LIVING WITH KERATOCONUS: EVIDENCE-BASED LITERATURE REVIEW AND POLICY DEVELOPMENT IN DISASTER RISK REDUCTION

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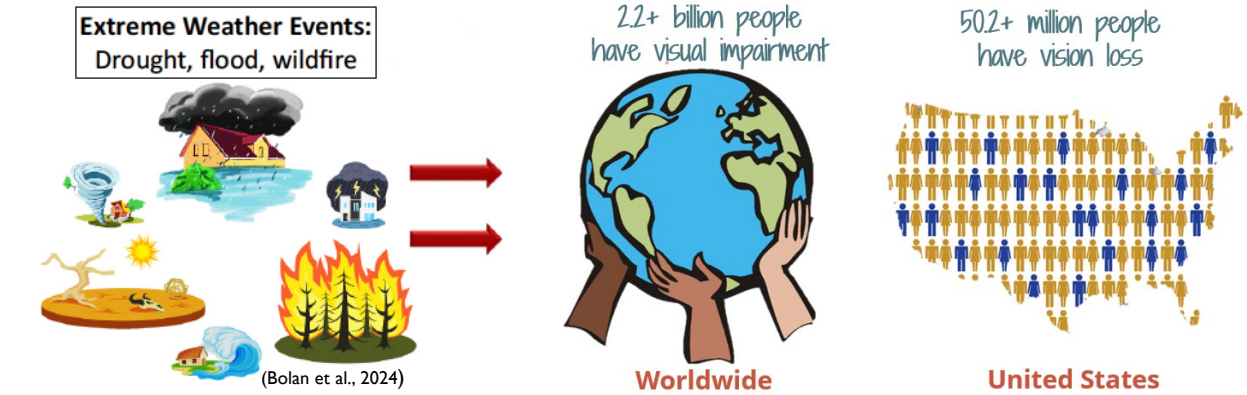
Background & Introduction

Climate change-related emergencies, such as wildfires and floods, are increasing worldwide. Individuals living with keratoconus (KC) and other forms of visual impairment are at increased risk for harm during these disasters. Community outreach through organizations like the Carolyn E. Wiley Center play a vital role in preparing individuals and families to face the daily personal challenges associated with disability and to plan ahead for optimal management of difficult events. To support equity and inclusiveness, public health policies must address the needs of vulnerable populations before, during, and after emergencies and disasters.



What is Keratoconus (KC)?

KC is an eye condition that affects the cornea, the outer protective layer of the eye. In KC, the cornea weakens, thins, and bulges forward into a cone shape. This causes vision to become severely distorted. Most eye conditions affect people during late middle age to senior years. KC is different and begins affecting people during their teens, 20s, and 30s. KC is a lifelong condition that worsens over time.

Why Does it Matter?

KC is one of many visually impairing conditions that can increase an individual's risk for harm during an environmental emergency or disaster. Caring about the needs of individuals with visual disabilities and other kinds of disability is of critical concern to public health aims. Nearly everyone will be impacted by some form of disability during their lifetime. Developing plans to ***prepare for disasters now*** can help to keep you, your loved ones, and the general public safer in the future.

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Fellowship Project Overview

Needs Assessment → Literature Review → Recommendations → Policy Proposal → Next Steps

Health Center Needs Assessment

The Wiley Center provides social support, outreach, counseling, mental health care, and education for individuals/families with cognitive and physical disabilities.

Identified Needs:

- Policy expansion to include individuals/families living with visual disabilities
- Develop disaster risk reduction (DRR) strategies to support these groups

Literature Review

- Visual impairment creates a unique sense of daily vulnerability, requiring an increased need to plan daily routines and prepare for emergencies.
- Coping measures must include DRR strategies to reduce harm and maximize safety for individuals living with visual disability.
- Gaps in the evidence reveal a lack of visual-related disability inclusion in DRR.

3E Health Policy Analysis

Effectiveness
Meeting the goal

Efficiency
Benefits vs Risks

Equity
Balanced inclusivity

Recommendations

- Provide education and resources to assist individuals/families in developing vision-specific toolkits, communication plans, and DRR checklists
- Use 3E analysis to guide the development and evaluation of DRR policies to support individuals/families with visual disability

Policy Proposal

Emergency planning should specify the inclusion of individuals with visual and multiple comorbid disabilities at the individual, interpersonal, community, institutional, and system levels. Specifically, emergency preparedness should include plans for education, training, communication, evacuation, and shelter, with a focus on addressing the vulnerabilities of populations affected by visual and other disabilities.

Next Steps

- Policy implementation and evaluation guided by 3E health policy methodologies
- Research expansion to include DRR planning in KC-related and other forms of visual disability
- Evaluate shelter capacity to accommodate vision-specific needs, such as eye care hygiene stations, low-vision-compliant signage, and clutter-free pathways