

Adjustment to acquired vision loss in adults presenting for visual disability certification

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Context: Rehabilitation of the visually disabled depends on how they adjust to loss; understanding contributing factors may help in effective rehabilitation. **Aim:** The aim of this study is to assess adjustment to acquired vision loss in adults. **Settings and Design:** This observational study, conducted in the Department of Ophthalmology at a tertiary-level teaching hospital, included thirty persons (25–65 years) with <6/60 in the better eye, and vision loss since ≥6-months. **Materials and Methods:** Age, gender, rural/urban residence, education, current occupation, binocular distance vision, adjustment (Acceptance and Self-Worth Adjustment Scale), depression (Center for Epidemiologic Studies-Depression Scale), social support (Duke Social Support and Stress Scale), and personality (10-item Personality Inventory scale) was recorded. **Statistical Analysis:** To determine their effect on adjustment, Student's *t*-test was used for categorical variables, Pearson's correlation for age, and Spearman's correlation for depression, personality trait and social support and stress. **Results:** Of 30 persons recruited, 24 were men (80%); 24 lived in urban areas (80%); 9 were employed (30%); and 14 (46.6%) had studied < Class 3. Adjustment was low (range: 33%–60%; mean: 43.6 ± 5.73). Reported support was low (median: 27.2; interquartile range [IQR]: 18.1–36.3); reported stress was low (median: 0.09; IQR: 0–18.1). Predominant personality traits (max score 14) were "Agreeableness" (average 12.0 ± 1.68) and "Conscientiousness" (average 11.3 ± 2.12). Emotional stability (average 9.2 ± 2.53) was less prominent. Depression score ranged from 17 to 50 (average 31.6 ± 6.01). The factors studied did not influence adjustment. **Conclusions:** Although adjustment did not vary with factors studied, all patients were depressed. Since perceived support and emotional stability was low, attention could be directed to support networks. Training patients in handling emotions, and training family members to respond to emotional needs of persons with visual disability, might contribute to reducing stress and depression.

Key words: Depression, personality, social adjustment, social support, visually impaired persons

Visual disability impacts activities of daily living and burdens caregivers who provide emotional, financial, and physical support.^[1,2] Like most other chronic disorders, it can cause psychosocial distress leading to maladjustment.^[3] Maladjustment, a negative outcome, can further reduce the quality of life. Adjustment is described as the process of responding to life's demands and stresses. People differ greatly in their ability to tolerate stressful experiences and many external factors, such as age, gender, formal and informal support systems, and internal factors like personality are thought to influence adjustment.^[3] During adjustment to vision loss, one accommodates to the loss by changing one's goals and expectations in response to the new restrictions imposed by the visual loss.^[4] Simultaneously, there is an acquisition of new capabilities that depend on available resources. The adjustment may not start immediately after vision loss; usually, the patient passes through a cycle of emotions that might include denial, anger, and depression before he accepts the loss, grieves over it, then begins adjusting.^[5] There is neither definite timeline nor sequence for these emotions to develop and different people will behave differently. For this reason, we chose to recruit only

those patients who had a minimum of 6 months elapse after the loss. Our assumption was that 6 months was long enough for adjustment to have begun.^[4]

The literature suggests that a person with visual disability who adapts well to the changed circumstances is able to manage better and rehabilitation would be easier, thus reducing some of the burden on care providers and on society.^[2] Rehabilitation is an active process that aims to help in adjustment to the disability.^[4] Considering straitened resources for people with visual disability, it is important to study the various factors that could help them to adjust well. Despite recognizing its importance, very few studies have been conducted to study adjustment in people with visual disability; most are from countries other than India.^[3,4] This study was conducted to assess adjustment to acquired vision loss in adults. Our hypothesis was that better adjustment would be associated with lower depression scores, better social support, and with extraverted and emotionally

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stable personalities. An understanding of factors impacting adjustment might give a direction to redesigning the existing rehabilitation services.

Materials and Methods

This was an observational, cross-sectional study conducted in the Ophthalmology Outpatient Department of a tertiary level teaching hospital from November 2014 to April 2016. Consecutive adult patients (25–65 years of age) with acquired, permanent vision loss, presenting for visual disability certification, were recruited. Permanent visual impairment was defined as best-corrected visual acuity (BCVA) <20/200 in the better eye, that could not be treated by any means. We excluded those patients who were not willing to participate in the study; had a cognitive impairment such that they could not respond to the items in the scales; had a history of any co-morbid condition (except that which related to vision loss); had a history of psychosocial disorders or of taking long-term psychiatric medications.

A previous study from this institution was able to recruit fifty persons with vision <20/200 in the better eye over a 1-year period.^[6] Some of the participants had acquired vision loss of <6 months duration. Thus, we set a sample size 30.

After the Institutional Ethics Committee approval, participants were briefed about the purpose and procedure of the study in their own language. After informed consent, age, gender, rural/urban place of residence, highest education, and current occupation was recorded, and binocular distant visual acuity assessed using Snellen's chart after current refraction. Adjustment was measured by the Acceptance and Self-Worth Adjustment Scale (AS-WAS), degree of depression was measured using the Center for Epidemiologic Studies-Depression Scale (CES-D), the Duke Social Support and Stress Scale (DUSOCS) measured how supportive or stressful a person's relationships were, and personality was assessed by the 10-item Personality Inventory Scale (TIPI). Questionnaires were administered in confidence by one of the authors (Aditya Nakade) in a room away from the patient's relatives and other patients.

The AS-WAS is indicated for use in subjects with established vision loss.^[7] It estimates the level of adjustment concerned with acceptance (4 items), attitude (4 items), self-efficacy (3 items), self-esteem (8 items), and locus of control (2 items). Each item is rated on a four-point scale-strongly agree, agree, disagree, and strongly disagree. Higher scores mean better adjustment.^[7] We chose this scale as it assesses the unidimensional latent construct of adjustment to vision loss;^[7] it was an improvement over the original Nottingham adjustment scale, which had 55 items that were reduced on the basis of Rasch analysis to remove misfitting items;^[7] and it is a second generation patient reported outcome measure that demonstrates good precision of measurement for most subjects.^[7] In those with established vision loss it is a reliable and valid instrument. The developers of the AS-WAS scale recommend the use of a separate measure of depression to assess adjustment in a broader sense, which is the reason that we used the CES-D to assess depression in our patients.

The CES-D has 20 items which assess the level of depression during the past week. It is reported to be valid

and reliable ($\alpha > 0.85$) including in studies on Indians living in India.^[8,9] Each item is rated according to four different frequencies of occurrence of symptoms 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). Scores may range from 0 to 60, with higher scores indicating the presence of more symptoms. A score of <15 indicates no depression; score of 15–21-mild to moderate depression; and score of >21-major depression.

The DUSOCS measures how supportive or stressful a person's relationships are.^[10] Social support is multi-dimensional and several instruments measure one or more dimensions of social support. The selection of the instrument depends on what dimensions are required to be studied; as our study was related to persons with disability and their adjustment, we wanted to measure both the perceived support and the stress experienced, which is why we chose DUSOCS. Six scores are generated: family support and family stress; nonfamily support and nonfamily stress; social support and social stress. Each support and stress division has 12 items each that the respondent rates on a four-point scale (none, some, a lot, and there is no such person). Total support and stress are calculated by adding all scores using formulas suggested by the developers of the scale.

The TIPI is a measure of Big Five Personality dimensions: Agreeableness (2 items), emotional stability (2 items), extraversion (2 items), openness (2 items), and conscientiousness (2 items). The scale is found to be useful in studies where the main focus is not on personality, but where personality can affect the outcome of the study in some way.^[11] It is also useful in studies with time limitations as it can be performed within minutes. Each item is graded on a 7-point scale ranging from 1 (disagree strongly) to 7 (agree strongly). The higher the score, the more is that personality attributable to the person.

Data were handled as per the Declaration of Helsinki (1964; revised 2008). Participants were referred to by serial number and data kept confidential. Descriptive statistics were used to calculate mean and standard deviation (age, total adjustment, depression, and personality traits) or median and IQR (social support and stress). Proportions were calculated for gender, residence, occupation, and education; Student's *t*-test was used to determine their effect on total adjustment.

The effect of age on adjustment was calculated using Pearson's correlation. Correlation between total adjustment score, depression score, personality trait score and social support and stress scores was calculated using Spearman's correlation. Results were considered as statistically significant at $P < 0.05$.

Results

Thirty persons were recruited; 24 were men (80%); age ranged from 25 to 65 (average 48.1 ± 16.4) years. Most had BCVA of <20/400 in the better eye (96.7%); of these, no perception of light was seen in seven persons (23.3% of all people with visual disability). Most resided in urban areas ($n = 24$; 80%); 21 were unemployed (70%); 14 (46.6%) had studied to less than Class 3.

The most common involvement resulting in blindness related to the cornea ($n = 25$ eyes; 41.6%). Others were phthisis

bulbi ($n = 12$; 20%); retinitis pigmentosa ($n = 10$; 16.6%); optic atrophy ($n = 5$; 8.3%); myopic degeneration ($n = 4$; 6.8%); glaucomatous optic atrophy ($n = 3$; 5%); and fundal coloboma ($n = 1$; 1.7%).

The degree of adjustment to visual disability was not very good (range: 33%–60%; mean 43.6 ± 5.73). Patients were most likely to be agreeable personalities and to demonstrate conscientiousness and were least likely to be extraverts [Table 1]. While the overall support felt by our patients was low, the reported level of stress induced by family and nonfamily members was also very low [Table 2]. Total stress did not correlate with total support (Spearman's $\rho = 0.150$; $P = 0.430$). The degree of depression ranged from 17 to 50 (average 31.6 ± 6.01); Table 3 shows the factors that could affect adjustment. None of them were found to significantly enhance or prevent adjustment to visual disability in our patients.

Discussion

This cross-sectional study was conducted in a hospital setup and included adult patients with acquired vision loss. Our patients had adjusted to vision loss to varying degrees; however, adjustment was low and ranged from 33% to 60%. Age, gender, educational status, family income, formal and informal support systems, and internal factors such as personality may play a role in adjustment to blindness.^[3] Sociodemographic parameters did not seem to influence adjustment. When we evaluated personality parameters, our patients were more likely to be agreeable and conscientious, and least likely to demonstrate extraversion and openness to experiences. Both

these traits are expected to be very helpful when a patient has to adjust to vision loss.^[4] It was consequently surprising that, in our study, adjustment did not vary with personality type. Perhaps, if the trait of extraversion had been there in greater measure, our patients would have demonstrated higher levels of adjustment. In fact, studies have shown that extraversion promotes adjustment since it is associated with an outgoing, energetic, and assertive positivity.^[12]

As far as other personality traits were concerned, our patients also had low emotional stability, meaning that they were sensitive and nervous as opposed to secure and confident. This is not surprising since they were blind, their disability imposing inevitable restrictions, and making them depend on others on a daily basis. Other authors have shown this as well and also relate it to dependence on others; such patients show lack of initiative and greater anxiety.^[13] Research has shown that neurotic symptoms in people with visual impairment are mostly due to external factors such as family environment, stress, and low self-esteem.^[13] Perhaps by providing some degree of emotional support and training in the handling of emotions could help more patients become secure and confident. Simultaneously, if family members were also trained to respond to the emotional needs of persons with visual disability, perhaps emotional stability would improve.^[14]

Adjustment to vision loss often occurs within the context of family members and friends. Keeping this in mind, we examined support experienced by our patients; they reported feeling poorly supported and the DUSOCS score averaged about 38% for family support and a mere 10% for nonfamily support. The large gap between family support and nonfamily support can be anticipated in the Indian context where family offers unconditional support and participates in caring for persons with disability;^[15] however, the level of support was not correspondingly high. The DUSOCS measures patient perceived support which may have been biased by patient perceptions; second, patient expectations from family, and family expectations about the abilities of the visually disabled patient, may be different leading to a mismatch;^[16] in addition, personality of the individual may play a role – an introvert may find it harder to ask for help. Our patients had very low extraversion scores and this may have contributed to them feeling relatively under-supported. The literature supports our belief; persons with extraverted personality traits are more likely to maintain relationships; these traits may lead to more satisfying interactions and greater perceived social support over time.^[17]

The level of social support experienced by our patients did not influence their adjustment to visual disability. Another study on visual disability has also shown that social support does not impact adjustment.^[4] We found this odd since adjustment to conditions like spinal cord injury and cancer is enhanced by social support.^[18,19] Perhaps other factors that we did not study played a role. This highlights the need for more research to uncover factors that could promote adjustment to visual disability.

The literature suggests that a person with disability who perceives support from family or others may still feel stressed as a result of the same individuals.^[20] For example, the person with disability may be stressed from the knowledge that the

Table 1: Personality traits in thirty persons with visual disability

Personality trait	Range (average \pm SD)
Extraversion (maximum score 14)	2-12 (6.7 \pm 2.38)
Agreeableness (maximum score 14)	8-14 (12.0 \pm 1.68)
Conscientiousness (maximum score 14)	7-14 (11.3 \pm 2.12)
Emotional stability (maximum score 14)	3-14 (9.2 \pm 2.53)
Openness to experiences (maximum score 14)	3-11 (7.0 \pm 2.57)

SD: Standard deviation

Table 2: Social support and stress reported by thirty persons with visual disability

	From family members	From nonfamily members	Total score
Social support (maximum score 100)			
Median	39.25	5.00	27.20
IQR	19.6-57.1	0-20	18.1-36.3
Social stress (maximum score 100)			
Median	7.10	0	0.09
IQR	0-14.2	0-10	0-18.1

IQR: Interquartile range

Table 3: Factors affecting adjustment (Acceptance and Self-Worth Adjustment Scale) in thirty persons with visual disability

Categorical variables	Degree of adjustment (mean±SD), Student's <i>t</i> -test	<i>P</i>
Gender		
Female (<i>n</i> =6)	42.3±5.65	0.544
Male (<i>n</i> =24)	43.9±5.83	
Residence		
Urban (<i>n</i> =24)	43.3±5.83	0.523
Rural (<i>n</i> =6)	45.0±5.62	
Occupation		
Employed (<i>n</i> =9)	43.0±5.79	0.699
Unemployed (<i>n</i> =21)	43.9±5.83	
Education		
Less than Class 3 (<i>n</i> =14)	43.4±5.37	0.859
Class 4 and above (<i>n</i> =16)	43.8±6.20	
Continuous variables	Correlation coefficient	<i>P</i>
Age (Pearson correlation)	0.025	0.896
Depression (Spearman rho)	-0.268	0.152
Perceived support (Spearman rho)		
Family support	0.048	0.803
Nonfamily support	0.306	0.100
Total support	0.103	0.587
Perceived stress (Spearman rho)		
Family stress	0.035	0.853
Nonfamily stress	0.017	0.929
Total stress	0.048	0.802
Personality traits (Spearman rho)		
Extraversion	-0.360	0.051
Agreeableness	0.117	0.537
Conscientiousness	-0.118	0.534
Emotional stability	0.260	0.166
Openness to experiences	0.037	0.846

SD: Standard deviation

person providing support is spending time and money on him and perhaps losing time at work because of the care he has to provide. We found that our patients did not report much stress attributable to any family or nonfamily member. Perhaps, since the predominant traits demonstrated by our patients were agreeableness and conscientiousness, these traits helped them harmonize with people.^[4] Alternatively, their need to be accepted by peers and family may have prompted them to try harder to get along with others.^[13] Studies have shown a negative relationship between stress and adjustment. We did not see any association in our patients. We believe this may be so because the adjustment we assessed was the amount that they had adjusted up to that point; since the adjustment is an ongoing process, for some patients, it may have been just starting, while for others, the adjustment may have ended. There is no way to determine which of these two scenarios hold true for a particular person unless a longitudinal study is conducted.

Although we found no association between social support and adjustment, or between stress and adjustment, we suggest that by paying greater attention to the support networks of persons with visual disability, and to the sources of stress within it, we may be able to identify those at risk and refer them for family-centered psychological interventions.^[1] This has been recommended in other nonvisual disorders where early detection and treatment of family stress by family physicians helps.^[21]

Our patients reported many symptoms of depression. Depression and disability may have a bidirectional relationship; thus, depression may lead to disability while disability may cause depression.^[22] The CES-D has been reported to overdiagnose depression since it may not be able to differentiate distress from depression.^[23] Nevertheless, whether distressed or depressed, such people may not seek eye care when they need it and may not adhere to treatment for diagnosed eye conditions, thus resulting in blindness.^[24] In any case, vision-specific distress is a strong predictor of depressive symptoms, and its effect may be separate from that related to the severity and duration of the visual impairment.^[25] In this cross-sectional study, it is not possible to say whether disability came first or depression; however, the fact that our patients were depressed to varying degrees deserves attention. Depression is a treatable condition and can be identified by screening.^[26]

The present study has limitations. This is a hospital-based study and its findings may not be representative of the general population. Since all of our patients self-reported to the hospital for visual handicap certificate, the study is likely to have selection bias. We had many more men than women so the findings of this study are likely to have a gender bias. We collected data through interviewer-administered questionnaires; it is possible that participants became conscious and misinterpreted the questions.^[27] Had the questionnaires been self-administered, the responses might have been more accurate; although, there is a risk that participants take self-administered questionnaires casually.^[28] We did not record precise duration of blindness except to make sure that patients fulfilled the inclusion criteria and had been visually disabled for more than 6 months. Thus, we cannot comment on how adjustment would have varied with the duration of vision loss. Statistical analysis adjusted by duration of vision loss might have elicited the influence of time over adjustment, even though adjustment is known to be a continuum and there may be no set sequence or timeline.^[4]

Conclusion

This cross-sectional study found that some degree of adjustment had taken place in all our adult patients to their acquired vision loss. Although adjustment did not vary with the factors we studied – social support and stress, depression, personality traits, and sociodemographic factors – we found that all our patients had symptoms of depression, or at the very least felt distressed. In addition, self-reported social support was low, and emotional stability was also poor. By examining support networks, and the sources of stress within it, and the predominant personality type of persons with visual disability, we may be able to identify those at risk and refer them for family-centered counseling. Training them in how to best handle their emotions, and training family members to respond

to the emotional needs of persons with visual disability, might contribute to reducing stress and depression.

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Conflicts of interest

There are no conflicts of interest.

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