



Published in final edited form as:

Surv Ophthalmol. 2023 ; 68(4): 567–577. doi:10.1016/j.survophthal.2023.03.005.

A Scoping Review of Patients' Barriers to Eye Care for Glaucoma and Keratitis

Patrice M. Hicks, PhD MPH¹, Linda Kang, BS¹, Mikhayla L. Armstrong, BA², Joseph R. Pongrac, BS¹, Brian C. Stagg, MD MS^{3,4}, Kate M. Saylor, MSI⁵, Paula-Anne Newman-Casey, MD MSc^{1,6}, Maria A. Woodward, MD MSc^{1,6}

¹Department of Ophthalmology and Visual Sciences, University of Michigan, Ann Arbor, Michigan, USA

²University of Chicago Medical School, Chicago, Illinois, USA

Corresponding Author: Maria A. Woodward, MD, MS, 1000 Wall Street, Department of Ophthalmology and Visual Sciences, University of Michigan, Ann Arbor, Michigan, 48105, USA. mariawoo@med.umich.edu.

VII. Author Contributions

Conceptualization: PMH, BCS, PANC, and MAW; *Methodology:* KMS; *Software:* KMS; *Validation:* PMH and KMS; *Formal Analysis:* PMH, KMS, LK, MLA, JP, PANC, and MAW; *Investigation:* PMH, KMS, PANC, and MAW; *Resources:* MAW and PANC; *Data Curation:* PMH and KMS; *Writing - Original Draft:* PMH, LK, MLA, JP, PANC, and MAW; *Writing - Review and Editing:* PMH, LK, MLA, JP, BCS, PANC, MAW, and KMS; *Visualization:* PMH, KMS, BCS, PANC, and MAW; *Supervisor:* PMH, PANC, and MAW; *Project Administration:* PMH, PANC, and MAW; *Funding Acquisition:* MAW, PANC, and BCS.

Publisher's Disclaimer: This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

VI. Disclosure

The funders had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

VIII. Literature Search Statement:

The databases that were selected for utilization in this scoping review included: Ovid MEDLINE, Embase (ELSEVIER), CINAHL Complete (EBSCO), PsycInfo (EBSCO), Web of Science (SCI-EXPANDED, SSCI, and ESCI), and Scopus (ELSEVIER). Initial search strategies were conducted in PubMed and analyzed and refined. The team determined that Ovid MEDLINE would be the primary database for searching MEDLINE. Inclusion criteria was as follows: Studies that include only include adults 18 years of age and older, unless barriers specifically stated for adults only, studies published in peer-reviewed journals, studies that look at the barriers were for care (loss to follow-up appointments), studies that only pertain to glaucoma and/or corneal ulcers, or specifically state what the barriers were for these specific conditions, studies that were Qualitative, quantitative or mixed-methods that evaluated the follow-up barriers in Cornea Ulcer or glaucoma care. Exclusion criteria included articles about dry eye or medication non-adherence, publications that were not primary research including reviews, commentaries, unpublished dissertations, and book chapters; studies that examined the incorrect outcome; and studies with no data on barriers to loss to follow-up. Studies other than in English were not included as we were not able to provide translation for these articles. The team examined the references of any relevant scoping or systematic review, the primary research articles identified, and the articles not written in English to search for additional articles to screen for inclusion. The final searches were completed between July 14 and 19, 2021 and included all sources published before July of 2021. Final MEDLINE Search strategy was as follows: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions(R) 1946 to June 08, 2021. 1. exp No-Show Patients/ OR exp Health Services Accessibility/ OR exp "Treatment Adherence and Compliance"/ OR Office Visits/ OR "Appointments and Schedules"/ OR Waiting Lists/ OR (Non-attendance OR nonattendance OR non-attending OR absenteeism OR truancy OR non-appearance OR "No Show" OR "missed appointment" OR "missed appointments" OR nonadherence OR noncompliance OR non-adherence OR non-compliance OR adherent OR compliant OR non-adherent OR non-compliant OR accessibility OR barriers OR adherence OR compliance OR obstacles).ti,ab. 2. Corneal Ulcer/ OR Acanthamoeba Keratitis/ OR Keratitis, Herpetic/ OR Keratitis, Dendritic/ OR (Keratitis OR Keratitides).ti,ab. OR ((Corneae OR Corneal OR Cornea OR Corneas) adj3 (Ulcer OR ulcus OR Ulcers OR ulceration OR Ulcerative OR inflammation OR irritation OR inflamed)).ti,ab. OR Ocular Hypertension/ OR Glaucoma/ OR Glaucoma, Angle-Closure/ OR Glaucoma, Neovascular/ OR Glaucoma, Open-Angle/ OR Hydrophthalmos/ OR Low Tension Glaucoma/ OR (Glaucomas OR Glaucoma OR "Ocular Hypertension" OR Hydrophthalmos).ti,ab. 3. (animals.sh. NOT humans.sh.) (1 AND 2) NOT 3

Conflict of Interest: The authors have no proprietary or commercial interest in any materials discussed in this article.

³John Moran Eye Center, University of Utah, Salt Lake City, Utah, USA

⁴Department of Population Health Sciences, University of Utah, Salt Lake City, Utah, USA

⁵Taubman Health Sciences Library, University of Michigan, Ann Arbor, Michigan

⁶Institute for Healthcare Policy and Innovation, University of Michigan, Ann Arbor, Michigan, USA

Abstract

In this scoping review, we examine underlying causes of loss to follow-up for chronic (glaucoma) and acute (corneal ulcers) eye conditions using the Penchansky and Thomas access to care framework. We explore barriers by World Health Organization income levels and by study geographical location. We identified 6363 abstracts, with 75 articles retrieved and 16 meeting inclusion criteria. One article discussed barriers to follow-up care for people with corneal ulcers and the other 15 were for people with glaucoma. The most frequent barriers to care were affordability, awareness, and accessibility. The international studies had a greater percentage of studies report acceptability as a barrier to loss to follow-up. Countries with universal healthcare included affordability as a loss to follow-up barrier, emphasizing that cost goes beyond the ability to pay for direct treatment costs. Understanding and addressing barriers to follow-up care can aid the goal of continued care and decrease the risk of poor outcomes and vision loss.

Keywords

Loss to follow-up; barriers to care; corneal ulcers; glaucoma; scoping review

I. Introduction

Adherence to follow-up is a widespread issue in the field of ophthalmology and is a major risk factor for disease progression. Patient loss to follow-up occurs for both chronic and acute eye diseases and is linked to worse outcomes and increased risk of vision loss and blindness for conditions such as glaucoma, diabetic retinopathy, and central retina vein occlusion.^{1,10,26,37,38,41,45} The global cost of vision loss is estimated at \$3 trillion, with the majority attributed to direct healthcare costs.¹² Vision loss and blindness can impact both an individual's physical health and mental health.^{7,23} Thus, it is essential to understand the reasons for loss to follow-up to improve patient care and decrease risk for preventable vision loss and blindness.

Glaucoma and corneal ulcers are 2 eye conditions that require substantial follow-up care for optimal vision outcomes. There are 57.7 million people globally with glaucoma, making it the most common cause of irreversible blindness.¹³ Glaucoma is a chronic, slowly progressive disease that requires routine monitoring and treatment to prevent vision loss and blindness. Typically, clinicians recommend visits every 3 to 6 months and more frequently for severe disease.³⁶ Corneal ulcers, on the other hand, are an emergent, rapidly progressing eye condition that causes severe pain, red eye, and light sensitivity and can cause severe vision impairment and blindness if left untreated. There are 1.5 to 2 million patients affected by corneal ulcers annually across the globe.⁴³ Ulcers require prompt treatment and frequent monitoring. Unfortunately, for both corneal ulcers and glaucoma - examples of high risk

acute and chronic eye diseases - many patients do not return for follow-up care, putting them at risk for vision loss and its related complications.^{6,36}

Penchansky and Thomas put forward a framework to examine multifold studies focused on healthcare access and barriers to care.^{28,29,31,42} The framework includes 5 different dimensions of access: accessibility, availability, accommodation, affordability, and acceptability. Saurman expanded the framework to include awareness as an additional dimension.³² This scoping review explored the barriers for loss to follow-up care for glaucoma and corneal ulcers from studies of patients in the United States and internationally. Glaucoma and corneal ulcers were selected to determine if there are any differences in barriers between chronic and acute eye conditions. Penchansky and Thomas framework and Saurman's addition were utilized to examine and organize the literature.

II. Methods

The scoping review literature identification methodology followed the search frameworks proposed by Arksey and O'Malley and Levac and colleagues using the methods outlined in the JBI Manual for Evidence Synthesis: Chapter 11 - Scoping Reviews.^{3,19,30} A priori protocol was developed and reported according to the PRISMA extension for Protocols (PRISMA-P) and is available here: <https://deepblue.lib.umich.edu/handle/2027.42/168393>. This review was reported according to the PRISMA extension for scoping reviews (PRISMA-ScR). The review team followed the multi-step, iterative process for developing and refining the search strategy.

Search strategy:

The team worked with an informationist (KMS) to identify the target outcomes and created a search strategy to select potential databases, concepts, and search terms to obtain evidence. Two researchers (PMH, LK) reviewed search terms and results for each database and provided feedback on the search terms. The final MEDLINE search strategy can be found in Appendix 1. EndNote 20 (Clarivate, London, United Kingdom) was used to manage the citations and remove any duplicate articles included in the search.

Evidence selection:

The Rayyan-Intelligent Systematic Review program (Rayyan Systems Inc., Cambridge, MA) was used for review of citations. Article selection was based on the criteria described above and included a review of title and abstract, followed by a full-text review of the evidence. All reviewers completed a training by examining/studying the protocol developed for this scoping review. To evaluate interrater reliability a pilot test was conducted on 10% of the total articles found. Screening began once a 75% agreement had occurred between the 2 primary reviewers on these pilot studies (PMH and LK). When completing the screening, at least 2 reviewers checked each source at each level (title abstract and full-article review) and disagreements were reconciled by consensus or by a third reviewer (PANC or MAW). After initial review, only one study included corneal ulcer barriers to care. Though this study did not examine follow-up barriers, it did examine barriers in the initial presentation for corneal

ulcers. Thus, we included the paper within our analysis to examine differences between eye conditions with and without symptoms.

Data extraction/charting: Data extracted from the articles included: author, year of publication, country, type of study conducted, study aims, population demographics (number of participants, participant age, race, ethnicity, gender or sex (study dependent), and location), participant diagnoses, study outcomes (e.g., barriers identified leading to loss to follow-up for care of corneal ulcers and glaucoma), how outcomes were obtained (e.g., survey, phone call, chart review, etc.), and methodology. Income group by the World Health Organization (WHO) classification and universal healthcare status of the countries were also identified.

Dimensions of barriers to healthcare: We measured and analyzed 8 different dimensions of barriers to care across the sources reviewed. The first five are from Penchansky and Thomas and include accessibility (location), availability (supply and demand), accommodation/adequacy (organization), affordability (financial and incidental costs), and acceptability (consumer perception).^{29,32} The sixth, awareness (communication and information), is from Saurman.³² After reviewing the literature, we added an additional 1 categories to encompass all encountered barriers to care. These two categories included patient-level (patients could not access care due to situations that arose within their life), and undefined (no specific reason given) factors. Reviewers (PMH, LK, MLA) sorted the outcomes of all included studies and categorized them into one or more of the 8 dimensions.

III. Results

Search Results and Studies Included:

A search was conducted utilizing the search terms from Supplemental Figure 1. The search yielded a total of 6,363 records. After 2,059 duplicate records were removed, the remaining 4,304 were screened by title and abstract, 75 of which were selected for full-text review. A total of 16 articles, published between April, 2008, and May, 2021, were included in this review. In accordance with the PRISMA-ScR statement,³⁰ a flowchart and narrative description of the evidence selection process is presented in Figure 1. Fifteen of the included studies investigated barriers to follow-up among individuals with glaucoma, and one study investigated barriers to follow-up among those with corneal ulcers. Five studies were conducted in the United States, and 11 were conducted internationally. Seven studies were conducted in WHO high income countries, 2 in upper-middle income countries, 4 in lower-middle income countries, and 3 in low-income countries. Three studies were in countries with universal healthcare. The reasons for loss to follow-up cited in each article are found in Supplemental Table 1. Barriers to follow-up were organized into the eight dimensions according to the codebook outlined in Supplemental Table 2. All included articles and the identified barriers in each study are summarized in Table 1. In total, the review identified the following number of studies that described barriers for each dimension: 14 studies noted affordability as a barrier, 12 noted accessibility, 12 noted awareness, 10 noted acceptability, 9 noted accommodation/adequacy, nine noted availability, eight noted patient-level factors, and 8 noted undefined factors as barriers to follow-up care. (Table

2) Table 2 includes both glaucoma and corneal ulcer studies due to the lack of studies for corneal ulcers, as we were not able to make definitive comparisons between the 2 eye conditions.

Dimensions Assessed for Review

Affordability was the most reported barrier to follow-up care in our review, present in 88% of studies. (Table 2) The most commonly cited reasons were related to the cost of medical care, specifically a lack of money and insurance.^{9,11,15,24,33,34} For example, a participant with glaucoma in Nigeria stated that the hospital asked them to pay N60,000 [about \$325.00 in 2016], and they did not have even N100 [about \$0.54 in 2016], so they returned home without care.¹⁵ Costs related to transportation were mentioned in 25% of studies.^{11,16,20,40} Insufficient income due to missed days of work was also reported.^{17,22,40} Affordability and cost barriers were present in every WHO income group level. Accessibility, the third most cited barrier (75%), was cited in every WHO income group, including travel time to the clinic, lack of an escort, and transportation (e.g., too far and number of transfers needed to get to appointment) (Table 2).^{5,9,11,16,17,20,22,33,34,39,40}

Awareness was cited as many times as accessibility (75% of papers) and was present in every WHO income group and every U.S. study. (Table 2) Awareness barriers included the patient being unaware of the importance of follow-up treatment, being unaware that they had a follow-up appointment, and being unaware of their diagnosis.^{11,14,16,17,22} In papers that cited awareness as a barrier, 41.7% of papers mentioned that awareness was related to lack of staff or provider education, explanations, and communication. In a study from South Korea, 56.8% of study participants with glaucoma reported that they were “very dissatisfied” and 38.3% “dissatisfied” with the medical staff’s explanation about their upcoming appointments and glaucoma status.¹⁴ In South Africa, study participants reported a lack of awareness of the initial asymptomatic nature of glaucoma and the need for continued chronic therapy and follow up to avoid future vision loss.”⁴⁰

Acceptability, availability, and accommodation/adequacy were reported in 63%, 56%, and 56% of studies, respectively. (Table 2) One important aspect of acceptability was that participants reported that the poor doctor-patient relationship was the reason they did not return for care.^{15,24,40} One U.S. participant with glaucoma mentioned that physician’s ask patient questions that takes time, which physicians either do not have or are willing to do. In addition, a lack of professionalism in the clinic staff, dissatisfaction with the clinic location (e.g. safety of area where the service is provider), fear of treatment, and not feeling safe coming to the location to get care were also leading acceptability barriers.^{2,4,14,16,17,34} Acceptability as a barrier was not reported in any of the studies in WHO low-income countries.^{11,20}

Leading **availability** barriers included long wait times at the location for care and lack of available appointment times that worked for the patient’s schedule. In a study from Nigeria, one patient stated that they had spent the entire day at the clinic because they were seen after individuals that had arrived after them.² Availability barriers were observed in all WHO income classifications and were not dependent on having universal health care.

Accommodation/adequacy barriers that were most frequently mentioned included language barriers and difficulty taking time away from home or work and was observed in all WHO income classifications and was not dependent on having universal health care.^{16,17,22,40} A participant in South Africa stated, “I work on weekdays only and don’t have time to come to the clinic for my medications, I am afraid to ask permission because I am still new in this firm.”⁴⁰

Patient-level factors were not an outlined dimension within the Penchansky and Thomas framework, but were included in our review and were each mentioned in 81% of studies. **Patient-level factors** impacting access to care were situations that arose in the patient’s life that prevented follow-up. Patient-level factors mentioned included illness and the inability to take time away from work or household responsibilities.^{4,14,16} Those concepts overlap with the dimension of accommodation and adequacy.^{16,17,22,40} An example of this would be the inability to take time away from work or home could be in either dimension because it could pertain to the health service in which they did not have the flexibility to change appointment times that would accommodate a working schedule or hours in which a parent needed to be home to watch their children. From the patient-level, patients may have planned to attend the appointment, but then they could not get the time off of work or needed to be at home to take care of the household. Lee and colleagues found that the patient-level factors of “the lack of an escort to assist patients in attending the clinic, and inability to be absent from work responsibilities” were barriers to attending follow up appointments.¹⁷ Other reports mentioned activities that took priority over follow-up care including weddings and leisure travel.^{16,34} Patient-level factors also included Undefined barriers such as “other”, “unknown”, and “unspecified”.^{4,9,16,17,33} An example from Abdull and colleagues study in northern Nigeria stated that “many patients did not specify why they defaulted from follow-up, explaining that the reasons were beyond their control.”²

IV. Discussion

This scoping review mapped the current literature on barriers to follow-up for both glaucoma and corneal ulcers utilizing eight dimensions of access to care defined by Penchansky and Thomas, Saurmen, and our team. We identified 16 studies that explored barriers to follow-up care and of these studies, only one study, conducted in Nepal, focused on barriers to care for people with corneal ulcers. The other studies focused on why people with glaucoma did not return for follow-up care, highlighting the need for further research into what barriers to follow-up care exist for patients with corneal ulcers. Studies conducted in the United States and internationally reported the dimensions examined by the theoretical framework chosen for this review. International studies had a greater percentage of acceptability as a barrier of loss to follow-up, and United States studies reported a greater percentage of the remaining dimensions as barriers of loss to follow-up. Countries with universal healthcare included affordability as a follow-up barrier, emphasizing that cost goes beyond the ability to pay for direct treatment costs. In countries without universal healthcare, private insurance and co-pays are an additional affordability barrier to care. No countries with the WHO low-income designation (Tanzania and Nepal) reported acceptability as a barrier. In these countries accessibility of healthcare could take precedent over factors of acceptability.^{11,20,33}

Previous research has utilized the Penchansky and Thomas framework to assess barriers to eye care. Mohd Rosnu and colleagues conducted a scoping review on enablers and barriers of accessing health care services among older adults in South-East Asia.²¹ Two studies included in the review examined eye care. One study was in Cambodia and observed gender barriers to eye care, while the other was conducted in Timor-Leste and observed changing barriers over time from 2005 to 2010 for eye care services. When mapping the barriers to the framework, these studies identified only the acceptability dimension.^{18,25} None of our studies included countries in South-East Asia, but did include countries from other areas of Asia where 67% of the studies listed acceptability as a barrier dimension.^{14,16}

This is the first review to utilize the Penchansky and Thomas framework to assess loss to follow-up barriers for corneal ulcers and glaucoma. Barriers for glaucoma follow-up were affordability, accessibility, awareness, acceptability, accommodation/adequacy, availability, and patient-level factors. Barriers for people with corneal ulcers included affordability, accessibility, awareness, and patient-level factors. Though only one study looked at these barriers for ulcers, few barriers may have been listed because they are usually very painful with acute visual effects, providing a need for them to be quickly resolved. Future qualitative research beyond this retrospective study can enhance the data in further understanding these barriers for corneal ulcer patients. Corneal ulcers are considered an ocular emergency, and clinics are more inclined to add ulcer patients even for a full schedule, which could be one of the reasons that availability was not mentioned as a barrier by those with corneal ulcers. Glaucoma may have had more barriers listed because it is slowly progressive for patients and may be seen as a health matter that can be delayed.

Affordability and cost barriers were present in every WHO income group level including all five U.S. studies, highlighting the universality of the barrier. Two of the 3 studies from countries with universal health care also listed affordability as a barrier to follow-up care for glaucoma. Elliot and colleagues found that 46% of participants in their study reported that cost and insurance concerns hindered follow-up care for glaucoma.⁹ Sitoula and colleagues observed that 22% of study participants with corneal ulcers stated that money was their reason for delayed care.³³

Accessibility barriers highlight the need to ensure that patients have quality care within a reasonable distance from their homes. Health care providers are needed in more locations and improved access to transportation is needed to get to specialty care services.⁸ People need options outside of relying on family or friends, for example ride shares, telehealth visits, free shuttles, or reimbursement for travel.^{27,35,44} This is true regardless of WHO income level (high-, middle-, and low-income groups). For example, U.S. studies, a high-income group country, listed both distance and transportation issues as a barrier. This was also seen in low-income group countries such as Nepal and Tanzania as well as Middle-income group countries such as Nigeria and South Africa.

Corneal ulcers cause pain and acute vision loss, yet 27% of ulcer patients were unaware of the serious nature of their condition in the study conducted by Sitoula and colleagues.³³ Some participants had very little to no information about their condition. This lack of awareness of the severity of the condition is a barrier to care and demonstrates a need

for solutions to improve patient education such as patient advocates and care navigators, information presented at the reading level of the patient, and follow up phone calls to answer questions and clarify information. It is of utmost importance that patients are aware of the next steps in their treatment plan for their eye disease to mitigate associated complications. Acceptability, availability, and accommodation/adequacy of the eye clinics, while not observed among those with corneal ulcers, were important barriers keeping those with glaucoma from accessing appropriate follow-up care.

Acceptability barriers were not observed for WHO low-income category countries.^{11,20,33} With efforts that improve the quantity and quality healthcare for individuals in low-income countries, acceptability may present as a new barrier for patients because lack of services, not the quality of services, of health care services could be more of a priority for patients. Similarly, to acceptability, patient-level factors were not reported for WHO low categorization for income levels. This implies that person-level factors may be more prevalent when the quantity of healthcare services increases in countries and individuals have more resources.

Awareness barriers were observed in each WHO income category and all the studies in the U.S. mentioned awareness as a dimension of barriers. Awareness barriers in this review include unawareness of condition diagnosis, importance of follow-up, and frequency/scheduling of appointments. A key component within the awareness domain is that is highlighted by this review includes the lack of education, communication, and explanation by the provider and medical staff. Thus, it is imperative that there is a partnership between the patient and the clinicians and medical staff to ensure that awareness barriers are addressed to prevent vision threatening eye conditions.

There are limitations to this review. First, the Penchansky and Thomas framework did not include dimensions to classify barriers identified for patient-level factors. Second, the results are subject to limitations of a scoping review including selection bias, date limitations, and database selection. Lastly, only one study observed barriers for corneal ulcer patients and included barriers for initial treatment, rather than follow-up. This study was conducted in Nepal, limiting the generalizability of identified barriers to other countries.

Policy changes are needed to address the identified barriers. Affordability as a barrier was named in the greatest number of articles. Affordability was even mentioned for studies in countries with universal healthcare, highlighting the multiple sources of costs outside of the direct cost of care including the costs of not working, the costs of travel and the costs of bringing a companion. Though, it is important to mention that in South Korea and India, where there is universal healthcare, a significant portion of healthcare is privately funded or provided in the private sector and though there is coverage, there may still be out of pocket costs due to co-pays. To obtain better eye health outcomes, resources are needed to help support these costs for those who cannot afford them. While affordability was the most prominent barrier, all dimensions of barriers to care in the Penchansky and Thomas framework were observed across people with glaucoma and corneal ulcers and should be considered in informing eye care delivery policies.

V. Conclusion

A multidimensional approach to addressing barriers to follow-up eye care for both chronic and acute vision threatening conditions is needed. Multidimensional approaches are needed for both patients in the U.S. and internationally. Barriers to care for patients with corneal ulcers is understudied and should be examined in more detail in other countries to help inform health care delivery systems that mitigate vision loss due to loss to follow-up.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments:

The personnel who conducted this study was supported in part by a gift by Ms. Susan Lane.

Funding Support:

The funding support played no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication. This work was supported by the National Eye Institute (R01EY031033, M.A.W., K23EY032577, B.C.S.), Research to Prevent Blindness Career Advancement Award (M.A.W.), the National Institute of Health (R01EY031337-01, P.A.N.C.), the Centers for Disease Control and Prevention (U01 DP006442-01, P.A.N.C.), National Institutes of Health Core Grant (EY014800, B.C.S.), and an Unrestricted Grant from Research to Prevent Blindness, New York, New York, to the Department of Ophthalmology & Visual Sciences, University of Utah (B.C.S.). All additional authors did not report any funding sources.

References

1. Abdelmotaal H, Ibrahim W, Sharaf M, Abdelazeem K. Causes and Clinical Impact of Loss to Follow-Up in Patients with Proliferative Diabetic Retinopathy. *J Ophthalmol* 2020;2020:7691724. Published 2020 Feb 8. doi:10.1155/2020/7691724 [PubMed: 32089871]
2. Abdull MM, Chandler C, Gilbert C. Glaucoma, “the silent thief of sight”: patients’ perspectives and health seeking behaviour in Bauchi, northern Nigeria. *BMC Ophthalmol* 2016;16:44. [PubMed: 27102524]
3. Arksey H, O’Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8(1):19–32.
4. Ashaye AO, Adeoye AO. Characteristics of patients who dropout from a glaucoma clinic. *J Glaucoma* 2008;17(3):227–232. [PubMed: 18414110]
5. Bhargava JS, Bhan-Bhargava A, Foss AJE, King AJ. Views of glaucoma patients on provision of follow-up care; an assessment of patient preferences by conjoint analysis. *British Journal of Ophthalmology* 2008;92(12):1601–1605. doi:10.1136/bjo.2008.140483 [PubMed: 18664502]
6. Chen EM, Ahluwalia A, Parikh R, Nwyanwu K. Ophthalmic Emergency Department Visits: Factors Associated With Loss to Follow-up. *Am J Ophthalmol* 2021;222:126–136. doi:10.1016/j.ajo.2020.08.038 [PubMed: 32882220]
7. Crews JE, Chou CF, Zack MM, et al. The Association of Health-Related Quality of Life with Severity of Visual Impairment among People Aged 40–64 Years: Findings from the 2006–2010 Behavioral Risk Factor Surveillance System. *Ophthalmic Epidemiol* 2016;23(3):145–153. doi:10.3109/09286586.2016.1168851 [PubMed: 27159347]
8. Elam AR, Lee PP. Barriers to and Suggestions on Improving Utilization of Eye Care in High-Risk Individuals: Focus Group Results. *International Scholarly Research Notices* 2014;2014:1–8. doi:10.1155/2014/527831
9. Elliott AF, Chou CF, Zhang X, Crews JE, Saaddine JB, Beckles GL, Owens-Gary MD. Eye-Care Utilization Among Women Aged 40 Years With Eye Diseases—19 States, 2006–2008. *Morbidity and Mortality Weekly Report (MMWR)* 2010;59(19):588–591. [PubMed: 20489682]

10. Foot B, MacEwen C. Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome. *Eye (Lond)* 2017;31(5):771–775. doi:10.1038/eye.2017.1 [PubMed: 28128796]
11. Gilmour-White JA, Shah P, Cross V, Makupa W, Philippin H. Glaucoma awareness and access to healthcare: perceptions among glaucoma patients in Tanzania. *Postgraduate Medical Journal* 2015;91(1077):373–378. doi:10.1136/postgradmedj-2014-133094 [PubMed: 26069217]
12. Gordon KD, Cruess AF, Gordois A, et al. The Global Cost of Vision Loss. *Invest Ophthalmol Vis Sci* 2011;52(14):5543–5543.
13. Kapetanakis VV, Chan MPY, Foster PJ, Cook DG, Owen CG, Rudnicka AR. Global variations and time trends in the prevalence of primary open angle glaucoma (POAG): a systematic review and meta-analysis. *Br J Ophthalmol* 2016;100(1):86–93. [PubMed: 26286821]
14. Kim YK, Jeoung JW, Park KH. Understanding the reasons for loss to follow-up in patients with glaucoma at a tertiary referral teaching hospital in Korea. *British Journal of Ophthalmology* 2017;101(8):1059–1065. doi:10.1136/bjophthalmol-2016-309103 [PubMed: 27941049]
15. Kyari F, Chandler CI, Martin M, Gilbert CE. So let me find my way, whatever it will cost me, rather than leaving myself in darkness: experiences of glaucoma in Nigeria. *Global Health Action* 2016;9(1):31886. doi:10.3402/gha.v9.31886 [PubMed: 27924740]
16. Lee BW. Predictors of and Barriers Associated With Poor Follow-up in Patients With Glaucoma in South India. *Archives of Ophthalmology* 2008;126(10):1448. doi:10.1001/archophth.126.10.1448 [PubMed: 18852425]
17. Lee BW, Murakami Y, Duncan MT, et al. Patient-Related and System-Related Barriers to Glaucoma Follow-up in a County Hospital Population. *Investigative Ophthalmology & Visual Science* 2013;54(10):6542. doi:10.1167/iov.13-12108
18. Lee L, Ramke J, Blignault I, Casson RJ. Changing barriers to use of eye care services in Timor-Leste: 2005 to 2010. *Ophthalmic Epidemiol* 2013;20(1):45–51. doi:10.3109/09286586.2012.742551 [PubMed: 23350555]
19. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69. [PubMed: 20854677]
20. Lewallen S, Hassan HG, Al Attas AH, Courtright P. A Population-based Study of Care-seeking Behavior in Rural Tanzanians With Glaucoma Blindness. *Journal of Glaucoma* 2011;20(6):361–365. doi:10.1097/ijg.0b013e3181eda983 [PubMed: 20717055]
21. Mohd Rosnu NS, Singh DKA, Mat Ludin AF, Ishak WS, Abd Rahman MH, Shahar S. Enablers and Barriers of Accessing Health Care Services among Older Adults in South-East Asia: A Scoping Review. *Int J Environ Res Public Health* 2022;19(12):7351. Published 2022 Jun 15. doi:10.3390/ijerph19127351 [PubMed: 35742597]
22. Racial Murakami Y. and Ethnic Disparities in Adherence to Glaucoma Follow-up Visits in a County Hospital Population. *Archives of Ophthalmology* 2011;129(7):872. doi:10.1001/archophthalmol.2011.163 [PubMed: 21746977]
23. National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Committee on Public Health Approaches to Reduce Vision Impairment and Promote Eye Health; Welp A, Woodbury RB, McCoy MA, et al., editors. *Making Eye Health a Population Health Imperative: Vision for Tomorrow* Washington (DC): National Academies Press (US); 2016 Sep 15. 3, The Impact of Vision Loss. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK402367/>
24. Newman-Casey PA, Shtein RM, Coleman AL, Herndon L, Lee PP. Why Patients With Glaucoma Lose Vision: The Patient Perspective. *Journal of Glaucoma* 2016;25(7):e668–e675. doi:10.1097/ijg.0000000000000320 [PubMed: 26317482]
25. Neyhouser C, Quinn I, Hillgrove T, et al. A qualitative study on gender barriers to eye care access in Cambodia. *BMC Ophthalmol* 2018;18(1):217. Published 2018 Aug 29. doi:10.1186/s12886-018-0890-3 [PubMed: 30157788]
26. Obeid A, Su D, Patel SN, et al. Outcomes of Eyes Lost to Follow-up with Proliferative Diabetic Retinopathy That Received Panretinal Photocoagulation versus Intravitreal Anti-Vascular Endothelial Growth Factor. *Ophthalmology* 2019;126(3):407–413. doi:10.1016/j.ophtha.2018.07.027 [PubMed: 30077614]

27. Oluyede L, Cochran AL, Wolfe M, Prunkl L, McDonald N. Addressing transportation barriers to health care during the COVID-19 pandemic: Perspectives of care coordinators. *Transp Res Part A Policy Pract* 2022;159:157–168. doi:10.1016/j.tra.2022.03.010 [PubMed: 35283561]
28. Paisi M, Baines R, Burns L, et al. Barriers and facilitators to dental care access among asylum seekers and refugees in highly developed countries: a systematic review. *BMC Oral Health* 2020;20(1):337. [PubMed: 33238954]
29. Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. *Med Care* 1981;19(2):127–140. [PubMed: 7206846]
30. Peters MDJ, Godfrey C, McInerney P, et al. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E, Munn Z (Editors). *JBIManual for Evidence Synthesis*, JBI, 2020. Available from <https://synthesismanual.jbi.global>.
31. Retrouvey H, Solaja O, Gagliardi AR, Webster F, Zhong T. Barriers of Access to Breast Reconstruction: A Systematic Review. *Plast Reconstr Surg* 2019;143(3):465e – 476e. [PubMed: 30688887]
32. Saurman E Improving access: modifying Penchansky and Thomas’s Theory of Access. *J Health Serv Res Policy* 2016;21(1):36–39. [PubMed: 26377728]
33. Sitoula RP, Singh SK, Mahaseth V, Sharma A, Labh RK. Epidemiology and etiological diagnosis of infective keratitis in eastern region of Nepal. *Nepalese Journal of Ophthalmology* 2015;7(1):10–15. doi:10.3126/nepjoph.v7i1.13146 [PubMed: 26695600]
34. Stagg BC, Granger A, Guetterman TC, Hess R, Lee PP. The Burden of Caring for and Treating Glaucoma: The Patient Perspective. *Ophthalmology Glaucoma* 2022;5(1):32–39. doi:10.1016/j.ogla.2021.04.011 [PubMed: 33984555]
35. Starbird LE, DiMaina C, Sun CA, Han HR. A Systematic Review of Interventions to Minimize Transportation Barriers Among People with Chronic Diseases. *J Community Health* 2019;44(2):400–411. doi:10.1007/s10900-018-0572-3 [PubMed: 30206755]
36. Summary Benchmarks for Preferred Practice Pattern Guidelines American Academy of Ophthalmology; 2021.
37. Suresh R, Yu HJ, Thoveson A, et al. Loss to Follow-Up Among Patients With Proliferative Diabetic Retinopathy in Clinical Practice. *Am J Ophthalmol* 2020;215:66–71. doi:10.1016/j.ajo.2020.03.011 [PubMed: 32209344]
38. Thompson AC, Thompson MO, Young DL, et al. Barriers to Follow-Up and Strategies to Improve Adherence to Appointments for Care of Chronic Eye Diseases. *Invest Ophthalmol Vis Sci* 2015;56(8):4324–4331. doi:10.1167/iovs.15-16444 [PubMed: 26176869]
39. Tshivhase SE, Khoza LB, Tshitangano TG. Loss to follow-up amongst glaucoma patients in selected hospitals of the Limpopo Province, South Africa. *African Vision and Eye Health* 2020;79(1). doi:10.4102/aveh.v79i1.559
40. Tshivhase S, Khoza LB. Challenges Contributing to Loss to Follow-up as Experienced by Glaucoma Patients in the Vhembe District of Limpopo Province, South Africa. *The Open Public Health Journal* 2020;13(1):531–537. doi:10.2174/1874944502013010531
41. Ung C, Murakami Y, Zhang E, et al. The Association Between Compliance With Recommended Follow-up and Glaucomatous Disease Severity in a County Hospital Population. *American Journal of Ophthalmology* 2013;156(2):362–369. doi:10.1016/j.ajo.2013.03.005 [PubMed: 23601654]
42. van Gaans D, Dent E. Issues of accessibility to health services by older Australians: a review. *Public Health Rev* 2018;39:20. [PubMed: 30027001]
43. Whitcher JP, Srinivasan M, Upadhyay MP. Corneal blindness: a global perspective. *Bull World Health Organ* 2001;79:214–221. [PubMed: 11285665]
44. Wolfe MK, McDonald NC. Innovative health care mobility services in the US. *BMC Public Health* 2020;20(1). doi:10.1186/s12889-020-08803-5
45. Yang KB, Liu L, Feng H, et al. Outcomes of Eyes Lost to Follow-Up in Patients with Central Retinal Vein Occlusion Who are Receiving Anti-Vascular Endothelial Growth Factor Treatment. *Ther Clin Risk Manag* 2021;17:489–496. [PubMed: 34079270]

Highlights

- Affordability was the most reported barrier to follow-up care.
- Affordability was a barrier regardless of country income level.
- Future research should examine barriers to follow-up for corneal ulcer care globally.
- All dimensions of barriers to care in the Penchansky and Thomas framework were observed.
- Policy changes are needed to address barriers for eye care loss to follow-up.

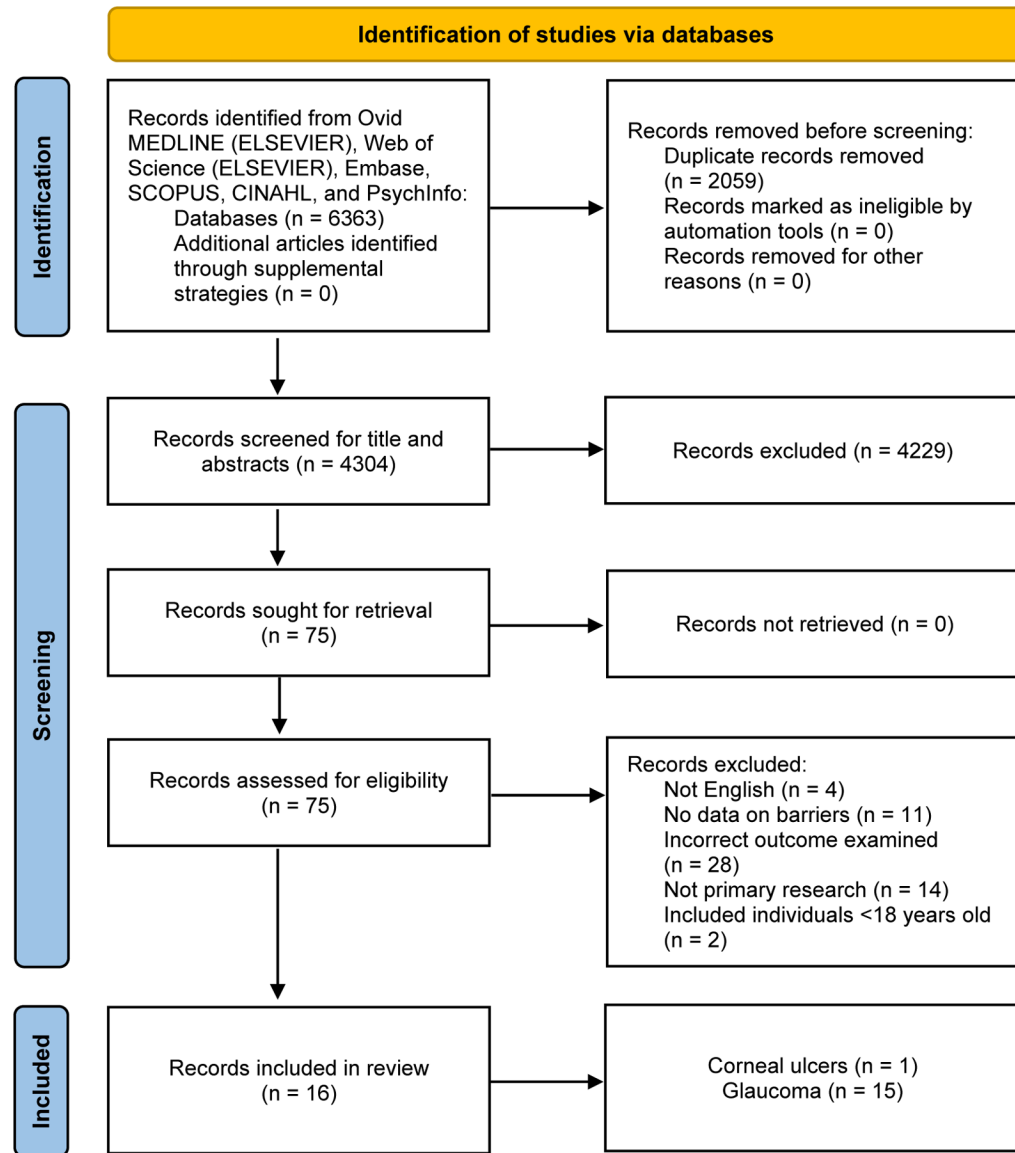


Figure 1.
PRISMA flowchart for the scoping review process.

Table 1.

Identified loss to follow-up barriers in care for Glaucoma and Corneal Ulcers.

Author / Year	Country	Affordability ^a	Accessibility ^a	Awareness ^b	Acceptability ^a	Accommodation/ Adequacy ^a	Availability ^a	Patient- Level Factors ^c	WHO Income Group [^]
Chronic Disease: Glaucoma									
Lee et al. 2013	U.S.A.	•	•	•	•	•	•	•	
Stagg et al. 2021	U.S.A.	•	•	•	•	•	•	•	
Murakami et al. 2011	U.S.A.	•	•	•		•	•	•	High
Elliott et al. 2010	U.S.A.	•	•	•			•	•	
Newman-Casey et al. 2016	U.S.A.	•		•	•			•	
Kim et al. 2016	S. Korea *	•		•	•	•		•	
Bhargava et al. 2008	U.K. *		•		•		•	•	
Tshivhase and Khoza 2020	S. Africa	•	•	•	•	•	•	•	Upper Middle
Tshivhase et al. 2020	S. Africa	•	•						
Lee et. al 2008	India *	•	•	•	•	•	•	•	
Ashaye et al. 2008	Nigeria		•	•	•	•		•	Lower Middle
Abdull et al. 2016	Nigeria	•			•		•	•	
Kyari et al. 2016	Nigeria	•		•	•	•			
Gilmour-White et al. 2015	Tanzania	•	•	•		•	•		
Lewallen et al. 2011	Tanzania	•	•					•	Low
Acute Disease: Corneal Ulcers									
Sitoula et al. 2015	Nepal	•	•	•				•	

U.S.A., United States of America; S. Korea, South Korea; U.K., United Kingdom; S. Africa, South Africa; WHO, the World Health Organization

^aPenchansky and Thomas five dimensions framework;^bSaurman addition to the Penchansky and Thomas framework;^cNot listed within the framework

* Universal Healthcare at the time of the study

[^]Countries designated within the income categories

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2.

Dimension frequency and percentage by location and WHO income groups.

Dimension	Location			WHO Income Group			
	Total 16	U.S.A. 5	Intl 11	High 7	Upper Middle 2	Lower Middle 4	Low 3
	Percentage (Frequency)						
Affordability ^a	88% (14)	100% (5)	82% (9)	86% (6)	100% (2)	75% (3)	100% (3)
Accessibility ^a	75% (12)	80% (4)	73% (8)	71% (5)	100% (2)	50% (2)	100% (3)
Awareness ^b	75% (12)	100% (5)	64% (7)	86% (6)	50% (1)	75% (3)	67% (2)
Acceptability ^a	63% (10)	60% (3)	64% (7)	71% (5)	50% (1)	100% (4)	0% (0)
Accommodation/Adequacy ^a	56% (9)	60% (3)	55% (6)	57% (4)	50% (1)	75% (3)	33% (1)
Availability ^a	56% (9)	80% (4)	46% (5)	71% (5)	50% (1)	50% (2)	33% (1)
Patient-level Factors ^c	81% (13)	100% (5)	73% (8)	100% (7)	50% (1)	75% (3)	67% (2)

U.S.A., United States of America; Intl, International, WHO, the World Health Organization

^aPenchansky and Thomas five dimensions framework;^bSaurman addition to the Penchansky and Thomas framework;^cNot listed within the framework