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Depressive and anxiety symptoms in caregivers of children with congenital ectopia lentis: a prospective cross-sectional study

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ABSTRACT

Objectives To evaluate the frequency and severity of depressive and anxiety symptoms and explore possible risk factors among caregivers of children with congenital ectopia lentis (CEL).

Design A prospective cross-sectional study was conducted.

Participants 108 patients and 108 informal caregivers (mainly parents) were included. Participants were grouped based on whether patients had systemic abnormalities: group 1 were children without systemic abnormalities and group 2 were children with systemic abnormalities.

Outcome measures The 9-item Patient Health Questionnaire (PHQ-9) and the 7-item Generalized Anxiety Disorder Scale (GAD-7) were used to assess depressive and anxiety symptoms, respectively.

Results More than half of caregivers (51.9%) have depressive or anxiety symptoms of some degree. 38.0% of caregivers suffered from both depressive and anxiety symptoms. 19.4% of caregivers had moderate to severe depressive symptoms (PHQ-9 score ≥10) while 16.7% reported moderate to severe anxiety symptoms (GAD-7 score ≥10). Between the two groups, the mean PHQ-9 and GAD-7 scores significantly differed (p=0.026 in PHQ-9; p=0.018 in GAD-7). The proportion of caregivers with moderate to severe symptoms was greater in group 2 than in group 1. In addition, there was a significant positive correlation between PHQ-9 and GAD-7 scores (r=0.827; p<0.001). Furthermore, best corrected visual acuity in the better eye of patients was positively correlated with both the PHQ-9 and GAD-7 scores (r=0.314, p<0.05 in PHQ-9; r=0.325, p<0.05 in GAD-7).

Conclusions Depressive and anxiety symptoms were common in caregivers of children with CEL, especially among those whose children had other systemic disease manifestations or low vision. This study illustrates the importance of depressive and anxiety symptom screening for these caregivers to implement effective psychological interventions and support strategies.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The study tried to address the symptoms and associated factors of the two most widely prevalent mental illnesses (depression and anxiety) in caregivers of congenital ectopia lentis children at a time.
⇒ The 9-item Patient Health Questionnaire and the 7-item Generalized Anxiety Disorder questionnaires used in this study are simple, rapid, effective and reliable tools for screening and evaluation of the severity of depressive and anxiety symptoms.
⇒ The in-person interviews were conducted in a large-scale ophthalmology hospital in China, which might result in potential sample selection bias.
⇒ The tool used in the study was a screening tool and the outcome measures should not be interpreted as diagnoses of mental health conditions.

INTRODUCTION

Congenital ectopia lentis (CEL) is defined as the displacement of the crystalline lens from its normal position caused by congenital dysplasia of the zonule fibres.[1 2] CEL could be potentially deleterious to visual function and can be highly burdensome with progressive multisystem involvement, such as cardiovascular and skeletal abnormalities.[3] Following initial diagnosis and surgical intervention, children with CEL usually require lifelong follow-up visits and may suffer disease progression.[4] In addition, there is an increased need for assistance with basic activities of daily living among paediatric patients with low vision.[5] Therefore, caregivers play an important role in the disease management and daily life support.

Childhood disease or disability affects more than the child since the primary caregiver and family are also affected. Numerous studies indicate parental caregivers of sick children are at increased risk for psychological difficulties and decreased quality of life (QOL), especially in cases of congenital or chronic conditions.[6–8] Leske *et al* found significantly lower QOL scores for parents of children across eye conditions compared with those of visually normal controls, with the greatest difference in the 'Worry about

Child's Functional Vision' domain.[9] CEL may have more adverse effects on patients and their caregivers compared with other eye diseases since this disease can lead to severe vision impairment among children and cause other systemic abnormalities. Parents of affected children have to cope with changes in normal routine and shoulder increased responsibility, such as sudden extra expenses for medication and equipment, extended time necessary to care for the child and social isolation due to time spent caring for the child, which may likely increase their psychological stress and have adverse effects on their mental health.[7 10 11]

Having a caregiver with depression or anxiety may cause challenges for children with CEL, as suboptimal mental well-being of the caregiver can have a negative impact on the quality of care they provide. Although prior studies have mainly examined rates of mental disorders and diminished QOL among patients with CEL, to date few studies have undertaken a quantitative evaluation of depression and anxiety experienced by caregivers.[12] Thus, in the present study, we aim to screen caregivers with depressive or anxiety symptoms and identify risk factors. Findings from this study may be important for providing caregivers with appropriate counselling on their mental health, thereby maximising their ability to care for children with CEL.

METHODS

This study was conducted in accordance with the principles of the Declaration of Helsinki from January to June 2023. Informed consent was obtained from all participants.

Participants

Patients with CEL and their primary caregivers were recruited by verbal invitation in the outpatient clinic or ward at Zhongshan Ophthalmic Center. One of our researchers explained the research process in detail to ensure the participants fully understood the whole study and answered all questions. Participants who wished to enrol signed the study consent form.

Medical records of patients with CEL were examined to identify eligible participants for the present study. The inclusion criteria were as follows: (1) previous CEL diagnosis, (2) age under 18 years, (3) completed echocardiography and X-ray studies on skeletal system and (4) the oldest age at lensectomy under 18 years. The exclusion criteria were as follows: (1) lens dislocation caused by trauma or other reasons and (2) those with cataract, secondary glaucoma, strabismus or other associated ocular complications except refractive error.[13] Patients were divided into two groups based on whether they have systemic abnormalities: group 1 were children without systemic abnormalities and group 2 were children with systemic abnormalities.

Caregivers were eligible if they were a family member that patients identified as the 'person they usually turn to for help regarding their care'.[14] Designated as 'caregiver' were adults over the age of 18 who were unpaid for their support. As CEL children aged under 18 were mainly cared for by their parents, in our study we only included their parents as their primary caregivers. If there was more than one caregiver, we recruited the caregiver who most frequently cared for the child to ensure that the number of caregivers enrolled was the same as the number of patients. Prior to enrolment, the researcher conducted a face-to-face interview with caregivers. Those with one of the following conditions would be excluded: (1) experienced a major life trauma in the last 2 weeks (car accident, natural disaster, death of a loved one, etc) and (2) with other serious diagnosed physical or mental illness (cancer, autism, schizophrenia, etc).

Because there is no previous study on depressive and anxiety symptoms in CEL caregivers, we estimated the sample size based on the results of the pretest. According to PASS software (PASS V.15, NCSS, Kaysville, Utah), assuming 80% power and a 5% significance level, a sample size of 30 in each group was calculated. Assuming a 20% loss to follow-up, we estimated the minimum sample size for each group to be 38.

Baseline data collection

The following data were collected for each patient from medical records: demographic information, including gender, age at diagnosis, age at time of study, the oldest age at lensectomy, previous treatment, number of previous treatment types (including wearing glasses, amblyopia treatment, surgery), number of lens subluxation surgeries, degree of ametropia and best corrected visual acuity (BCVA) in each eye (converted to logarithm of minimum angle of resolution).

After enrolment, caregivers were required to complete a general information questionnaire from which we obtained sociodemographic details, including age, gender, marital status, place of residence, number of children, educational attainment and annual household income.

Assessment of mental health of caregivers

For the assessment of depressive and anxiety symptoms, we administered two questionnaires for caregivers: the 9-item Patient Health Questionnaire (PHQ-9) and the 7-item Generalized Anxiety Disorder Assessment (GAD-7). Both questionnaires were completed in the way of self-administration.

The PHQ-9 is a nine-item scale that assesses the nine depressive symptom criteria of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, for frequency of occurrence during the 2-week period prior to screening. It consists of nine items scored on a 4-point Likert scale from 0 to 3. A score of 0 corresponds to the absence of symptoms, whereas scores of 1, 2 and 3 indicate that a symptom was present on several days, more than half of the days or nearly every day in the past month, respectively. PHQ-9 screens based on a summed score ranging from 0 (no depressive symptoms)

to 27 (all symptoms occurring daily).[15] PHQ-9 shows good reliability, validity and high adaptability for both patients with major depressive disorder and the general population.[16 17] PHQ-9 has been translated into Chinese and validated with an internal consistency of 0.857 in Chinese.[18]

The GAD-7 is a seven-item screening scale that assesses the severity of anxiety symptoms. Patients were asked to indicate how often, during the last 2 weeks, they were bothered by each symptom using a 4-point Likert-type rating scale. GAD-7 screens based on a summed score ranging from 0 (no anxiety symptoms) to 21 (all symptoms occurring daily).[19] Among clinical and general population samples, the GAD-7 has demonstrated good reliability and cross-cultural validity as a measure of generalised anxiety disorder.[20] GAD-7 has been translated into Chinese and validated with an internal consistency of 0.898 in Chinese.[21]

The score ranges for results of the depressive and anxiety symptom severity from both the PHQ-9 and GAD-7 are as follows: no symptoms (0–4), mild (5–9), moderate (10–14) or severe (15+).[22] A cut-off score of '10+' was used to determine moderate to severe depressive and anxiety symptoms, in which case psychological or psychopharmacological interventions would be recommended.[23] Once caregivers completed both questionnaires, one of our researchers calculated the scores and informed participants of the results. For those who showed obvious depressive or anxiety symptoms, participants were advised to seek mental health counselling from a professional psychologist or counsellor.

Statistical analysis

Statistical analyses were performed using SPSS (V.25.0, IBM). All continuous variables were expressed as means and SDs, whereas categorical variables were expressed as proportions. The normal distribution of continuous variables was evaluated using the Kolmogorov-Smirnov test. Group differences for normally distributed continuous variables and categorical variables were evaluated using the Student's t-test and χ^2 test, respectively. The Mann-Whitney U test was used for group comparison analysis between PHQ-9/GAD-7 scores and other continuous variables as they were not normally distributed. Spearman's r correlation coefficient was used to assess the relationship between PHQ-9/GAD-7 scores and demographic and clinical variables.

Factors associated with PHQ-9 and GAD-7 scores were determined using univariate and multivariable linear regression analysis. Duration of disease was calculated using the child's current age and age at diagnosis of CEL. Covariates in the multivariable regression model included variables with p<0.10 in univariate models. Regression diagnostics and variance inflation were checked for all models. All of the statistical tests were two tailed, and a p value <0.05 was considered to denote statistical significance.

Patient and public involvement

Patients or the public were not involved in any design, operation, reporting or information dissemination elements of our research.

RESULTS

Demographics and clinical characteristics of the study cohort

Of the total 108 caregivers of children with CEL recruited for this study, 57 children were without systemic abnormalities and 51 children had systemic abnormalities. The demographics and clinical characteristics of the study sample are presented in table 1. There were no significant differences in characteristics between the two groups (p>0.05).

Depressive and anxiety symptoms in caregivers of patients with CEL

The mean scores were 5.9±6.3 for PHQ-9 and 5.1±5.3 for GAD-7. Among the caregivers of children with CEL, more than half (51.9%) had different degrees of depressive or anxiety symptoms. 44.8% of caregivers had varying degrees of depressive symptoms and 44.8% had varying degrees of anxiety symptoms. It was also found that 41 (38.0%) caregivers suffered from both depressive and anxiety symptoms. PHQ-9 scores showed 19.4% of caregivers had moderate to severe depressive symptoms (PHQ-9 score ≥10) while 16.7% reported moderate to severe anxiety symptoms (GAD-7 score ≥10) in GAD-7 (table 2). 'Feeling tired or having no energy' was the most common depressive symptom (figure 1). 'Becoming easily annoyed or irritable' and 'Worrying too much about different things' were the most common anxiety symptoms (figure 2). PHQ-9 showed nearly one-fourth of caregivers (23.1%) had thoughts of being dead or harming themselves in some way in the past 2 weeks (figure 1).

Comparison of survey results among study groups

The scores for the caregivers of children with CEL are presented in table 2. The mean PHQ-9 scores were 4.6±5.7 (range=0–25) in group 1 and 7.2±7.1 (range=0–25) in group 2. The mean GAD-7 scores were 4.0±4.7 (range=0–18) in group 1 and 6.3±5.8 (range=0–21) in group 2. There were significant differences in both PHQ-9 and GAD-7 scores between the two groups (p=0.026 in PHQ-9; p=0.018 in GAD-7; table 2). In PHQ-9, 36.8% had varying degrees of depressive symptoms in group 1 and 52.9% in group 2. The numbers of caregivers who showed moderate to severe depressive symptoms were 8 (14.0%) in group 1 and 13 (25.5%) in group 2. 'Feeling tired or having no energy' was the most common symptom in these two groups (figure 1). In GAD-7, 38.6% had varying degrees of anxiety symptoms in group 1 and 52.9% in group 2. The numbers of caregivers who showed moderate to severe anxiety symptoms were 7 (12.3%) in group 1 and 11 (21.6%) in group 2 (table 2). 'Trouble relaxing' was the most common symptom among group 1 while 'Becoming easily annoyed or irritable' and 'Worrying

Table 1 Baseline demographics and clinical characteristics of the study cohort

	Group 1 Without systemic abnormalities (n=57)	Group 2 With systemic abnormalities (n=51)	P value
Caregiver age (year)	38.0±6.9	40.0±5.7	0.117*
Caregiver gender, n (% female)	39 (68.4)	32 (62.7)	0.535†
Number of children	2.1±0.9	1.9±0.8	0.345‡
Place of residence, n (% city)	34 (59.6)	29 (56.9)	0.769†
Caregiver marital status, n (% married)	52 (91.2)	45 (88.2)	0.608†
Caregiver's highest level of education, n (%)			0.536‡
Primary school or below	8 (14.3)	2 (3.9)	
Middle school	18 (31.6)	17 (33.4)	
Technical secondary school	4 (7.0)	5 (9.8)	
High school	4 (7.0)	8 (15.7)	
Junior college	7 (12.2)	6 (11.8)	
Undergraduate university	13 (22.8)	11 (21.6)	
Postgraduate university or above	3 (5.3)	2 (3.9)	
Annual household income (¥), n (%)			0.621‡
<30 000	16 (28.0)	14 (27.5)	
30 000–80 000	16 (28.0)	20 (39.2)	
80 000–150 000	14 (24.6)	6 (11.8)	
150 000–300 000	6 (10.5)	9 (17.6)	
>300 000	5 (8.8)	2 (3.9)	
Child's gender, n (% female)	25 (43.9)	23 (45.1)	0.897†
Child's age at diagnosis (year)	4.9±2.6	4.9±2.5	0.913‡
Child's age at time of study (year)	9.5±3.2	10.2±3.7	0.487‡
Previous treatment			0.653‡
No previous treatment	1 (1.7)	1 (2.0)	
Wearing glasses	36 (63.2)	38 (74.5)	
Amblyopia therapy	9 (15.8)	8 (15.7)	
Surgery	45 (78.9)	41 (80.4)	
Number of previous treatment types	1.6±0.7	1.7±0.7	0.249‡
Number of lens subluxation surgeries	1.4±0.9	1.5±0.9	0.876‡
BCVA in better eye (logMAR)	0.2±0.1	0.2±0.2	0.382‡

*Student's t-test.
†X^2 test.
‡Mann-Whitney U test.
.BCVA, best corrected visual acuity; logMAR, logarithm of minimum angle of resolution.

too much about different things' were the most common symptoms in Group 2 (figure 2).

Associations of explanatory variables with depressive and anxiety symptoms

There was a significant positive correlation between PHQ-9 and GAD-7 scores (r=0.827; p<0.001; online supplemental figure 1). Furthermore, BCVA in the better eye of patients was positively correlated with both the PHQ-9 and GAD-7 scores (r=0.314, p<0.05 in PHQ-9; r=0.325, p<0.05 in GAD-7; table 3). There were no associations between both the PHQ-9 and GAD-7 scores and the explanatory variables of caregiver's gender, caregiver's age, number of children, caregiver education, annual household income, child's age, duration of disease, number of previous treatment types or number of lens subluxation surgeries (p>0.05; see table 3 and online supplemental table 1). In univariate and multivariable analyses, only BCVA in the better eye of patients was significantly associated with PHQ-9 (β=11.782; 95% CI 5.039 to 18.524; online supplemental table 2) and GAD-7 scores (β=9.249; 95% CI 3.267 to 15.230; online supplemental table 3).

Table 2 Mean scores of PHQ-9 and GAD-7 and percentages of depression and anxiety symptoms by severity

	Group 1 (n=57)	Group 2 (n=51)	P value
PHQ-9 scores	4.6±5.7 (0–25)	7.2±7.1 (0–25)	0.026*
No symptoms, n (%)	36 (63.2)	24 (47.1)	
Mild, n (%)	13 (22.8)	14 (27.5)	
Moderate, n (%)	4 (7.0)	3 (5.9)	
Severe, n (%)	4 (7.0)	10 (19.6)	
GAD-7 scores	4.0±4.7 (0–18)	6.3±5.8 (0–21)	0.018*
No symptoms, n (%)	35 (61.4)	24 (47.1)	
Mild, n (%)	15 (26.3)	16 (31.4)	
Moderate, n (%)	5 (8.8)	6 (11.8)	
Severe, n (%)	2 (3.5)	5 (9.8)	

PHQ-9 and GAD-7 scores are mean±SD (range).
0–4, no symptoms; 5–9, mild; 10–14, moderate; 15+, severe.
*Mann-Whitney U test.
GAD-7, 7-item Generalized Anxiety Disorder; PHQ-9, 9-item Patient Health Questionnaire.

DISCUSSION

This prospective study aimed to screen depressive and anxiety symptoms in caregivers of children with CEL using the standardised psychometric instruments PHQ-9 and GAD-7. The results showed that more than half of caregivers suffered from depressive or anxiety symptoms in different degrees, and 38.0% of them had depressive and anxiety symptoms concomitantly. Moreover, 19.4% of caregivers had moderate to severe depressive symptoms while 16.7% reported moderate to severe anxiety symptoms. Additionally, caregivers of patients with CEL with systemic abnormalities show higher PHQ-9 and GAD-7 scores and larger proportion of moderate to severe symptoms than those without systematic abnormalities. In addition, there was a significant positive correlation between PHQ-9 and GAD-7 scores. Furthermore, BCVA in better eye was positively correlated with both the PHQ-9 and GAD-7 scores.

In the current study, we found that a significant proportion of CEL caregivers experienced various degrees of depressive or anxiety symptoms. For the general population, it has been reported that about 20% had varying degrees of depressive or anxiety symptoms, and about 5% had moderate to severe depression or anxiety.[24 25] As for congenital eye disease, Wy *et al* found that among caregivers of children with congenital glaucoma, 23.6% had some degree of depressive symptoms and 20.0% had anxiety-related symptoms. It was also found that 7.8% of subjects had moderate to severe depression and 8.5% had moderate to severe anxiety.[13] It is suggested that compared with the general population and caregivers of children with other eye diseases, CEL caregivers are more likely to develop mental health diseases and experience higher levels of depressive and anxiety symptoms. As CEL is a progressive disease, children diagnosed with CEL usually need long-term medical follow-up visits because of the risk of developing medical complications of the cardiovascular (aortic aneurysm, mitral valve prolapse), musculoskeletal and ophthalmic (ectopia lentis, severe myopia) systems.[26] Therefore, caregivers may have extended caregiving responsibilities leading them to become more socially isolated, which undoubtedly further increases the psychological distress and living burden of caregivers.

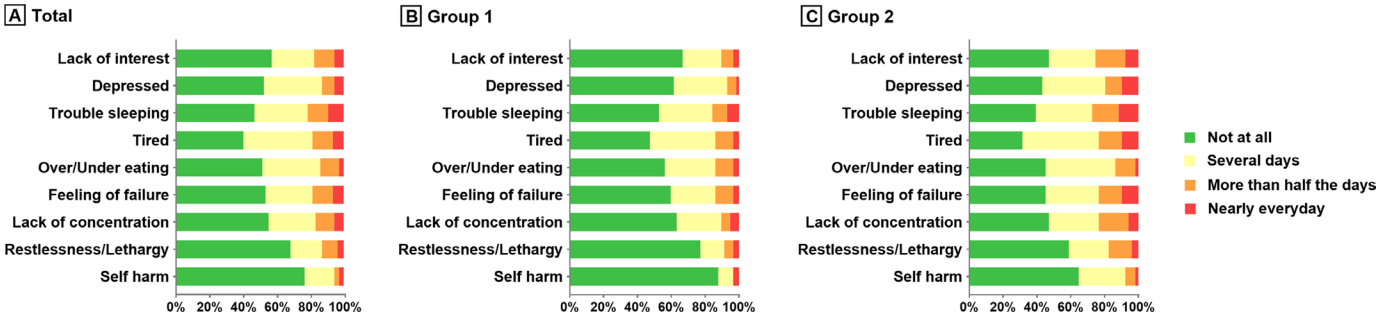

Figure 1 Distribution of responses to the 9-item Patient Health Questionnaire (PHQ-9). Item response options are colour coded. Survey items are arranged vertically. The horizontal axis depicts the proportion of participants who chose each response option. (A) Distribution of responses to the PHQ-9 in the total sample. (B) Distribution of responses to the PHQ-9 in Group 1. (C) Distribution of responses to the PHQ-9 in Group 2.

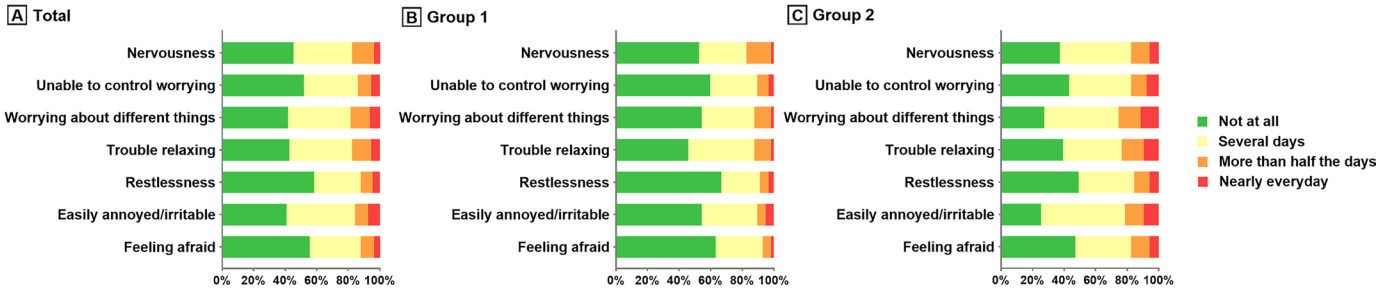

Figure 2 Distribution of responses to the 7-item Generalized Anxiety Disorder Assessment (GAD-7). Item response options are colour coded. Survey items are arranged vertically. The horizontal axis depicts the proportion of participants who chose each response option. (A) Distribution of responses to the GAD-7 in the total sample. (B) Distribution of responses to the GAD-7 in Group 1. (C) Distribution of responses to the GAD-7 in Group 2.

Among the caregivers of patients with CEL, we found that those whose children had other systemic abnormalities suffered from greater levels of depressive and anxiety symptoms. CEL, a hereditary connective tissue disorder, may occur alone or combined with abnormalities in skeletal system and cardiovascular system, such as Marfan syndrome (MFS), homocystinuria and Weill-Marchesani syndrome.[27–29] Caregivers of children with MFS have been shown to often suffer from anxiety and depression, parenting stress and parental burden.[30] On top of that, MFS is an autosomal dominant inherited disease and family members of some patients also suffer from the same disease. Due to phenotypic features and chronicity of MFS, more worries among caregivers were observed regarding the present and future health of the child, the care process at home and the long-term adverse impact on the mental health of the siblings of the child with CEL. It is also reported that parents of children with congenital heart disease show a high degree of depression and anxiety.[31] Notably, apart from patients with MFS, there are CEL children who still experience ocular and other systemic abnormalities. However, the psychological status of caregivers of patients with CEL has not yet been well studied. This study brings attention to the overall psychological status of CEL caregivers and highlights the importance of ongoing research on their mental health.

The significant association between depressive and anxiety symptoms among our subjects is similar to results in the general population.[32–34] Since caregivers of patients with CEL had a higher incidence of depressive symptoms, the logical consequence is also the higher incidence of anxiety symptoms in this study. However, prior studies have shown that the co-occurrence of depression and anxiety is associated with a poorer prognosis, lower remission rate and greater functional disability than seen in persons with a single disorder.[34 35] Recent data suggest that depression and anxiety comorbidity can effectively be treated, and early intervention may significantly reduce chronicity and negative consequences, which confirms the need for professional and long-term psychological care.[36]

In our study, we found that poor BCVA in the better eye of patients was correlated with more depressive and anxiety symptoms. Wy *et al* reported that increased number of glaucoma surgeries and poor visual acuity in better eye were associated with more depressive and

Table 3 Spearman's r correlation results of relationship between PHQ-9/GAD-7 and demographic and clinical variables

	Total (n=108)		Group 1 (n=57)		Group 2 (n=51)	
	PHQ-9	GAD-7	PHQ-9	GAD-7	PHQ-9	GAD-7
Caregiver age	0.034	0.066	0.159	0.158	−0.170	−0.142
Number of children	0.054	0.089	−0.090	−0.016	0.246	0.269
Caregiver education	0.047	0.024	0.209	0.077	−0.182	−0.086
Annual household income	−0.085	−0.068	0.034	−0.055	−0.201	−0.064
Child's age	−0.156	−0.096	−0.154	−0.061	−0.190	−0.171
Duration of disease	−0.082	−0.037	−0.167	−0.134	−0.046	0.002
Number of previous treatment types	0.232*	0.162	0.170	0.106	0.250	0.160
Number of lens subluxation surgeries	0.141	0.061	0.187	−0.005	0.108	0.126
BCVA in better eye (logMAR)	0.314**	0.325**	0.293*	0.396**	0.316*	0.243

Correlation coefficients are presented in the table.
*P<0.05, **p<0.01.
BCVA, best corrected visual acuity; GAD-7, 7-item Generalized Anxiety Disorder; logMAR, logarithm of minimum angle of resolution; PHQ-9, 9-item Patient Health Questionnaire.

anxiety symptoms, and the relation might be stronger in cases of more than moderate depression or anxiety.[13] Similarly, Braich *et al* also found that parent caregivers of patients with lower vision experienced a higher level of depression.[5] This can be explained by the fact that patients with more severe visual impairment usually require more assistance with their activities of daily living and additional hours of close supervision per day, which increase care burden of caregivers and psychological stress.

We have also compared our results with other studies on caregivers' mental health status in the care of blind or low-vision patients.[14 37 38] In our study, the results that more severe visual disability is associated with poorer psychological status of caregivers are consistent with previous results. Notably, we found a higher prevalence of depressive symptoms in our study than in these studies, which mainly included older patients and their informal caregivers. This may be explained by our study's assessment of caregivers of paediatric patients, with some patients having comorbidities in the setting of severe systemic diseases. In some of these previous studies, female caregivers have been found to be more depressed while some have been found to be more depressed in males. However, in our study, we found no significant differences in depressive symptoms between female and male caregivers. This inconsistency may be partly due to the fact that mother and father caregivers were both eligible to be selected as a primary caregiver in our study. Additionally, this may be explained by sample sizes of two groups not being equal (65.7% of caregivers were females.) We expect to expand the sample size for further analysis of the effect of gender on caregivers' mental status.

In this study aiming to measure depressive and generalised anxiety symptoms, we used two widely used and validated questionnaires: the PHQ-9 and GAD-7 questionnaires. Construct validity, reliability and responsiveness of these two instruments have been previously evaluated among clinical and general population samples. Therefore, they can be simple, rapid, effective and reliable tools for screening and evaluation of the severity of depressive and anxiety symptoms. Moreover, the PHQ-9 and GAD-7 are tested to be closely linked and even equated with some other depression and anxiety scales, which broadens their use scope to some extent.[39] Hence, we took advantages of these two questionnaires and included a relatively large sample of CEL caregivers in our research. To our knowledge, the current study is the first to use the PHQ-9 and GAD-7 to detect depressive and anxiety symptoms among CEL caregivers.

There are several limitations to this study. First, as it was based on a cross-sectional survey, we cannot establish causality. Second, as it relied on self-reported instruments, there may be a margin of difference between the actual prevalence of depressive or anxiety symptoms and study results. Third, this study was designed to survey the one caregiver who most frequently cared for the child, but the effect of CEL on the mental health of the whole family has not been fully considered. Despite these limitations, this study highlights the importance of ongoing research on the mental health of caregivers of children with CEL. Future research is needed to assess the impact of caregivers' mental health on the care they provide for CEL children. Furthermore, it is important to provide psychological or pharmacological treatment to address and improve the mental health of caregivers.

CONCLUSIONS

Depressive and anxiety disorders are common in caregivers of children with CEL, especially among those whose children have other systemic abnormalities. Our study also found that poor BCVA in the better eye of patients was associated with increased depressive and anxiety symptoms in caregivers. However, a decline in the mental health of patients' caregivers can potentially compromise their functional abilities which may in turn have negative effects on not only themselves, but the quality of care for affected children. Therefore, awareness of the extent of depressive and anxiety symptoms among caregivers of CEL children would be of great value to ophthalmologists treating patients with CEL to identify at-risk caregivers and implement effective interventions and support strategies.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Consent obtained from parent(s)/guardian(s)

Ethics approval This study involves human participants and was approved by the Institutional Review Board of Zhongshan Ophthalmic Center (ZOC; 2022KYPJ207) in Sun Yat-sen University, Guangzhou, China. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data are available upon reasonable request. Requests can be submitted to the corresponding author.

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