Original Article

Perception of care and barriers to treatment in individuals with diabetic retinopathy in India: 11-city 9-state study

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ABSTRACT

Background: Diabetic retinopathy is a leading cause of visual impairment. Low awareness about the disease and inequitable distribution of care are major challenges in India. **Objectives:** Assess perception of care and challenges faced in availing care among diabetics. **Materials and Methods:** The cross-sectional, hospital based survey was conducted in eleven cities. In each city, public and private providers of eye-care were identified. Both multispecialty and standalone facilities were included. Specially designed semi-open ended questionnaires were administered to the clients. **Results:** 376 diabetics were interviewed in the eye clinics, of whom 62.8% (236) were selected from facilities in cities with a population of 7 million or more. The mean duration of known diabetes was 11.1 (±7.7) years. Half the respondents understood the meaning of adequate glycemic control and 45% reported that they had visual loss when they first presented to an eye facility. Facilities in smaller cities and those with higher educational status were found to be statistically significant predictors of self-reported good/adequate control of diabetes. The correct awareness of glycemic control was significantly high among attending privately-funded facilities and higher educational status. Self-monitoring of glycemic status at home was significantly associated with respondents from larger cities, privately-funded facilities, those who were better educated and reported longer duration of diabetes. Duration of diabetes (41%), poor glycemic control (39.4%) and age (20.7%) were identified as the leading causes of DR. The commonest challenges faced were lifestyle/behavior related. **Conclusions:** The findings have significant implications for the organization of diabetes services in India.

Key words: Clients, diabetic retinopathy, health care utilization, India, perceptions, risk factors

Introduction

Diabetic retinopathy (DR) is a leading cause of visual impairment and blindness throughout the world.[1] It is estimated that the global magnitude of DR will increase from 126.6 million in 2010 to 191 million by 2030.[2] In India, 12–22.4% of known diabetics have DR,[3] which is lower than in high-income countries (30–50%).[3] However, since diabetes occurs at a younger age in Indians than Caucasians,[4,5] the improving life expectancy in India,[6] means that individuals will now will live longer with diabetes

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than ever before. Since duration of diabetes is a major risk factor for DR,[1] rates of DR are likely to increase over the next decade.

Low awareness about the disease and inequitable distribution of care are major challenges to providing adequate care to diabetic individuals in India.[7] To ensure that adequate and equitable care is provided to all with DR, it is important to evaluate levels of awareness among people living with diabetes, their perceptions of care, and the barriers they face in accessing services for diabetes and DR. A better understanding of these factors will allow us to address the challenges faced by persons with diabetes in managing their diabetes and DR.

The present study was conducted in 11 cities across India to provide evidence on available human resources, infrastructure, client perceptions and service utilization. We report here the findings regarding perception of care and the challenges faced in availing eye care services among individuals with DR across nine states in India. This information will be used to develop need-based community directed programs for reducing the risk of sight-threatening DR (ST-DR).

Materials and Methods

The study was a cross-sectional, hospital based survey conducted in 11 cities in nine states across India. Sampling entailed a two stage process wherein cities were first stratified based on their population (more than or less than seven million). Cities to be included in the study were identified by ranking all cities in India in descending order of population size (2011 census) and the 10 most populated cities were first selected. As only one city (Kolkata) from eastern India was represented, an additional city from the eastern part of India was included, i.e., the twin cities of Bhubaneshwar and Cuttack. Thus, 11 cities were finally covered. The 11 cities were Ahmedabad, Bengaluru, Bhubaneshwar (including Cuttack), Chennai, Delhi, Hyderabad (including Secunderabad), Jaipur, Kolkata, Mumbai, Pune, and Surat.

In each city, public and private providers of eye care services were identified. The size of the facility (number of beds) was taken into consideration in classifying the facilities as "large" (dedicated eye hospitals/general hospitals with an eye facility [20 or more bedded hospital with functioning ophthalmic super-specialty services, hospitals with satellite facilities, eye care departments in general hospitals]) or "small" (individual eye care practitioners or eye hospitals with <20 eye beds) for inclusion in the study. The sampling frame was developed using the list of hospitals identified in each city from the internet and from the list of physicians who underwent training in evidence-based diabetes management programs which covered more than 5000 physicians across the country over the past 3 years.

After obtaining permission from hospital administrators at each clinic/facility, outpatients were randomly sampled at eye care hospital/clinics. At each facility, four to six clients with DR were identified among those waiting for doctor's consultation. Care was taken to select comparable numbers of males and females. Patients were stratified by age and then interviewed (<50 years, and ≥50 years). Specially designed semi-open ended questionnaires were administered to the clients waiting in the clinics. Data were entered into an Access-based software package specially developed for the study. All data were cleaned before analysis.

Stata 12 SE for Windows (Stata Corp, Texas, US) was used for statistical analysis. Frequencies of the variables were tabulated. The *T*-test was used for continuous variables and the Chi-square test was used for categorical variables. Results were adjusted for age, sex, education, type of city, and type of healthcare sector (public or private).

Detailed methodology used in the study has been published as a companion article.

Results

Demographic characteristics

A total of 376 persons with diabetes were interviewed in the eye clinics, nearly a third of whom were recruited in public-funded institutions [Table 1]. Among the 376 respondents, 62.8% (236) were in facilities in cities with a population of 7 million or more (more populated cities). More than half (55.6%) stated that their diabetes had been diagnosed within the last 10 years. The mean duration of known diabetes was 11.1 (standard deviation [SD] ±7.7) years.

Table 1: Annual performance statistics reported by responding eye care facilities

Parameter	Facilities with data	Mean per year per facility (range)
Total outpatient registrations/year	79	45,909 (50-323,730)
Mean new outpatient registrations/year	72	22,330 (30-286,154)
Average ST-DR registered/year	30	630.6 (10-5,000)
Inpatient beds/institution	77	50.8 (2-557)
Cataract surgeries/year	77	3879.7 (30-41,763)
Diabetic patients treated with one or more sessions of laser/year	52	511.0 (5-3,500)
Average vitreoretinal surgeries/year	48	261.0 (5-2,637)
Diabetic patients given intravitreal injections/year	56	301.2 (3-3,500)

ST-DR: Sght threatening diabetic retinopathy

The mean age of respondents was 55.6 (±10.5) years. Only a quarter (26.3%) were aged below 50 years and 55.3% were male. A significant proportion (67.8%) had completed either secondary schooling or more (including graduation/postgraduation etc.).

Perception of good glycemic control

Respondents were asked what adequate control of diabetes meant to them. Fifty percent (188) mentioned that adequate control meant that their blood sugar/hemoglobin A1c levels were within normal limits. Three quarters (76.3%; $n = 287$) stated that they perceived their glycemic control to be adequate/good.

Determinants of self-reported good/adequate control of diabetes, including facility related parameters, demographic characteristics, and some diabetic care patterns, were assessed [Table 2]. On univariate analysis respondents interviewed in smaller cities (85%) reported better perceived glycemic control compared to those from larger cities (71.2%) ($\chi^2 = 9.28$; $P = 0.002$). Statistically significant differences were also observed between younger respondents (83.8%) compared to respondents aged 50 + years (73.6%) ($\chi^2 = 4.19$; $P = 0.04$), those with higher educational attainment (80.8%) compared to those who were less educated (66.9%) ($\chi^2 = 8.70$; $P = 0.003$), and among those respondents who regularly monitored their diabetic status at home (82.7%) compared to those who did not (73.1%) ($\chi^2 = 4.28$; $P = 0.04$).

However, on multivariate analysis, after adjusting for variables which were significantly different on univariate analysis [Table 2], only facilities in smaller cities and clients with higher educational status remained statistically significant.

The correct awareness of glycemic control was significantly higher among respondents attending privately-funded hospitals compared to public-funded hospitals (57.6% vs. 33.6%; $\chi^2 = 18.7$; $P < 0.001$), among those interviewed at exclusive/stand-alone eye hospitals compared to multispecialty hospitals (54.6% vs. 39.5%; $\chi^2 = 7.25$; $P = 0.007$), among the better educated (56.1% vs. 37.8%; $\chi^2 = 11.72$; $P = 0.001$), persons with known diabetes of more than10 years (57.6% vs. 44.0%; $\chi^2 = 6.78$; $P = 0.009$), those who regularly self-monitored their glycemic status (62.1% vs. 44.0%; $\chi^2 = 10.83$; $P = 0.001$) and among those who perceived their glycemic control as adequate (100.0% vs. 18.3%; $\chi^2 = 238$; $P < 0.001$). However, on multivariate analysis only those attending privately-funded facilities and higher educational status remained statistically significant [Table 3].

Determinants of self-reported self-monitoring of glycemic status at home were also assessed [Table 4] with the following variables being statistically significant in univariate analysis: Larger cities vs. smaller cities (38.6% vs. 25.7%; $\chi^2 = 6.48$; $P = 0.01$); private versus public-funded facilities (38.1% vs. 24.4%; $\chi^2 = 6.88$; $P = 0.009$); stand-alone eye facilities compared to eye units in multispecialty eye facilities (36.6% vs. 27.2%; $\chi^2 = 3.17$; $P = 0.07$), higher versus lower educational attainment (41.2% vs. 18.2%; $\chi^2 = 19.4$; $P < 0.001$), longer versus shorter duration of diabetes (52.1% vs. 19.6%; $\chi^2 = 43.44$; $P < 0.001$), and those perceiving their diabetes to be adequately controlled versus those reporting poor control (36.6% vs. 24.7%; $\chi^2 = 4.28$; $P = 0.04$). In multivariate analysis, the associations that remained statistically significant were respondents from larger cities, privately-funded facilities, those who were better educated and those with a longer duration of diabetes [Table 4].

Vision loss at presentation

Almost half the respondents (172, 45.7%) reported that they had some degree of visual loss before they attended an

Table 2: Need for training of ophthalmologists, focusing on training in medical retina

Parameter	*N*	%	Chi; *P* value	Adjusted OR	95% CI
Expressed need for training in medical retina					
Type of city					
Smaller cities (≤7 million population) (34)	17	50.0		-	-
Larger cities (> 7 million population) (52)	25	48.1	χ^2=0.03; *P*=0.86	-	-
Type of sector					
Private funded clinics/hospitals (63)	26	41.3		1.0	
Public funded clinics/hospitals (23)	16	69.6	χ^2=5.39; *P*=0.02	1.7	0.1-1.3
Type of facility					
Stand-alone eye clinic/hospital (59)	22	37.3		1.0	
Multispecialty clinic/hospital (27)	20	74.1	χ^2=10.0; *P*=0.002	2.66	0.74-9.52
Teaching status					
Teaching institution (42)	22	52.4			
Non-teaching institutions (44)	20	45.4	χ^2=0.41; *P*=0.52		
Availability of a dedicated retina unit					
Dedicated retina unit (59)	24	40.7		1.0	
Absence of dedicated retina unit (27)	18	66.7	χ^2=5.01; *P*=0.02	2.32	0.78-7.0

CI: Confidence interval, OR: Odds ratio

Table 3: Human resource availability at eye clinics

Parameter	*N*	%	Chi; *P* value
Nurses trained in ophthalmology	70	81.4	
General trained nurses	16	18.6	
Trained qualified low vision skilled personnel	38	44.2	
Eye unit in multispecialty hospital (27)	3	11.1	χ^2=17.46; *P*<0.001
Stand-alone eye units (59)	35	59.3	
Teaching facilities (42)	24	57.1	
Non-teaching facilities (44)	14	31.8	χ^2=5.58; *P*=0.02
Private-funded (63)	33	52.4	χ^2=6.41; *P*=0.01
Public-funded (23)	5	21.7	
Personnel trained in retinal photography	31	36.0	
Multispecialty hospital (27)	2	7.4	χ^2=14.0; *P*<0.001
Stand-alone eye units (59)	29	49.1	
Fully qualified counselors available	37	43.0	
Private-funded (63)	20	31.7	χ^2=11.5; *P*=0.001
Public-funded (23)	3	13.0	
Multispecialty hospital (27)	3	11.1	χ^2=16.35; *P*<0.001
Stand-alone eye units (59)	34	57.6	
Fully qualified optometrist	70	81.4	
Smaller cities (≤ 7 million) (34)	23	67.6	χ^2=7.01; *P*=0.008
Larger cities (> 7 million) (52)	47	90.4	
Trained equipment technician	34	39.5	
Public funded facilities (23)	4	17.4	χ^2=6.44; *P*=0.01
Private-funded facilities (63)	30	47.6	

eye care facility. Visual loss was not associated with place or type of facility or demographic characteristics such as age, sex or education but was associated with the knowledge of what constituted adequate control of diabetes (34.9% among those who knew what adequate control meant compared with 58.8% among those who did not know; $\chi^2 = 21.01$; $P < 0.001$) and their perceived level of control of their diabetes (adequate 35.9% compared poor 53.8%, $\chi^2 = 11.37$; $P = 0.001$). Factors such as duration of diabetes or self-monitoring of the glycemic status were associated with presentation with vision loss at an eye clinic before DR was diagnosed.

Place of diagnosis of diabetic retinopathy

Respondents were asked to identify the facility where their DR was first detected, and 72.3% (272) stated it was identified at a secondary or tertiary eye care facility. Vision centers (n = 56; 14.9%) and outreach eye camps (n = 42; 11.2%) were other locations cited. Only 1.6% (6) stated that their DR was first identified at a physician's clinic.

Perceived causes of diabetic retinopathy

Duration of diabetes (41%), poor glycemic control (39.4%) and age (20.7%) were identified as the leading causes of DR [Table 5]. High blood pressure, smoking, and high lipid levels were also mentioned as important causes but 14.6% stated that they were not aware of the causes of DR. Individuals living in smaller cities were more likely to attribute DR to both long duration of diabetes and poor glycemic control than those living in larger cities (20.7% vs. 8.5%; $P = 0.001$).

Table 4: Availability of fully functional equipment at eye facilities

Type of fully functional equipment	*N* (*n*=86)	%	Chi; *P* value
Indirect ophthalmoscope	85	98.8	
FFA facility available	67	77.9	
Stand-alone eye facility (59)	50	84.7	χ^2=5.10; *P*=0.02
Multispecialty hospitals (27)	17	63.0	
Teaching hospital (42)	39	92.9	χ^2=10.66; *P*=0.001
Non teaching (44)	28	63.6	
Dedicated retina clinic (59)	53	89.8	χ^2=15.52; *P*<0.001
No dedicated retina clinic (27)	14	51.8	
Laser facilities available	65	75.6	
Stand-alone eye facilities (59)	51	86.4	χ^2=12.0; *P*=0.001
Multispecialty hospitals (27)	14	51.8	
Dedicated retina clinic (59)	53	89.8	χ^2=20.67; *P*<0.001
No dedicated retina unit (27)	12	44.4	
Functional AB scan available	76	88.4	
Larger cities (52)	49	94.2	χ^2=4.39; *P*=0.04
Smaller cities (34)	27	79.4	
Dedicated retina clinic (59)	58	98.3	χ^2=18.04; *P*<0.001
No dedicated retina unit (27)	18	66.7	
Functional fundus camera available	67	77.9	
Stand-alone eye facilities (59)	50	84.7	χ^2=5.51; *P*=0.02
Multispecialty hospitals (27)	17	63.0	
Teaching hospital (42)	39	92.9	χ^2=10.66; *P*=0.001
Non teaching (44)	28	63.6	
Dedicated retina clinic (59)	53	89.8	χ^2=15.52; *P*<0.001
No dedicated retina unit (27)	14	51.8	
Functional OCT available	56	65.1	
Public funded facilities (23)	8	34.8	χ^2=12.72; *P*<0.001
Private-funded facilities (63)	48	76.2	
Stand-alone eye facilities (59)	49	83.1	χ^2=26.61; *P*<0.001
Multispecialty hospitals (27)	7	25.9	
Dedicated retina clinic (59)	47	79.7	χ^2=26.61; *P*<0.001
No dedicated retina unit (27)	9	33.3	
Set of contact lenses for laser available	66	76.7	
Teaching hospital (42)	37	88.1	χ^2=5.92; *P*=0.015
Non teaching hospital (44)	29	65.9	
Public funded facilities (23)	14	60.9	χ^2=4.43; *P*=0.04
Private-funded facilities (63)	52	82.5	
Stand-alone eye facilities (59)	52	88.1	χ^2=13.66; *P*<0.001
Multispecialty hospitals (27)	14	51.9	
Dedicated retina unit (59)	54	91.5	χ^2=23.0; *P*<0.001
No dedicated retina unit (27)	12	44.4	
Functional VR surgery facilities	55	63.9	
Teaching hospital (42)	32	76.2	χ^2=5.33; *P*=0.02
Non teaching (44)	23	52.3	
Stand-alone eye facilities (59)	45	76.3	χ^2=12.37; *P*<0.001
Multispecialty hospitals (27)	10	37.0	
Dedicated retina unit (59)	46	78.0	χ^2=16.0; *P*<0.001
No dedicated retina unit (27)	9	33.3	

OCT: Optical coherence tomography, VR: Vitreo retina

Challenges in managing diabetes

The most common challenges respondents faced were lifestyle/behavior related, such as modifying their diet and taking exercise, and access related (including costs) [Table 6]. Nearly three of every ten respondents (29%) mentioned that costs of treatment/investigations or loss of wages were major challenges. Only a fifth stated that they did not face any challenge in managing their diabetes. Those

Table 5: Availability of treatment facilities at eye hospitals

Treatment available	Frequency (*n*=86)	%	Chi; *P* value
Laser photocoagulation	68	79.1	
Public-funded (23)	14	60.9	χ^2=6.28; *P*=0.01
Private-funded (63)	54	85.7	
Dedicated retina clinic (59)	55	93.2	χ^2=22.74; *P*<0.001
No dedicated retina clinic (27)	13	48.1	
Teaching hospitals (42)	37	88.1	χ^2=4.04; *P*=0.04
Non-teaching hospitals (44)	31	70.4	
Stand-alone eye hospital (59)	53	89.8	χ^2=13.15; *P*<0.001
Multispecialty hospital (27)	15	55.6	
Anti-VEGF preparations	70	81.4	
Public-funded (23)	15	65.2	χ^2=5.42; *P*=0.02
Private funded (63)	55	87.3	
Dedicated retina clinic (59)	56	94.9	χ^2=22.68; *P*<0.001
No dedicated retina clinic (27)	14	51.8	
Triamcinalone or other IV steroid	72	83.7	
Dedicated retina clinic (59)	55	93.2	χ^2=12.44; *P*<0.001
No dedicated retina clinic (27)	17	63.0	
Uncomplicated vitrectomy	54	62,8	
Teaching hospitals (42)	32	76.2	χ^2=6.31; *P*=0.01
Non-teaching hospitals (44)	22	50.0	
Dedicated retina clinic (59)	45	76.3	χ^2=14.62; *P*<0.001
No dedicated retina clinic (27)	9	33.3	
Stand-alone eye hospital (59)	43	72.9	χ^2=8.19; *P*=0.004
Multispecialty hospital (27)	11	40.7	
Complex VR surgery	55	63.9	
Stand-alone eye hospital (59)	44	74.6	χ^2=9.20; *P*=0.002
Multispecialty hospital (27)	11	40.7	
Dedicated retina clinic (59)	46	78.0	χ^2=16.01; *P*<0.001
No dedicated retina clinic (27)	9	33.3	
All retina treatment facilities provided	53	61.6	
Dedicated retina clinic (59)	44	74.6	χ^2=13.33; *P*<0.001
No dedicated retina clinic (27)	9	33.3	
Stand-alone eye hospital (59)	42	71.2	χ^2=7.27; *P*=0.007
Multispecialty hospital (27)	11	40.7	
Teaching hospitals (42)	32	76.2	χ^2=7.37; *P*=0.007
Non-teaching hospitals (44)	21	47.7	

VEGF: Vascular endothelial growth factor, VR: Vitreo retina

Table 6: Practice patterns at eye facilities

Practices	Frequency (*n*=86)	%	Chi; *P* value
Routine urine testing for glycosuria of all adults	20	23.3	
Stand-alone eye hospital (59)	10	16.9	χ^2=4.19; *P*=0.04
Multispecialty hospital (27)	10	37.0	
Public-funded (23)	10	43.5	χ^2=7.19; *P*=0.007
Private funded (63)	10	15.9	
HbA1c testing			
Routine for all known diabetes	30	45.3	
Only patients with diabetic retinopathy	15	17.4	
Printed protocols available in OPD			
On indications for treatment of diabetic retinopathy	20	23.3	
For laser treatment of diabetic retinopathy	9	10.5	
Patient information sheets available	43	50.0	
Stand-alone eye hospital (59)	40	67.8	χ^2=23.8; *P*<0.001
Multispecialty hospital (27)	3	11.1	
Public-funded (23)	3	13.0	χ^2=17.15; *P*<0.001
Private funded (63)	40	63.5	
Dedicated retina clinic (59)	34	57.6	χ^2=4.37; *P*=0.04
No dedicated retina clinic (27)	9	33.3	
Referral patterns			
Regular referrals from general practitioners/physicians	68	79.1	
Regularly refer to physicians for diabetic management	64	74.4	
Stand-alone eye hospital (59)	48	81.4	χ^2=4.75; *P*=0.03
Eye unit in multispecialty hospital (27)	16	59.3	
Records			
Eye personnel can access physician records	34	39.5	

OPD: Out patient department

interviewed in the privately-funded hospitals were more likely to report no challenges than those in public-funded eye clinics (25.3% vs. 12.6%; $P = 0.005$).

Barriers in accessing care for diabetic retinopathy

More than half of the respondents (53.5%) stated that they did not face any barriers in accessing eye care services [Table 7], with the less educated having more barriers than the educated. (44.6% vs. 57.6%; $P = 0.02$). Among those reporting barriers, the distance was the most important barrier ($n = 114$, 65.1%) followed by the cost of travel ($n = 23$, 13.1%).

Awareness of complications of diabetes

The majority of participants (84.0%) were aware that diabetes could be associated with complications, with awareness being greater among those with higher levels of education (89.0% vs. 73.5%; $\chi^2 = 14.64$; $P < 0.001$). Awareness of complications was also significantly higher among those who regularly self-monitored their glycemic control compared to those who did not (92.7% vs. 79.8%; $\chi^2 = 10.44$; $P = 0.001$) and those with a longer duration of diabetes (90.3% vs. 78.9%; $\chi^2 = 8.82$; $P = 0.003$).

Vision loss/blindness was the most common complication mentioned by respondents (62.8%). Kidney failure (59%), heart attack (37%), and foot ulcers (28%) were the other commonly known complications [Table 8]. Participants with higher levels of education were significantly more aware of the following complications - losing a leg (16.1% vs. 8.3%; $P = 0.04$), kidney failure (69.0% vs. 37.2%; $P < 0.001$), blindness (69.8% vs. 47.9%; $P < 0.001$), and heart attack (42.3% vs. 24.8%; $P = 0.001$).

Blindness was the complication participants were most concerned about (54%) followed by kidney failure (31%) and heart attacks (17%).

Perceptions on management of diabetic retinopathy

Respondents reported that they underwent investigations regularly. When asked when the last investigations were

Table 7: Outreach services provided by eye hospitals for diabetic retinopathy

Parameter	N	%
Provide outreach services for diabetic retinopathy	33	38.4
Start with identification of persons with diabetes		
Conduct house-to-house survey to identify diabetics who are then examined	5	15.2
Screening using a camp approach		
Clinical examination by an ophthalmologist	19	57.6
Retinal imaging with interpretation at the site	9	27.3
Retinal imaging with interpretation via tele-ophthalmolog	5	15.2
Screening in static facilities such as vision centres		
Clinical examination by an ophthalmologist	5	15.2
Retinal imaging by vision centre staff with interpreted by them	3	9.1
Retinal imaging by vision centre staff with interpretation via tele-ophthalmology	5	15.2
Screening in a physician's clinic		
Ophthalmologist visits and conducts clinical examination	10	30.3
Retinal photography/imaging with interpretation on the site	7	21.2
Retinal imaging by physician staff and interpretation via tele-ophthalmology	4	12.1
Mass media educational campaigns	9	27.3

Table 8: Awareness of complications of diabetes

Complications known	Frequency (*n*=376)*	%
Blindness/vision loss	236	62.8
Kidney failure	221	58.8
Heart attack	138	36.7
Foot ulcers	104	27.7
Tingling or numbness of limbs	72	19.1
Amputation/losing lower limbs	51	13.6
Stroke	30	8.0

*Participants could report more than one complication

done, the mean duration since the most recent blood tests were done was1.9 ± 2.0 (mean ± SD) months before the interview. Intervals for other investigations were as follows: Blood pressure measurement 2.0 ± 2.0 (mean ± SD) months; weight measurement 2.6 ± 3.4 (mean ± SD) months, and urine testing 3.5 ± 4.9 (mean ± SD) months. Participants in public-funded facilities had more frequent blood tests than those in privately-funded facilities (1.4 ± 1.0 months since the last test vs. 2.1 ± 2.3 months; $P = 0.002$) and blood pressure measurement (1.6 ± 1.5 vs. 2.1 ± 2.2 months; $P = 0.02$). Individuals living in larger cities (>7 million) also had more frequent blood tests (1.3 ± 0.8 vs. 2.9 ± 2.8 months; $P < 0.001$), weight measurements (2.1 ± 3.1 vs. 3.3 ± 3.6 months; $P = 0.003$), and blood pressure measurements (1.4 ± 1.3 vs. 2.9 ± 2.7 months $P < 0.001$) compared to respondents from smaller cities.

Respondents were also asked about their awareness of the type of treatment that they received for DR. About a third (34%; $n = 129$) were awaiting treatment, 31% ($n = 117$) had received laser treatment, 13% ($n = 50$) received an eye injection (possibly anti vascular endothelial growth factor) and 11% ($n = 41$) had undergone surgery for DR with 8% ($n = 31$) stating that they were told that no treatment was possible.

Sources of information on diabetic retinopathy

A third (33.8%; $n = 127$) of the respondents had not received any information on DR; whatsoever, with the proportion being higher amongst those living in larger cities compared to smaller cities (39.4% vs. 24.3%; $P = 0.003$). Among those who had received information 61.7% ($n = 232$) said that the information was clear and adequate, with those in privately-funded clinics being more satisfied than those in public-funded facilities (67.3% vs. 49.6%; $P = 0.001$). Individuals living in smaller cities were more likely to report that the information they received was clear and adequate than those living in larger cities (69.3% vs. 57.2%; $P = 0.02$).

Half of the persons with DR (50.8%) reported being counseled about DR, and 14.1% received information from the clinic in written formats (i.e., a leaflet or a pamphlet). More than half (51.1%) of the respondents also obtained information from other sources (family and friends, health worker, television/radio/newspaper, internet etc.,), this being higher among the better educated (57.2% vs. 38.0%; $P < 0.001$) and those living in smaller cities (67.1% vs. 41.5%; $P < 0.001$). They were also more likely to obtain this information from family and friends than their counterparts in the more populated cities (59.3% vs. 19.5%; $P < 0.001$).

Discussion

This study is unique at it highlights the perceptions and practices adopted by persons with diabetes attending eye clinics across 11 cities in India. Findings are therefore reflective of what is happening in the country.

Perception of glycemic control

Poor glycemic control is an important risk factor for DR and there is evidence that intensive glycemic control can reduce the incidence and progression of DR.[1,8-11] Glycemic control is an excellent indicator of the awareness and behavior of persons with long-standing diabetes. We observed that a significant proportion of our study population perceived their control of diabetes to be adequate or good. This however does not reflect the actual glycemic level of the persons with diabetes. It is important to explore associations between the actual glycemic level and self-reported glycemic level as some

studies have shown that misrepresentation of the level of glycemic control is much higher among poorly controlled diabetics.[12]

We observed that half the respondents understood the meaning of adequate glycemic control. The correct interpretation of what constituted "adequate control of diabetes" was significantly higher in private-funded facilities, those who were better educated and those who reported regular self-monitoring of their glycemic state. It was also observed that 100% of respondents who reported that their glycemic control was adequate/good had correct knowledge on what adequate control meant. This implies that the information they had received, from whatever source, was helpful in translating knowledge into practice.

Previous studies have documented that those with a higher educational status were more likely to be aware of diabetes and its complications.[13] Recent studies from Nepal and Turkey showed that higher educational status also enhanced the awareness of DR.[14,15] A study from Singapore demonstrated that a significant proportion of persons with diabetes were unaware of eye complications and that poor level of awareness was significantly higher among those who had poor glycemic control and other risk factors for DR.[16] They are also more likely to be able to afford devices such as a glucometer, which would enable them to monitor their blood glucose frequently.

As in the present study, in Malaysia, people who regularly tested their glucose levels at home were more literate.[17] There are other factors like financial barriers which can also be a hurdle for persons with diabetes to self-monitor their glycemic control.[18] Our study also observed that literacy is a strong determinant of awareness as well as practice. Similarly, respondents who were attending privately-owned facilities generally had better awareness and practiced self-monitoring of glycemic control at home significantly more than those attending public-funded facilities. There could be many confounders including literacy and socioeconomic status which may be more important than mere attendance at privately-owned facilities and could reflect better counseling and access to health information.

Vision at presentation to an eye facility

We observed that 45% of the respondents reported that they had visual loss when they first presented to an eye facility and before their DR was detected. This is consistent with findings reported from many parts of the world that between 25 and 50% of persons with diabetes present with visual loss at the first visit to an eye facility.[19-21] In a long-standing condition like diabetes, compliance with medication and follow-up is a major problem. Therefore, educational/counseling interventions for persons with diabetes should emphasize the critical importance of regular medication and glycemic control as well as the need for regular retinal examination even if they do not have symptoms of visual loss.

We observed that even though nearly half the persons with diabetes presented with vision loss at attendance, only 1.6% stated that their DR had been detected at a diabetic physician's clinic. This is critical as it means that there is an urgent need for a paradigm shift wherein screening for DR should be undertaken at a diabetic service rather than wait for a person with diabetes to come to an eye care facility if vision loss is to be prevented effectively. This needs an integrated approach where the eye care and diabetic care services work together toward the goal of improved quality of life of all persons with diabetes.

Perception of cause of diabetic retinopathy

Long duration of diabetes and poor glycemic control were identified as causes of DR in the present study. Previous studies in India have reported poor awareness about causation of DR. A study in South India observed that though 84% of diabetics could identify that diabetes caused eye problems, only 19% stated that it could affect the "nerves in the eye" (presumed to be retinopathy by the authors).[22] A study in South Central India documented that only 27% of an urban population were aware of DR,[23] while among self-reported diabetics in another study in South India, 57.8% knew about eye complications.[24] However, only 5.8% of the self-reported diabetics could attribute long duration of diabetes as a cause for DR.

We observed that respondents from smaller cities were better informed about the causes of DR compared to respondents in the bigger cities. This is interesting as it is generally perceived that bigger cities provide better opportunities to access information.

Challenges and barriers in controlling diabetes

Lifestyle modifications and cost of managing diabetes were major challenges in the present study. In contrast, only 13% felt that taking medications was a challenge. This reflects that lifestyle modification is a bigger challenge for controlling diabetes in India rather than compliance with anti-diabetic treatment. Similar challenges in relation to diet modification,[25] or exercise,[26] have also been identified in other parts of the world among diabetes of South Asian origin. The beneficial effects of lifestyle modifications have been well documented and are also more cost-effective, but lifestyle modification

requires consistent motivation, discipline, and support from family members.[27,28] It is, therefore, important that physicians and affiliated health care personnel counsel and motivate patients and their families to ensure adherence to lifestyle modification at each visit to the clinic.

It was encouraging to see that more than half the study population did not perceive any barrier to accessing healthcare. Individuals with a higher education were less likely to report barriers to access. About a third of the patients felt that distance was a barrier. This was irrespective of the sector or type of city.

Perception of complications

Eighty-four percent of individuals were aware of the complications of diabetes which is comparable to the Indian Council Medical Research Study where 72.7% of known diabetics were aware of complications.[29] In our study visual loss and renal failure were the most common complications listed by the respondents, which is similar to studies in Turkey and Malaysia, where nearly 9 of 10 persons with diabetes stated that diabetes can affect the eyes.[15,21,30] In India, awareness of eye complications of diabetes among self-reported diabetics ranges from 40 to 80%.[22,24] The greater awareness of eye and kidney complications in diabetes is corroborated by a study which showed that among persons with diabetes, awareness about microvascular complications such as vision loss and nephropathy seemed to be higher than the awareness of macrovascular complications such as heart attack and stroke.[24]

Our study had a few limitations. Being a hospital-based study, it may not be representative of the general urban population and data were collected using a standard questionnaire and recall bias cannot be ruled out.

In conclusion, our study highlights the perceptions of treatment and care among individuals with DR. This information will help in developing evidence-based strategies for reducing the risk of ST-DR in India.

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Conflicts of interest

There are no conflicts of interest.

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