Caregiver Burden in Primary Congenital Glaucoma

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- PURPOSE: **To evaluate the demographic, clinical, and socioeconomic factors associated with variation in the quality of life (QOL) in caregivers of children with primary congenital glaucoma (PCG) in south India.**
- DESIGN: **Cross-sectional survey.**
- METHODS: **Caregivers of children younger than 18 with diagnosed PCG were prospectively enrolled at Aravind Eye Hospital in Madurai and Coimbatore, India. Participants completed 2 questionnaires, the PHQ-9 (9-item Patient Health Questionnaire) and the CarCGQoL (Caregivers Congenital Glaucoma QOL Questionnaire). Clinical, demographic, and socioeconomic data were obtained for each child-caregiver dyad. Rasch-calibrated scores were calculated for patient-reported outcome measures. Spearman correlation and linear regression were used to analyze data to determine associations with caregiver QOL.**
- RESULTS: **There were 70 caregivers (mean age 32.1, 77.1% female) of 70 children with PCG (mean age 7.7, 37.1% female) included in the study. In univariate and multivariable analyses, child's age ($\beta = -0.04$; 95% confidence interval, -0.08 to -0.01) and duration of disease ($\beta = -0.03$; 95% confidence interval, -0.07 to -0.01) were the only factors associated with CarCGQoL. Survey items related to anger, self-confidence, irritability, appetite, and interest in leisure activities had the lowest scores. There was a negative correlation between CarCGQoL and PHQ-9 scores ($r = -0.66$, $P < .01$), indicating that worse caregiver QOL was significantly correlated with more depressive symptoms.**
- CONCLUSION: **This study identified traits associated with QOL decline, as well as the QOL issues most likely to affect caregivers of children with PCG in south India. Findings from this study may be important for designing interventions to improve caregivers' QOL, thereby maximizing their ability to care for children with PCG.**

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IN MOST DISEASES, THE PRIMARY EMPHASIS IS ON CARING for the patient. However, the life of a parent or primary caregiver can be affected considerably, especially in the case of a severe or chronic condition. One such condition is primary congenital glaucoma (PCG), which is a relatively rare disease with a prevalence that varies in different populations from 1 in 3300 to 1 in 10 000[1–4] and accounts for 4.2% to 5.0% of childhood blindness.[1,5] Following initial diagnosis and surgical intervention, children with PCG require lifelong follow-up and may still experience disease progression.[2] Caregivers therefore play an important role in management of the disease, and this can have important implications for the emotional and physical well-being of a caregiver and his or her family.[6–13] In addition, the burden of being a caregiver also can indirectly influence the quality of care they provide.[3] Accordingly, providing optimal and holistic care for a child with PCG, not only requires managing glaucoma, but also may require being attuned to caregiver quality of life (QOL) and well-being.

There are numerous survey instruments that have been developed to assess QOL in caregivers of children with chronic diseases such as asthma,[14] cancer,[15] and chronic renal disease.[16] These surveys evaluate the impact of the child's illness on family resources, family strain, social stigma, physical stress associated with care giving, and the time required to provide care.

Dada et al[4] published the first study on caregiver QOL among those caring for a child with PCG. In that study, the prevalence and severity of depressive symptoms in caregivers was assessed using the Patient Health Questionnaire (PHQ); however, depressive symptoms likely represent only one of several important QOL domains in PCG caregivers. The Caregivers Congenital Glaucoma Quality of Life Questionnaire (CarCGQoL), developed by Gothwal et al,[17] provides a more comprehensive assessment of QOL for those caring for a child with PCG.

To target PCG caregivers most likely to benefit from counseling and additional support, it is important to understand the clinical, demographic, and socioeconomic factors are associated with PCG caregiver QOL. To date, no study has evaluated this among PCG caregivers in India. In the future, interventions to improve caregiver QOL could complement the ophthalmic care of children with PCG to

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improve caregivers' own QOL, as well as their ability to provide optimal care to a child with PCG. Therefore, in the current study we sought to identify the factors associated with variation in PCG caregiver QOL.

METHODS

THE STUDY WAS APPROVED BY THE INSTITUTIONAL REVIEW board at Aravind Eye Hospital in Madurai and Coimbatore, Tamil Nadu, India, and followed the tenets of the Declaration of Helsinki. The study was conducted over 9 months, from January to September 2017. The investigators obtained both oral and written informed consent from all participants.

- **PARTICIPANTS:** Caregivers of children younger than 18 years with a diagnosis of PCG were included. Children diagnosed with aphakic, pseudophakic, or any forms of secondary glaucoma, or children with comorbid ocular/systemic illnesses were excluded from the study. A trained research assistant fluent in the local language (Tamil) administered questionnaires in either the eye hospital or child's home. If there was more than 1 caregiver, we invited the caregiver who most frequently cared for the child to participate.

Because there have been no previous studies on PCG caregiver QOL, the binomial distribution of discrete data and the procedure described by Agresti and Min[18] were used to estimate that a minimum of 30 participants were needed for interval estimation. In addition, empirical studies have demonstrated that a sample size of at least 50 is needed to produce Rasch item calibrations stable within ± 1 logit with 99% confidence.[19] Therefore, we sought to recruit a minimum of 50 participants to satisfy both of these criteria.

- **VARIABLE DEFINITIONS:** We administered 2 previously validated questionnaires, the PHQ-9[20,21] and the CarCGQoL.[17]

The PHQ-9 consists of 9 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. Based on established criteria,[20] depressive symptoms were measured on a scale from 0 to 27 and categorized as minimal (1-4), mild (5-9), moderate (10-14), moderately severe (15-19), or severe (20-27). The 20-item CarCGQoL questionnaire was developed and validated in India to assess the QOL of caregivers of children with PCG.[17] Using Rasch analysis, the CarCGQoL was shown to have robust psychometric properties, including good validity, reliability, and measurement precision.[17]

TABLE 1. Baseline Demographics of the Study Cohort

Demographic Variables	Distribution
Child's age at diagnosis (mo)	12.3 ± 32.6
Child's age at time of study (y)	7.7 ± 4.6
Child's gender, n (% female)	26 (37.1)
Caregiver age (y)	32.1 ± 5.7
Caregiver gender, n (% female)	54 (77)
Caregiver marital status, n (% married)	70 (100)
Caregiver education, n (%)	
< Primary school	3 (4)
Primary school	11 (16)
Middle school	16 (23)
High school	19 (27)
Higher secondary school	9 (13)
Undergraduate university	7 (10)
Postgraduate university	5 (7)
Caregiver occupation, n (%)	
Farmer	16 (23)
Laborer	18 (26)
Technician	6 (8)
Homemaker	13 (18)
Business	3 (4)
Others	14 (20)
Mean income (per mo, INR)	10 664 ± 17 183
Standard of Living Index,[a] n (% high)	27 (39)

INR = Indian Rupees.

[a] Standard of living index scores were classified as low (0-14), medium (15-24), or high (25-67) according to the standard wealth index, based on the Demographic and Health Survey questionnaire adapted for India.[22]

We obtained sociodemographic details of caregivers, including age, gender, marital status, relationship to the child with PCG, educational attainment, occupation, and income. Family wealth was measured using the standard of living (SLI) index,[22] based on the Demographic and Health Survey questionnaire adapted for India. The SLI is a composite measure of a household's wealth, which is calculated using data on a household's ownership of selected permanent assets, such as televisions and bicycles; materials used for housing construction; and types of water access and sanitation facilities. Using established criteria,[22] SLI scores were classified as low (0-14), medium (15-24), or high (25-67). We also obtained basic sociodemographic details of children with PCG, including, age, age at diagnosis, and gender.

- **STATISTICAL ANALYSIS:** All continuous variables were expressed as means and standard deviations or medians and interquartile ranges (IQR), whereas categorical variables were expressed as proportions.

Rasch analysis of the CarCGQoL and PHQ-9 survey response data was performed using the Andrich rating scale model. Interval scores for each item and each respondent

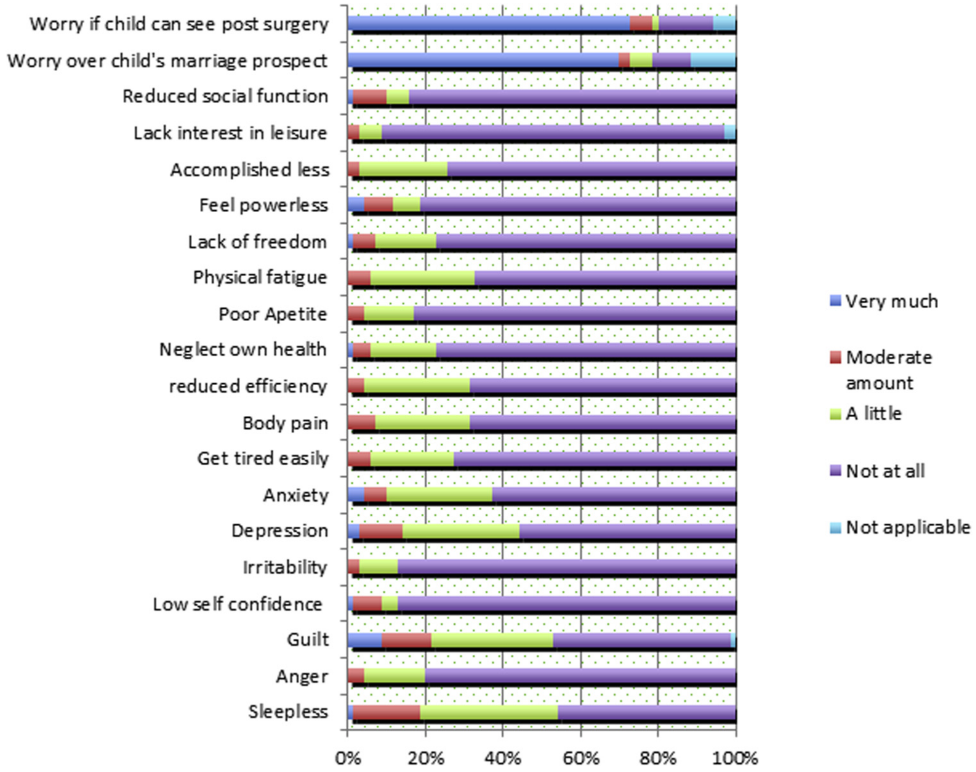

FIGURE 1. Distribution of responses to the Caregivers Congenital Glaucoma Quality of Life Questionnaire (CarCGQoL) questionnaire. Item response options are color coded. Survey items are arranged vertically. The horizontal axis depicts the proportion of participants who chose each response option.

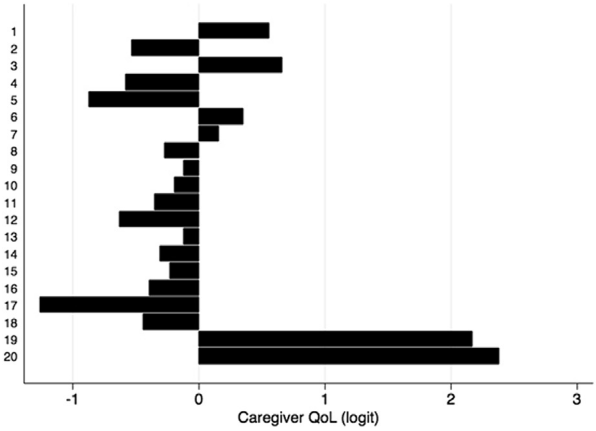

FIGURE 2. Rasch-calibrated scores for Caregivers Congenital Glaucoma Quality of Life Questionnaire survey items.

were expressed as logits on a single scale. For the CarCGQoL questionnaire, lower item scores reflected that participants experienced a greater degree of the item questioned (ie, lower QOL). For the PHQ-9, higher item measures indicated that participants had more depressive symptoms. For both questionnaires, the average item score was set at zero.

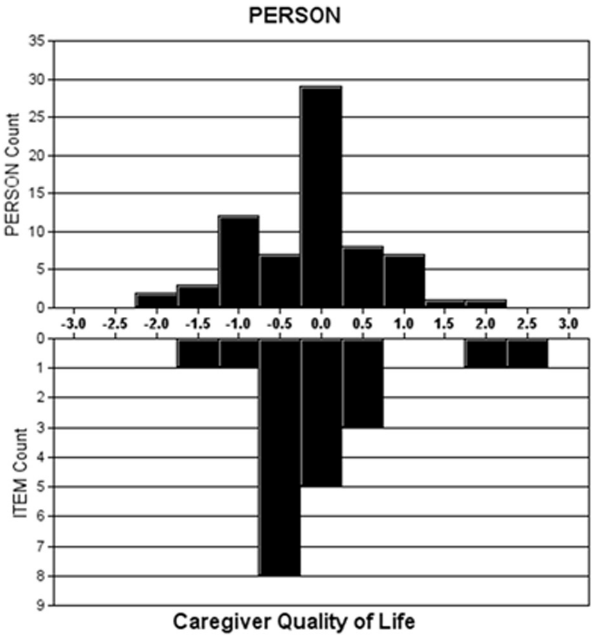

FIGURE 3. Person-item map for the Caregivers Congenital Glaucoma Quality of Life Questionnaire survey response data.

The median value of the Rasch analyzed measure of CarCGQoL was used to divide participants into 2 groups.

TABLE 2. Comparison Between Caregivers With Low and High Quality of Life

Variable	Low CarCGQoL (n = 35)	High CarCGQoL (n = 35)	*P* Value
CarCGQoL score	−0.73 ± 0.56	0.45 ± 0.44	<.001
Age of child (y)	8.5 ± 4.4	6.9 ± 4.8	.16
Age at diagnosis (mo)	13.7 ± 13.7	10.9 ± 32.3	.73
Caregiver age (y)	32.08 ± 5.2	32.1 ± 6.4	.96
Gender of child (boys), n (%)	23 (66)	21 (60)	.62
Gender of caregiver (men), n (%)	6 (17)	10 (28)	.25
Monthly income (Indian Rupees)	11 000 ± 17 977	10 328 ± 16 606	.87
Socioeconomic status (upper), n (%)	14 (40)	13 (37)	.81
Hours of missed work/wk	8.5 ± 13	9.6 ± 10	.69
Number of surgeries	1.5 ± 1.9	1.5 ± 2.0	.90

CarCGQoL = Caregivers Congenital Glaucoma Quality of Life Questionnaire.

TABLE 3. Linear Regression Analysis of Factors Influencing Caregivers' Quality of Life

		Univariate Analysis		Multivariable Analysis	
Variable	Interval or Reference Category	β	95% CI	β	95% CI
Child's current age (y)	1-y increment	**−0.05**[a]	−0.08 to −0.01	**−0.04**[a]	−0.08 to −0.01
Male gender	vs female gender	0.02	−0.37 to 0.40	—	—
Duration of disease[b] (y)	1-y increment	**−0.04**[c]	−0.07 to 0.01	**−0.03**[a]	−0.07 to −0.01
Parent age	1-y increment	0.01	−0.03 to 0.03	—	—
Caregiver education	vs primary schooling	−0.03	−0.15 to 0.08	—	—
Socioeconomic class	vs lower socioeconomic class	0.02	−0.36 to 0.41	−0.13	−0.37 to 0.11
Number of surgeries	per 1 surgery increment	−0.01	−0.11 to 0.08	−0.02	−0.12 to 0.08

CI = confidence interval.

[a] $P < .05$.

[b] Current age and duration of disease were analyzed in separate multivariable models due to collinearity between these variables.

[c] $P < .1$.

Group differences for continuous variables were evaluated using the Student *t* test or χ^2 test. Factors associated with CarCGQoL and PHQ 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 PCG. Covariates in the multivariable regression model included variables with $P < .10$ in univariate models, as well as other conceptually relevant variables, including wealth index category and number of surgeries. Regression diagnostics and variance inflation were checked for all models.

The Spearman correlation coefficient was calculated comparing CarCGQoL and PHQ-9 scores. Locally weighted scatter plot smoothing was used to obtain a smooth curve through the data points.[23]

Rasch analyses were performed using Winsteps (Winsteps, Chicago, Illinois, USA) and other analyses were performed using STATA 12.0 I/C (Stata Corp, College Station, Texas, USA). All statistical tests were 2-tailed and *P* values less than or equal to 0.05 were considered statistically significant.

RESULTS

A TOTAL OF 104 CHILD-CAREGIVER DYADS WERE recruited for the study. Due to incomplete data for 34 respondents, the final sample consisted of 70 caretakers of 70 children with PCG. Characteristics of the study sample are presented in Table 1. The mean age of children with PCG was 7.7 ± 4.6 years (median = 7, IQR = 4-11 years, range = 1.5-18 years) and 26 (37.1%) were female.

- **CARCGQOL RESULTS:** The distribution of responses to CarCGQoL survey items is depicted in Figure 1. The

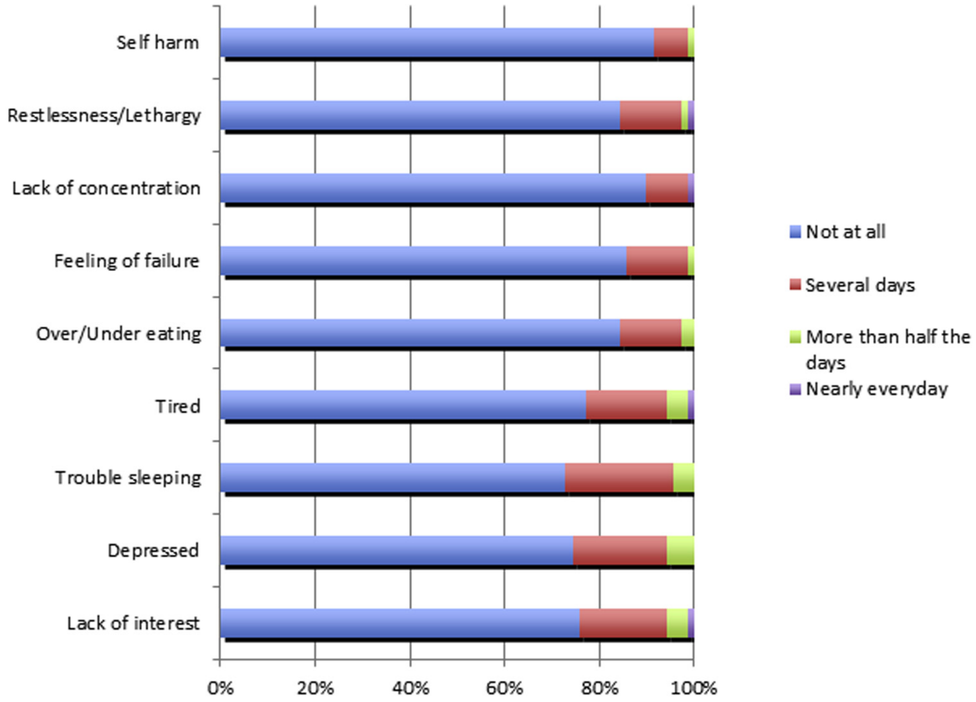

FIGURE 4. Distribution of responses to the Patient Health Questionnaire-9. Item response options are color coded. Survey items are arranged vertically. The horizontal axis depicts the proportion of participants who chose each response option.

mean Rasch-calibrated CarCGQoL score was −0.13 ± 0.78 logits (median = −0.005, IQR = −0.66 to 0.23). Items related to anger (item 2), self-confidence (item 4), irritability (item 5), appetite (item 12), and interest in leisure activities (item 17) had the lowest scores. The Rasch-calibrated scores for survey items are presented in Figure 2 and the distribution of the person and item scores is in Figure 3.

When participants were divided into 2 groups based on CarCGQoL scores, there were no significant differences in caregiver or child traits between caregivers with lower and higher QOL (Table 2). In univariate and multivariable analyses, child's age ($\beta = -0.04$; 95% confidence interval, −0.08 to −0.01) and duration of disease ($\beta = -0.03$; 95% confidence interval, −0.07 to −0.01) were significantly associated with CarCGQoL scores (Table 3).

- **PHQ RESULTS:** The distribution of responses to PHQ-9 items is depicted in Figure 4. The mean Rasch-calibrated PHQ-9 score was −5.9 ± 1.78 logits (median = −7.31; IQR = −7.3 to −4.8); this was far from the mean item difficulty (0.0), indicating that the PHQ-9 was not well targeted to this study sample. The Rasch-calibrated scores for survey items are presented in Figure 5 and the distribution of the person and item scores is in Figure 6.

In univariate and multivariable analyses, no variables were significantly associated with PHQ-9 scores.There was a statistically significant negative correlation between the CarCGQoL and PHQ scores ($r = -0.66$; $P < .01$; Figure 7), indicating that those with more depressive symptoms also tended to report lower caregiver QOL.

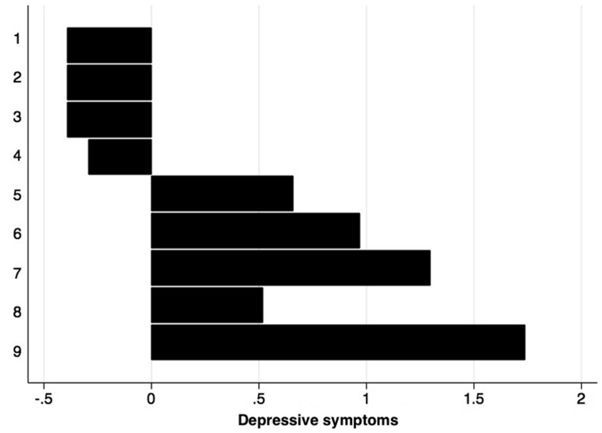

FIGURE 5. Rasch-calibrated scores for the Patient Health Questionnaire-9 survey items.

DISCUSSION

PRIMARY CONGENITAL GLAUCOMA, ALTHOUGH A RARE condition, is the most frequently occurring form of

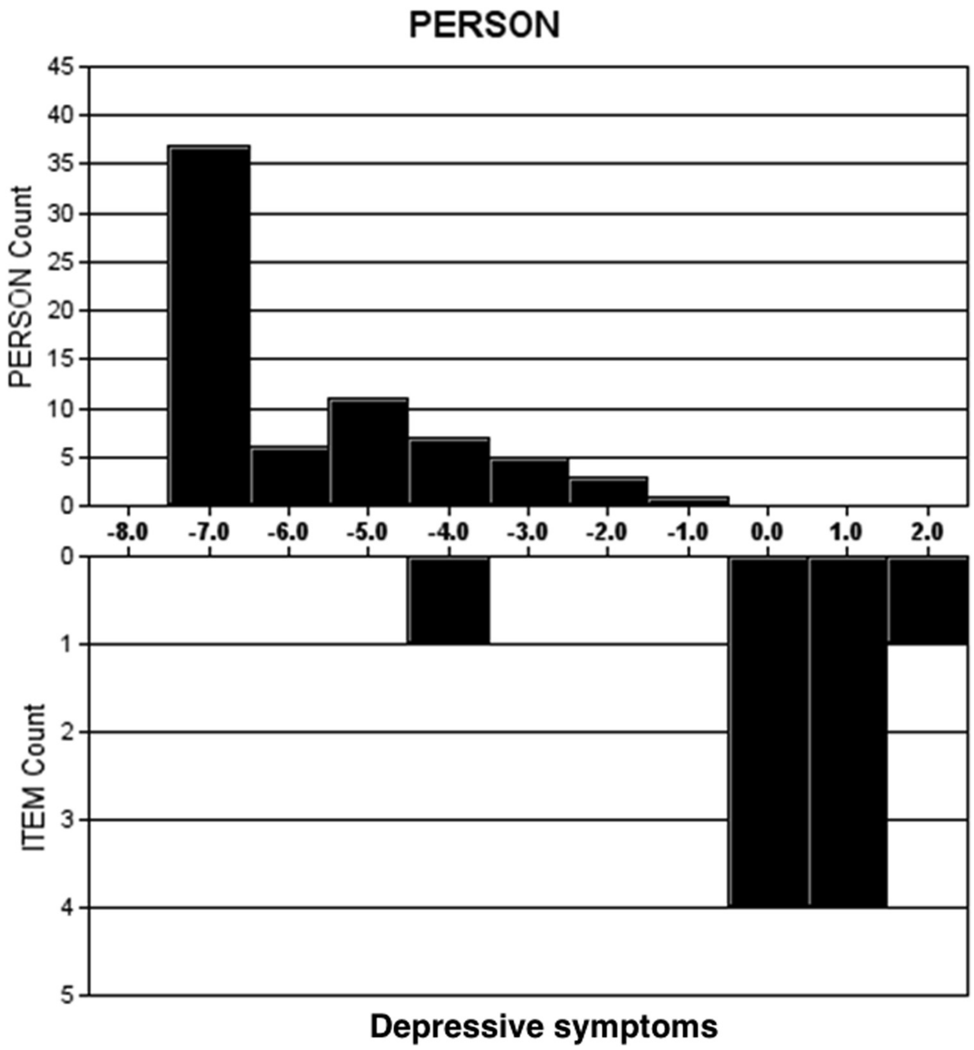

FIGURE 6. Person-item map for the Patient Health Questionnaire-9 survey response data.

glaucoma in infancy and childhood and the most common cause of childhood blindness.[24] Visual prognosis often is poor due to late presentation and the lifelong nature of the disease.[25] Diagnosis and treatment of PCG pose unique challenges due to the young age of patients who are affected and the need for intensive long-term care on the part of physicians, patients, and caregivers. Prior studies found that depressive symptoms and QOL decline are common in caregivers of children with PCG.[4,17] The current study builds on these prior investigations to identify the demographic, socioeconomic, and clinical factors associated with decreased caregiver QOL. These findings may be useful for designing and targeting psychosocial interventions to improve QOL in this population.

The emotional burden of providing care has led to caregivers being labeled as "hidden patients."[26] In fact, a significantly increased prevalence of mental illness, including anxiety and depression, has been described in the caregivers of individuals with chronic diseases like cancer, stroke, dementia.[27,28] Among the caregivers of children with PCG, one-third have been found to have moderate to severe depression.

A prior study demonstrated that the primary factors affecting the QOL of the caregivers of patients in the intensive care unit were prolonged financial stress, interference with normal daily activities, poor disease prognosis, and social stigma.[27,28] In the current study, only longer duration of disease and older age of the child were significantly associated with lower QOL among PCG caregivers in south India. We were surprised to learn that socioeconomic status, gender, age of caregiver, and number of prior surgeries was not significantly associated with caregiver QOL. This may have been due to the young age of children with PCG and their caregivers, as well as a shorter duration of dependency at the time of the study. In addition, survey responses may have been biased toward better QOL if some caregivers were not fully aware of the

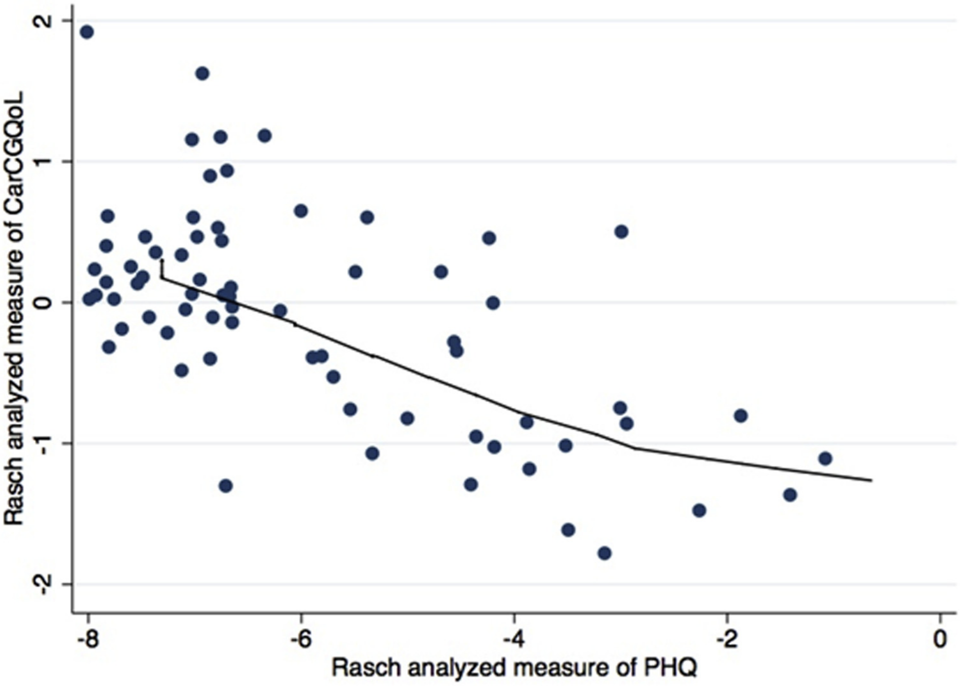

FIGURE 7. Correlation between Rasch-calibrated Caregivers Congenital Glaucoma Quality of Life Questionnaire (CarCGQoL) and Patient Health Questionnaire (PHQ)-9 scores using Spearman correlation and locally weighted scatter plot smoothing. There is a negative correlation between CarCGQoL and PHQ-9 scores ($r = -0.66$, $P < .01$), indicating that worse caregiver quality of life was correlated with more depressive symptoms.

long-term caregiver demands and risk of blindness in many children with PCG. It is also possible that a different caregiver QOL assessment tool may have generated different results.

Depression is a common and well-known finding in the caregivers of individuals with chronic diseases. In the current study 44% of respondents had varying degrees of depressive symptoms, which was similar to a prior study using the same scale in which one-third of PCG caregivers were depressed.[4] Khare et al[29] measured depression using the Center for Epidemiologic Studies Depression Scale and found that all caregivers had have high levels of depression, and that degree of depression was correlated with level of caregiver burden. Notably, however, no respondents in the current study had severe depressive symptoms. This could have been due to poor targeting of the PHQ-9 to our study sample, as Rasch analysis showed that items in this instrument were not well-matched to the behavioral and emotional symptoms of participants. In addition, strong family support systems and varied cultural expressions of depression may have also contributed to better PHQ-9 scores in this study. Still, the results of the PHQ-9 indicate that although most caregivers were unlikely to have symptoms consistent with a clinical depression disorder, many still experienced concerning symptoms like sleep problems and low interest in activities of daily living.

Declines in caregiver QOL were driven in large part by anger, low self-confidence, irritability, poor appetite, and a loss of interest in leisure activities. Moreover, a large proportion of caregivers worried about the child's marriage prospect and whether they would be able to see after having eye surgery. These findings, particularly related to marriage prospects, may be due to the familial and the sociocultural environment in south India. This information can help in the design of interventions, such as problem-centered counseling to improve caregiver coping, and thereby caregiver QOL and well-being. Future research should focus on the impact of caregiver QOL on the quality of care provided to children with PCG and whether interventions to improve caregiver QOL can also improve the care that they deliver.

There were several limitations to this study. This was a cross-sectional study, so we cannot establish causality. Desirability bias could have affected caregiver responses to some survey questions, especially because surveys were completed with the assistance of an interviewer. There were also a number of strengths to this study. We had a relatively large sample given the low prevalence of PCG. We also used instruments that have been validated in Indian populations and we calculated Rasch-calibrated scores specific to our own study sample, which allowed for linear modeling of patient-reported outcomes on an interval scale.

CONCLUSIONS

CAREGIVER BURDEN IS AN IMPORTANT FACTOR IN MANY chronic diseases, including PCG. Caregivers of children with PCG are likely to experience decreased QOL. This study makes an important contribution to the existing literature on caregiver burden in PCG by identifying traits associated with QOL decline, as well as the specific QOL issues most likely to affect caregivers in south India. Ophthalmologists treating PCG should be cognizant of the well-being of both the affected child and the child's caregiver. Findings from this study are important for informing the design of interventions to improve caregivers' QOL and well-being, and to maximize their ability to care for children with PCG.

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A.K. and M.R.P. contributed equally as first authors. All authors attest that they meet the current ICMJE requirements to qualify as authors.

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