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SUMMARY

OBJECTIVES

- Approximately 900 rare diseases are known to lead to visual impairment or sight loss.¹ 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).^{2,3} 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 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 (≥18 years of age), published before June 2024, were included.
- Data was analysed using content analysis as a form of 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.
- After initial searches had been completed, the LHON Society published a patient survey that highlights the significant impact of LHON on both individuals and their carer's, emphasizing the emotional, practical, financial, and social challenges they face⁶.
- When asked the number of carers people had the respondents show an average of 1.58 carers, on average of 24.8 days out of 31 per month (83% of the time). This would reasonably translate to an average of 1.30 carers continually. This finding is consistent across adults and children

BACKGROUND & AIMS

- Approximately 900 rare diseases are known to lead to visual impairment or sight loss.¹ 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).^{2,3} 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 qualitative systematic review⁴ was conducted to identify relevant publications investigating the burden and experiences of informal caregivers providing care to individuals with low vision (≥18 years of age), published before June 6th, 2024.
- Electronic database searches utilising the Boolean logic were conducted in Embase, MEDLINE, and EBM Reviews involving the Cochrane Library via the Ovid platform. Secondary searches were conducted including forward and backward citation tracking via Google Scholar, bibliographic lists and identified literature reviews.
- Database search strategies included both controlled keywords, free text, and Medical Subject Headings (MeSH) terms for visual impairment, caregivers and quality of life. The 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 i.e., content analysis, to determine/ quantify and analyse the presence and relationships of themes concerning the impact of adult patient sight loss on caregiver quality of life.⁵

Table 1. Inclusion/exclusion criteria.

Category	Inclusion criteria	Exclusion criteria
Population	Male and female adults (≥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 Not applicable
Intervention/comparator	None	Non-quality of life outcomes
Outcomes	Themes surrounding: <ul style="list-style-type: none">- 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	
Study design	<ul style="list-style-type: none">- Observational studies- Surveys- Reviews- Commentaries	Clinical and safety studies or economic assessments of interventions or preventive measures
Limitations	None	Not applicable

RESULTS

- The electronic database retrieved a total of 138 records (without duplicates). Following independent dual screening at title/abstract and full-text stages, 134 articles were. 2 relevant records were retrieved following citation tracking, and in total, 6 publications met the review eligibility criteria.
- The following themes were identified (**Figure 2**):
 - (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.

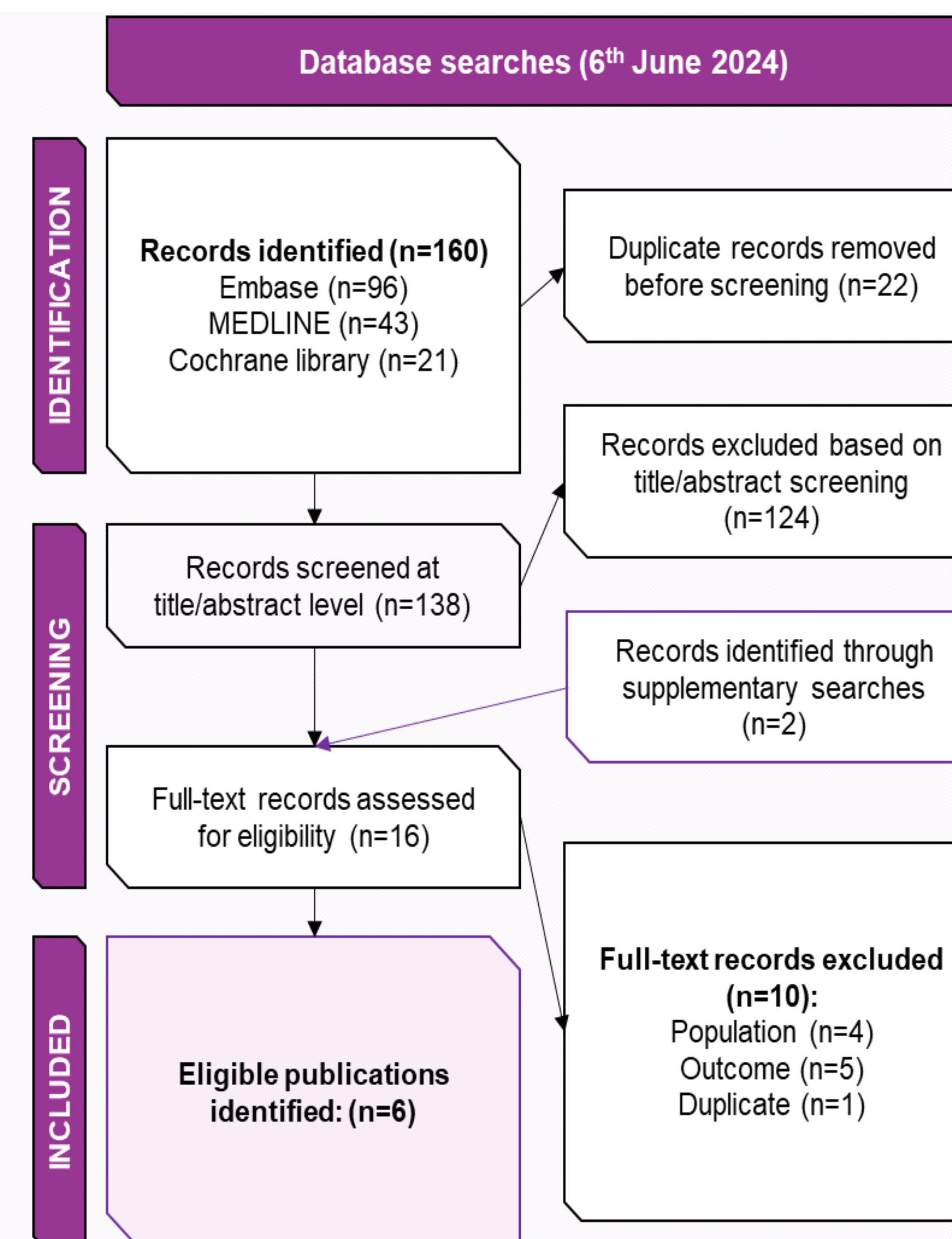


Figure 1. PRISMA flow diagram.

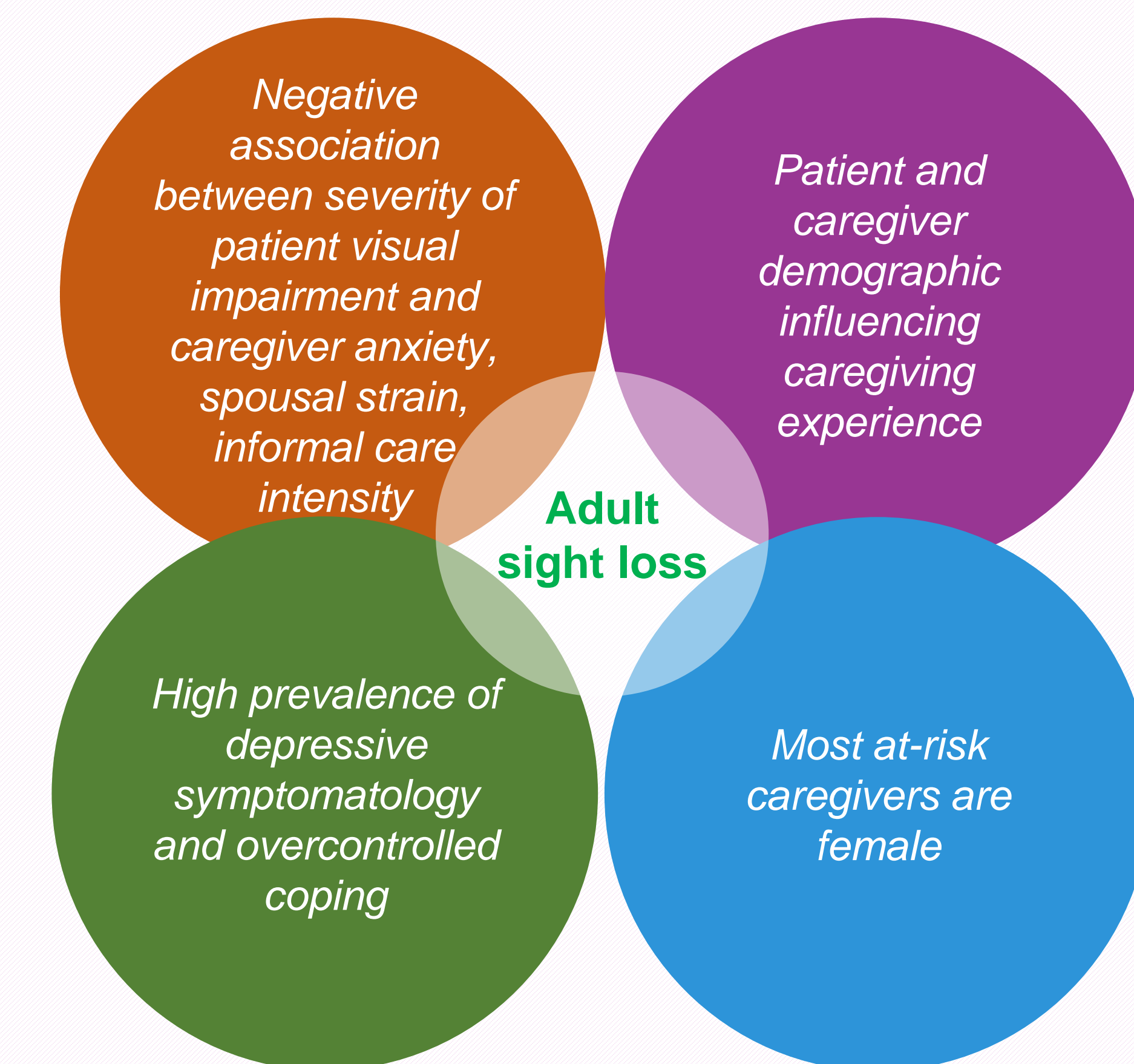


Figure 2. Caregiver QoL themes in adult sight loss.

- A survey of people (n=916) affected by inherited sight loss, provided as part of a HTA submission, revealed a significant decline in QoL since the point of diagnosis². Key findings were:
 - More than 50% of respondents reported a severe or very severe impact on QoL².
 - 36% reported a more moderate impact on QoL².
 - The strain of losing their vision also has a profound impact on mental health, leading to heightened anxiety, stress, depression and feelings of loneliness². Key findings suggest:
 - 92% of respondents reported that their sight loss had impacted their mental health².
 - 75% experience increased anxiety, 62% stress, 41% depression and 33% loneliness².
- As disclosed by one study participant, "Almost every aspect of my life that I can think of is impacted by my sight, from the place I choose to live so as to be close to public transport, to the people I socialise with, the places I go, and the confidence with which I live my life²."

CONCLUSIONS

- 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.
- The patient group survey supports the findings from the SLR. Visual impairment does have a significant impact on caregivers.

References

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