

# Psychological Impact of Glaucoma: Does it Affect Compliance and Disease Progression?

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## ABSTRACT

**Objective** – To identify the association between the psychological variables, namely coping mechanisms and perceived social support, with adherence to medical treatment and progression of glaucoma.

**Study Design** – Prospective Cohort Study

**Methods** – A group of 113 glaucoma patients were asked to answer questionnaires to assess their coping and social support system. These patients were then analyzed for visual field progression with 2 year data.

**Results** – The predominant coping mechanism in 86.7% was problem-oriented coping and mean score for social support was maximum for family. Patients with history of glaucoma surgery had higher scores for emotion-oriented coping (p value – 0.016). Subjects with a family history of glaucoma had higher mean score for friends as a social support system (p value – 0.049). Adherence to anti-glaucoma medications (AGMs) was least and progression of glaucoma was maximum in those with disease duration of 3-5 years.

**Conclusion** – Family history of glaucoma and a history of glaucoma surgery have a psychological impact on a patient's adaptation to the disease. No correlation was found between the psychological variables and disease progression. However, adherence is lowest and progression of glaucoma highest, 3-5 years post diagnosis of disease.

## INTRODUCTION

Glaucoma, being the third most common cause of blindness in India [1], is a significant cause of disability. Once diagnosed, the goal of glaucoma management is to prevent progression of disease and irreversible vision loss. The first line of management is always the use of anti-glaucoma medications (AGMs)<sup>[1]</sup>. However, the disease control will depend heavily on the patient's compliance (or adherence) to their medications, which physicians might not always be able to gauge from their patients<sup>[2]</sup>. We have attempted to look into two psychological variables which could influence their compliance – coping mechanisms and perceived social support.

Coping is defined as ongoing cognitive and behavioral efforts to manage psychological stress<sup>[2]</sup>. Coping style is broadly divided into two types: problem-oriented coping (where a person tries to resolve the stressor) and emotion-oriented coping (where the person aims to regulate the negative emotions that come with the stressor)<sup>[3]</sup>. Each of these categories have 7 subtypes. On the other hand, social support is the support received (emotional, informative or instrumental) that enhances the recipient's self-esteem and provides stress related inter-personal aid<sup>[4]</sup>. Strong social support is known to be associated with psychological well-being and can alleviate the negative impact of a stressor, like dealing with a chronic

illness.

In the current study, we looked to identify the psychological impact of glaucoma, via coping mechanisms and social support systems

## METHODS

Institutional Ethics Committee clearance was received for the above study (EC registration number – ECW705/Inst/KA/2015/RR-18). Informed consent was obtained from all the subjects who agreed to take part in the study. The research adhered to the tenets of the Declaration of Helsinki.

A total of 113 glaucoma patients who were on AGMs were enrolled for the study. Patients with other significant vision disabling conditions e.g., post keratoplasty, were excluded to avoid confounding factors.

The history collected from each patient included demographics like age and sex, duration of disease, surgical history and family history of glaucoma. The patients were asked to answer a set of questionnaires – The Brief COPE Questionnaire was used for assessing coping strategy, Multidimensional Scale of Perceived Social Support for the predominant social support system and Morsiky Medication Adherence Scale (MMAS-8) to assess the patient's compliance to the AGMs.

The questionnaires were provided in English, Kannada and Hindi. Translation of questionnaires was done as per recommended guidelines by Tsang S et al. [5]

The patients had their visual fields recorded by Humphrey's Visual Field Analyzer (HFA) 24-2 SITA Standard. The test was repeated after a year when patients came for follow up and the field reports from a year prior to enrolment were included. Progression was defined as per Early Manifest Glaucoma Trial, as minimum 3 progressive points of  $p < 0.05$  in Pattern Standard Deviation (PSD) over 3 consecutive visual fields tests [6].

## STATISTICAL METHODS

Data was analyzed using R version 4.03. All categorical data was summarized using frequency and percentages, all continuous data was described using mean and standard deviation or Median and inter quartile range based on the distribution. The association of clinical parameters and coping mechanism with Adherence categories and Progression categories was assessed using ANOVA or Kruskal Wallis test for comparing more than two category and Independent sample t-test for comparing two categories for the continuous measurements. After checking normality assumption, Chi-square test or Fisher's exact test was applied for the categorical observations based on the expected frequency. P-value will be considered significant at 5% level of significance for all comparisons.

## RESULTS

A total of 113 patients, 74 males and 39 females, enrolled for the study. Mean age of the population was 63.7 years (range 22-84 +/- 13.4yrs).

Years since diagnosis	Number of patients	Percentage
1-2 years	23	20.35%
3-5 years	22	19.47%
6-8 years	38	33.63%

>8 years	30	26.55%
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Table 1: Distribution of patients based on years since diagnosis of glaucoma

Family history of glaucoma was present in 22% of the patients and. Patients were segregated into four groups, based on the number of years since their diagnosis as shown in Table 1. Trabeculectomy had been performed on 34% of patients, at least 1 year prior to enrolment, and they were being maintained on AGM.

On analysis of the coping mechanisms, most patients, 98(86.7%), used problem oriented coping strategies and 15 (13.3%) used emotion oriented coping mechanisms. In patients who underwent trabeculectomy in the past, a higher mean score for emotion-oriented strategies was observed (p value = 0.016).

Analysis of the predominant social support showed that 82% of the candidates chose family with a mean score of 28. But among patients who had a family history of glaucoma, the mean score was higher for friends (score- 23) compared to family (score- 19). The p value is 0.049.

Out of the 43 patients with high adherence, only 7 (16%) showed signs of progression and 84% were stable. Among the 39 patients with low adherence, 18 (46%) showed progression and 21 (54%) were stable. Among those with medium adherence, 13 out of 31 patients (41%) showed progression.

Figure 1 compares the duration of disease and adherence to medications.

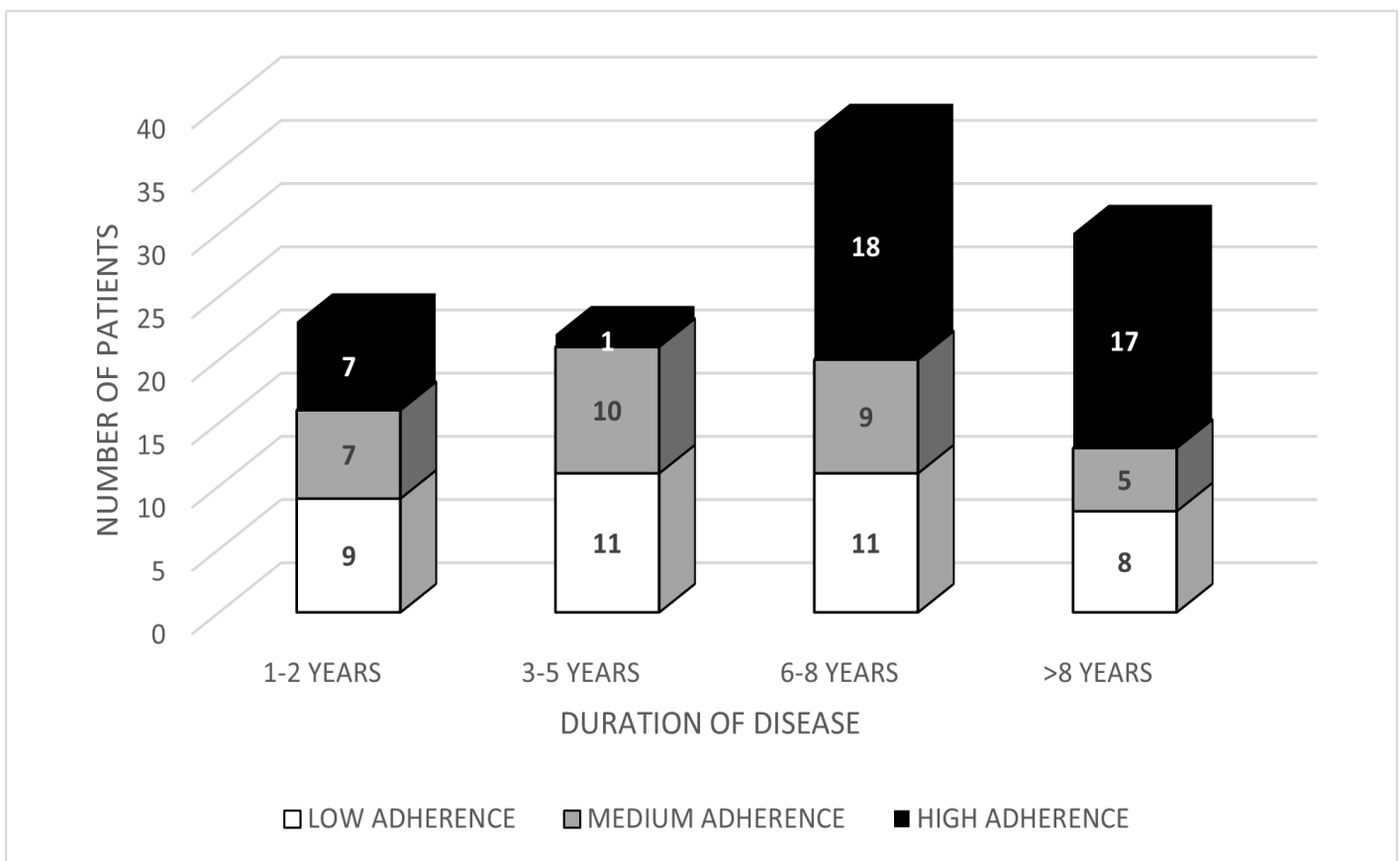


Figure 1: Change in adherence to medications with duration of disease

Progression, as measured by analysis of visual fields, revealed worsening of fields in 37 patients (33%) over the course of 1-2years. As with compliance, progression was compared to duration of disease to reveal a similar pattern as in Figure 2.

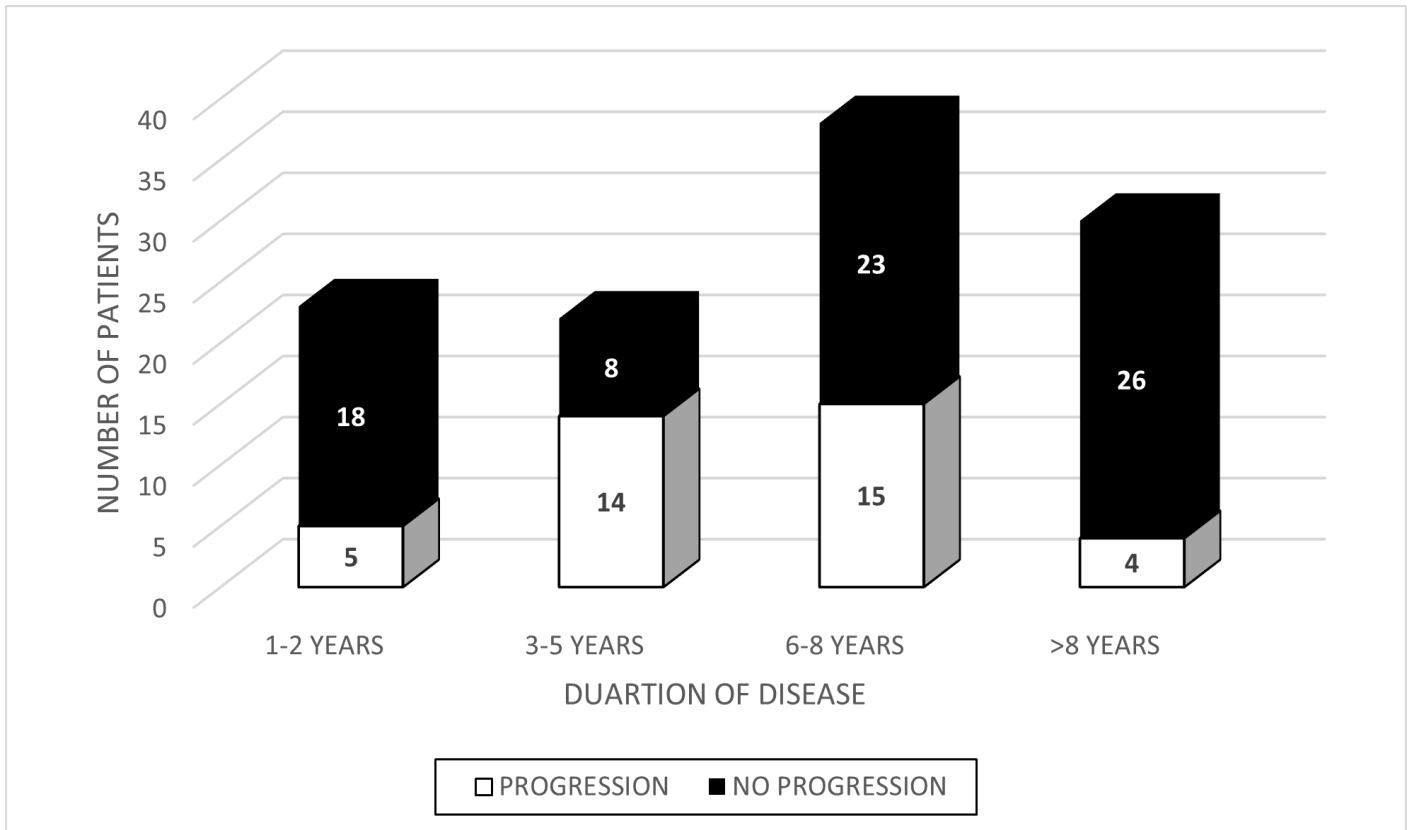


Figure 2: Change in incidence of progression with duration of disease

Overall, patients with low adherence to medication had a higher mean score for problem-oriented coping mechanisms. However, no coping strategy was found to be associated with progression of glaucoma. In addition, no correlation was found between coping strategy and years of disease.

## DISCUSSION

It has been known that factors like coping can affect outcome of diseases [1]. Also, while change in disease parameters is apparent to physicians, an important determinant like low adherence to medications is often under-reported [2]. Hence it becomes important to understand the various ways these variables can affect the disease process.

Glaucoma patients enrolled for the study were those who were known to have the disease for a minimum period of 1 year. This was done to remove the bias which would occur in a newly diagnosed glaucoma patient<sup>[11]</sup>. It has been reported that most patients experience negative emotions on first diagnosis but gradually change their attitude after living with the disease.

In our study, problem oriented coping mechanism predominated (86.7%). Although we can't classify any coping mechanism as positive or negative, according to literature, visually impaired patients with problem-based coping, are more likely to adapt to their condition and less likely to suffer from anxiety, pessimism and loneliness.<sup>[8]</sup>

We did not find any association between coping and severity of glaucoma. This was similar to the results by Rai et al<sup>[7]</sup>, who found no association between coping and best corrected visual acuity (BCVA) for distance. They did, however, find that those who had some residual vision had higher proactive coping compared to those who had no perception of light.

The second psychological variable we looked into was perceived social support, where family, as a support system, predominated. Various studies on systemic illnesses like diabetes mellitus, have shown that a higher social support improves a person's psychological adjustment to a disease and quality of life [12-18]. Karatas and colleagues also reported that most of their patients relied on family for support in managing their disease.[13]

Family history has always been a significant factor in glaucoma<sup>[1]</sup>, not only because it is an indication for routine testing for the disease, but also because patients are well aware of the disease prior to their diagnoses. Family history of glaucoma was present in 22% of our subjects and we found these patients tend to rely more on friends as their support system. While there have been no other studies on this aspect, Glen FC and colleagues<sup>[11]</sup> stated that social support was a vital tool in dealing with the disease, but patients also tend to feel anxiety and a sense of burden on the other person. In our interaction with the patients, we noted a similar hesitancy to rely on family who was already burdened with the disease. However, this was not separately analysed.

History of glaucoma surgery also seems to have an effect on the patient's coping. Thirty four percent of our enrolled patients have had trabeculectomy prior to enrolment. This group of patients had a more emotion oriented coping mechanism than those who have not undergone surgery. Since there aren't many diseases like glaucoma where surgery is intended to reduce or possibly eliminate the need for long term medications, there aren't any other studies which support this finding. It is our inference that surgery is presented to the patient often as a last option when maximum medical therapy is not able to control the IOP. Having been on multiple eye drops, they usually are hopeful that they won't have to rely on AGMs after surgery. Hence, we believe that having to continue medications post-surgery because of persistently high IOP, seems to have an effect on their psychological adaptation.

In our patients, no coping mechanism was seen to show an association with progression. This is in contrast to the study by Freeman et al <sup>[19]</sup> on glaucoma patients, which reported that patients with denial (a subset of emotion oriented coping where the person refuses to believe what happened) had visual field progression. In our study denial as a coping mechanism was not reported by any of our patients. This can be attributed to the fact that we have not taken treatment naïve patients and denial as a coping mechanism contributes to late presentation to the hospital and tends to delay getting help <sup>[19]</sup>.

A factor that seems to have a significant effect on the way patients deal with the disease is the duration for which they have had the condition. This has not been researched in any other study to the best of our knowledge.

Maximum adherence was seen in patients with long duration of disease (>8 years) and also in those who were recently diagnosed with glaucoma (1-2 years). In the period of 3-5 years after the diagnosis, however, the adherence to medications is found to be lowest. Similarly, progression, seen as worsening of visual fields, is maximum during the period of 3-5 years since diagnosis, with 64% of our patients in that group showing visual field loss. Based on our interactions and reasoning, we can speculate that following the diagnosis of glaucoma, since the most common reaction is fear and anxiety, patients listen to medical advice and are very likely to be adherent to the medications. As years go by, the routine tends to get monotonous and as the fear and anxiety gradually reduce, the drive to be adherent and careful with their medications also comes down.

But it is also seen that those with long duration of disease i.e., more than 6 years, are more adherent to medications and those above 8 years are highly adherent. This can be attributed to the fact that by the time they reach this stage, they have had multiple check-ups and reinforcements by the treating physician, possible hiccups with pressure control or they might begin to sense the changes in their visual field

themselves, triggering an improved adherence.

The limitations of our study include unavailability of Glaucoma Progression Analysis (GPA). This might have caused us to overestimate progression.

Further, our study doesn't represent the general population, as we have taken those who have themselves come to the hospital for check-up. This will underestimate the number of patients with certain coping strategies, for example, denial. Also, we did not include socio-economic status and education of the patient in our data which could be a confounding factor.

Our study is based heavily on self-report and it is important that patients answer the questionnaires honestly. People will have the tendency to answer what 'should' be right. This is a drawback in studies using questionnaires.

## CONCLUSION

Our study did not reveal a direct correlation between coping and progression of glaucoma. However, it does draw focus to the psychological aspects of patient care. Awareness among glaucoma consultants and a holistic approach can go a long way in helping them manage their disease.

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