



## Ways through which the 'sneak-thief of sight' slips away – an analysis of non-compliance

### KEY WORDS

glaucoma, follow-up, non-compliance

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### ABSTRACT

Good adherence to treatment and regular follow up visits are important in a glaucoma patient to prevent blindness. This is a questionnaire based cross sectional study which assessed why the follow-up visits are not very satisfactory. The most common factors associated with non-compliance were financial constraints, patient not realising the importance of follow up visits and forgetting the dates. Elderly patients with low education levels and with co morbidities had poor compliance. Better health advocacy, good patient counselling and creating reminders can be good measures to improve the compliance with follow-up visits.

### Introduction:

Glaucoma is one of the leading cause of blindness worldwide and in India. Glaucoma is known as sneak thief of vision as it usually causes painless, progressive and irreversible loss of vision. Vision loss in glaucoma is preventable with proper and timely treatment. Hence compliance with treatment and regular follow up visits are very important.

However, there are some challenges faced in glaucoma management such as inadequate utilization of eye care services for screening and diagnosis, loss of follow up, delayed follow up, poor compliance for treatment and advice.<sup>2</sup>

Good adherence to treatment and regular follow up visits provide an opportunity to the treating ophthalmologist to keep a strict vigil on patient's condition, so that glaucoma blindness can be nipped at bud. However due to some fear, inhibitions, poor knowledge or personal problems the patient may not give importance to his own health condition. Patients may not realise the importance of follow up and may never turn up. They may miss their follow up date, fail to re-schedule the date, present very late or even may get completely lost for further follow up visits.

Several studies have suggested that because the vision loss and disease progression are often subtle, patients may be less motivated to have timely follow-up due to a perception that their eye disease is not serious. It is critical to understand the reasons why patients miss recommended appointments because lack of monitoring and inadequate treatment may worsen the prognosis.<sup>1,4</sup>

It is the responsibility of the treating ophthalmologist to find out the barriers which hinder the follow up visits and formulate suitable measures to overcome these barriers. The objective of this study is to find out the factors influencing compliance of follow up visits among glaucoma patients and glaucoma suspects.

### Methods:

The study was conducted after obtaining the clearance from the institutional ethics committee. By referring the glaucoma clinic register, the files of glaucoma patients and glaucoma suspects were retrieved. Patients with poor follow up visits were noted down. Patients with poor follow up were defined as patients who missed any of their follow up visits, and failed to report to hospital even one

month after the given date; patients who did not attend their regular follow up as advised; who presented very late (after a month) and patients who never came for any follow up visit. The patients who could be contacted were included in the study. The study was conducted during a period from April-September 2016. The patients were counselled over phone to come back and were given an appointment date. Data was collected by interview method using a predesigned and prestructured questionnaire. If a patient fails to come on the day of appointment and fails to re-schedule his appointment or does not come even after 15 days of telephonic counselling, they were called up again and data was collected using telephonic interview. Patient who said that they are receiving treatment/ follow up from another ophthalmologist were excluded. The questionnaire contained 20 questions pertaining to factors hindering with patient follow up. Questions are intended to investigate causes related to lack of awareness; financial and accessibility factors; co- morbidities, personal and societal beliefs. Socio demographic details were noted down which included age, gender, place of residence, distance from base hospital, education levels, employment, income, health insurance, comorbidities, family details of the patient and also duration and severity of glaucoma.

### Results:

A total of 81 patients participated in this study. Out of all the patients, 59.3% were males and 40.7% were females. The patients attributed their non-compliance with follow-up visits to various factors. The factors are related to lack of awareness, financial constraints, accessibility factors and factors related to attitude and beliefs. (Table 1)

**Table 1: Factors leading to non-compliance with follow-up visits in glaucoma patients. n=81(100%)**

Factors related to awareness:	
1. I did not come to follow up because I was not aware about the blinding nature of the disease. n=32(39.5%)	
2. I did not realise the importance of follow up. n=48(59.2%)	
3. I did not understand properly what my doctor advised. n=40(49.3%)	
Factors related to financial constraints:	
4. I did not have money to come. n=46(56.7%)	
5. I did not have money for tests or treatment. n=51(62.9%)	
6. I could not afford to lose my daily wages. n=38(46.9%)	

7.My health insurance does not cover all my needs adequately. n=27(33.4%)
<b>Factors related to accessibility:</b>
8.I could not come due to lack of escort (no attendant to accompany me to hospital) n=41(50.6%)
9.Distance from hospital (it is very far from my home) n=27(33.3%)
10.I could not come as I was not keeping well/ I have other health problems also n=28(34.6%)
<b>Factors related to attitude and beliefs:</b>
11.I did not feel the need for coming- my eyes are just fine, I don't have any problem. n=41(50.6%)
12.I forgot the dates. n=45(55.6%)
13.I could not come, as I was out of station. n=18(22.2%)
14.I had other commitments which were more important. n=35(43.2%)
15.I do not bother much about my health. n=42(51.8%)
16.My family is not concerned much about my health. n=16(19.8%)
17.I don't like going to hospital. n=38(46.9%)
18.I don't have time. Hospital consultations are too time consuming. n=42(51.8%)
19.I thought if I start using a drug- I will get used to it. n=23(28.4%)
20.I have fear of surgery. n=44(54.3%)

The following were the four most important reasons cited for not coming for follow up: 51 (62.9%) patients did not have money for tests and treatment; 46(56.7%) did not have money to come to hospital; 48(59.2%) did not realise the importance of follow up and 45 (55.6%) forgot the dates.

These four most common factors leading to non-compliance were correlated with the demographic details of the patients using chi-square test. Data were analyzed using SPSS version 16.0 and statistical significance was defined as a p-value of <0.001.No significant association was found between the factors and demographics like gender, place of residence, occupation, income or distance from hospital. However, statistically significant association was found with age, education level and presence of co morbid conditions. (Table 2) Elderly patients (age more than 65 years), patients with low education levels (below seventh standard) and patients suffering from co morbidities were most likely to be non-compliant with their follow up visits. The most common association for unsatisfactory follow up was presence of co morbidities like diabetes mellitus, hypertension, asthma, chronic obstructive pulmonary disease, tuberculosis, arthritis, physical disabilities or mental illness.

**Table 2: Association of Socio demographic variables with Factors causing non-compliance**

Variable	No money for treatment n=51		No money to come to hospital n=46		Did not understand the importance of follow up n=48		Forgot dates n=45	
	N (%)	P value	N (%)	P value	N (%)	P value	N (%)	P value
Age								
<65 years	9(17.6%)	<0.001	6 (13%)	<0.001	18	<0.001	8	<0.001
>65 years	42(82.4%)		40(87%)		30		37	
Education								
>7th standard	14(27.5%)	<0.001	16(34.8%)	<0.001	13	<0.001	6	<0.001

<7th standard	37(72.5%)	<0.001	30(65.2%)	<0.001	35		39	
<b>Co morbidity</b>								
No	2(3.9%)	<0.001	9(19.6%)	<0.001	19	<0.001	5	<0.001
Yes	49(96.1%)		37(80.4%)		29		40	

**Discussion:**

Patients with glaucoma require life-long treatment and follow-up care to preserve vision.5 But the compliance with follow up visits in glaucoma patients is not satisfactory. 1,4 The cause for this could be multi factorial including financial constraints, loss of wages, forgotten dates, out of station, distance from the hospital, negligence from family or self, fear of cost, fear of unknown disease, other personal or health problems, lack of escort, unawareness regarding the disease or treatment, false beliefs, attitude problems and not considering it as a priority. Low disease knowledge scores, legal blindness, and difficulty getting time away from work for appointments adversely impacted follow-up independent of eye disease diagnosis. 4 This study intended to assess the reasons from patient's perspectives. A study opines that subjects with poor follow-up adherence were significantly more likely to have severe glaucomatous disease suggesting that poor follow-up may contribute to disease worsening or, alternatively, those with more severe disease are less inclined to follow up at appropriate intervals.6 Around 41% of patients fail to undergo subsequent eye examination after screening positive for glaucomatous disease and approximately 50%–59% of patients with a glaucoma diagnosis are unwilling to use follow-up eye services.7

Glaucoma can result in severe visual disability. Given the unpredictable course of glaucomatous disease, the only reliable way to distinguish those who are destined for poor outcomes from the many who are not, is to make sure that all those with the disease are seen at prescribed intervals. These follow-up visits are important in allowing practitioners to gauge the stability or progression of the disease, modify medical therapy, and consider surgical options as needed. Without such visits, patients can worsen markedly without recognizing that they are losing their vision from glaucoma.7

Hence emphasis has to be laid on finding a strategy to overcome this problem of non-compliance. We need to a further step to positively encourage and educate our patients with improved counselling.

Understanding patient-reported barriers to glaucoma follow-up and their variation based on ethnicity may give providers insight as to why patients do not adhere to follow-up recommendations. Strategies to improve follow-up may include reduced clinic wait times, simplified appointment scheduling, and provision of appropriate education and counselling regardless of the patient's native language and ethnicity.1 Intensive counselling, audiovisual aides, and patient support groups and escort provision may be of help.2 Patient education has been found to improve adherence.7 Another study has observed that telephone reminders, text message or mail reminders are effective and significant reductions in clinical nonattendance.8

Improvements in patient education, transportation services, and clinic efficiency may increase adherence to recommended appointment intervals.4 Health advocacy to provide investigations and treatment at an affordable cost could be of great help to patients.

**Conclusion:** The most common factors associated with non-compliance were financial constraints, patient not realising the importance of follow up visits and forgetting the dates. Better health advocacy, good patient counselling and creating reminders can be

good measures to improve the compliance with follow-up visits.

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