ABSTRACT

Purpose: To describe the degree of burden of care and the proportion at risk of depression among individuals caring for legally blind patients.

Methods: We performed a cross-sectional study of 486 individuals providing care to their family members who were legally blind. Best-corrected visual acuity of the better-seeing eye in patients determined group placement: Group 1, 20/200 – 10/200; group 2, 10/200 to light perception (LP); group 3, no light perception (NLP); group VF, visual field loss to <20 central degrees. Burden was evaluated using the Burden Index of Caregivers (BIC-11) and the prevalence at risk of depression was determined by the Center for Epidemiologic Studies Depression (CES-D) scale.

Results: Total mean BIC-11 scores ranged from 8.78 ± 4.82 (group 1) to 12.03 ± 5.22 (group 3; \( p < 0.05 \)). Daily hours spent on close supervision, intensity of caregiving and presence of multiple chronic illnesses in caregivers were the significant covariates affecting BIC-11 scores (\( p < 0.05 \)). The prevalence of caregivers at risk of depression increased with vision loss from 6.9% (group 1) to 17.9% (group 3; \( p < 0.05 \)). Female caregivers had an odds ratio (OR) of 2.89 for depression (95% confidence interval, CI, 1.07 – 3.97; \( p = 0.04 \)). Caregivers with \( \geq 2 \) comorbidities had OR 4.24 (95% CI 2.41 – 6.11) for risk of depression (\( p < 0.01 \)).

Conclusion: Burden of care was highest among caregivers who provided greater hours of supervision. Patients with more limitations in their activities of daily living had caregivers who reported higher burden. Female caregivers and caregivers with multiple chronic illnesses were at higher risk of depression.

Introduction

Burden of care can be described as the physical, psychological, financial, and social discomfort experienced by the principal caregiver of a disabled family member.\(^1\) Care burden has been cited as an independent risk of mortality among caregivers of elderly spouses with at least moderate disability irrespective of etiology.\(^2\) Furthermore, depression among caregivers is higher during the years they provide care, and burden is positively correlated with depression within this timeframe.\(^3\)

The majority of the literature in this field comes from the evaluation of caregivers of patients with intractable neurological diseases (e.g. Alzheimer disease, Parkinson disease).\(^4\) However, recent studies have examined the role of burden of care in the caregivers of patients with cancer,\(^5\) eating disorders\(^6\) and lung transplants.\(^7\) In the ophthalmic literature, although prior studies have examined rates of depression and diminished quality of life reported by blind patients themselves,\(^8,9\) our previous work was the first to undertake a quantitative evaluation of burden and depression faced by caregivers of legally blind individuals.\(^10\) This study examines this relationship in an American population.

In 2011, the Centers for Disease Control and Prevention (CDC) reported that vision problems place a substantial burden on patients, caregivers, healthcare payers, and the United States economy, with the total cost estimated at $51.4 billion annually.\(^11–13\) Although it is difficult to disentangle the financial toll experienced by caregivers in the above statistic, there is other evidence that is more striking. Bernbaum and colleagues\(^14\) found that diabetes-related visual impairment was a major stressor in marital relationships.\(^14\) In their small sample of either legally blind or no light perception (NLP) patients, 50% were separated or divorced within a mean of 1.6 years of the onset of
visual impairment regardless of the length of the relationship prior to vision loss. The risk of separation or divorce was comparatively higher in couples where one partner had NLP vision. A longitudinal study conducted by Strawbridge and co-workers found that spouses of patients with vision loss had an increased risk of poorer physical and emotional wellbeing over 5 years. Westaway and co-authors postulated that visual impairment results in the loss of unseen gestures and body language, thus having an effect on communication between partners.

Severe visual impairment is known to impact the social and economic prosperity of the patient, family and community in which they reside. As the proportion of older adults in the US rises, the number of Americans with age-related eye disease and visual impairment is predicted to double within the next 2–3 decades. In light of these facts and the growing attention of public health issues surrounding the burden of disease, we conducted a cross-sectional study to measure the care burden and the proportion of those at risk of depression among caregivers of legally blind patients in New York State’s central and capital regions. The aims of this study were to: (1) clarify the burden faced by caregivers of patients with varying degrees of blindness, (2) explore factors related to the multiple dimensions of burden faced by caregivers, (3) elucidate the proportion of those at risk for depression among caregivers of blind patients, and (4) explore factors related to being at risk of depression in these caregivers.

Materials and methods

Patients receiving care at the following institutions were screened for enrollment based on their visual acuity (VA) and visual field (VF) restrictions: Albany Medical Center, Department of Ophthalmology; Northeastern Association of the Blind at Albany (NABA) and affiliates; AURORA of Central New York and affiliates; Central Association for the Blind and Visually Impaired, Utica, NY. Patients whose corrected vision in the better eye was <20/200 or whose VF loss was <20° were informed of the nature of the study and asked to provide consent and identify their primary caregiver for enrollment. Caregivers were eligible if they were a relative that the patient identified as “the person they usually turn to for help regarding their care.” Caregivers had to be adults who were unpaid for their support, able to converse in English and who provided care at the patients’ homes (nursing home and assisted living center patients were excluded). The study period was from April 2010 to February 2012. After consent was obtained, several self-rated questionnaires were completed by all caregivers. Exclusion criteria consisted of the patient having intractable neurological disease, physical handicap, mental handicap, prior stroke, renal dialysis, cancer, dementia, severe motor deficits, or any condition which rendered the patient unable to ambulate. Examples of patient co-morbidities that were not excluded were hypertension, diabetes mellitus, hyperlipidemia, mild inflammatory arthritis, mild degenerative joint disease, osteoporosis, mild to moderate chronic obstructive pulmonary disease, hearing impairment, obesity (excluding morbid obesity), congestive heart failure of New York Heart Association class I or II (classes III and IV were excluded). These criteria were directed to isolate those caregivers that needed to provide care predominantly due to a patient’s visual impairment. The same exclusion criteria applied to caregivers.

### Measurements

**Burden Index of Caregivers (BIC-11)**

The BIC-11 is a multi-dimensional scale that measures care burden. The BIC-11 is composed of 11 questions with five domains: time-dependent burden, emotional burden, existential burden, physical burden, and service-related burden (Table 1). Each domain consists of two questions. Each question was assessed using a 5-point Likert scale (0, never; 1, almost never; 2, sometimes; 3, often; 4, always) and one item for overall burden, i.e. “how burdensome do you think providing care is to you?”. This last question has been termed as the “personal estimate of overall burden.” Higher scores

| Time-dependent burden | Emotional burden | Existential burden | Physical burden | Service-related burden |
|-----------------------|-----------------|-------------------|----------------|-----------------------|
| 1. I cannot freely leave the house because of caregiving | 1. I do not have enough time for myself because of caregiving | 1. I am experiencing hardship because caregiving does not give me a sense of satisfaction | 1. My body aches when providing care to my family member | 1. It is a burden that public aid service personnel enter our house |
| 2. I do not have enough time for myself because of caregiving | 2. I am completely distressed by caregiving | 2. Caring is hard because I cannot find the meaning of providing care | 2. I have ruined my health in the course of providing care | 2. I have a hard time because patients resent receiving public aid care services |
| 3. I want to delegate the care to someone else | 3. I am completely distressed by caregiving | 3. Caring is hard because I cannot find the meaning of providing care | 3. I have ruined my health in the course of providing care | 3. I have a hard time because patients resent receiving public aid care services |
| 4. I am completely distressed by caregiving | 4. I am completely distressed by caregiving | 4. Caring is hard because I cannot find the meaning of providing care | 4. I have ruined my health in the course of providing care | 4. I have a hard time because patients resent receiving public aid care services |
| Personal estimate of overall burden | 11. How burdensome do you think providing care is to you? | 11. How burdensome do you think providing care is to you? | 11. How burdensome do you think providing care is to you? | 11. How burdensome do you think providing care is to you? |

Each question was rated on a Likert scale; 0, never; 1, almost never; 2, sometimes; 3, often; 4, always. Adapted from Miyashita et al.
indicate higher levels of burden. The validity and reliability of the BIC-11 has been confirmed in earlier studies.\textsuperscript{22} In our validation of the survey for the American population we also found similar internal consistency. We reached this conclusion by calculating several Pearson’s correlation coefficients between the BIC-11 and the preexisting Zarit Burden Interview (ZBI).\textsuperscript{1} The ZBI is a care burden scale that comprises 22 items assessed by a 5-point Likert scale to provide a total score of 0 to 88, with a higher score representing a greater care burden (Supplemental Appendix 1 – online only). The correlation was high for the specific domains in the BIC-11 and the ZBI; ranging from 0.63–0.72 for individual domains, and 0.82 for the aggregate total BIC-11.

Center for Epidemiologic Studies Depression scale (CES-D)

The CES-D, an instrument developed by the US National Institute of Mental Health, has been proven to be a reliable instrument for identifying patients with major depression. The CES-D is a 20-question survey,\textsuperscript{23} where responses to the questions indicate the number of days per week the subject is affected by depressive symptoms. As in our prior study,\textsuperscript{10} we adopted a CES-D score $\geq 16$ to indicate someone at risk of depression, a value which has been used and validated in many earlier studies implementing the CES-D.\textsuperscript{24–26}

Intensity of caregiving score

The intensity of caregiving score was determined by patient responses on the Katz index of independence in activities of daily living (ADL)\textsuperscript{29} and the Lawton-Brody instrumental ADL index.\textsuperscript{30} A score was generated from the combination of the ADL indices to provide an intensity of caregiving score enumerating the degree of supportive care needed (0, none or needs only social support; 1, needs part-time caregiving; 2, needs slight caregiving; 3, needs moderate caregiving; 4, needs frequent caregiving; and 5, needs constant caregiving).

The Katz index of independence ADL (Supplemental Appendix 2 – online only), is an instrument commonly used to assess functional status as a measurement of an individual’s ability to perform ADLs independently.\textsuperscript{2,15} Patients are scored yes/no for independence in each of the six functions; bathing, dressing, toileting, transferring, continence, and feeding. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment.

The Lawton-Brody instrumental ADL (Supplemental Appendix 3 – online only) is a popular instrument used to assess independent living skills measuring eight domains of function.\textsuperscript{9,15} These skills are considered more complex than the basic ADL as measured by the Katz index. Users are scored according to their highest level of functioning in each category. A summary score ranges from 0 (low function, dependent) to 8 (high function, independent).

In general, a score between 0 and 2 on the Katz index in combination with a score of 0–2 in the Lawton-Brody instrumental ADL would give an intensity of caregiving score of 4 or 5. A score of 3 or 4 on the Katz index in combination with a score of 3–5 in the Lawton-Brody instrumental ADL would give an intensity of caregiving score of 2 or 3. Finally, a score of 5 or 6 on the Katz index in combination with a score of 6–8 in the Lawton-Brody instrumental ADL would give an intensity of caregiving score of 0 or 1.

Statistical analysis

Mean scores for each BIC-11 domain along with total BIC-11 score and a personal estimate of overall burden were calculated and stratified by severity of VA into four groups; group 1, 20/200 to 10/200; group 2, 10/200 to light perception (LP); group 3, NLP; and group VF, VF loss to $<20^\circ$.

Analysis of variance (ANOVA) was performed to test for significant differences in BIC-11 scores for various forms of blindness. Scores for the seven BIC-11 measures were modeled using linear regression models to learn which factors significantly contributed to caregiver burden. Dependent variables for the seven different models were; each of the domain scores (five models), total BIC-11 score (one model), and personal estimate of overall burden (one model). The independent variables were the numerous participant characteristics (Table 2). With these parameters defined, a backwards selection technique was used.

To determine the covariates associated with risk of depression, we applied the same independent variables to a logistic regression model. The binary dependent variable was risk of depression (yes or no, based on a CES-D score $\geq 16$). Backwards selection was also used for logistic regression. All covariates were excluded in both the linear and logistic regression models if they did not contribute significantly to the fit of the model and 2-sided t-tests were used along with a significance of $p < 0.05$. All


Table 2. Participant characteristics of patients with varying degrees of blindness and their caregivers, New York State, United States (N = 486).

| Characteristic                          | N   | SD      |
|----------------------------------------|-----|---------|
| Patient age, mean ± SD years           | 70.1| 13.3    |
| Patient sex, n (%)                     |     |         |
| Male                                   | 194 | 40      |
| Female                                 | 292 | 60      |
| Patient visual acuity*, n (%)          |     |         |
| Group 1                                | 185 | 38      |
| Group 2                                | 39  | 8       |
| Group 3                                | 73  | 15      |
| Group VF                               | 219 | 45      |
| Intensity of caregivingb, n (%)        |     |         |
| 0                                      | 185 | 38      |
| 1                                      | 121 | 25      |
| 2                                      | 97  | 20      |
| 3                                      | 73  | 15      |
| 4                                      | 10  | 2       |
| 5                                      | 0   | 0       |
| Caregiver sex, n (%)                   |     |         |
| Male                                   | 180 | 37      |
| Female                                 | 306 | 63      |
| Caregiver age, mean ± SD years         | 56.8| 15.2    |
| Caregiver literacy (≥12th grade education), n (%) | 422 | 87 |
| Relationship to patient, n (%)         |     |         |
| Child                                  | 131 | 27      |
| Parent                                 | 83  | 17      |
| Sibling                                | 54  | 11      |
| Spouse                                 | 219 | 45      |
| Caregiver chronic conditions, n (%)    |     |         |
| 0                                      | 277 | 57      |
| 1                                      | 75  | 16      |
| ≥2                                     | 134 | 27      |
| Patient chronic conditions, n (%)      |     |         |
| 0                                      | 219 | 45      |
| 1                                      | 97  | 20      |
| ≥2                                     | 170 | 35      |
| Duration of caregiving, mean ± SD years| 10.3| 7.2     |
| Time spent caregiving, mean ± SD hours/day| 4.3 | 2.7   |
| Required close supervision time of the patient, mean ± SD hours/day | 1.9 | 0.7 |
| Supplemental caregivers, mean ± SD n   | 2.8 | 1.6     |

*Group 1, 20/200–10/200; group 2, 10/200 to light perception; group 3, no light perception; group VF, blind by visual field criteria.

bObserved, none or patient needs only social support; 1, needs part-time caregiving; 2, needs slight caregiving; 3, needs moderate caregiving; 4, needs frequent caregiving; and 5, needs constant caregiving.

SD, standard deviation.

Statistical analyses were performed with SAS 9.3 (SAS Institute Inc, Cary, NC, USA).

Ethics considerations

Before implementing this study, ethical and scientific validity was approved by the institutional review boards of the Albany Medical College, and State University of New York Upstate Medical University, Syracuse, NY. Primary caregivers and patients were informed that participation in the study was voluntary and that privacy would be strictly protected.

Results

Participant characteristics

A total of 533 caregivers filled out the survey, however, 47 surveys were eliminated due to incomplete data or illegible writing, leaving 486 surveys for the final analysis. Of the 486 participating caregivers, 204 were from group 1, 185 from group 2, 39 provided care for patients with NLP (group 3), and 58 were from group VF. Table 2 shows demographic and other information collected from participants. Unlike our prior study conducted in India with face-to-face interviews of caregivers, we did not ask American participants about household income because it has been shown to result in incomplete responses or refusal to partake in surveys, even anonymous ones.27,28

The mean ages of patients and caregivers were 70.1 years and 56.8 years, respectively. The majority of patients and caregivers were female (60% and 63%, respectively). Roughly 83% of patients had intensity of caregiving scores of 2 or below. About 87% of caregivers had completed at least 12th grade education, and the majority of caregivers were either adult children (27%) or spouses (45%). The proportions of patients and caregivers with at least one chronic illness were 55% and 43%, respectively.

Care burden for varying degrees of blindness

Mean scores for each of the BIC-11 measures were stratified by group number (Table 3). BIC-11 scores were significantly higher for group 3 compared to the other groups for time-dependent burden (<0.01), emotional burden (<0.01), personal estimate of overall
burden (<0.01), and total mean BIC-11 scores (0.04). Scores for the remaining domains were not statistically different for any of the four groups. Post-hoc ANOVA tests using Tukey’s method indicated that there were no significant differences in any of the mean domain scores between groups 1, 2 and VF. For all groups, the highest domain scores were for the time-dependent domain followed by emotional burden. The lowest scores were for service-related burden.

**Covariates impacting the fit of the seven linear regression models: response variable BIC-11 scores**

Covariates significantly impacting the fit of the seven models are shown in Table 4. Intensity of caregiving and multiple chronic illnesses in caregivers were significant for all measures except for service-related burden. Intensity of caregiving was inversely proportional to independence with ADL. Daily hours of close supervision was significant for all measures except physical burden, existential burden, and service-related burden. Examples of close supervision included bathing the patient, grooming the patient, acting as a walking guide, and transferring and transporting the patient. The only participant characteristics that were not significant in any of the measures were visual acuity, age, education level, relationship to the patient and duration of caregiving years, and number of supplemental caregivers. The only covariates impacting the score for service-related burden were female sex of the patient or caregiver. Female caregivers, compared to male, had a 0.41 higher score for service-related burden. Female patients, compared to male, had a 0.53 lower score for service-related burden (protective effect).

After controlling for covariates, VA or VF restrictions were not statistically significant in any of the seven measures for burden.

**Prevalence of caregivers at risk of depression**

Figure 1 illustrates the prevalence of those at risk of depression, reflected by a CES-D ≥16. The proportion of caregivers at risk of depression increased as vision loss diminished among their blind family members. Group 1 and group VF had 14 and 4 caregivers, respectively, at risk of depression (6.9% for both). Group 2 had 14 at-risk caregivers (11.4%) and group 3 had 7 at-risk caregivers (17.9%).

| Burden of care | Regression coefficient | Standard error | p-value |
|---------------|------------------------|----------------|--------|
| Time dependent (R^2 = 0.46) | 0.96 | 0.10 | 0.03 |
| Intensity of caregiving | 0.94 | 0.10 | 0.01 |
| Hours of close supervision | - | - | - |
| Number of chronic conditions 0 (reference) | 1.87 | 0.27 | <0.01 |
| ≥2 | 0.84 | 0.56 | 0.62 |
| Emotional (R^2 = 0.42) | 0.83 | 0.37 | <0.01 |
| Intensity of caregiving | 0.87 | 0.46 | <0.01 |
| Hours of close supervision | - | - | - |
| Number of chronic conditions 0 (reference) | 1.47 | 0.43 | 0.04 |
| ≥2 | 1.47 | 0.43 | <0.01 |
| Existential (R^2 = 0.31) | 0.34 | 0.14 | 0.01 |
| Intensity of caregiving | - | - | - |
| Number of chronic conditions 0 (reference) | 1.91 | 0.36 | <0.01 |
| ≥2 | 1.97 | 0.43 | <0.01 |
| Physical (R^2 = 0.33) | 0.40 | 0.17 | 0.01 |
| Intensity of caregiving | - | - | - |
| Number of chronic conditions 0 (reference) | 0.84 | 0.56 | 0.62 |
| ≥2 | 1.87 | 0.27 | <0.01 |
| Service-related (R^2 = 0.27) | 0.38 | 0.28 | 0.71 |
| Intensity of caregiving | - | - | - |
| Number of chronic conditions 0 (reference) | 1.97 | 0.43 | <0.01 |
| ≥2 | 1.97 | 0.43 | <0.01 |

**Factors related to depression in caregivers**

Covariates significantly correlated to depression risk are shown in Table 5. Caregivers providing close supervision for ≥2.5 hours/day were at 5.33 increased odds of depression compared to those who provided <2.5 hours/day. Intensity of caregiving score ≥3 (more than a moderate level of care-based on ADL limitations) was associated with 3.14 higher odds of depression compared to those with a score <3. Caregivers with ≥2 chronic illnesses compared to those without any chronic illnesses had 4.24 higher odds of being at risk of depression. Caregivers of patients with ≥2 chronic illnesses compared to those without any chronic illn

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**Table 4. Covariates impacting seven measures of visually impaired patient caregiver burden (seven linear regression models), New York State, United States.**

| Burden of care | Regression coefficient | Standard error | p-value |
|---------------|------------------------|----------------|--------|
| Time dependent (R^2 = 0.46) | 0.96 | 0.10 | 0.03 |
| Intensity of caregiving | 0.94 | 0.10 | 0.01 |
| Hours of close supervision | - | - | - |
| Number of chronic conditions 0 (reference) | 1.87 | 0.27 | <0.01 |
| ≥2 | 0.84 | 0.56 | 0.62 |
| Emotional (R^2 = 0.42) | 0.83 | 0.37 | <0.01 |
| Intensity of caregiving | 0.87 | 0.46 | <0.01 |
| Hours of close supervision | - | - | - |
| Number of chronic conditions 0 (reference) | 1.47 | 0.43 | 0.04 |
| ≥2 | 1.47 | 0.43 | <0.01 |
| Existential (R^2 = 0.31) | 0.34 | 0.14 | 0.01 |
| Intensity of caregiving | - | - | - |
| Number of chronic conditions 0 (reference) | 1.91 | 0.36 | <0.01 |
| ≥2 | 1.97 | 0.43 | <0.01 |
| Physical (R^2 = 0.33) | 0.40 | 0.17 | 0.01 |
| Intensity of caregiving | - | - | - |
| Number of chronic conditions 0 (reference) | 0.84 | 0.56 | 0.62 |
| ≥2 | 1.87 | 0.27 | <0.01 |
| Service-related (R^2 = 0.27) | 0.38 | 0.28 | 0.71 |
| Intensity of caregiving | - | - | - |
| Number of chronic conditions 0 (reference) | 1.97 | 0.43 | <0.01 |
| ≥2 | 1.97 | 0.43 | <0.01 |

**BIC-11, Burden Index of Caregivers questionnaire.**

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**Factors related to depression in caregivers**

Covariates significantly correlated to depression risk are shown in Table 5. Caregivers providing close supervision for ≥2.5 hours/day were at 5.33 increased odds of depression compared to those who provided <2.5 hours/day. Intensity of caregiving score ≥3 (more than a moderate level of care-based on ADL limitations) was associated with 3.14 higher odds of depression compared to those with a score <3. Caregivers with ≥2 chronic illnesses compared to those without any chronic illnesses had 4.24 higher odds of being at risk of depression. Caregivers of patients with ≥2 chronic illnesses compared to those without any chronic illn
There are two major contributions of this study. First is the observation that legally blind patients in the US may have caregivers at risk of depression or experiencing feelings of burden. Our study excluded patients with severely debilitating comorbidities in order to understand how visual impairment uniquely affects care-related burden or depression. Moreover, we also excluded caregivers with severely debilitating comorbidities, as have other authors,9,20 in order to limit the confounding effect that medical illness and disability would play in reports of depression. However, in real settings, blind patients and their caregivers may also have coexisting medical conditions (e.g. stroke, Alzheimer disease), which may either warrant greater support from a patient perspective or prove to be more distressing from a caregiver perspective, both of which could result in higher caregiver burden or depression. Second, the identification of various risk factors associated with either higher burden or risk of depression; greater daily hours of close supervision provided, greater intensity of caregiving score determined by more limitations in ADL, multiple chronic illnesses in the patient or caregiver, and female sex in caregivers.

The study of burden and depression among caregivers of visually impaired patients is an emerging field in public health and an important one since caregivers play a vital role in the well-being of patients. Instrumental assistance (e.g. providing transportation, managing finances) from family members is associated with better adaptation to vision loss, fewer depressive symptoms and greater life satisfaction.32–36

Four of seven burden-related measures demonstrate that caregivers of patients with NLP (group 3) experience significantly higher burden than caregivers of legally blind patients with better vision (groups 1, 2 and VF). Visually-impaired patients need more intermittent instrumental support than constant hands-on personal care (e.g. bathing and toileting).37–41

We propose the reason that caregivers for patients in groups 1, 2 and VF do not score significantly different from each other is because these patients still have some vision remaining which can be improved by low vision aids (e.g. magnifying glasses, closed-circuit television systems). Perhaps this results in greater independent functioning and a decreased reliance on caregivers. Patients meeting the criteria of blindness by VF restriction in particular may be prevented from operating motor vehicles but may still have excellent central acuity which would provide them with the ability to perform more ADL over someone with poor central vision. When adjusting

### Table 5. Covariates impacting risk of depression among caregivers of visually impaired patients in the logistic regression model, New York State, United States.

| Covariate                              | Risk of depression, odds ratio (95% confidence interval) | p-value* |
|----------------------------------------|----------------------------------------------------------|----------|
| Intensity of caregiving score ≥3       | 5.33 (3.67–7.05)                                         | <0.01    |
| Hours of close supervision ≥2.5 hours  | 3.14 (2.03–4.30)                                         | 0.01     |
| Number of chronic conditions in caregiver |                                      |          |
| 0 (reference)                          | -                                                        | -        |
| 1                                      | 1.67 (0.97–2.40)                                         | 0.07     |
| ≥2                                     | 4.24 (2.41–6.11)                                         | <0.01    |
| Number of chronic conditions in patient |                                      |          |
| 0 (reference)                          | -                                                        | -        |
| 1                                      | 1.56 (0.94–2.21)                                         | 0.08     |
| ≥2                                     | 3.50 (2.24–4.76)                                         | <0.01    |
| Caregiver sex                          |                                      |          |
| Male (reference)                       | -                                                        | -        |
| Female                                 | 2.89 (1.07–3.97)                                         | 0.04     |

* Chi-square test.
for all covariates modeling for burden scores, VA and VF restriction did not significantly impact the fit of any model. This demonstrates that VA and VF restrictions alone do not correlate with higher caregiver burden. Higher burden was explained by the intensity of caregiving, greater daily hours spent on close supervision and caregivers with multiple chronic illnesses. This would make it appear that a patient with bilateral NLP vision, or bilateral VF defects limited to the central 20° or a patient with bilateral 20/200 could pose equal care-related burden to their caregiver. The presence of multiple chronic illnesses in the caregiver, compared to none, was related to significantly higher scores in six of seven burden measures. This result is readily interpretable.

The risk of depression was more than 2.5 times higher for caregivers of patients in group 3 compared to groups 1 and VF (17.9% vs. 6.9%, p = 0.03) and more than 1.5 times higher compared to group 2 (11.4% vs.6.9%, p = 0.04). The values for groups 1 and VF are comparable to the 6.7% prevalence of major depression among US adults\(^4\) and the 7.8% prevalence of depression among a sample of 3444 adults from New York State collected by the CDC.\(^5\) Subgroup analysis may reveal some insights regarding this trend. For most of the covariates that significantly affected the risk of depression in our regression model (Table 5) we observed that the groups with worse vision were disproportionately represented. Patients with the greatest limitations in their ADL in this study (intensity of caregiving scores ≥3) accounted for 83 of the total 486, yet 61.5% of patients (24 of 39) in group 3 met this threshold compared to 24.3% of patients (45 of 185) in group 2 (p < 0.05). Group 2 had a higher proportion of caregiving scores ≥3 than group 1 (5.4%, 11 of 204) and group VF (5.2%, 3 of 58), but these latter two groups were not significantly different from each other (p = 0.91). This trend continued regarding patients with chronic illnesses as well as caregivers with chronic illnesses. Additionally, the proportion of caregivers providing ≥2.5 hours/day was higher in group 3 compared to group 2 (41.0% vs. 20.0%, p < 0.05), which was higher than groups 1 and VF (20.0% vs. 7.8% and 12.1%, p < 0.05). The latter two groups were not significantly different from each other (p = 0.36).

The proportion at risk of depression in this study was lower than that found among caregivers of blind patients in India; group 1 (6.9% vs. 16%), group 2 (11.4% vs. 24%), and group 3 (17.9% vs. 48%; there was no group VF in the prior study). This may be attributed to three reasons which better facilitate debilitated patients and create favorable socioeconomic circumstances. First, the US has greater accommodation for individuals with disabilities (e.g. ramps vs. stairs, braille, traffic lights with voice commands for blind pedestrians) than rural India.\(^4\) Second, there is more widespread use of vision rehabilitation services in the US which teach patients skills to adapt to their condition.\(^5\) Third, differences in socioeconomic determinants of health (e.g. poverty, homelessness, illiteracy) between these two locations may alter the perception of depression experienced by caregivers.\(^\text{46}\)

We believe these differences can be attributed to disparate differences in socioeconomic determinants of mental health between the developing and developed world as well as widespread use of vision rehabilitation in New York State.

There are some noteworthy limitations to this study. First, this study relied on convenience sampling among caregivers who agreed to be surveyed. The proportion of caregivers and patients refusing to do the survey may be systematically different from those who completed the study. Second, the cross-sectional design prevents any causal relationship to be implicated between blindness and caregiver burden or depression. Longitudinal investigations will help elucidate this relationship. Third, psychiatric histories for caregivers were not obtained and may have been relevant predictors of depression. Fourth, we did not look at social problem-solving abilities which have been shown to be correlated with caregiver burden and depression,\(^\text{34}\) namely, a negative orientation to problem solving (belief that a problem cannot be solved no matter how hard one tries), impulsive/careless outlook (proceeding with the first idea that comes to mind when trying to solve a difficult problem) and an avoidant outlook (procrastinating to solve problems that occur in one’s life). Fifth, we did not have a comparison group in this study to assess if there were differences specific to this sample regarding burden and depression among caregivers of legally blind patients and similar caregivers of patients who were not legally blind. However, it was unrealistic to obtain several hundred controls, given our stringent exclusion criteria for comorbidities.

The major implications of this study for vision health specialists in the US are 3-fold. First, to be cognizant that caregivers of legally blind patients may be at risk of depression as well as burden of care, and that these disorders should be considered when assessing low-vision patients. Second, to recognize the various risk factors mentioned in this study associated with either higher burden or risk of depression; greater daily hours of close supervision provided, greater intensity of caregiving score determined by more limitations in ADL, multiple chronic illnesses...
in the patient or caregiver, and female sex in caregivers. Third, when depression is suspected, the appropriate referral ought to be placed to mental health specialists.

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