# Title: Loss to follow-up barriers in care for Cornea Ulcers and Glaucoma: A Scoping Review Protocol

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#### Introduction:

Barriers to access to medical care are experienced by both individuals and families across the United States. Barriers to care is anything that may limit a patient or prevent a patient from seeking out or receiving medical care. Populations who are at the greatest risk for having barriers to care are individuals from racial/ethnic minority groups, individuals with lower income, individuals with poor health and individuals with who do not have private insurance.<sup>2-6</sup> Barriers to access to care can cause patients to not have the resources and opportunities needed to improve their health status or maintain their current health status.7 Within different communities and populations there are differences in access to care due to existing barriers. These differences by gender. race, ethnicity, socioeconomic status and geographic location cause health disparities to exist.8 Barriers to care can be assessed using the Penchansky and Thomas framework that highlights five dimensions associated with access to care. 9 These categories include accessibility, availability, accommodation, affordability, and acceptability. Table 1 describes each of the lists each of the five dimensions of associated with access to care, their meanings<sup>4</sup>, in addition to examples of these barriers.

Table 1. Penchansky and Thomas access to care framework

Barrier category	Meaning	Example(s)
Accessibility	"The relationship between	Transportation and
	the location of services and	travel time.
	the location of patients."	
Availability	"The relationship of the	Appointment systems
	volume of existing services	and hours of operation.
	and resources to patients'	
	volume and types need."	
Accommodation	"The relationship between	Language and cultural
	the manner in which the	barriers.
	supple resources are	
	organized to accept	
	patients as well as the	
	patients' perceptions of the	
	appropriateness of these	
	systems."	
Affordability	"The relationship of prices	Costs related to the
	of services to patients'	appointment such as

	income ability to pay, and existing health insurance."	transportation, cost of care/services, and lost income.
Acceptability	"The relationship between patients' attitudes about personal and practice characteristics of clinicians and facilities to actual characteristics of existing clinicians and facilities, as well as clinician attitudes about acceptable personal characteristics of patients."	Personal and practice characteristics of provider: age, race/ethnicity, gender, clinic neighborhood or type.  Patient characteristics: age, race/ethnicity, gender, socioeconomic status, insurance status, etc.

Barriers in care can occur in any medical concentration including eye care services. <sup>10-11</sup> Two vision threatening eye conditions in which barriers to eye care can occur are glaucoma <sup>12</sup> and corneal ulcers. <sup>13</sup> Glaucoma is the leading cause of irreversible blindness worldwide. <sup>14</sup> The effects of glaucoma are gradual, so many patients with the disease may not notice any symptoms in the beginning. <sup>14</sup> Those with glaucoma usually visit their eye care provider every 3 to 6 months for routine visits. <sup>15</sup> Routine visits to check on the progression of the disease are needed to prevent vision-loss and further damage to the optic nerve. <sup>15</sup> Corneal ulcers are the fourth leading cause of blindness worldwide. <sup>16</sup> When patients develop a corneal ulcer, it is imperative that they are treated right away by an eye care provider to avoid vision loss or blindness because of the condition's rapid progression. <sup>16</sup> For both of these eye conditions, care by an eye care provider is needed to avoid vision-loss and blindness. Barriers to eye care for patients with these conditions need to be identified and addressed to avoid life-long complications that can occur from these conditions.

In this scoping review, we sought to understand the barriers, both financial and nonfinancial, to accessing care for treatment of glaucoma and corneal ulcers utilizing Penchansky and Thomas' five dimensions associated with access to care as a framework. We have chosen both an acute and chronic eye condition to determine if there are barrier differences or similarities between the two conditions. Understanding these barriers can have implications to address these barriers so patients may avoid outcomes of vision-loss and blindness.

### Inclusion Criteria:

- 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, not medication adherence).
- Studies that only pertain to glaucoma and/or corneal ulcers, or specifically state what the barriers were for these specific conditions.
- Qualitative, quantitative or mixed-methods studies that evaluated the follow-up barriers in Cornea Ulcer or glaucoma care.
- Exclusion criteria: articles that focus on dry eye; articles that are reviews, case reports, or opinion pieces; articles that are not related to follow-up for appointments; We exclusively looked at articles written in the English language, as we were not able to provide translation of these articles.

# Types of participants:

- Adults that are 18 years and older
- Adults with cornea ulcer(s)
- Adults with glaucoma

# Concept:

The concept of interest for this scoping review is to understand the barriers that cause loss to follow-up and care for patients with corneal ulcers and glaucoma.

#### Context:

The context of the scoping review will be open, evidence from the literature pertaining to understand the barriers that cause loss to follow-up and care for patients with corneal ulcers and glaucoma within any contextual setting will be included. Though the evidence will be limited to that written in the English language.

## Types of evidence sources:

We will include the following study designs to obtain evidence for this scoping review: primary research reports of any study design (qualitative, quantitative and mixed methods studies). The following will be excluded: dissertations that are not yet published, literature reviews, editorials/ opinion pieces, and book chapters.

#### Methods:

The methods used in this scoping review will follow the frameworks proposed by Arksey and O'Malley<sup>17</sup> and Levac and colleagues<sup>18</sup> using the methods outlined in the JBI Manual for Evidence Synthesis. The review team followed a multi-step, iterative process for developing and refining the search strategy.

## Search Strategy

**Description of strategy:** The review team met with an informationist (KS) in April 2020. Consulting with the review team about their target outcomes, the informationist was able

to create a relevant search strategy that was utilized in selection of potential databases to obtain evidence, concepts as well as the search terms. This search strategy was utilized to identify evidence from primary research articles including quantitative, qualitative and mixed methods studies. 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).

After the team's initial search strategies in PubMed were analyzed and refined, it was determined that Ovid MEDLINE would be the primary database for searching MEDLINE. As the searches were translated across the remaining databases, the review team reviewed search terms and results for each database and provided feedback on the search terms.

The final search strategy focuses on the main concept of barriers to follow-up care for individuals with corneal ulcers and glaucoma. Publications that were not included were those that were not primary research including reviews, commentaries, unpublished dissertations and book chapters. The final searches were run in July 2021 and EndNote 20 (Clarivate) was used to manage the scoping review citations as well as remove any duplicate articles included in the search.

The complete search strategy that was utilized for Ovid MEDLINE has been included in Appendix A.

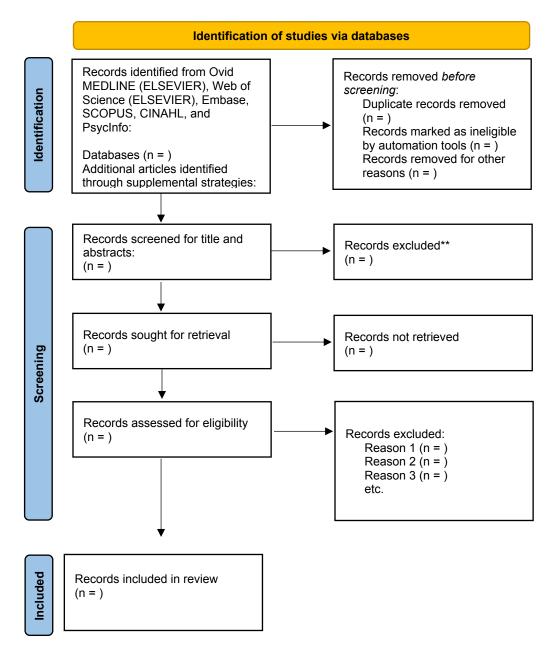
**Supplemental strategies:** The review team will also examine the references of any scoping review or systematic review as well as the references in the primary research articles that have been identified. In addition, we will review the references in any of the articles that were not written in the English language.

#### Source of evidence selection:

The review of sources will utilize the program Rayyan – Intelligent Systematic Review. Article selection will be based on the inclusion and exclusion criteria described above and will include a review of title and abstract, followed by a full-text review of the evidence.

All reviewers will be required to complete a training by reviewing the protocol developed for this scoping review. A pilot test will be conducted on 10% of the total articles found and screening will commence once 75% of agreement has occurred between the two primary reviews on these pilot study articles (PH and LK). When completing the screening, at least 2 reviewers will review each source at each level (title abstract and full-article review) and disagreements will be reconciled by consensus or by a third reviewer. Figure 1 depicts the flowchart of review process. In accordance with the PRISMA-ScR statement<sup>19</sup>, a flowchart and narrative description of the evidence selection process will be created as presented in figure 1.

Figure 1. Review Process



# Data extraction/charting:

The data extraction form will extract the following data from each source of evidence:

- 1) Author(s)
- 2) Year of Publication

- 3) Country (where the source was published or conducted)
- 4) Type of study conducted
- 5) Aims/Purpose of the Study
- 6) Population Demographics
  - a. Number of participants included in the study
  - b. Age range for study participants (if available)
  - c. Race/Ethnicity of study participants (if available)
  - d. Gender/Sex listed for study participants (if available)
  - e. Location (if available)
- 7) Type of Diagnoses
- 8) Outcomes: barriers identified to loss to follow-up for care of corneal ulcers and glaucoma.
- 9) How Outcomes were obtained (Survey, Phone-Call, Chart Review, etc.)
- 10)Methodology / methods (see Table 2 below)

The data extraction form will be utilized during the pilot phase of the scoping review and further refined, if needed. If additional data is determined to be needed during the screening and data extraction process, the data extraction form will also be updated.

## **Analysis of the evidence:**

Simple frequency counts of barriers identified to loss to follow-up for care of corneal ulcers and glaucoma, population demographics, types of diagnoses and other fields of data extracted from evidence will be calculated.

#### Presentation of the Results:

Scoping Review evidence will be presented in a table (see Table 2 for outline of table example).

**Table 2.** Example tabular presentation of data for a scoping review

Parameter	Results
Number of Publications	Total number of publications
	Number of publications by year
Types of Studies	Quantitative Studies
	Qualitative Studies
	Mixed Methods
Population Demographics	Age (Range)
	Number of participants included in the
	study
	Race/Ethnicity of study participants (if
	available)
	Gender/Sex listed for study participants (if
	available)
	Location (if available)

Type of Diagnosis	Cornea Ulcer(s)
	Ulcerative Keratitis
	Ulcerative Keratitides
	Acanthamoeba Keratitis
	Herpetic Keratitis
	Dendritic Keratitis
	Glaucoma
Barriers Outcomes	Affordability
	Accommodation
	Availability
	Accessibility
	Acceptability
	Additional barriers
Outcome Measurement	Qualitative interviews
	Standardized Survey
	Non-standardized items/questionnaire
	(such as phone call or chart review)
	Additional Measurements

#### References:

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# Appendix A:

**Ovid MEDLINE** (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