, embarrassment about visual aids, or fear of procedures. Families may also experience emotional and practical strain related to repeated visits, treatment decisions, financial costs, and school disruption. The economic burden was similarly insufficiently studied, despite the likelihood of costs related to consultations, imaging, spectacles, specialty lenses, cross-linking, medications, travel, parental time away from work, and possible surgery (41,42). These issues were especially relevant in low- and middle-income countries, where delayed diagnosis, limited access to corneal imaging, and reduced availability of cross-linking may worsen long-term visual outcomes.

### 4.6 Comparison with Previous Literature

The findings of this review were generally consistent with previous reviews that had described pediatric keratoconus as a more aggressive form of the disease and had emphasized the effectiveness of cross-linking in stabilizing progression (43–45). Previous reviews had also highlighted the diagnostic and management challenges encountered in children and adolescents, particularly the

difficulty of early detection and the need for timely treatment. The present review extended this understanding by integrating evidence across epidemiology, diagnostic assessment, therapeutic strategies, psychosocial impact, and economic burden rather than focusing on a single clinical domain. This broader synthesis showed that the main challenges in pediatric keratoconus were interconnected. Delayed diagnosis increased the likelihood of advanced disease, which increased the need for cross-linking, specialty lenses, or surgery. Visual impairment then affected education, daily functioning, and emotional well-being. Financial and caregiver burden could further influence treatment adherence and follow-up attendance. Therefore, pediatric keratoconus required a broader model of care that included early detection, disease stabilization, visual rehabilitation, allergy control, patient education, family support, and attention to psychosocial outcomes.

### 4.7 Implications for Clinical Practice

The findings had several practical implications. Clinicians needed to maintain a high level of suspicion when evaluating children with progressive astigmatism, frequent prescription changes, reduced best-corrected visual acuity, allergic eye disease, vernal keratoconjunctivitis, habitual eye rubbing, or a family history of keratoconus. In such cases, corneal imaging should be considered early rather than repeatedly adjusting spectacle prescriptions without further investigation. Early referral to corneal specialists may be particularly important in high-risk children or in those with rapidly changing refraction. Standardized monitoring was also needed. The lack of uniform progression criteria made treatment decisions more difficult and reduced comparability between studies. Clinical monitoring should ideally include visual acuity, refraction, corneal topography or tomography, pachymetry, maximum keratometry, posterior elevation, epithelial thickness where available, and documentation of symptoms and risk factors. Management should also include control of allergic eye disease and counseling to reduce eye rubbing, because these modifiable factors may influence progression. A multidisciplinary model involving ophthalmologists, optometrists, pediatricians, contact lens specialists, and mental health or educational support services may improve both clinical and patient-centered outcomes.

### 4.8 Implications for Future Research

Future research should prioritize large, multicenter, population-based studies using standardized diagnostic criteria to estimate the true prevalence and incidence of pediatric keratoconus across different ethnic and geographical populations. Such studies would help determine whether targeted school-based screening should be recommended in high-risk regions. Research should also establish internationally accepted pediatric progression criteria, because current variability in definitions limits clinical decision-making and weakens comparisons between studies. Long-term prospective studies were needed to assess the durability of cross-linking outcomes beyond five years, particularly in younger children and in those treated with accelerated protocols. Comparative effectiveness studies should directly evaluate conventional versus accelerated cross-linking, different contact lens modalities, and surgical interventions using standardized clinical and patient-reported outcomes. In addition, future studies should include quality of life, educational performance, psychological well-being, caregiver burden, treatment adherence, affordability, and access to care. These outcomes would provide a more complete understanding of pediatric keratoconus as a chronic condition affecting children and families rather than only as a corneal ectatic disorder.

### 4.9 Strengths and Limitations

This review had several strengths. It provided a broad synthesis of pediatric keratoconus across epidemiological, diagnostic, therapeutic, psychosocial, and economic domains. The scoping review design allowed inclusion of diverse study types and enabled mapping of the extent and nature of available evidence. The review also identified clinically relevant gaps that may guide future research, improve screening strategies, and support development of more comprehensive care models. Several limitations also needed to be acknowledged. Restricting the review to English-language publications may have excluded relevant studies from non-English-speaking regions. Formal methodological quality appraisal was not performed, which was consistent with many scoping review approaches but limited interpretation of the strength and reliability of individual studies. The included studies were heterogeneous in design, diagnostic criteria, sample size, population characteristics, disease severity, treatment protocol, follow-up duration, and outcome measures, which prevented quantitative synthesis. Publication bias could not be excluded, particularly because studies reporting favorable treatment outcomes may have been more likely to appear in the literature. Psychosocial and economic findings were also limited by the small number of studies addressing these outcomes in detail.

### 4.10 Overall Interpretation

Overall, the evidence suggested that pediatric keratoconus represented an important clinical and public health challenge. The condition appeared to be under-recognized in many settings, progressed more rapidly than adult disease, and produced consequences that extended beyond corneal structure and visual acuity. Earlier diagnosis, careful monitoring, timely treatment, visual rehabilitation, control of allergic eye disease, and support for children and families were central to improving outcomes. Future progress required standardized diagnostic and progression criteria, stronger long-term treatment evidence, targeted screening research in high-risk populations, and greater integration of patient-centered outcomes into pediatric keratoconus research and clinical care.

## 5. CONCLUSION

This scoping review concluded that pediatric keratoconus is an important and increasingly recognized ocular condition with clinical, developmental, and public health relevance. The review highlighted that affected children often experience a more aggressive disease course than adults, making early recognition, timely corneal imaging, close monitoring, and appropriate intervention essential to preserve visual function and reduce long-term complications. Corneal collagen cross-linking emerged as the key disease-stabilizing treatment, while contact lenses and surgical options remained important for visual rehabilitation and advanced disease management. However, the evidence also showed that current research is limited by inconsistent definitions of progression, variable outcome measures, and insufficient attention to the psychosocial, educational, economic, and quality-of-life burden experienced by children and families. These findings emphasize the need for standardized diagnostic and treatment protocols, targeted screening in high-risk populations, and more patient-centered research to support comprehensive care and improve long-term outcomes in pediatric keratoconus.

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## AUTHOR CONTRIBUTION

| Author | Contribution |
|---|---|
| Dr. Muhammad Kashif | conceptualized the review, designed the methodology, conducted the literature search, participated in study screening and selection, charted and synthesized the data, and wrote and revised the manuscript. |