

# Awareness of diabetic retinopathy among diabetes mellitus patients visiting a hospital of North India

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## ABSTRACT

**Context:** Diabetic retinopathy (DR) is a major cause of visual disability leading to irreversible blindness. Awareness of diabetes and its ocular co-morbidities may help in preventing vision loss. **Aim:** To assess the awareness of diabetic retinopathy among diabetic mellitus patients visiting a hospital in North India. **Setting and Design:** Cross-sectional study conducted at an outpatient clinic of ophthalmology department of a hospital. **Materials and Methods:** An interviewer-administered, pre-tested, semi-structured questionnaire was used to evaluate the awareness of DR for the period from July 2020 to January 2021. **Results:** A total of 272 patients with diabetes mellitus (44.4% females and 55.5% males) were included in the study. The mean age of the study population was  $53.4 \pm 10$  years. Of the 272 patients, 79% were aware that diabetes can affect the eyes, and 69.5% knew that DR can lead to blindness. Regarding prevention and treatment of DR, 58.1% of patients were aware that good glycemic control prevents DR and 52.6% knew that DR can be treated. Physicians were the main source of information in 47.4% of patients. The participants were not compliant with a routine retinal assessment with only 26.5% of them having previous fundus examination for DR screening. **Conclusion:** Most of the participants were aware of DR but there existed major deficits in the knowledge and behavior of diabetic patients toward management of DR. There is a need to create awareness about DR and emphasize the importance of retinal screening to reduce visual disability caused by diabetes.

**Keywords:** Awareness, diabetic retinopathy, screening

## Introduction

The world's commonest endocrine disorder, diabetes mellitus, is characterized by chronic hyperglycemia, which, in turn, causes multiple microvasculopathic and neuropathic abnormalities compromising various organs leading to diabetic retinopathy (DR), diabetic nephropathy, renal failure, autonomic neuropathy, and cardiovascular complications.<sup>[1]</sup>

Diabetes mellitus is a global pandemic with countries struggling to manage it throughout the world.<sup>[2]</sup> The prevalence of diabetes

in 2019 had been estimated to be 9.3% affecting 463 million people worldwide and is estimated to rise to 10.9% (700 million) by 2045.<sup>[3]</sup> Among individuals with diabetes, the global prevalence was 22.27% for DR, 6.17% for VTDR (vision-threatening DR), and 4.07% for CSME in a study by a Teo *et al.*<sup>[4]</sup> When considering diabetes-related mortality, poor societies, as low- and middle-income countries are disproportionately affected accounting for 80% of worldwide mortality related to diabetes.<sup>[5]</sup> India had over 77 million people living with diabetes in 2019, and this number is expected to increase to 134 million by 2045 as reported by the International Diabetes Federation.<sup>[6]</sup>

DR has emerged as a major cause of visual disability leading to irreversible blindness among adults. It begins as a neuro-retinopathy with vascular changes occurring later as a result of a breakdown of the blood-retinal barrier and obliteration of retinal

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capillaries.<sup>[2]</sup> Uncontrolled glucose levels, age, longer duration of DM, hypertension, smoking, and hypercholesterolemia are some of the risk factors that aggravate DR complications.<sup>[7]</sup>

A systematic review evaluating 59 population-based studies estimated the worldwide prevalence of DR to be 35%,<sup>[4]</sup> whereas its prevalence in India has been reported to range between 12% and 22% in various Indian studies.<sup>[8,9,10]</sup> The age-standardized proportion of DR was 32.3% and VTDR was 19.1% in the SPEED study by Rajalakshmi *et al.*<sup>[11]</sup>

If left unsupervised and untreated for 1 year or longer, DR may lead to severe permanent vision loss. Timely detection and treatment of DR play a significant role in saving the eyesight of diabetes patients.<sup>[12]</sup> Increasing the degree of awareness about eye screening to detect DR among individuals with diabetes is an important factor for the management of DR.<sup>[13]</sup> Increasing the knowledge about DR would make diabetic patients more aware and may help in changing their attitude toward early eye screening and regular visits to the diabetes care provider. This will be helpful in better management of diabetes and its ocular co-morbidities, which, in turn, may prevent DR-related vision loss.<sup>[14]</sup>

Awareness about DR and other diabetes related visual complications as reported by different community based studies in India varied in the range from 16.1% to 71.3%.<sup>[10-12,15-17]</sup> This suggests that there exists a lot of difference in the level of awareness regarding DR among people residing in different areas of the country.

To date, there stays a lack of studies assessing individual awareness and knowledge about diabetes-related ocular complications in this part of North India. Accordingly, this study was intended to survey the awareness about diabetes mellitus and DR among patients with diabetes. Patients' awareness about diabetes and its complications is a necessity toward proper compliance in seeking timely and appropriate intervention. Also, it will help in assessing the current awareness program for diabetes and its complications.

## Materials and Methods

### Aims

The aim of the study was to assess awareness about DR among diabetes mellitus patients visiting the ophthalmology department.

### Study design

Facility-based cross-sectional study

### Study participants

Patients with diabetes mellitus, aged >18 years, regardless of the type and duration of diabetes.

### Study site and duration

Patients visiting the ophthalmology outpatient department of our hospital from July 2020 to January 2021.

### Sample size

By considering the overall prevalence of 21.7%<sup>[18]</sup> and absolute allowable error of 5%, the sample size was calculated using the following formula:  $N = (Z_{\alpha/2})^2 PQ/D^2$ ,

where  $Z_{\alpha/2} = 1.96$ ,  $P =$  prevalence = 21.7%,  $D =$  absolute allowable error (5%),

and  $Q = (100-P) = 78.3\%$

The minimum required sample size calculated was =  $(1.96)^2 \times 21.7 \times 78.3/5^2 = 6558/25 = 262$

So, the final sample size for the study purpose was calculated as **270**.

### Sampling techniques

Consecutive sampling was done and only 10 to 15 participants were recruited per day so that adequate time could be given to each individual and quality be ensured at every step of recruitment of the respondent for the study—informed consent form, data filling form.

### Inclusion criteria

- Patient with diabetes, aged >18 years
- Willingness to participate in the study

### Exclusion criteria

- Participants having congenital eye disease, suffering previous eye trauma
- Participants with visually disabling cataract or corneal opacity
- Participants having a previously known cognitive impairment that would affect their ability to complete the survey or follow directions.
- Participants not giving consent

### Tools

A pre-tested, pre-validated, and semi-structured questionnaire was filled separately by each participant. The questionnaire included socio-demographic details, questions related to knowledge about the effect of diabetes on the eyes, and other aspects.

### Methodology

A facility-based, cross-sectional study was undertaken at the Ophthalmology Outpatient Department. A pre-designed and pre-tested questionnaire was used for data collection. Consent was taken from each participant.

[Table 1 shows the questions related to DR].

Awareness of DR and its complications was evaluated using an interviewer-administered questionnaire designed using the available literature. The questionnaire included information on demographic details (age, sex, and urban/rural), the awareness of

effects of diabetes on the eyes, frequency of retinal evaluation, duration of diabetes mellitus, presence of hypertension, and other significant systemic problems. Subsequently, best-corrected Snellen's visual acuity and any anterior segment abnormalities were tested. Detailed fundus evaluation was done after pupillary dilation. DR findings, including diabetic macular edema (DME), were graded according to the Early Treatment Diabetic Retinopathy Study (ETDRS) classification.<sup>[19]</sup>

### Ethical considerations

The institutional ethics clearance was taken from the ethics committee before the start of the study, and informed consent was taken from every participant. The certificate number is AIIMS/IEC/2020-21/3050.

### Data analysis

Data collected from the participants were entered in an MS Excel sheet and further taken up for analysis using appropriate statistical methods. The study results were statistically analyzed using Pearson's Chi-square test. Discontinuous or categorical data were expressed as a percentage. *P* values were reported and interpreted at a 0.5% level of significance.

### Definitions

**Diabetes mellitus** is defined as self-reporting of a previous diagnosis of the disease, use of diabetic medications, or hemoglobin A1c (HbA1c) of 6.5% or greater.<sup>[20]</sup>

**Diabetic retinopathy:** Presence of any DR that includes non-proliferative diabetic retinopathy (NPDR), proliferative diabetic retinopathy (PDR), diabetic macular edema (DME), or any combinations of these.

## Results

A total of 340 subjects were enrolled in the study, of which 305 (89.7%) agreed to participate. The posterior segment could not be examined in 33 subjects because of ocular pathologies causing media opacity (cataract, corneal opacity). A total of 272 patients were recruited for the study, of which 151 (55.5%) were males and 121 (44.4%) were females.

The mean age of the study group was  $53.4 \pm 10$  years and it ranged from 20 to 76 years, of which 163 (60%) patients were in the age range of 40 to 59 years and 89 (32.7%) were above 60 years of age. All patients had previously diagnosed type 2 diabetes. Of the study sample, 120 (44.1%) were diagnosed with the disease from less than 5 years, 89 (32.7%) between 6 and 10 years, and 63 (23.1%) for more than 11 years. The majority (179 [65.8%] participants) belonged to rural areas, whereas 93 (34.2%) resided in an urban area. Table 2 shows the demographic characteristics of the study sample.

Out of 272 patients assessed, 90 (33.1%) were observed to have DR, of which 11 (4%) were diagnosed with PDR,

**Table 1: Questions related to awareness of diabetic retinopathy**

Does diabetes cause blindness? Yes/No
Does good blood sugar control prevent diabetic retinopathy? Yes/No
Is diabetic retinopathy treatable? Yes/No
Time of undertaking first retinal examination. This time/previously
Are you referred by health professional/worker for eye examination? Yes/No
How frequently should you undergo eye examination to r/o diabetic retinopathy? 6 month/annually/only when vision decreases/not aware about frequency
Reason for not undertaking eye/retina examination? Lack of knowledge about DR/from remote area/lack of money/lack of time/no visual problem/no caretaker/other reasons
What is the source of your knowledge regarding diabetes or diabetes retinopathy? Doctor/friends/relatives/mass media/not aware

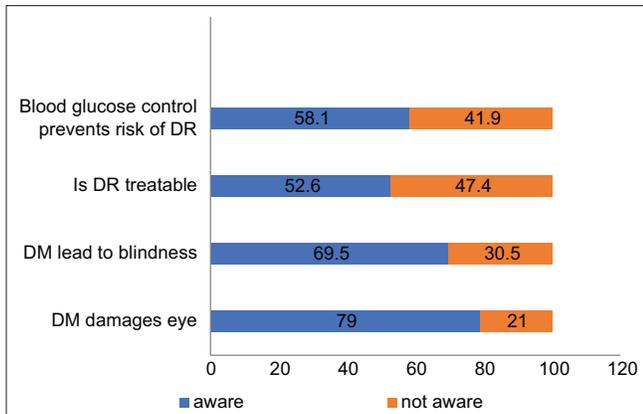
**Table 2: Demographic features of the study population**

Sociodemographic indicators	n=272
Mean age (years)	53±10
Gender	
Male, n (%)	151 (55.5%)
Female, n (%)	121 (44.5%)
Age (years)	
20-39	20 (7.3%)
40-59	163 (59.9%)
60-69	74 (27.2%)
>70	15 (5.5%)
Locality	
Rural	179 (65.8%)
Urban	93 (34.2%)
Duration of DM	
<5 years	120 (44.1%)
6-10 years	89 (32.7%)
11-20 years	56 (20.6%)
>20 years	7 (2.6%)

and 26 (9.6%) had severe NPDR. Diabetic macular edema was found in 41 (15.1%) cases of DR. The visual acuity was 6/6–6/18 in 176 (64.7%) patients and less than 6/60 in 31 (11.4%) subjects.

Data obtained showed that out of 272 participants, 215 (79%) were aware that DM damages the eyes and 189 (69.5%) reported that diabetes can lead to blindness [Figure 1 shows awareness related to DR (based on the questionnaire)].

In response to awareness related to prevention and treatment of DR, 158 (58.1%) subjects were aware that strict control of blood glucose levels can prevent the risk of DR, and 143 (52.6%) were aware that DR can be treated although details of treatment were not known. When asked about the frequency for eye screening in diabetic patients, 102 (37.5%) answered every 6 months, 37 (13.6%) were aware of annual eye examination, and 104 (38.2%) participants responded that eye examination was needed only when there was any vision loss, whereas 29 (10.7%) did not know how frequently the eyes should be examined.



**Figure 1:** Awareness related to diabetic retinopathy (based on the questionnaire)

Among all subjects, 77 (28%) had no knowledge of DR and 129 (47.4%) responded that they were informed by the physicians regarding diabetes and its complications, 38 (14%) gained information through their family members, 28 (10.3%) had their information through mass media such as internet/newspaper, etc.

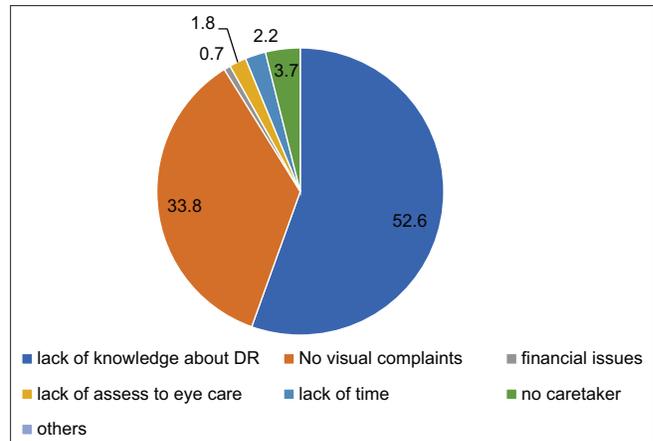
Analysis showed that awareness of DR was significantly associated with patient gender ( $P = 0.000$ ), duration of diabetes ( $P = 0.035$ ), and their place of residence (rural/urban;  $P = 0.003$ ). Awareness of DR was not significantly associated with the patient's age. Gender, location, and duration of diabetes were significant factors influencing awareness and knowledge of diabetes. Participants from a rural background ( $P = 0.003$ ) and those having DM for a longer duration (>5 years;  $P = 0.035$ ) were found to be more aware of DR.

Among the study participants, 225 (82.7%) were compliant with their treatment for diabetes and 206 (75.7%) were undergoing regular investigations for blood glucose measurement. Regarding the screening for DR, only 72 (26.5%) diabetic participants had undertaken previous eye examination and 200 (73.5%) had never undergone a previous examination for DR screening.

Assessing the motivation levels of participants for retinal examination for DR screening, only 79 (29%) subjects were referred by healthcare workers for fundus evaluation and the rest of the participants 193 (70.9%) had themselves examined due to self-awareness of DM or for some visual complaints or routine eye examination. The reason for not undertaking eye examination was a lack of knowledge about screening for DR in 143 (52.6%) patients and no visual problem in 92 (33.8%) patients [Figure 2 shows the reasons for not undergoing eye examination for DR screening].

## Discussion

The lack of awareness about DR is a major health concern as it interferes with the treatment and prevention of visual impairment due to diabetes.



**Figure 2:** Reasons for not undergoing eye examination for DR screening

The prevalence of DR among diabetic patients was 33.1% in the present study, which is similar to that reported in some Indian studies that have documented a prevalence of 21.7%, 32.5%, 34.6%, 28.2%.<sup>[9,18,20,21]</sup> the prevalence of DR from other Asian countries such as Singapore, Malaysia, Hong Kong, and Nepal have been reported to be 28.2%, 14.9%, 39%, 15.3%, respectively.<sup>[7,22-24]</sup>

In this study, 79% of subjects were aware that diabetes can affect the eyes and 69% were aware that diabetes can lead to blindness. Our study was hospital-based and participants were previously diagnosed diabetes patients, which may be attributed to an increased awareness of DR among the study group. Lingam *et al.* in their study from Hyderabad observed 74% of diabetics knew DM could affect the retina.<sup>[25]</sup> This finding is of interest in our study as most of the participants were from a rural background (65.8%) and increased awareness of diabetes and its complication among the rural population can be because of greater sensitization through mass media (television, internet, newspaper, social media, etc.).

Furthermore, females were observed to be less aware of diabetes and its ocular complications as they have less interaction with the outside world as compared to males in families. This warrants creating awareness among females through the involvement of women's self-help groups as women would further influence other family members about diabetes and its complications and may motivate them for a regular visit for DR screening.

General practitioners and physicians are usually the primary people to access patients with diabetes. About 47.4% of our subjects had their information from their treating doctors/physicians, which is similar to the numbers (56%) reported by Venugopal *et al.*<sup>[26]</sup> This emphasizes the role of physicians and other health care professionals in creating awareness about diabetes and its complications and therefore need for programs for updating and training them. Few studies such as Namperumalsamy *et al.*<sup>[27]</sup> (16%) and Murugesan *et al.*<sup>[28]</sup> (22%) have reported lower awareness among paramedical staff.

In the present study, 43.7% of subjects were aware that eye screening should be performed at least once a year (annually or every 6 months) but there was still 38.2% of patients who thought of screening only when vision decreases and 10.7% had no knowledge about eye screening for DR. This implicates that diabetes patients are not aware of how frequently they should undergo eye screening.

Despite having awareness of DR, about three-fourths (73.5%) of our study subjects had never undertaken dilated eye examination for DR screening previously. Such differences between patient knowledge and their compliance behavior are common as suggested by different studies.<sup>[30-33]</sup> These findings implicate further inspection into methods to increase the compliance of diabetic patients toward DR screening. This knowledge deficit has also been observed in other populations around the world, for example, in Hongkong, Turkey, and Jordan.<sup>[29-32]</sup>

Most of our interviewed participants had come for routine eye checkups or some visual problems on the day surveyed and only 17.6% of participants were referred to ophthalmologists by their health care provider/physician for DR screening. This summons an approach of mandatory referral to an ophthalmologist by a general physician/diabetes care provider for DR screening on a regular basis.

It is the responsibility of primary care physicians to counsel patients regarding screening and also lookup for their compliance in follow-up. All newly detected diabetic patients should be sent by physicians for fundus examination at the earliest and thereafter at least an annual fundus examination should be emphasized again and again. Patient education received from the physician or other healthcare providers plays a pivotal role in a successful attempt to prevent this cause of preventable blindness. Practitioners should not wait for any complaint of visual deterioration for the referral. Depending on resource availability, visual acuity with pinhole, mydriatic DR screening, as well as fundus imaging can be easily performed in diabetic patients at primary care levels.<sup>[33]</sup> The recommendations for time-bound fundus examination need to be followed in type 1 diabetics as well as gestational diabetics.<sup>[33-35]</sup> The general practitioners should also educate the masses regarding the role of near-normal glucose levels and blood pressure as well as the role of serum lipid level control and lifestyle modification in the prevention of DR.<sup>[36]</sup> The possible reasons given by participants for not getting a regular retinal examination for DR screening in our study were the absence of visual symptoms (33.8%) and lack of knowledge (52.6%) about DR screening. Other reported reasons were lack of access to the eye care facility, lack of time, and financial issues. This implicates further exploration into novel methods of encouraging diabetic patients to undergo routine vision and retinal examination as recommended and also to increase the availability of eye care facilities for rural populations.

To the best of our knowledge, there are very limited studies assessing the awareness among the rural population of North

India. This study was therefore conducted to assess the awareness regarding DR as a possible complication of diabetes among known diabetics in this region of North India.

Such studies play a significant role in community health considering the fact that diabetes affects all communities and although DR cannot be prevented, its vision-threatening complications can be minimized with timely interventions.

## Conclusion and Recommendations

The study was conducted to assess the awareness of DR among known diabetes mellitus patients. The majority of patients were aware of DR as a possible complication of diabetes but were not compliant with regard to management and screening to reduce the risk of sight-threatening complications of DR.

There is an urgent need to create awareness about DR and the importance of retinal screening among the community to reduce visual disability caused by diabetes. Community healthcare workers should be sensitized so that they may advise and refer diabetes patients for regular eye screening to an ophthalmologist for DR screening. Awareness campaigns specifically targeting rural populations need to be undertaken. Services for screening might also be strengthened at the community health center level. Screening programs for DR should be organized on a frequent basis.

Community screening recommendations by All India Ophthalmological Society (AIOS) should be followed.<sup>[34]</sup>

- DR screening in diabetes clinics/general physician clinics/pharmacy and/or medical laboratories-telescreens should be emphasized<sup>[37]</sup>
- Screening in Primary Health Centers (PHCs) and Vision Centers (Primary Eye Care Centers) with help of trained optometrists should be encouraged.
- The mobile van approach in DR screening is useful to reach the unreachable as well as to increase compliance.

## Key points

- The prevalence of DR among diabetic patients was 33.1% in the present study
- Participants from a rural background ( $P = 0.003$ ) and those having diabetes mellitus for a longer duration ( $>5$  years;  $P = 0.035$ ) were found to be more aware of DR.
- Increased awareness of diabetes and its complication among the rural population can be because of greater sensitization through mass media (television, internet, newspaper, social media, etc.).
- Females were less aware of diabetes and its ocular complications as compared to males.
- Three-fourth (73.5%) of our study subjects had never undertaken dilated eye examination for DR screening previously despite the fact that 79% were aware that DM damages the eyes and 69.5% reported that diabetes can lead to blindness, which strongly suggests the differences between patient knowledge and their compliance behavior.

- In addition, 47.4% of our subjects had their information from their treating doctors/physicians but only 17.6% of participants were referred to ophthalmologists by their healthcare provider/physician for DR screening.

### Key messages

Awareness about diabetic retinopathy may help to reduce visual disability caused by diabetes.

### Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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### Conflicts of interest

There are no conflicts of interest.

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