

Burden and depression in primary caregivers of persons with visual impairment

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Context: Caregivers who assist persons with visual impairment often neglect their needs, resulting in burden and depression. Rehabilitation efforts, directed to the disabled, seldom target the caregiver. **Aim:** To assess burden and depression in persons caring for blind individuals. **Settings and Design:** This was a cross-sectional study carried out in the outpatient department of a tertiary-level teaching hospital in New Delhi. **Materials and Methods:** Institutional Ethical Board approval was obtained and written informed consent too was obtained from the participants involved in this study. Persons with best-corrected vision <20/200 in the better eye, and their primary caregivers, were recruited. We recorded demography, other illness/disability, household income, relationship with disabled person, and caregiver burden (Caregiver Burden Scale) and depression (Centre for Epidemiologic Studies Depression Scale). **Statistical Analysis:** Statistical analysis was carried out using SPSS version 20 (Released 2011. Armonk, NY: IBM Corp.); range, average, and standard deviation were determined for age, burden, and depression. The association between burden and depression was determined using Pearson's correlation; the relationship between degree of disability and caregiver burden and depression was determined using unpaired *t*-test; using multiple linear regression, factors were found to be statistically significant; significance was taken at $P < 0.05$. **Results:** Twenty-seven (53.0%) men and 24 (47.0%) women had visual impairment. Most caregivers ($n = 40$; 81.6%) were first-degree relatives or a spouse; 32 (65%) had schooling <5 years; and 29 (59%) were unemployed. Depression ranged from 21 to 52 (average 43.2 ± 5.71); it correlated with degree of disability ($P = 0.012$), household income ($r = -0.320$; $P = 0.025$), and burden ($r = 0.616$; $P < 0.001$). Burden ranged from 30 to 73 (average 54.5 ± 6.73) and correlated with degree of disability ($P = 0.006$). On multiple linear regression, burden predicted depression ($r = 0.557$; $P < 0.001$). **Conclusions:** Caregivers merit community support, financial benefit, interventions to diagnose and treat depression, and training in coping. Centers that provide disability certification could offer counseling.

Key words: Blindness, caregivers, caregiving burden, depression, rehabilitation

People with impaired vision often need help with everyday activities, treatment, finances, and emotional support.^[1-3] Caregivers, unable to fulfill their own needs, may find the physical, psychological, financial, and social burden oppressive and may get depressed.^[6-10] Rehabilitation programs address the needs of the disabled, but ignore caregivers.^[5,6,9,11] Research focuses on caregivers of neuropsychiatric and cancer patients;^[5,12,13] there is limited work on visual disability,^[6-8] mainly from the West where rehabilitation is advanced, and caregiver burden could be different. This study sought to assess burden and depression in caregivers of blind individuals with a view to helping plan effective rehabilitation.

Materials and Methods

This cross-sectional study was conducted between November 2013 and February 2015 in a tertiary-level teaching hospital in New Delhi. After the Institutional Ethical Committee approval and written informed consent, persons with permanent visual impairment and their primary caregivers were recruited for the study. Permanent visual impairment was defined as best-corrected visual acuity (BCVA) of <20/200 in the better

eye that was untreatable by any means; a primary caregiver was defined as the individual whom the person with visual impairment identified as being chiefly responsible for providing some form of assistance. The unwilling participants, and caregivers who were receiving financial compensation for services, were excluded from the study.

The sample size was based on data from a previous study where eighty persons with visual acuity $\leq 20/200$ in the better eye were available over a 1-year period.^[14] Not all of the patients in that study had permanent visual impairment; since the current study was based on disability of a permanent nature, we set sample size at 50.

Age, gender, urban/rural residence, years of schooling (none, 1–5 years, and >5 years), and employment status and type of occupation were documented for both groups – persons with visual disability and their primary caregivers. Those not bringing in an income were classified as unemployed. In

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addition, for the person with visual disability, BCVA, main cause of blindness (based on self-stated history, records, if any, and examination), details of chronic illness or other disability, and relationship with the caregiver were recorded; for the caregiver, monthly household income, burden (Caregiver Burden Scale) and depression (Centre for Epidemiologic Studies Depression Scale [CES-D]) were recorded. For our study, both the Caregiver Burden Scale and the CES-D were translated into the local language, Hindi, by following a modification of the procedure recommended by the World Health Organization. One author (Shubhank Khare) translated all instruments into Hindi using a conceptual framework (forward translation); all the authors reviewed the translation and edited it, where required, for concepts and to simplify terms so that the target population could be expected to understand them. The Hindi translations were compared with the original instruments by pretesting on bilingual colleagues (three men and three women) who were not involved in the study. Both versions were presented at different times and responses compared to check for intra-respondent discrepancy. Once those were resolved through debriefs, the translated versions were pretested on persons who brought their relatives for ophthalmic care (two men and two women), followed by debrief sessions with them to identify any ambiguous terms that remained. The final version was used in the study.

We chose the Caregiver Burden Scale since it assesses caregiver health, psychological well-being, finances, social life, and relationship with the impaired person, factors that we considered relevant to our context.^[15,16] It consists of 22 questions reflecting how people feel when they are taking care of another person. After each question, the caregiver has to answer how often he/she feels burden (never, rarely, sometimes, frequently or nearly always, where “never” has score of 0, and “nearly always” has score of 4). A score of 0–20 indicates little or no burden, 21–40 = mild to moderate burden, 41–60 = moderate to severe burden, 61–88 = severe burden.

The CES-D has twenty questions which assess the current level of depression;^[17] it has been validated several times over in Indians living in India.^[18,19] Each question has four different frequencies of occurrence of symptoms from rarely (<1 day in the preceding week and a score of 0), sometimes (1–2 days and a score of 1), occasionally (3–4 days and a score of 2) and most of the time (5–7 days and a score of 3). Eight of the twenty questions are “positive” questions for which the scoring is reversed. The score can range from 0 to 60, with higher scores indicating the presence of more symptoms.

The data were entered into Excel worksheet; range, average, and standard deviation were determined for age, burden score, and depression score. The relationship of caregiver burden and depression (separately) with caregiver gender, their occupation, and presence of systemic illness in the person they were caring for was tested by unpaired *t*-test. The relationship of caregiver burden with degree of visual disability was tested by analysis of variance and *post hoc* Tukey test; for caregiver depression we used Welch Allen test and *post hoc* Dunnett T3 test. ANOVA was used to correlate degree of caregiver burden and depression, separately, with their literacy status, and with their relationship with the person with visual disability. Pearson’s correlation was used to determine the strength of association between caregiver burden and depression. Multiple linear regression was applied

on factors that were found significant taking depression as the dependent variable. Results were considered to be statistically significant at $P < 0.05$.

Results

Of the 53 persons who fulfilled the inclusion criteria, two had mental disability as well as visual, of a degree that they could not respond to the questionnaire and the caregiver was reluctant to wait or visit again; these were excluded from the study. The remaining, including two who had reported that they were living alone and did not have caregivers, consented to participate in the study and were recruited.

Persons with visual disability included 27 (53.0%) men and 24 (47.0%) women; 17 (33.3%) had economic blindness (best-corrected vision from <20/200 to 20/400 in the better eye or visual field $\leq 20^\circ$), 34 (66.7%) had social blindness (best-corrected vision <20/400 in the better eye, or visual field $\leq 10^\circ$). Among the people with social blindness, ten persons had no perception of light in either eye. Of the two persons without a caregiver, one had economic blindness (male, aged 48 years) and another had social blindness (female, aged 60 years). The chief causes of blindness are listed in Table 1. Globe disorders accounted for the majority (29; 29.4%); 21 (20.5%) were familial disorders.

No person had any other disability; however, 12 (23.5%) had other medical problems like diabetes ($n = 7$), hypertension ($n = 2$), coronary artery disease ($n = 2$), and both diabetes and coronary artery disease ($n = 1$). None of the persons with disability were employed.

The age of persons with visual disability ranged from 5 to 90 years (average 46.9 ± 21.45); the primary caregivers were significantly younger (range 16–65 years; average 39.9 ± 13.77 ; $P = 0.03$). One-third of the caregivers were illiterate and half were unemployed [Table 2]. The reported monthly household income was very variable and ranged from Rs. 200 to 5000 (average 1459.1 ± 723.47).

Primary caregivers were equally likely to be men ($n = 24$; 48.9%) or women ($n = 25$; 51.1%). Most ($n = 40$; 81.6%) were either a first-degree relative or a spouse. Thus, progeny ($n = 18$; 36.73%; two were underage at <18 years), a spouse ($n = 14$; 28.57%), a parent ($n = 7$; 14.28%), or an older sibling ($n = 1$; 2.04%) looked after the needs of the person with visual disability. The remaining primary caregivers ($n = 9$; 18.4%) were either a nephew ($n = 3$; 6.12%), a niece ($n = 1$; 2.04%), a grandson ($n = 2$; 4.08%), an older male cousin ($n = 1$; 2.04%), a daughter-in-law ($n = 1$; 2.04%), or a paternal aunt ($n = 1$; 2.04%). Sons were more likely to look after their father, and daughters their mother (Chi-square = 4.219; degrees of freedom = 1; $P = 0.039$). Of parents, mothers were primary caregivers much more often than fathers (mother:father - 6:1).

Degree of depression in primary caregivers ranged from 21 to 52 (average 43.2 ± 5.71). Table 3 shows the factors that affected depression in caregivers. Degree of burden ranged from 30 to 73 (average 54.5 ± 6.73); most caregivers reported feeling moderate to severe burden [Table 4]. The factors affecting burden are shown in Table 5. On multiple linear regression, burden was found to be a significant predictor of depression ($r = 0.557$; $P < 0.001$).

Table 1: Causes of visual deprivation in 102 eyes of 51 persons with visual disability

Chief cause of blindness	Number of eyes (%)
Corneal	
Adherent leukoma	6 (5.8)
Dry eye with leukomatous corneal opacity	4 (3.9)
Pseudophakic bullous keratopathy	1 (0.9)
Retinal	
Fundal coloboma	7 (6.8)
Retinal detachment	5 (4.9)
Proliferative diabetic retinopathy	4 (3.9)
Choroidal scar	2 (1.9)
Retinopathy of prematurity	2 (1.9)
Refractive	
Amblyopia	4 (3.9)
Pathological myopia	4 (3.9)
Globe	
Phthisis bulbi	17 (16.6)
Microphthalmos	8 (7.8)
Secondary anophthalmos	4 (3.9)
Neurological	
Primary/secondary optic atrophy	14 (13.7)
Cortical blindness	6 (5.8)
Glaucoma	2 (1.9)
Retinitis pigmentosa	2 (1.9)

Table 2: Years of schooling and occupation of 49 primary caregivers of persons with visual impairment

	Number of caregivers (%)
Years of schooling	
Nil	18 (36.7)
1-5	14 (28.6)
>5	17 (34.7)
Occupation	
Unemployed	23 (46.9)
Daily wages	11 (22.4)
Homemaker	4 (0.8)
Student	2 (0.4)
Rickshaw puller	2 (0.4)
Vegetable seller	2 (0.4)
Labor	1 (0.2)
Maid	1 (0.2)
Pensioner	1 (0.2)
Private job	1 (0.2)
Tailor	1 (0.2)
Business	1 (0.2)

Discussion

This cross-sectional study was conducted in a hospital setup and included patients with permanent visual disability and their caregivers. The aim was to measure the burden and depression of caregivers. Fifty-one persons with visual

disability and 49 caregivers consented to participate; two persons were living alone and had no primary caregiver.

Using the Centre for Epidemiological Study Depression Scale, a cutoff score of ≥ 16 indicates risk of clinical depression and higher scores indicate greater depression. In our study, all caregivers had scores higher than 16. This information is alarming, and there could be various reasons for such a finding, and for the severity of depression (average was 42.1 ± 5.21). Low family income is a known cause for depression,^[7] and was reported by our caregivers also. The fact that there are fewer public resources in our country for people with disability could have contributed. Studies have uniformly suggested that greater governmental support should be instituted in this area. In India, a disability pension is provided for disability above 40%, rail travel is free for completely blind persons and for one co-traveler, there are job reservations and tax benefits for $\geq 40\%$ of disability.^[20] An additional liability is not given consideration – the financial burden on caregivers – apart from taking physical and emotional care of the relative with visual disability, they have to spend money on the person's daily needs, medications, and transportation.^[11,21] The financial burden is aggravated by insufficient public resources at the community level,^[11] and perhaps primary caregivers too could receive financial support.

Caregivers are likely to be more depressed when the disability is greater. This has been reported for disabilities other than visual.^[6,13] Greater disability may demand more effort from the caregivers, and take up more time and money. Similar data for depression and visual disability are lacking. In our study, greater disability did not predict caregiver depression; we speculate that since all had permanent disability, the caregiver, knowing that the vision loss was permanent, may have given up hope for recovery, whatever the degree of disability.^[2]

We chose the CES-D since its psychometric properties and screening efficacy are not affected by age, gender, cognitive impairment, functional impairment, physical disease, or social desirability.^[17] The fact that it diagnosed all our caregivers as depressed may be the actual state of affairs; however, it is possible that some degree of over-diagnosis resulted since the CES-D may not effectively distinguish between distress and depression.^[22,23] We suspect it is more distress than clinical depression that has been measured; nevertheless, we referred all visually disabled persons and their caregivers to the psychiatry department in our hospital for further counseling and management.

The degree of depression in caregivers, and the burden felt by them, did not depend on their relationship with the visually impaired person. Thus, aunts, nieces, and cousins were as depressed and as burdened as spouses, parents, and children. This finding is a surrogate marker for the social structure of family in India, where members of the extended family are equally invested in providing care for persons with visual disability; however, these results pertain to a hospital-based sample – in the community visually impaired people may not be getting the same level of support from the family.

Persons who have multiple disabilities are known to have greater difficulty performing daily tasks. The burden on the caregiver also is higher, especially when one of the disabilities is visual or neurological.^[24] We were intrigued by this aspect;

Table 3: Factors affecting depression in 49 caregivers of persons with visual disability

Variable	Level of depression average (SD)	Statistics
Categorical variable (Student's <i>t</i> -test)		
Gender		
Male (<i>n</i> =26; 53.0%)	42.5 (6.94)	<i>P</i> =0.716
Female (<i>n</i> =23; 47.0%)	43.2 (5.89)	
Categorical variables (ANOVA)		
Degree of disability in person being cared for*		Overall <i>P</i> =0.012
Economic blindness (<i>n</i> =16; 32.7%)	39.6 (6.92)	Economic: Social=0.162
Social blindness (<i>n</i> =23; 46.9%)	43.9 (6.54)	Economic: No PL=0.016
No PL (<i>n</i> =10; 20.4%)	45.5 (2.32)	Social: No PL=0.688
Relationship - primary caregiver is a		
Spouse (<i>n</i> =14; 28.5%)	45.1 (3.76)	<i>P</i> =0.304
Parent (<i>n</i> =18; 36.7%)	42.6 (5.81)	
Child (<i>n</i> =7; 14.2%)	42.6 (5.25)	
Other (<i>n</i> =10; 20.4%)	40.3 (10.07)	
Systemic illness		
Yes (<i>n</i> =12; 24.4%)	40.6 (8.67)	<i>P</i> =0.176
No (<i>n</i> =37; 75.6%)	43.5 (5.45)	
Literacy of caregivers		
Illiterate (<i>n</i> =18; 36.7%)	44.8 (4.92)	<i>P</i> =0.192
1-5 years of schooling (<i>n</i> =14; 28.7%)	42.7 (4.61)	
>5 years of schooling (<i>n</i> =17; 34.6%)	40.9 (8.47)	
Occupation of caregivers		
Unemployed (<i>n</i> =27; 56.2%)	43.4 (7.11)	<i>P</i> =0.234
Employed (<i>n</i> =21; 44.8%)	42.5 (5.50)	
Continuous variables (Pearson correlation) (<i>r</i> , <i>P</i>)		
Age of person with disability	0.027, 0.85	
Age of caregiver	0.076, 0.60	
Household monthly income	-0.320, 0.025	
Degree of burden felt by caregiver	0.616, <0.001	

*Welch Allen test; *post hoc* test is Dunnett T3, SD: Standard deviation, PL: Perception of light

Table 4: Distribution of degree of burden experienced by primary caregivers of persons with visual disability

Degree of burden ^[15]	Number of primary caregivers experiencing burden (%)
Score of 0-20 - little or no burden	0
Score of 21-40 - mild to moderate burden	4 (8.2)
Score of 41-60 - moderate to severe burden	32 (65.3)
Score of 61-88 - severe burden	13 (26.5)

however, none of our disabled persons or caregivers had any other disability which could have contributed to their depression or burden.^[25] While they did not have other disabilities, concurrent chronic illnesses such as diabetes mellitus, coronary artery disease, and hypertension did coexist in a few persons (about one-fourth); we did not plan to exclude them from the study because a perusal of the literature suggested that these common conditions would be seen often,

and exclusion would make achieving the sample size difficult in the fixed time frame.^[26] We expected that these illnesses would add to depression through difficulties such as additional effort in daily tasks,^[27] poor quality of life,^[28] additional expense of buying medicines, additional time required for going for checkups, and pain or other discomfort related to the illness;^[29] however, they did not. It is likely that visual disability *per se* is a significantly depressing condition and other difficulties pale in its presence.^[1]

The caregivers in our study felt moderate to severe burden in the performance of caregiving. This is a matter of great concern. Caregivers who are under considerable stress often end up as patients themselves.^[10] An intervention directed at diagnosing and treating depression in caregivers might reduce the burden they feel in providing care. Training in coping and problem-solving skills for both patient and caregiver has been shown to reduce burden.^[6] Perhaps access to vocational and emotional rehabilitation for persons with visual disability could help.

Many caregivers were unemployed, and all the persons with disability were also unemployed. Although we did not assess reasons for unemployment, caregiving responsibilities

Table 5: Factors affecting degree of burden in caregivers of persons with visual disability

Variable	Degree of burden average (SD)	Statistics
Categorical variables (Student's <i>t</i> -test)		
Gender		
Male (<i>n</i> =26; 53.0%)	55.5 (10.29)	<i>P</i> =0.310
Female (<i>n</i> =23; 47.0%)	52.7 (8.96)	
Caregiver variable (ANOVA)		
Degree of disability*		<i>P</i> =0.006
Economic blindness (<i>n</i> =16; 32.7%)	48.8 (7.02)	Economic: Social=0.007
Social blindness (<i>n</i> =23; 46.9%)	58.1 (9.52)	Economic: No PL=0.375
No PL (<i>n</i> =10; 20.4%)	53.7 (10.36)	Social: No PL=0.407
Relation with patient		
Spouse (<i>n</i> =14; 28.5%)	58.4 (8.66)	<i>P</i> =0.467
Parents (<i>n</i> =18; 36.7%)	54.5 (8.36)	
Children (<i>n</i> =7; 14.2%)	47.3 (12.13)	
Other (<i>n</i> =10; 20.4%)	52.5 (9.79)	
Systemic illness		
Yes (<i>n</i> =12; 24.4%)	53.3 (9.98)	<i>P</i> =0.737
No (<i>n</i> =37; 75.6%)	54.3 (9.73)	
Literacy of caregivers		
Illiterate (<i>n</i> =18; 36.7%)	53.9 (9.67)	<i>P</i> =0.160
1-5 years of schooling (<i>n</i> =14; 28.7%)	51.1 (10.58)	
>5 years of schooling (<i>n</i> =17; 34.6%)	54.2 (9.70)	
Occupation of caregivers		
Unemployed (<i>n</i> =27; 56.2%)	55.2 (10.78)	<i>P</i> =0.351
Employed (<i>n</i> =21; 44.8%)	53.3 (9.19)	
Continuous variables (Pearson correlation) (<i>r</i> , <i>P</i>)		
Age of person with disability	0.168, 0.248	
Age of caregiver	-0.015, 0.916	
Family monthly income	-0.174, 0.232	
Depression in caregivers	0.616, <0.001	

**Post hoc* test used is Tukey test. SD: Standard deviation, PL: Perception of light

may have taken precedence over employment for some of the caregivers. This factor has been reported by other researchers; time for caregiving duties has to be taken out from employment hours.^[6] A matter of great concern is that all the persons with visual impairment were unemployed. That they can be useful members of society may not be known to them.^[30] In addition, they may be unaware of the possibility of vocational rehabilitation or the presence and location of rehabilitation centers. Their attitude of helplessness, or the reluctance of caregivers to send a visually disabled person out to earn, may be another factor.^[30,31] Although our sample is small, our results suggest that family, community, and government/nongovernmental organization (NGO) efforts need to improve in multiple directions. Nationwide data on the number of visually impaired people should be updated, campaigns to make people aware and to motivate them for rehabilitation should be undertaken, and strengthening of the existing rehabilitation centers may be needed.^[32] Community-based rehabilitation support for the visually impaired individuals as well as for the caregivers should be enhanced so that they do not feel isolated.^[32]

Our study had a few limitations. The sample was small and might not be representative of the population. A larger

sample might have determined associations where none were found. It was a hospital-based study; the findings may not be representative of the community. The design was cross-sectional; thus, we cannot deduce whether greater caregiver depression was due to greater burden or vice versa. Further, we did not measure the duration of blindness, the number of hours devoted to caregiving, or the type of care provided; perhaps these factors influence caregiver burden and depression.

Conclusions

Caregivers felt burden and were depressed. Since burden was a major predictor of depression, community, and government/NGO efforts need to work to reduce burden felt by caregivers. Community-based support for the visually impaired individuals as well as for the caregivers should be a priority. In addition to the benefits available to people with visual disability, caregivers too could receive support, financial and otherwise. Training in coping and problem-solving skills for both patient and caregiver may help; vocational and emotional rehabilitation of the persons with visual disability might reduce caregiver burden and depression. We strongly recommend that all centers that provide disability certification to persons with

visual disability should have a disability counselor in place. All persons with visual disability and their caregivers should be required to visit the counselor and, if required, a psychiatrist, to provide management of depression.

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Conflicts of interest

There are no conflicts of interest.

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