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**SUMMARY**

**OBJECTIVES**

- Approximately 900 rare diseases are known to lead to visual impairment or sight loss and patients' visual impairments understandably affect the QoL of their families and friends who provide regular care and support.
- To highlight the often-overlooked burden of giving care to adults with sight loss, this study investigated the association between the QoL of informal caregivers and the care they provide to adults with severe visual impairments, with a focus on rare disease.

**METHODS**

- A comprehensive systematic literature review was conducted, involving electronic databases and secondary searching.
- QoL publications investigating the burden and experiences of informal carers providing care to individuals with severe visual impairment ( $\geq 18$  years of age), published before June 2024, were included.
- Data was analysed using qualitative descriptive methodology.

**FINDINGS**

- The study found that increased severity of visual impairment is linked to higher caregiver anxiety, spousal strain, and more intense informal care, with demographic factors of both patients and caregivers influencing the caregiving experience.
- There is a high prevalence of depressive symptoms and overcontrolled coping among caregivers, with female caregivers being the most at risk.

**INTRODUCTION**

- Approximately 900 rare diseases are known to lead to visual impairment or sight loss.<sup>1</sup> Many of these have no cure or treatment. These impairments can profoundly impact patients and their families, resulting in substantial challenges and lifestyle adjustments.
- While considerable attention has been given to understanding the diminished quality of life (QoL) reported by patients with visual impairment, the burden on family and friends who provide 'informal' care to severely visually impaired adults is less explored.
- When designing this study, efforts were initially focused on rare diseases that have treatments available, and have been, or are in the process of being appraised through formal health technology assessment (HTA). This led to the most recent submissions in Retinitis Pigmentosa (RP) and Leber's Hereditary Optic Neuropathy (LHON).<sup>2,3</sup> HTA submissions in these indications had challenges regarding the impact on the QoL for caregivers to adults living with these rare eye conditions.
- This study investigated the association between the QoL of informal caregivers and the care they provide to adults with severe visual impairments. To provide depth of data, we expanded our search beyond rare diseases to encompass any relevant sight loss condition.

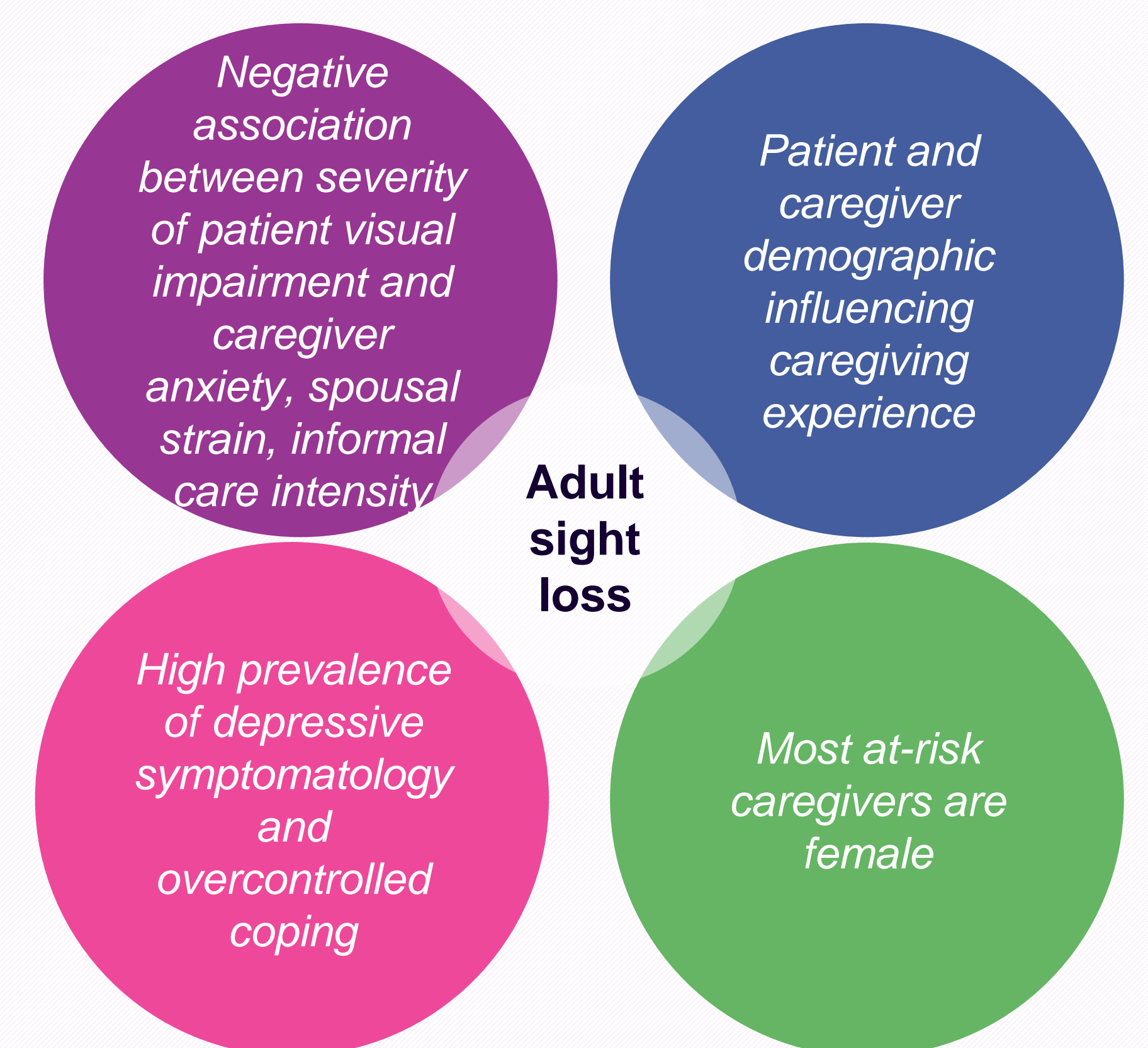
**METHODS**

- A PRISMA-adherent systematic review<sup>4</sup> was conducted to identify relevant QoL publications investigating the burden and experiences of informal carers providing care to individuals with low vision ( $\geq 18$  years of age), published before 6th June 2024.
- Electronic database searches were conducted in Embase, MEDLINE(R) ALL, and the Cochrane Library via Ovid, with secondary searching involving citation tracking of included studies and identified literature reviews.
- Database search strategies were peer reviewed.

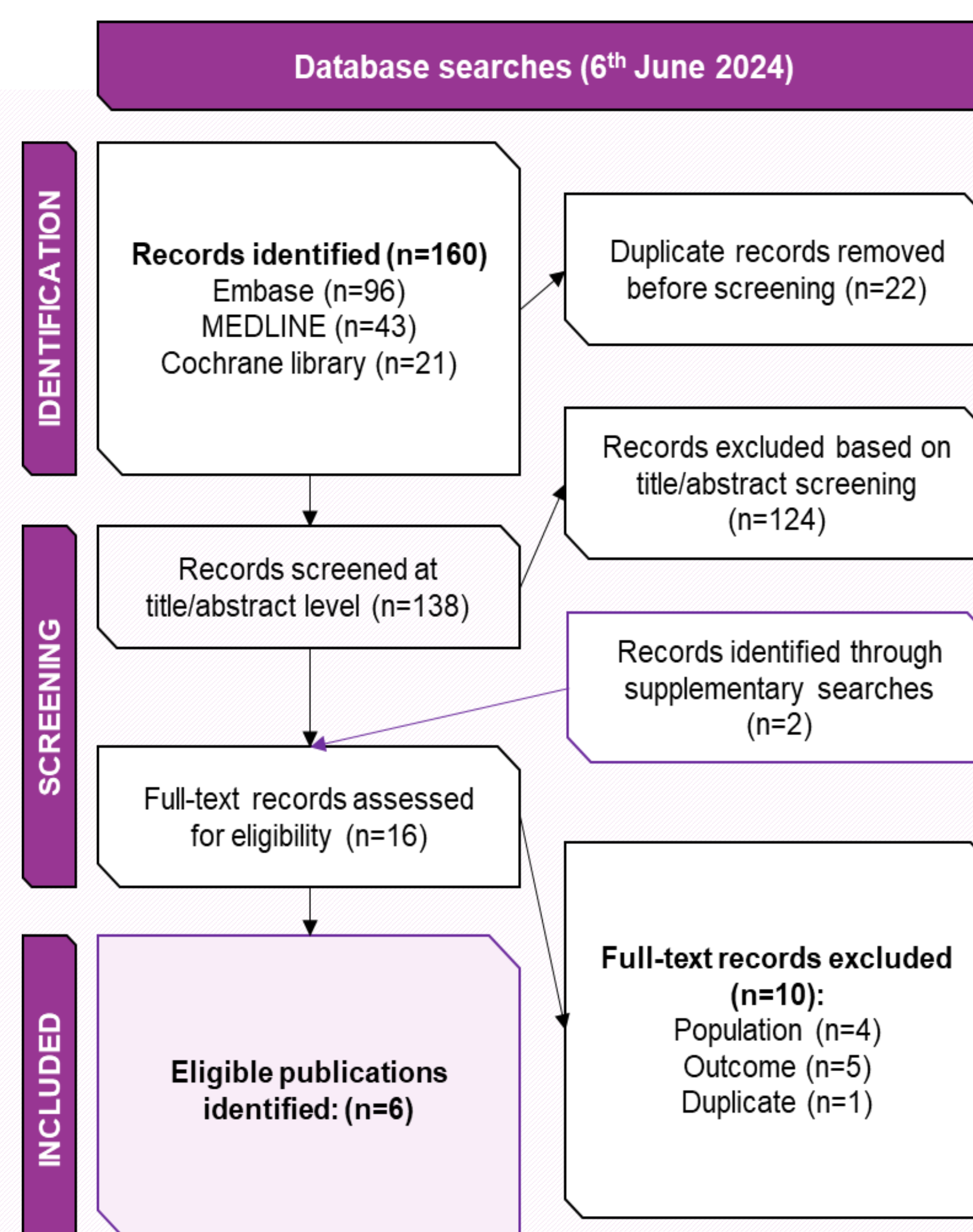
- Two reviewers independently screened the literature and extracted data from full publications. The eligibility criteria for screening in the review are shown in **Table 1**.
- Extracted data were analysed and summarised using qualitative descriptive methodology.

**RESULTS**

- Of the 140 articles identified, 6 met the review eligibility criteria.
- The following themes were identified: (1) negative associations between the severity of patient visual impairment and caregiver anxiety, spousal strain, and intensity of informal care; (2) patient and caregiver demographic influencing caregiving experience; (3) high prevalence of depressive symptomatology and overcontrolled coping; and (4) most at-risk caregivers are female (**Figure 2**).



**Figure 2. Caregiver QoL themes in adult sight loss.**



**Figure 1. PRISMA flow diagram.**

**Table 1. Inclusion/exclusion criteria.**

Category	Inclusion criteria	Exclusion criteria
Population	Male and female adults ( $\geq 18$ years of age) with sight loss, severe visual impairment, low vision, or legal blindness	Mixed population with majority (>60%) being elderly individuals with sight loss due to age-related macular degeneration
Intervention/comparator	None	Not applicable
Outcomes	Themes surrounding: - Impact of patient sight loss on caregiver/spouse/ family QoL - Extent of patient's dependence on informal caregivers after sight loss - Impact of high responsibility, anxieties and emotional burden on caregiver/ family health, life and finances - Amount of time spent caregiving	Non-quality of life outcomes
Study design	- Observational studies - Surveys - Reviews - Commentaries	Clinical and safety studies or economic assessments of interventions or preventive measures
Limitations	None	Not applicable

**DISCUSSION**

- The impact of low vision is far-reaching. This review's findings not only underscore the clear association between caregiver QoL and the burden of caring for adults with severe visual impairment but also emphasise the urgent need for greater awareness and research on the negative psychosocial impacts of providing care to adults with low vision.

**References**

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