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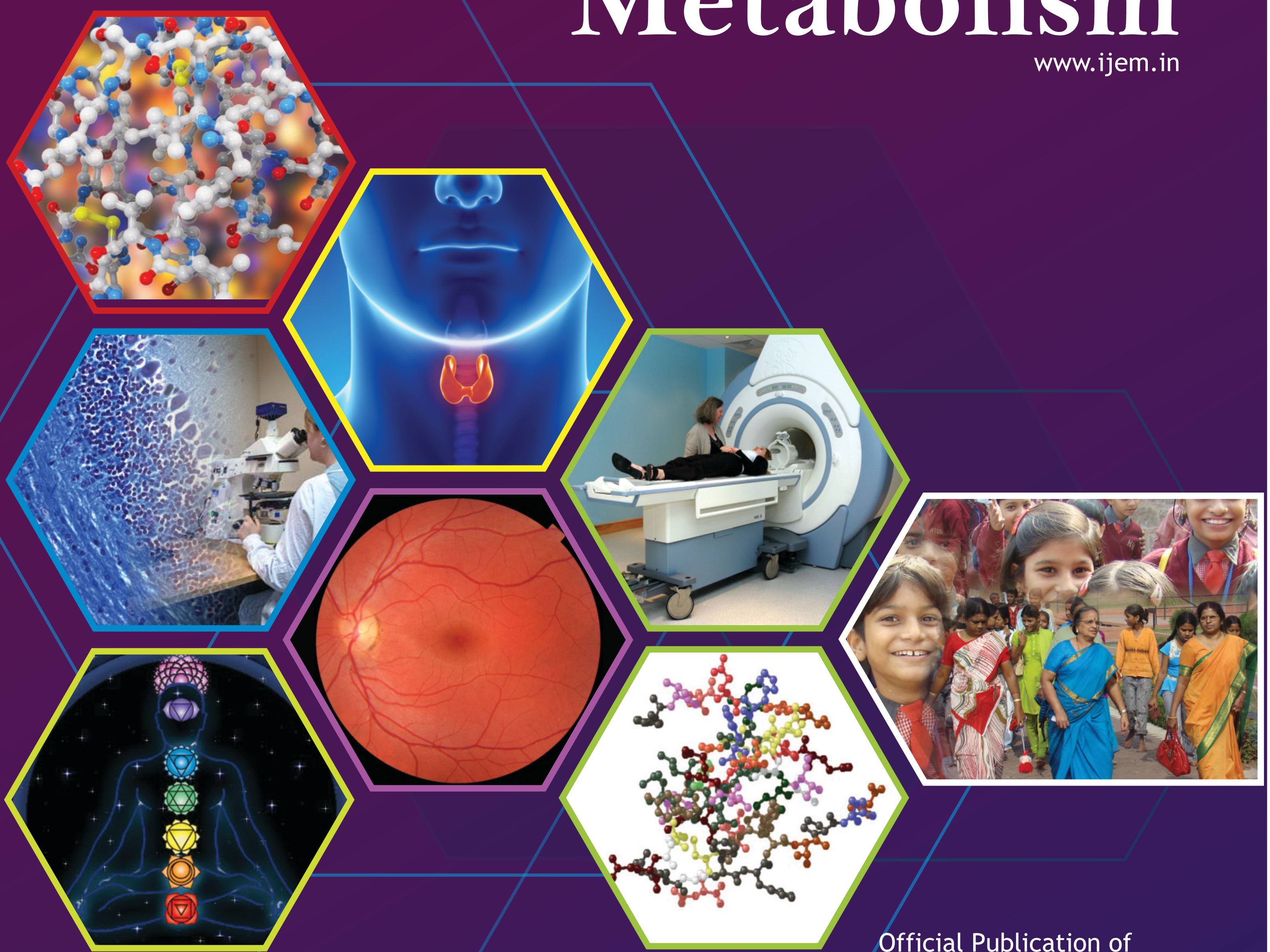

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Diabetic Retinopathy India Initiative

A five year programme aimed at developing and integrating services for detection and treatment of Diabetic retinopathy within the indian public health system
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69 million people in India live with Diabetes.
1 in 5 people with diabetes in India suffer from diabetic retinopathy

Goal of the programme

To achieve a reduction in avoidable blindness due to diabetic retinopathy by improved control of diabetes, early detection and treatment of sight threatening retinopathy with high quality, affordable treatment, and increased awareness in the population

Approach

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Programme Areas

1. **Advocacy and communication**
2. **Improving capacity of physicians, dieticians and counsellors to improve control of diabetes**
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4. **Implement and evaluate integrated district models for the control of diabetic retinopathy that strengthen health systems**
5. **Increase awareness of professionals, by publishing and disseminating the findings of the situation analysis**
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To fulfil the mandate of the Constitution and Bye-Laws of the Endocrine Society of India.

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Editorial

Diabetic retinopathy care in India: An endocrinology perspective

Ambika Gopalakrishnan Unnikrishnan[1], Sanjay Kalra[2], Nikhil Tandon[3,4]

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Diabetes is a disease that affects over 65 million persons in India.[1] Diabetes-related eye disease, of which retinopathy is the most important, affects nearly one out of every ten persons with diabetes, according to point prevalence estimates.[2] However, the prevalence increases with increasing duration of diabetes, and it is common in subjects with high-glucose levels and on more complex regimens. For example, in a study of 17,995 subjects with diabetes from across India, the overall prevalence of retinopathy was about 15%. In subjects on diet control, the prevalence of diabetic retinopathy was 4.4%, on oral drugs, the prevalence was 12.5%, and in subjects on insulin, the prevalence was nearly 27%.[3]

Clearly, these results show that increasing duration of diabetes associated with glycemic deterioration requiring increased treatment regimen complexity are all associated with a higher prevalence of retinopathy. Retinopathy assessment is more objective and operator-independent than that of other microvascular complications, and is therefore a better marker for monitoring diabetes-related complications. Retinopathy is duration-dependent, and as endocrinologists succeed in taking care of acute co-morbidities, in an aging diabetic population, the burden of retinopathy is bound to increase. This should be limited by early detection and management of retinopathy aided by prompt referrals and teamwork between the endocrinologists and the ophthalmologists.

Therefore, the Indian Journal of Endocrinology and Metabolism (IJEM) has embarked on this special supplement – aimed at documenting the current status of diabetic retinopathy and related health-care management scenario in India. It has been clearly shown that glucose control can reduce the onset and progression of diabetic eye disease. The vast majority of diabetes in the country is treated by general physicians, and training them in the management of diabetes-related complications is the need of the hour.

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Like diabetic neuropathy and nephropathy, retinopathy too can be detected early. Making a dilated fundus examination by trained ophthalmologists is the norm in referral centers specializing in endocrinology and diabetes. But, what about primary care practitioners with little access to such facilities? Simple handheld ophthalmoscopes can, but do not completely supplement the need for a specialist examination. Technology is coming to help, as there are nonmydriatic fundus cameras which screen for retinopathy in a matter of minutes. Mobile eye clinics with the ability to screen for retinal disease are practicable solutions.[4] Mobile diabetes clinics (different from mobile eye clinics) which carry out screening of eye, foot, and kidney disease, bringing diabetes care to the door step, have been another innovation, as they are diabetes-specific and also screen for complications beyond retinopathy.[5] Finally, the stage is set for the arrival of the smartphone as a tool for retinopathy diagnosis, as technology start-ups are increasingly applying point of care; smartphone-based retinal photography to augment the diagnosis.[6]

Retinal therapies, consisting of anti-vascular endothelial growth factor agents such as aflibercept, bevacizumab, or ranibizumab, and surgical approaches are all excellent tools in the hands of ophthalmologists.[7] However, as the average reader of IJEM would ask - How best can an endocrinologist prevent diabetic retinopathy? Well, glucose control is probably the most important factor, and keeping the glycated hemoglobin close to 6.5% without hypoglycemia can help. While a sudden control of blood glucose levels may cause a transient deterioration of retinopathy in the long term, strict glucose control will help eventually reduce complication risk. Individuals with type 2 diabetes and pre-existing retinopathy are more prone to such deterioration after intensive glucose control, when compared to subjects without baseline retinopathy.[8] In landmark diabetes intervention studies such as Diabetes Control and Complications Trial and the United Kingdom Prospective Diabetes Study, in addition to glucose control, the control of hypertension was shown to be quintessential.[9,10] Studies focusing on lipid control have also shown a trend toward a favorable outcome in retinopathy.[11,12] Given that endocrinologists see tertiary-level cases, which are more likely to represent advanced disease, a prompt referral to an ophthalmologist is very important to prevent and treat diabetic retinopathy.

This supplement, designed to document the current status of diabetes-related eye care infrastructure in the country, is a valuable resource for physicians, diabetologists, and endocrinologists. In addition to the estimates of the burden of disease in the country, the document also suggests the need for an increased national focus on this cause of avoidable blindness.

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Original Article

Eye care infrastructure and human resources for managing diabetic retinopathy in India: The India 11-city 9-state study

Clare E. Gilbert[1], R. Giridhara Babu[2], Aashrai Sai Venkat Gudlavalleti[2], Raghupathy Anchala[2], Rajan Shukla[2], Pant Hira Ballabh[2], Praveen Vashist[3], Srikrishna S. Ramachandra[2], Komal Allagh[2], Jayanti Sagar[2], Souvik Bandyopadhyay[2], G. V. S. Murthy[1,2]

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ABSTRACT

Background: There is a paucity of information on the availability of services for diagnosis and management of diabetic retinopathy (DR) in India. **Objectives:** The study was undertaken to document existing healthcare infrastructure and practice patterns for managing DR. **Methods:** This cross-sectional study was conducted in 11 cities and included public and private eye care providers. Both multispecialty and stand-alone eye care facilities were included. Information was collected on the processes used in all steps of the program, from how diabetics were identified for screening through to policies about follow-up after treatment by administering a semistructured questionnaire and by using observational checklists. **Results:** A total of 86 eye units were included (31.4% multispecialty hospitals; 68.6% stand-alone clinics). The availability of a dedicated retina unit was reported by 68.6% (59) facilities. The mean number of outpatient consultations per year was 45,909 per responding facility, with nearly half being new registrations. A mean of 631 persons with sight-threatening-DR (ST-DR) were registered per year per facility. The commonest treatment for ST-DR was laser photocoagulation. Only 58% of the facilities reported having a full-time retina specialist on their rolls. More than half the eye care facilities (47; 54.6%) reported that their ophthalmologists would like further training in retina. Half (51.6%) of the facilities stated that they needed laser or surgical equipment. About 46.5% of the hospitals had a system to track patients needing treatment or for follow-up. **Conclusions:** The study highlighted existing gaps in service provision at eye care facilities in India.

Key words: Diabetes complications, diagnostic equipment, diabetic retinopathy, health facilities, human resources, India

Introduction

India is experiencing a rapid increase in the number of people with diabetes, and as the epidemic of diabetes matures the incidence of sight-threatening-diabetic retinopathy (ST-DR) is also likely to increase dramatically. Currently approximately 10% of the 65 million known diabetics are likely to have ST-DR, which means there are currently 6,500,000 diabetics who require a confirmatory diagnosis, treatment, and follow-up. Although much has been written about screening for DR in the middle- and low-income settings, including in India,[1-6] little has been

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published on the availability and quality of services for confirmatory diagnosis and treatment of ST-DR in these settings.[7]

The purpose of the study was to assess the availability of services for the diagnosis and management of DR in order to identify gaps that need to be addressed, and to ascertain whether facilities included in the study are engaged in screening for DR. Large eye care facilities in the largest cities in India were purposely selected for the study.

Methods

The study was a cross-sectional, hospital-based survey, and was conducted in 11 cities in 9 states across India. Sampling entailed a two-stage process wherein cities were first stratified based on their population (more than or <7 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 ranked in the most populous cities in the country from the eastern part of India, it was decided to include an additional city from the region to provide adequate representation to the eastern part of India. Therefore the twin cities of Bhubaneshwar and Cuttack were included in the study. Thus 11cities were finally covered.

The 11 cities were Ahmedabad, Bengaluru, Bhubaneshwar, Chennai, Delhi, Hyderabad, Jaipur, Kolkata, Mumbai, Pune, and Surat.

In each city, public and private providers for 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 superspecialty 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.

Prior permission was taken from the hospital administrators at the clinic/facility. At each facility semistructured interviews were conducted with the eye care provider representative who was either the head of the institution/eye department or a senior member of staff nominated by the head of the institution. Each of the six elements of the World Health Organization's framework for health systems was evaluated, i.e., number of staff and their skills; availability of infrastructure, equipment, laboratories and medication; whether clinical guidelines and protocols were available as well as information for patients. All interviews were audio-recorded after seeking permissions from the responding providers.

Information was collected on the processes used in all steps of the program, from how diabetics were identified for screening through to policies about follow-up after treatment. Multiple approaches were used to assess parameters such as collaboration and partnerships, financial sustainability, comprehensiveness and responsiveness of services; referrals between eye care and diabetic care, and the coverage of programs.

Data collection teams

Five dedicated teams were constituted for data collection. All teams were first trained at the Indian Institute of Public Health (IIPH), Hyderabad, for 3 days. Mock interviews were conducted by the team members followed by a pilot at two locations in Medak District, Telangana State. Each team consisted of a public health specialist/senior researcher from IIPH, a trained interviewer and two research assistants.

Data were entered into an access-based software package specially developed for the study and were cleaned before analysis. Stata 12 SE for Windows (Stata Corp, 4905 Lakeway Drive, Texas, US) was used for statistical analysis. Frequencies of the variables were tabulated. *t*-test was used for continuous variables and Chi-square was used for categorical variables. Results were adjusted for age, gender, education, type of city, and type of healthcare sector (public or private).

Details of the methodology used in the study have been published as a companion article.

Results

A total of 86 eye units were visited and information collected regarding available human resources, outpatient consultations and number of treatments, training needs and practices in relation to DR. About 68.6% (59) were stand-alone eye hospitals/clinics whereas 31.4% (27) were eye units located in multispecialty hospitals. Almost 60.5% (52) eye units were located in larger cities (7 million population and above) and 39.5% (34) were in smaller cities (population <7 million). Almost three quarters (73.3%) were private-funded eye units (both for profit and not-for-profit) and the remaining 26.7% (23) being public-funded. Almost half (48.8%, 42) were teaching institutions with ophthalmology residency and/or fellowship training. Around 68.6% of eye institutions had a dedicated retina clinic. This was significantly higher in stand-alone eye hospitals compared to eye units in multispecialty facilities (78% vs. 48.1%; $\chi^2 = 7.6463$; $P = 0.006$).

The availability of a dedicated retina unit was reported by 68.6% (59) facilities. This was significantly higher in stand-alone eye facilities compared to multispecialty facilities (78.0% vs. 48.1%; $\chi^2 = 7.65$; $P = 0.006$).

Patient load

The mean number of outpatient consultations per year was 45,909 per responding facility, with nearly half being new registrations [Table 1]. A mean of 631 persons with ST-DR were registered per year per facility. However, only 34.9% (30) eye units provided information related to clients with ST-DR seen at the facilities. The commonest treatment for ST-DR was laser photocoagulation (mean of 511 treatments per year per facility). Mean outpatient consultations were higher in teaching hospitals, bigger cities, private-funded hospitals and stand-alone eye hospitals. Similar trends were observed with all other parameters.

A quarter of the facilities stated that they have a waiting list for laser for DR ($n = 21$; 24.4%). The waiting list was significantly longer in teaching hospitals compared to nonteaching hospitals (38.1% vs. 11.4%; $\chi^2 = 8.32$; $P = 0.004$), multispecialty hospitals compared to stand-alone eye hospitals (71.2% vs. 40.7%; $\chi^2 = 7.26$; $P = 0.007$), public-funded compared to private-funded hospitals (47.8% vs. 15.9%; $\chi^2 = 9.32$; $P = 0.002$) and hospitals with a dedicated retina unit compared to those without a dedicated retina unit (32.2% vs. 7.4%; $\chi^2 = 6.17$; $P = 0.013$). The mean waiting time was 4 weeks (range 2–6 weeks). Waiting time was only reported by 15% (13) of the facilities.

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: Sight-threatening-diabetic retinopathy

Human resources

Data were provided by 64 facilities on the number of retina specialists (including part-time consultants) at their institution (Mean: 2.9 retina specialists/per reporting facility). Only 50 facilities reported having a full-time retina specialist (Mean: 3.5 full-time retina specialists per reporting facility). Facilities in larger cities (≥7 million population) and privately funded facilities had a higher mean number of retina specialists. Almost 15% (13) of facilities reported that they had residency training programs in ophthalmology, training from 1 to 35 residents per year.

More than half the eye care facilities (47; 54.6%) reported that their ophthalmologists would like further training in retina; 42/47 (89.4%) needed training in medical retina while 5 (10.6%) wanted training in vitreo-retinal surgery. The expressed need for training in medical retina was significantly higher among public-funded than private-funded facilities (69.6% versus 41.3%; $\chi^2 = 5.39$; $P = 0.02$), eye clinics in multispecialty hospitals compared to stand-alone eye hospitals (74.1% vs. 37.3%; $\chi^2 = 10.03$; $P = 0.002$) and in hospitals where there was no dedicated retina unit (66.7% vs. 40.7%; $\chi^2 = 5.01$; $P = 0.02$) on univariate analysis [Table 2]. However, after adjusting for variables which were found to be significant in univariate analysis, none of the associations remained statistically significant.

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

A high proportion of the eye care facilities had nursing personnel trained in ophthalmology [Table 3]. However, the availability of other human resources was inadequate with only 4 out of every 10 facilities employing staff qualified in low vision care and a counselor, while around a third had a trained retinal photographer. Qualified low vision personnel were more likely to be present in stand-alone facilities compared with multispecialty facilities ($\chi^2 = 17.46$; $P < 0.001$), teaching facilities compared to nonteaching institutions ($\chi^2 = 5.58$; $P = 0.02$) and in privately funded facilities compared to public-funded institutions ($\chi^2 = 6.41$; $P = 0.01$). Trained retinal photographers were more likely to be present in stand-alone compared to multispecialty institutions ($\chi^2 = 14.0$; $P < 0.001$), while qualified counselors were more likely to be present in private compared to public-funded facilities ($\chi^2 = 11.5$; $P = 0.001$) and stand-alone eye hospitals compared to multispecialty hospitals ($\chi^2 = 16.35$; $P < 0.001$). Trained optometrists were more likely to be present in larger cities compared to smaller cities ($\chi^2 = 7.01$; $P = 0.008$) whereas equipment technicians were more likely to be present in the private-funded facilities compared to public-funded facilities (47.6% vs. 17.4%; $\chi^2 = 6.44$; $P = 0.01$).

Equipment for diagnosis and treatment

Standard ophthalmic equipment, such as indirect ophthalmoscopes, was available in all facilities, but equipment for the diagnosis and management of ST-DR were not available in all facilities [Table 4]. Facilities for fundus fluorescein angiography were more likely to be present in stand-alone eye care facilities than multispecialty hospitals ($\chi^2 = 5.10$; $P = 0.02$), teaching versus nonteaching facilities ($\chi^2 = 10.66$; $P = 0.001$) and if there was a dedicated retina unit ($\chi^2 = 15.52$; $P < 0.001$). Functional lasers for treating DR were significantly higher in stand-alone facilities compared to multispecialty hospitals ($\chi^2 = 12.0$; $P = 0.001$) and in hospitals with a dedicated retina unit ($\chi^2 = 20.67$; $P < 0.001$). Differences in the availability

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	

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, FFA: Fluorescein fundus angiography, VR: Vitreo-retinal, AB: AB ultrasound scan - A stands for amplitude scan and B stands for brightness scan of functional AB scans were statistically significant when comparing larger cities to smaller cities (χ^2 = 4.39; P = 0.04) and facilities where a dedicated retina unit was available (χ^2 = 18.04; P < 0.001). Significantly higher availability of functional fundus cameras was observed in the stand-alone eye facilities (χ^2 = 5.51; P = 0.02), teaching hospitals (χ^2 = 10.66; P = 0.001) and where dedicated retina units were located (χ^2 = 15.52; P < 0.001). Similar differences between types of eye care facilities were also observed with optical coherence tomography (OCT), the availability of a set of contact lenses for laser treatment and VR surgery facilities. Overall functional equipment status was better in stand-alone eye hospitals, teaching hospitals, private-funded hospitals and hospitals with a dedicated retina unit [Table 4].

Half (51.6%) the facilities stated that they needed laser or surgical equipment to increase the treatment options they could provide with the need being significantly higher in multispecialty hospitals than in stand-alone eye hospitals (85.2% vs. 35.6%; χ^2 = 18.23; P < 0.001), larger cities compared to smaller cities (61.5% vs. 35.3%; χ^2 = 5.67; P = 0.02) and public-funded compared to private-funded hospitals (78.3% vs. 41.3%; χ^2 = 9.23; P = 0.002).

Available treatment modalities for DR were also assessed [Table 5]. Significant differences were observed between stand-alone eye hospitals and multispecialty hospitals, teaching and nonteaching hospitals, private- and public-funded hospitals for different treatment modalities offered. Comprehensive retina treatment services were significantly better in hospitals with a dedicated retina unit (χ^2 = 13.33; P < 0.001), stand-alone eye hospitals (χ^2 = 7.27; P = 0.007), and teaching compared to nonteaching hospitals (χ^2 = 7.37; P = 0.007).

Systems, procedures, and protocols

Nearly half the hospitals (n = 40; 46.5%) had a system to track patients needing treatment or for follow-up. Better tracking systems were reported by stand-alone versus multi-specialty hospitals (62.7% vs. 11.1%; χ^2 = 19.8; P < 0.001) and by private- versus public-funded facilities (57.1% vs. 17.4%; P = 0.001).

Hospitals were asked to comment on the proportion of persons with diabetes who completed a complete course of laser. Among those who responded (68), 77.9% (53) stated that ≥75% completed the full course, the pattern being similar in all types of hospitals. Among the 72 facilities which responded on the proportion of diabetics treated with laser coming back for a follow-up 72.25% (52), stated that ≥75% of persons who received laser generally attend for the follow-up after laser. There were no significant differences between different facilities in this regard also.

Less than a quarter (23.3%) of the facilities performed routine glycosuria testing on adult patients [Table 6]. This was a more common practice in eye units in multispecialty hospitals than in stand-alone eye hospitals (37% vs. 16.0%; χ^2 = 4.19; P = 0.04) and in public- versus private-funded hospitals (43.5% vs. 15.9%; χ^2 = 7.19; P = 0.007). A higher proportion (45.3%, 30) routinely measure glycosylated hemoglobin (HbA1C) on all persons with diabetes with 17.4% only testing those with DR. Nonteaching hospitals were more likely to test HbA1C levels compared to teaching hospitals (47.7% vs. 26.2%; χ^2 = 4.27; P = 0.04) with no other significant differences by hospital type. Less than a quarter of facilities (23.3%) stated that printed protocols on indications for treatment of DR were available in outpatient clinics.

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

Patient information sheets on DR were available in 50% of hospitals [Table 6] being more likely in stand-alone than multispecialty hospitals (67.8% vs. 11.1%; $\chi^2 = 23.8$; $P < 0.001$), private-funded compared to public-funded hospitals (63.5% vs. 13%; $\chi^2 = 17.15$; $P < 0.001$) and hospitals with a dedicated retina unit compared to hospitals without (57.6% vs. 33.3%; $\chi^2 = 4.37$; $P = 0.04$). Access to records from the diabetic physicians was stated to be poor with only 39.5% stating that they had good access.

Outreach activities for diabetic retinopathy

Over a third of the 86 hospitals (38.4%) stated that they provided outreach screening for DR [Table 7], and many used more than one approach. There were no significant differences between the private-funded and public-funded facilities in this regard (41.3% vs. 30.4%; $\chi^2 = 0.84$; $P = 0.4$). In over half of these facilities, screening entailed clinical examination by ophthalmologists in eye camps. Only three facilities used an approach where retinal photography/digital imaging was performed by a nonophthalmologist with on the spot interpretation. All the other screening approaches were dependent on ophthalmologists either to take and/or remotely interpret images via telemedicine mechanisms. About a quarter of the facilities engaged in outreach undertook mass media campaigns to increase awareness of DR.

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	

HbA1c: Glycated hemoglobin, OPD: Out patient department

Discussion

In this study, the largest cities in India were purposively selected, as were the facilities in each city, in order to provide a snap shot of services for the management of ST-DR. These locations were selected for two broad reasons: Firstly, the prevalence of diabetes and rates of ST-DR among diabetics is higher in urban areas than in rural communities, and hence the need for eye care for diabetic eye disease is, therefore, greater. Second, concentrating data collection in 11 locations was feasible from a logistical point of view. However, the findings are likely to be biased, and will not reflect the level of service delivery in smaller cities and in rural areas. Our study is likely to reflect the best of what is currently available, acknowledging that services for diagnosis and treatment of ST-DR are likely to be less good in smaller cities and rural areas, even in training institutions.[8]

A need for training, particularly in medical retina, was acknowledged by half the providers, particularly in facilities in the public sector. Expertise within India to support this capacity building already exists, and funding is available from the National Control of Blindness Programme as well as external funders such as the International Council of Ophthalmology. Increasing the number of ophthalmologists skilled in medical retina

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-ophthalmology	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

may help to reduce waiting lists and waiting times for laser treatment. Consideration could also be given to training senior ophthalmic nurses in giving intravitreal injections, as this is now practiced as a means of meeting the demands of repeat treatment of age related macular degeneration in high-income settings.[9,10] Facilities for surgical treatment of complex cases were available in almost two thirds of the eye units, with three quarters of teaching hospitals being able to provide this level of care. Overall, there was a lower need for training ophthalmologists in VR surgery which may reflect the fact that some facilities were relatively small.

A high proportion of facilities were able to provide laser treatment and intravitreal injections for clinically significant macular edema, both being lower in public- than in private-funded institutions. Three quarters of the teaching hospitals were able to provide all forms of treatment for ST-DR. OCT machines were only available in two-thirds of facilities, which will need to be addressed as diabetic macular edema is the commonest form of ST-DR requiring treatment. Ideally all teaching hospitals should have the capacity to provide the full range of treatment for DR so that all graduating ophthalmologists have the opportunity to gain skills in the diagnosis and management of ST-DR which will become an increasing problem in the decades to come.

In terms of other cadres of eye healthcare workers, there was a shortage of low-vision therapists, counselors and personnel trained in retinal photography across all types of facilities. These allied professional health workers can play a vital role in services for people with ST-DR, particularly counselors, as compliance with lifestyle modification, medication, treatment and regular follow-up is a challenge on all chronic diseases, including DR, although evidence of effectiveness is limited in relation to dietary modification,[11] with more evidence of impact on adherence to medication.[12] Counselors could also support diabetic patients to take up yoga, which leads to better health outcomes in India compared to walking.[13] Equipment technicians are also important members of the eye care team, particularly in centers offering advanced surgery which requires complex and expensive equipment. Equipment technicians were generally lacking in public-funded institutions, an issue that needs to be urgently addressed.

Other elements of the health system that require strengthening are health management information systems, particularly in the public sector, which will allow better tracking of patients with ST-DR. There is a need for developing/adapting standard guidelines for diagnosis of DR needing treatment, protocols for laser treatment and intravitreal therapies, and educational materials for diabetic patients with DR. The recently convened National Diabetic Retinopathy Task Force by the Government of India could play a role in supporting the development and dissemination and protocols, guidelines, and information for patients.

Outreach activities

Outreach activities for the detection of DR were being implemented by just over a third of the facilities included in the study, being more frequent among private providers. However, in over half of these initiatives clinical examination by an ophthalmologist was the modality being used to detect DR, and in all but three facilities ophthalmologists were engaged in interpreting retinal images taken by other cadres. However, using highly skilled ophthalmologists to detect ST-DR is not a good use of their time, particularly as there is a considerable body of evidence that nonophthalmologists can be trained to take and interpret retinal images with high levels of competence.[14-16] This approach was only being used by three facilities in this study. Indeed, in the United Kingdom's national program for DR, retinal images are taken and interpreted by trained nonphysician technicians, who have been shown to be better at detecting milder forms of DR than clinicians.[17,18] Another limitation highlighted in this study is the lack of engagement with physicians and endocrinologists in screening, as most activities did not entail joint planning, implementation or monitoring of screening.

Conclusion

Tackling the increasing threat of ST-DR will require extensive changes to eye healthcare systems, as well as greater engagement with physicians and endocrinologists, and patients. This will be a challenge in India where the emphasis has rightly been on scaling up highly cost effective, once-off interventions such as cataract surgery and correction of refractive errors, which remain the commonest causes of blindness and visual impairment. However, as the epidemic of diabetes matures, the incidence of visual loss from DR will increase, putting at risk the sight of those who are economically productive as well as the elderly. If only 0.5% of diabetics become blind each year (i.e., one in 20 of those with ST-DR), then DR has the potential to overtake cataract as the commonest cause of blindness, particularly among those of working age.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

Human resources, patient load, and infrastructure at institutions providing diabetic care in India: The India 11-city 9-state study

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ABSTRACT

Background: There is a lack of information on the practice patterns and available human resources and services for screening for eye complications among persons with diabetes in India. **Objectives:** The study was undertaken to document existing health care infrastructure and practice patterns for managing diabetes and screening for eye complications. **Methods:** This cross-sectional, hospital-based survey was conducted in 11 cities where public and private diabetic care providers were identified. Both multispecialty and standalone diabetic care facilities were included. A semi-structured questionnaire was administered to senior representative(s) of each institution to evaluate parameters using the World Health Organization health systems framework. **Results:** We interviewed physicians in 73 hospitals (61.6% multispecialty hospitals; 38.4% standalone clinics). Less than a third reported having skilled personnel for direct ophthalmoscopy. About 74% had provision for glycated hemoglobin testing. Only a third had adequate vision charts. Printed protocols on management of diabetes were available only in 31.5% of the facilities. Only one in four facilities had a system for tracking diabetics. Half the facilities reported having access to records from the treating ophthalmologists. Direct observation of the services provided showed that reported figures in relation to availability of patient support services were overestimated by around 10%. Three fourths of the information sheets and half the glycemia monitoring cards contained information on the eye complications and the need for a regular eye examination. **Conclusions:** The study highlighted existing gaps in service provision at diabetic care centers in India.

Key words: Diabetes, health care facilities, human resources, India, referrals

Introduction

Diabetes mellitus (DM) is one of the most common noncommunicable disorders,[1] affecting an estimated 382 million people worldwide.[2] India has the second highest number of people with diabetes,[3] which is estimated to increase from 65 million in 2013, to 109 million by 2025.[2] The prevalence of diabetes is estimated to be 4 times higher in urban areas compared to rural areas in India.[4]

With such a high prevalence of diabetes in India, it is imperative that the healthcare sector is equipped to deliver quality care for patients with diabetes and its management. However, that is not the case. Numerous health care

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providers, working without national guidelines or protocols for services including standards for health facilities, personnel and treatment protocols, makes it difficult to ensure good quality diabetic care in the country.[5]

In such a situation, it is necessary to study the existing health care infrastructure and practice patterns for managing diabetes and screening for eye complications and identify gaps so that appropriate remedial measures can be instituted. The paper presents results on the current status of available infrastructure and human resources for diabetic care from India 11 city study which was conducted in 2013–2014 in 11 of the largest cities across 9 states in India.

Methods

The study was a cross-sectional, hospital based survey, and was conducted in 11 cities across 9 states in India. All cities in India were ranked in descending order of population size (2011 census) and the 10 most populated cities were selected. As only one city (Kolkata) was in Eastern India another was added – Bhubaneshwar, making a total of 11. Sampling was done using a two stage process wherein cities were first stratified based on their population (> or <7 million). The 11 cities were Ahmedabad, Bengaluru, Bhubaneshwar, Chennai, Delhi, Hyderabad, Jaipur, Kolkata, Mumbai, Pune, and Surat.

In each city, public and private providers for diabetic care services were identified. The other variable in selecting diabetic care institutions was the size of the facility. We choose multispecialty hospitals (100 or more bedded hospital with three or more specialties providing services under one roof), polyclinics (with two or more specialties providing services under one roof), and standalone diabetes clinics (physician/endocrinologist run facilities providing only medical care for diabetes patients).

A semi-structured questionnaire was administered to senior representative(s) of each institution to evaluate different characteristics of each institution, using the World Health Organization health systems framework.[6]

Stata 12 SE for Windows (Stata Corp., Texas, USA) was used for statistical analysis. Frequencies of the variables were tabulated. *t*-test was used for continuous variables and Chi-square was used for categorical variables. Results were adjusted for the type of city (large cities [having a population of 7 million and above] or small cities), type of facility (multispecialty or standalone diabetic facility), sector (public funded or private-funded, including both the not-for-profit and for-profit sector), and whether the institution had teaching facilities.

Results

We interviewed physicians in 73 hospitals, 61.6% ($n = 45$) of which were multispecialty hospitals and 38.4% ($n = 28$) were standalone diabetic clinics [Table 1]. 37% ($n = 27$) of the hospitals were in the public-funded sector, whereas 63% ($n = 46$) were in the private-funded sector, a major proportion of which ($n = 38$) were not-for-profit organizations. About 53.4% of the facilities ($n = 39$) were in the larger cities and 39.7% ($n = 29$) were teaching hospitals. Institutes in larger cities were more likely to be standalone diabetic clinics than institutes in smaller cities (67.4% vs. 32.6%; $P = 0.04$) (adjusted for specialty, sector, teaching/nonteaching).

Public-funded institutions were more likely to have multiple specialties (odds ratio: 8.9 [95% CI: 2.4–40.2]; $P < 0.001$) and were more likely to be teaching hospitals (odds ratio: 8.5 [95% CI: 2.6–29.3]; $P < 0.001$). About 61.6% ($n = 45$) of the facilities had their own eye unit/department, and 13.7% ($n = 10$) had worked collaboratively with an ophthalmologist. Multispecialty hospitals were more likely to have an eye unit/tie up with an ophthalmologist compared to standalone diabetic clinics (95.1% (39) vs. 50% [16]; $P < 0.001$).

The healthcare personnel mix at the different facilities showed that there was a mean of 1.8 ± 2.7 (standard deviation [SD]) endocrinologists per hospital and 5.3 ± 8.1 (SD) general physicians working in the 73 institutions [Table 2]. Compared to standalone diabetic institutions, multispecialty institutions had significantly more endocrinologists (2.4 ± 3.3 standalone diabetic care clinics vs. 1.0 ± 1.4 in multispecialty; $P = 0.03$) and general physicians (8.1 ± 9.9 vs. 1.6 ± 1.7; $P < 0.001$). It was observed that there the mean number of endocrinologists per facility were significantly higher in larger cities compared to the smaller cities (2.3 ± 3.2 vs. 1.0 ± 1.6; $P = 0.04$).

Table 1: Profile of diabetic care facilities included in the study

	Characteristics	*N* (73)	%
Type of facility	Multispecialty facilities	45	61.6
	Standalone diabetic facilities	28	38.4
Sector	Public-funded	27	37.0
	Private funded	46	63.0
	Private: Not for profit	38	52.0
	Private for profit	8	11.0
Type of city	Large (≥7 million population)	39	53.4
	Small (<7 million population)	34	46.6
Teaching status	Teaching institution	29	39.7
	Non-teaching institution	44	60.3
Access to eye care facilities	In-house ophthalmologist available	45	61.6
	Tie up with an ophthalmologist available	10	13.7
	No direct linkage with an ophthalmologist	18	24.7

Public-funded institutions had a greater number of general physicians than private institutions (7.8 ± 11.5 public-funded vs. 3.7 ± 4.8 private-funded; $P = 0.04$). Teaching institutions also had more general physicians than nonteaching institutions, (9.5 ± 11.3 teaching vs. 2.5 ± 2.7 nonteaching; $P < 0.001$). Similar was the case with multispecialty compared to standalone diabetic care facilities (8.1 ± 9.9 physicians vs. 1.6 ± 1.7 physicians; $P < 0.001$). In standalone diabetic care clinics ($n = 28$), the mean number of general physicians was significantly higher than of endocrinologists (5.7 ± 9.3 vs. 2.6 ± 3.2; $P = 0.04$).

A nutritionist/dietician was available, most of the time in 60.3% ($n = 44$) of facilities and a counsellor was present in 39.7% ($n = 29$). There was a significant difference in the availability of a regular counsellor between the public funded and private funded facilities (χ^2 - 5.48; $P = 0.02$). Less than a third of the surveyed hospitals reported having personnel skilled to perform direct ophthalmoscopy, and this pattern was similar to private and public funded facilities.

Almost three quarters of the facilities (74%; $n = 54$) were able to provide glycated hemoglobin (HbA1c) testing [Table 3], with better provision in private-funded facilities than public-funded institutions (84.8% vs. 55.6%, respectively; $P = 0.006$). The majority of service providers had facilities for measuring blood glucose (87.7%, $n = 64$) and lipids (82.2%, $n = 60$), and to assess renal function (84.9%, $n = 62$). Most also had a dedicated pharmacy stocking drugs for diabetes, with significant differences between public-funded and private facilities (100% vs. 76.1%, respectively, $P = 0.006$).

Table 2: Human resources availability reported by the institutions

Human resources	Mean±SD		
	Public-funded (n=27)	Private-funded (n=46)	All
Endocrinologists	2.0±2.5	1.6±2.8	1.8±2.7
General physicians	7.8±11.5	3.7±4.8	5.3±8.1
Nutritionist	55.6% (15)	63.0% (29)	60.3% (44)
Counselor	22.2% (6)	50.0% (23)	39.7% (29)
	χ^2=5.48; P=0.02		
Staff skilled in direct ophthalmoscopy	29.6% (8)	30.4% (14)	30.1% (22)

SD: Standard deviation

Table 3: Services and equipment available at the institutions

	Public funded (n=27)		Private-funded (n=46)		All (n=73)	
	N	%	*N*	%	*N*	%
Service						
HbA1c testing available	15	55.5	39	84.8	54	74
	χ^2=7.55; P=0.006					
Blood sugar testing available	25	92.6	39	84.8	64	87.7
Lipid testing available	21	77.8	39	84.8	60	82.2
Renal function testing available	23	85.1	39	84.8	62	84.9
Pharmacy for diabetes available	27	100.0	35	76.1	62	84.9
	χ^2=7.60; P=0.006					
Functional equipment						
BP apparatus available	27	100.0	46	100.0	73	100
Direct ophthalmoscope available	12	44.4	29	63.0	41	56.1
Fundus/retinal camera available	3	11.1	10	21.7	13	17.8
Visual acuity charts available	5	18.5	18	39.1	23	31.5
Weighing scale available	27	100.0	46	100.0	73	100

HbA1c: Glycated hemoglobin, BP: Blood Pressure

All institutions had functioning equipment for measuring blood pressure and weighing scales [Table 3]. However, a lower proportion had a functioning direct ophthalmoscope (56.1%, $n = 41$) and adequate visual acuity charts (31.5%). Only 17.8% ($n = 13$) had a functional fundus/retinal camera.

The number of persons with diabetes (PWD) registered at the study institutions in 2011 and 2012 showed the work load to be similar in each year [Table 4]. The mean number of PWD attending in 2011 and 2012 were 10,944 ± 14,289 (SD) and 12,337 ± 18,029 (SD) per hospital, respectively. Teaching hospitals saw more than twice the number of new PWD than nonteaching facilities. A mean patient load of 3273 ± 4742 (SD) newly registered PWD per facility, was seen in 2011, whereas a mean patient load of 3114 ± 4548 (SD) newly registered PWD per facility was seen in 2012. In 2011 and 2012, teaching hospitals recorded significantly higher numbers of new PWD (2011: 5202 ± 6335 vs. 2010 ± 2787 [$P = 0.02$]; 2012: 5054 ± 5764 vs. 2030.5 ± 3413.4 [$P = 0.02$]). Multispecialty hospitals saw significantly more PWDs in 2012 than standalone diabetic care facilities (17270 ± 22541 vs. 6647 ± 7929; $P = 0.03$). The mean number of patients presenting for follow-up evaluation for diabetes at each facility was 5.5 ± 6.3 (SD) patients per week.

The majority of institutions stated that they received regular referrals from ophthalmologists (83.6%; $n = 61$). This did not differ by type of facility.

Two-thirds (67.1%) of the respondents stated that they knew about the National Program for Prevention and Control of Diabetes, Cancer and Stroke (NPCDCS). However, only 5% ($n = 4$) reported that they had received any support from the government under the NPCDCS.

Printed protocols on management of diabetes were available in 31.5% (23) of the facilities [Table 5]. The availability of such protocols was significantly higher in standalone diabetic care clinics compared to multispecialty facilities (χ^2 - 4.67; $P = 0.03$) and in the larger cities compared to the smaller cities (χ^2 - 11.9; $P = 0.001$). Printed protocols on detection

Table 4: Reported workload at the responding institutions

Characteristics	Public funded	Private funded	All
No. of persons with diabetes seen per week	4.6±3.9 (*n*=25)	6.0±7.3 (*n*=43)	5.5±6.3 (1-50) (*n*=68)
New diabetics seen in 2011	3764±5376 (*n*=16)	3028±4464 (*n*=32)	3273±4742 (19-21,900) (*n*=48)
Old + new diabetics seen in 2011	14,248±18,829 (*n*=18)	9142±11,009 (*n*=33)	10944±14289 (29-65,957) (*n*=51)
New diabetics seen in 2012	3033±4125 (*n*=18)	3156±4808 (*n*=35)	3114±4548 (25-21,900) (*n*=53)
Old + new Diabetics seen in 2012	16140±24723 (*n*=19)	10385±13396 (*n*=37)	12337±18,029 (169-84,439) (*n*=56)

n=No. of institutes which provided data

Table 5: Reported practice patterns at diabetic care facilities

Reported practice pattern	*N*	%	χ^2; *P*
Printed protocols on managing diabetes readily available in clinic (73)	23	31.5	
Standalone diabetic care clinics (28)	13	46.6	
Multispecialty hospitals (45)	10	22.2	χ^2=4.67; *P*=0.03
Large cities (42)	20	47.6	
Small cities (31)	3	9.7	χ^2=11.9; *P*=0.001
Printed protocols on detection of complications readily available in clinic (73)	15	20.5	No significant associations
Information sheets on diabetes available for distribution in clinic (73)	49	67.1	
Standalone diabetic care clinics (28)	25	89.3	
Multispecialty hospitals (45)	24	53.3	χ^2=10.11; *P*=0.001
Public-funded (27)	9	33.3	
Private-funded (46)	40	87.0	χ^2=22.17; *P*<0.001
Information sheets on diabetes contain advice on eye complications in diabetes (49)	39	79.6	No significant associations
Customized diet cards given to persons with diabetes (73)	47	64.3	
Standalone diabetic care clinics (28)	23	82.1	
Multispecialty hospitals (45)	24	53.3	χ^2=6.25; *P*=0.012
Each diabetic given a card to monitor glycemic status (73)	45	61.6	
Standalone diabetic care clinics (28)	23	82.1	
Multispecialty hospitals (45)	22	48.9	χ^2=8.07; *P*=0.004
Public-funded (27)	12	44.4	
Private-funded (46)	33	71.7	χ^2=5.36; *P*=0.021
Glycemic status monitoring card mentions need for eye examinations (45)	20	44.4	No significant associations
Standardized set of procedures established for assessment of diabetics (73)	50	68.5	No significant associations
Reminders sent to registered persons with diabetes for follow up (73)	20	27.4	
Standalone diabetic care clinics (28)	14	50.0	
Multispecialty hospitals (45)	6	13.3	χ^2=11.67; *P*=0.001
Teaching facilities (29)	4	13.8	
Non-teaching facilities (44)	16	36.4	χ^2=4.48; *P*=0.034
Access to records from ophthalmologists for individual persons with diabetes (73)	40	54.8	
Public-funded (27)	17	63.0	
Private-funded (46)	16	34.8	χ^2=5.45; *P*=0.02
Large cities (42)	25	59.5	
Small cities (31)	8	25.8	χ^2=8.19; *P*=0.004
Diabetic care clinics maintain records pertaining to eyes/vision of individual diabetics (73)	27	37.0	No significant associations
Referrals received from ophthalmologists every week (73)	56	76.7	No significant associations
Registered diabetics regularly referred to ophthalmologists (73)	63	86.3	
Large cities (42)	40	95.2	
Small cities (31)	23	74.2	χ^2=6.68; *P*=0.01
Physicians suggesting annual eye examination to registered diabetics (73)	58	79.4	
Suggest eye examination as soon as person with diabetes registered (73)	63	86.3	

and management of complication of diabetes were reported to be available in a fifth of the institutions but there were no significant differences observed in this regard [Table 5]. Information sheets on diabetes for distribution to PWD were reported to be available in the clinics by 67.1% (49) of the responding institutions, with significant differences between standalone diabetic care clinics compared to multispecialty hospitals (χ^2 - 10.11; $P = 0.001$) and private-funded compared to public-funded facilities (χ^2 - 22.17; $P < 0.001$). 79.6% of hospitals reporting availability of information sheets stated that eye complications were mentioned in the information sheets. Customized diet sheets were reported to be available by 64.3% (47) facilities with significant differences being observed between standalone diabetic care facilities and multispecialty hospitals (χ^2 - 6.25; $P = 0.012$). Cards to help PWD monitor their diabetic status were reported by

61.6% (45) facilities with significant differences between standalone diabetic care units and multispecialty units (χ^2 - 8.07; P = 0.004) and private-funded compared to public-funded institutions (χ^2 - 5.36; P = 0.021). 44.4% of such monitoring cards were reported to include information on the need for regular eye examinations. 68.5% facilities stated that they had established a standard set of procedures to assess PWD. Only 1 in 4 hospitals/clinics mentioned that they had a system for tracking PWD through a short messaging service to remind them of follow-up visits, with significant differences being reported by standalone compared to multispecialty facilities (χ^2 - 11.67; P = 0.001) and nonteaching facilities compared to teaching facilities (χ^2 - 4.48; P = 0.034).

Only half the facilities reported that they had access to records from the treating ophthalmologists. This was significantly better in public compared to private funded facilities (χ^2 - 5.45; P = 0.02) and in the larger cities compared to the smaller cities (χ^2 - 8.19; P = 0.004). The reported referral network between the diabetic care physicians and the treating ophthalmologists was good.

The interview team also personally observed the available facilities in the diabetic care institutions [Table 6]. It was observed that the reported figures with regard to the availability of printed protocols was a slight overestimate compared to the actual availability. The same was the case with regard to patient information sheets, customized diet cards, and glycemic monitoring cards. The difference between the observed and reported proportions was about 10% on each of the items observed.

Three-fourths of the information sheets and half the glycemia monitoring cards contained information on the eye complications and the need for a regular eye examination.

Retinal examination on the first visit of a person with diabetes to a diabetic care facility was mentioned to be the practice followed by 20.5% (15) of the responding facilities. 45.2% (33) stated that they referred a person with diabetes for a retinal examination at the very first visit to their clinic. Only 10% of the retinal examinations were reported to be done by physicians. About 4.1% facilities reported that they referred for a retinal examination only if they suspected an eye problem. In-house retinal photography/digital imaging were not very common in diabetic care facilities with only 6.8% (5) reporting that such a practice was followed.

The 73 responding diabetic care facilities stated that the most common risk factors for diabetic retinopathy observed by them in their clientele were poor glycemic control (79.4%), duration of diabetes (60.3%), concomitant hypertension (58.9%), and high lipids (35.6%).

Table 6: Observed practice patterns at diabetic care facilities

Observed practice patterns at clinic visit	*N*	%	χ^2; *P*
Printed protocols available in clinic on management of diabetes (73)	15	20.5	
Standalone diabetic care clinics (28)	10	35.7	
Multispecialty hospitals (45)	5	11.1	χ^2=6.4; P=0.011
Large cities (42)	13	30.9	
Small cities (31)	2	6.4	χ^2=6.56; P=0.01
Printed protocols available in clinic on detection of complications of diabetes (73)	8	11.0	
Standalone diabetic care clinics (28)	6	21.4	
Multispecialty hospitals (45)	2	4.4	χ^2=5.10; P=0.024
Public-funded (27)	0	0	
Private-funded (46)	8	17.4	χ^2=5.27;p=0.022
Information sheets for persons with diabetes available in clinic (73)	40	54.8	
Standalone diabetic care clinics (28)	20	71.4	
Multispecialty hospitals (45)	20	44.4	χ^2=5.07; P=0.024
Public-funded (27)	8	29.6	
Private-funded (46)	32	69.6	χ^2= 10.95; P=0.001
Information sheets for persons with diabetes mention eye complications (40)	29	72.5	
Prototype of individualized diet card for persons with diabetes available in clinic (73)	35	47.9	
Standalone diabetic care clinics (28)	18	64.3	
Multispecialty hospitals (45)	17	37.8	χ^2=4.86; P=0.03
Public-funded (27)	8	29.6	
Private-funded (46)	27	58.7	χ^2=5.76; P=0.02
Prototype of glycemic monitoring card for persons with diabetes available in clinic (73)	35	47.9	
Standalone diabetic care clinics (28)	19	67.9	
Multispecialty hospitals (45)	16	35.6	χ^2=7.22; P=0.007
Public-funded (27)	6	22.2	
Private-funded (46)	29	63.0	χ^2=11.36; P=0.001
Glycemic monitoring cards include advice on need for eye examination (35)	19	54.3	

Discussion

We interviewed individuals in 73 hospitals across 9 states. We observed that public-funded hospitals were more likely to be teaching hospitals and were also more likely to have multiple specialties which reflect the situation in the country as government institutions are more likely to provide postgraduate medical education (courses recognized by the Medical Council of India [MCI]) than private institutes.[7]

The number of endocrinologists was significantly higher in multispecialty hospitals and in larger cities. This documents the fact that specialists tend to aggregate in facilities with better infrastructure.

We observed that general physicians were generally managing diabetic care, which is consistent with what has been reported from India earlier. In a pan Indian study, 70% of diabetics were diagnosed by general physicians rather than specialized endocrinologists or diabetologists.[8]

Lifestyle modification including diet management is known to prevent the incidence of DM,[9] and also helps reduce HbA1c levels.[10] This would thus help reduce microvascular complications of diabetes.[11] Unfortunately physicians and nurses tend to spend less time in counseling for management of type 2 DM in low middle income countries like India.[12] We observed that about a quarter of the facilities ($n = 18$) neither had a nutritionist or a counselor. In the absence of such personnel, effective management of the glycemic state is compromised. Thus there is an urgent need for specialized nutritionists and counselors to be trained and employed so that they can advise and motivate patients to modify their lifestyle and comply with their treatment.

Teaching institutes, public-funded institutes, and multispecialty hospitals tended to have a significantly greater number of general physicians and residents. Again this reflects inequitable distribution of health care delivery and human resources in the country.

Monitoring of the glycemic state was regularly undertaken either by HbA1c testing or blood glucose testing especially in private-funded institutions. Blood glucose monitoring was the more common modality practiced in India diabetic care facilities. Testing for HbA1c has been included in the criteria for diagnosing DM by the American Diabetes Association in 2010,[13] in addition to the criteria pertaining to blood glucose. A study observed significant differences in the prevalence of diabetes when calculated via Oral glucose tolerance test (OGTT) and HbA1c levels across different countries including the UK, Australia, India, Kenya, and Denmark.[14] In the Indian and the Danish subset, HbA1c testing was more sensitive than OGTT,[14] whereas the opposite was true for individuals living in the UK and in Australia. In India, the prevalence of diabetes was 12.9% via HbA1c testing and 10.2% via OGTT. Thus, in India, which is home to the second largest population of diabetics,[15] increasing the sensitivity of detection by increasing HbA1c testing, would be very helpful.

Treating hyperlipidemia and proteinuria in diabetics is a very important aspect of management of diabetes, to reduce the risk of complications like diabetic retinopathy. Hyperlipidemia raises the risk of complications such as coronary artery disease, stroke, and diabetic retinopathy.[16,17] The ADA has recommended that the first priority of lipid lowering be a low density lipoprotein (LDL) level <100 mg/dL.[18] In our study, it was observed that more than 80% of institutions assessed possessed the capability of testing for lipids.

Diabetic kidney disease is one of the most common causes of end stage renal disease.[19] It is present in approximately 40% of patients with type 2 diabetes.[19] Hence, it is very important to be able to test for basic renal functions such as urine protein, urine, and serum creatinine. Approximately, 85% of institutions in the present study had the capability to perform renal function tests.

Thus, a majority of institutions could perform the basic, necessary tests to diagnose and manage diabetes. However, public-funded institutions would need to consider introducing tests for HbA1c to detect diabetes among their client population.

A majority of institutes also had a pharmacy attached, which distributed drugs for diabetes. All public-funded institutions had this facility, whereas 76.1% of the private institutions did. Having attached pharmacies would not just be convenient for the PWD, but would also play an additional complementary role as the pharmacists can be effective "counselors." Studies have shown that counseling by pharmacists reduces the level of postprandial blood glucose, triglycerides and LDL.[20]

All institutions assessed had a functional Sphygmomanometer. This is important as 30–35% PWD in India have concomitant hypertension.[21] Thus, it is important to be able to detect hypertension at the earliest, and provide adequate monitoring and care for the same. Although more than half the institutions had a functional direct ophthalmoscope, only 17.8% had a functional fundus camera. Use of a fundus camera is far more superior for screening compared to direct ophthalmoscopy.[22,23] The cost of a fundus camera may be a factor that could limit its use for screening purposes, but this can be made cost-efficient by coupling it with tele-ophthalmology facilities.[24,25]

Majority of the institutions stated that they received regular referrals from ophthalmologists. This is a positive finding as effective management of the glycemic status is critical to preventing blindness due to diabetic retinopathy.

The present study has few limitations. Only hospitals in urban areas were interviewed. Thus, the results cannot be generalized to the rural areas. The selection of hospitals/institutions was not randomized and hence the results may not be entirely representative of the situation of institutions across these cities. Since history was elicited using a questionnaire, recall bias cannot be ruled out.

Conclusion

Multispecialty and teaching institutions had a higher patient load as compared to other hospitals providing care for PWD. HbA1c testing was low in public-funded institutions as compared to private-funded ones. We observed significant differences in infrastructure among different facilities according to the sector (public-funded vs. private-funded institutions), type of facility (multispecialty vs. standalone diabetic care institutions), and teaching status (teaching vs. nonteaching institutions).

Reported and observed practice patterns at diabetic care facilities showed that there were significant differences with the type of facility. Overall, it was observed that standalone diabetic care centers and privately-funded institutions were better equipped to meet the needs of PWD.

The results from the present study will be used to develop a sustainable model for comprehensive diabetic care with an emphasis on prevention of blindness due to diabetic retinopathy. Such a model will be integrated into the existing district health systems. The study shows that the model will need interventions that include capacity building of diabetic care teams to augment efforts for screening for retinopathy at their clinics/hospitals and education of PWD and their care-givers/family members to inculcate lifestyle modification and improve compliance with prescribed medication.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

Situational analysis of services for diabetes and diabetic retinopathy and evaluation of programs for the detection and treatment of diabetic retinopathy in India: Methods for the India 11-city 9-state study

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ABSTRACT

Background: Diabetic retinopathy (DR) is a leading cause of visual impairment in India. Available evidence shows that there are more than 60 million persons with diabetes in India and that the number will increase to more than a 100 million by 2030. There is a paucity of data on the perceptions and practices of persons with diabetes and the available infrastructure and uptake of services for DR in India. **Objectives:** Assess perception of care and challenges faced in availing eye care services among persons with diabetics and generate evidence on available human resources, infrastructure, and service utilization for DR in India. **Methods:** The cross-sectional, hospital-based survey was conducted in eleven cities across 9 States in India. 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. Semi-structured interviews were administered to the service providers (both diabetic care physicians and eye care teams) and observational checklists were used to record findings of the assessment of facilities conducted by a dedicated team of research staff. **Results:** A total of 859 units were included in this study. This included 86 eye care and 73 diabetic care facilities, 376 persons with diabetes interviewed in the eye clinics and 288 persons with diabetes interviewed in the diabetic care facilities. **Conclusions:** The findings will have significant implications for the organization of services for persons with diabetes in India.

Key words: Access to health care, diabetes, diabetic retinopathy, India, patient care

INTRODUCTION

Worldwide, an estimated 382 million people are living with diabetes, nearly a fifth of whom live in India.[1] The Indian Council of Medical Research recently conducted a study across four states in India (India Diabetes Study) and estimated that there were 62.4 million people with diabetes and 77.2 million people with prediabetes in 2011.[2] In some parts of India, the prevalence rate is as high as 20% among adults in urban areas and 10% in rural areas in those aged 20 years and above age?.[3] The number of people with diabetes in India is predicted to

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increase to 109 million by 2035 on account of population ageing and continuing socioeconomic status coupled with environmental and lifestyle changes. There is also evidence that Asian populations have a genetic predisposition to diabetes.[4]

Diabetic retinopathy (DR) is an important complication of diabetes. Globally there are an estimated 93 million people with DR, 38 million with the sight-threatening DR (STDR) forms, i.e., proliferative type (17 million) and cystoid/macular edema (21 million).[5] Studies in India have shown that between 18% and 34% of known diabetics have DR (of any severity).[6,7] There is a considerable body of evidence that the risk of blindness from DR can be reduced by better management of the known risk factors (i.e., hypertension,[8] blood glucose,[9] and lipids[10]) and by early detection and treatment of STDR.[11-13]

In India, the government has recently responded to the increase in noncommunicable diseases (NCDs) by establishing the National Programme on the Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke. The program entails identification of those at risk at the community level, with referral to Primary and Community Health Centres for confirmatory diagnosis and treatment. However, the program does not currently emphasize control of the complications of diabetes, including DR. Lack of policies for control is compounded by the lack of knowledge of the risk of blindness among people living with diabetes as well as service providers in India.[14,15] A study from South India showed that only a fifth of the paramedical personnel and a tenth of the persons with diabetes were aware that poorly controlled blood glucose was an important risk factor for DR.[14] Many studies in India show that more than 50% persons with diabetes have poor glycemic control,[16,17] uncontrolled hypertension and dyslipidemia.[18] All these are potential risk factors for DR. Added to this is the finding that a significant proportion of persons with diabetes do not know that they have diabetes. For example, a recent study in 11 cities in India showed that 27.6% of newly detected middle-class diabetics did not know they were diabetic.[19] The situation is likely to be worse in economically and socially disadvantaged populations.

Recent data from India show that DR is responsible for 3.5% of blindness and severe visual impairment among people aged 50+ years.[20] As the prevalence of diabetes increases and persons with diabetes live longer, the risk of STDR increases exponentially. India is sitting at the threshold of an impending "epidemic" of STDR unless proactive measures are taken to integrate control into the Government of India's program for NCDs. Having said this, there are a number of initiatives in India, mainly initiated and run by the nongovernment eye care providers, for the detection and treatment of STDR,[21,22] but these have not been evaluated for coverage, cost effectiveness or sustainability and their ability to be taken to scale.

The Queen Elizabeth Diamond Jubilee Trust (the Trust) has recently provided support to develop a program for the prevention, early detection and management of STDR at district level in India. As the first step in the process, it was decided that baseline information should be gathered on existing services for the care of persons with diabetes and for managing DR and on the perceptions of persons with diabetes regarding the eye complications. The information was presented at a national, multidisciplinary Summit in April 2014 when the main gaps in service provision were identified and strategies for control delineated. In this paper, the methods used in the study are presented. A number of companion articles highlight the findings of this situational analysis.

The study had two broad aims: First, to assess services for the management of persons with diabetes and DR in hospitals and clinics in the largest (most populated) cities in India, and second, to evaluate the approaches being used by eye care providers to detect and treat STDR and to identify best practices in relation to responsiveness, acceptability, efficiency, equity, and sustainability. The specific objectives were to review current government policies for NCDs, focusing on diabetes and control of the complications; to map large public and private sector institutions providing services for diabetics and for DR (physician and eye care facilities) in the largest cities in India; to ascertain the workload and strategies adopted for DR and referral pathways; to determine the proportion of diabetics who know about the eye complications of diabetes, and the proportion who have had a retinal/eye examination; to assess the capacities of eye hospitals (both private and public sector) to manage DR and whether they are proactive in detecting STDR; to undertake in-depth evaluation of at least eight different models for detecting STDR (e.g., telemedicine; eye camps for diabetics; mobile training and treatment); and to identify best practices for screening and management of DR.

Methods

Ethical approval

Ethical approval was obtained from the Institutional Review Committees of London School of Hygiene and Tropical Medicine and the Indian Institute of Public Health (IIPH), Hyderabad.

Informed consent

Written informed consent was obtained separately from the head of the institution and from each of the interviewed clients of services.

Definitions used

For the purpose of this study the following operational definitions were used:

- Public funded: Facilities which were financed by the national or state governments or statutory bodies financed and controlled by the national or state governments
- Private-funded: Facilities which were financed by organizations or individuals on their own. These included both the not-for-profit as well as the for-profit agencies/individuals
- More populated/larger metropolitan cities: Cities with a population ≥7 million
- Less populated/smaller metropolitan cities: Cities with a population <7 million
- Standalone facilities: Facilities which provide only diabetic care facilities, irrespective of the size of the facility. This could include single practitioner clinics or hospitals with a large team of human resources
- Multispecialty facilities: Facilities which provided many specialty medical services including diabetic care facilities. These included polyclinics and large hospitals with both out-patient consultation and inpatient facilities
- Teaching facilities: All facilities providing postgraduate residency programs recognized by Medical Council of India (MCI) and National Board of Examinations (NBE) (MD/MS/DNB) or postdoctoral specialty fellowships
- Nonteaching facilities: Facilities without formal training programs approved by MCI or NBE for medical graduates.

Layout

The methods will be described in two sections. First, the situation analysis of service providers, and secondly, evaluation of current initiatives for the detection and treatment of STDR will be described.

Situation analysis of service providers

Mixed-methods, i.e., qualitative and quantitative techniques were used to collect data from provider and clients' perspectives. Providers were teams in diabetic clinics (diabetologists, physicians, counselors, dieticians) and eye care teams providing clinical services for patients with DR (ophthalmologists, senior managers). Clients' perspectives were also sought by interviewing outpatients attending diabetic clinics and outpatients with DR attending eye departments/clinics.

Study location

A wide consultative process was adopted to decide where the study would take place and which cities to include. As the prevalence of diabetes is higher in urban than rural areas a decision was made to focus on services in urban areas, recognizing that these would probably represent the best available in India. Many services in urban areas are tertiary level referral centers for neighboring districts and smaller towns in the vicinity. If the services in these cities were sub-optimal, it is highly unlikely that services in smaller cities and towns would be better.

Selection of cities

All cities in India were ranked in by population size (2011 census) and the 10 most populous cities were selected [Table 1].[23] As only one city (Kolkata) was in eastern India, the twin-cities of Bhubaneshwar and Cuttack were included to broaden geographical representation. Eleven cities were finally included in the study: Ahmedabad (Gujarat), Bengaluru (Karnataka), Bhubaneshwar (Odisha), Chennai (Tamil Nadu), Delhi, Hyderabad (Telangana), Jaipur (Rajasthan), Kolkata (West Bengal), Mumbai (Maharashtra), Pune (Maharashtra) and Surat (Gujarat). In addition, eye care models for screening for DR at the community level were assessed in three additional cities - Madurai (Tamil Nadu), Tiruvanthapuram (Kerala) and Noida (Uttar Pradesh).

Selection of health facilities

Two stage systematic, stratified random sampling was used to identify facilities to be included. In the first stage, cities were stratified based on their population (more than or less than 7 million) with a larger number of health facilities being included in bigger cities [Table 2]. In the second stage, a random sample was drawn from a list of hospitals/clinics meeting the inclusion criteria in each city.

The size of the health facility and provider (i.e., public funded; private-for-profit; private-not-for-profit) were used

Table 1: Cities included in the study for assessing providers and clients, and their populations

City	State	Population (2011)
Mumbai	Maharashtra	18,414,288
Delhi	Delhi	16,314,838
Kolkatta	West Bengal	14,112, 536
Chennai	Tamilnadu	8,696,010
Bengaluru	Karnataka	8,499,399
Hyderabad	Telangana	7,749,334
Ahmedabad	Gujarat	6,352,254
Pune	Maharashtra	5,049,968
Surat	Gujarat	4,585,367
Jaipur	Rajasthan	3.,073, 350
Bhubaneshwar + Cuttack	Odisha	1,540,974

(Ref: census of India 2011)[23]

Table 2: Selection of units

Diabetic units	≤7m cities	>7m cities	Sampling process
Large government DM/general clinics	2 or 3	4-5	Randomly selected if more
Large private DM clinics	2 or 3	4-5	Randomly selected if more
Small private practitioners	4 to 6		Purposive/snow balling
Total number of clinics	**10-12**		
Patients with diabetes	5-6/clinic		Purposive: Men and women aged ≥40 years
Eye units providing services for DR	**<8m cities**	**>8m cities**	
Large government eye hospitals/clinics	2 or 3	4-5	Randomly selected if more
Large private eye hospitals/clinics	2 or 3	4-5	Randomly selected if more
Private not for profit eye hospital/clinics	1 or 2		Randomly selected if more
Private for profit eye practitioners	4 to 6		Purposive/snow balling
Total number of clinics	**10-12**		
Patients with DR	5-6/clinic		Purposive: Men and women: 40-59 ys (x3); ≥60 ys (x3)

DM: Diabetes Mellitus, DR: Diabetic Retinopathy

to identify facilities for inclusion. Diabetes care facilities were classified as (a) multi-specialty hospitals (i.e., 100 or more beds with three or more specialties), (b) polyclinics (smaller facilities providing a range of specialties) and (c) stand-alone diabetes clinics (physician/endocrinologist run facilities providing care for diabetes patients only). Eye care facilities were classified as (a) large dedicated eye hospitals (20 or more beds with sub-specialty services), (b) eye hospitals with satellites facilities (i.e., facilities in more than one location under joint management), (c) eye departments in general, multidisciplinary hospitals, and (d) eye practitioners (individual ophthalmologist practice).

Assessment of infrastructure in eye care and diabetic care facilities

Semi-structured interviews were conducted with physicians/diabetologists and eye care providers. In both types of service, the six elements of the World Health Organization's framework for health systems were evaluated i.e., number of staff and their skills; availability of infrastructure, equipment, laboratories, and medication; whether clinical guidelines and protocols were available as well as information for patients. All interviews were audio-recorded after obtaining permission respondents. All interviews are transcribed and translated into English for analysis.

Selection of patients for interview

Patients were randomly sampled at diabetes hospital/clinics and eye care hospital/clinics [Table 2] after obtaining permission from hospital administrators. At each diabetic care facility, 4–6 patients with diabetes were identified among those waiting for doctor's consultation, selecting equal numbers of males and females. Two patients in each of the following age strata (<50 years and >50 years) were interviewed. Similar procedures were followed in eye care facilities, but patients were only recruited after they were identified as having DR by the ophthalmologist. Since it was very difficult to identify younger patients with DR, in some cities only three age groups (<50 years and >50 years) were recruited. Interviews were conducted by trained interviewers using structured questionnaires.

In both types of clinics, patients were interviewed to assess their knowledge of diabetes and DR, to assess their health seeking behavior and the challenges they face in controlling their diabetes and/or in accessing services.

Data collection instruments

Personnel managing the programs were interviewed and data recorded using pretested data collection instruments. A consultation of key stakeholders was organized to finalize the methodological questions, instruments, and scope of the study. The following protocol was used for data collection.

Diabetic care providers: The following instruments were used: Semi-structured questionnaires were administered to the Senior Administrator or Head of Endocrinology Department on diabetes services; in-depth interviews were conducted with Senior Physician/Heads of Endocrinology/Internal Medicine Units using interview guides; structured questionnaires were administered to counselors, dieticians and patients, and an observation checklist was used to assess available equipment and services.

Eye care providers: The following instruments were used: Structured questionnaires were administered to the Senior Administrator or Head of Department; in-depth interviews were conducted with the Senior Physician or Heads Departments in the eye clinics or retina unit; structured questionnaires were administered to DR patients attending eye hospitals, and an observation checklist was used to assess available equipment and services.

All data collection instruments for patients, and the information sheets and consent forms, were translated into the local language and back-translated into English. The instruments were translated into eight Indian languages - Hindi, Telugu, Tamil, Oriya, Bengali, Gujarati, Marathi and Kannada. The data collection instruments were pretested in an eye hospital and a general hospital in Medak district, Telangana. Some questions were subsequently dropped or modified.

Data collection teams

Five dedicated teams each comprising a public health specialist/senior researcher from IIPH, a trained interviewer and two research assistants were constituted for data collection. The teams were first trained at the IIPH, Hyderabad for 3 days. Mock interviews were conducted by team members followed by a pilot in two locations in Medak district, Telangana state.

Data management and analysis

Databases for all the structured questionnaires and observation checklists were created in MS Access 2010. The following features were included to reduce data entry error, i.e., validation, skip pattern, drop down menu, auto calculation, etc. Data was entered by trained data entry operators. For the purpose of data protection, a login and password were created, and copies of the database were stored in three different systems. Data were then cleaned using appropriate steps and transferred into Stata and R (Stata Corp, Texas, US and R Foundation, Vienna, Austria) software for analysis. Numerous cross-tabulations were performed, focusing on the counts/frequencies of different types of facilities of DR.

Evaluation of initiatives for the detection and management of diabetic retinopathy

The purpose of the evaluation was to describe and evaluate the different approaches being used across the country for the detection and management of DR and more specifically treatment of STDR. The evaluation assessed each approach from the perspectives of collaboration and partnerships, effectiveness and efficiency, sustainability, integration, comprehensiveness and responsiveness and cost effectiveness with a view to identifying approaches that could be adopted or modified and taken to scale with support from the Trust. A range of different models was identified through prior knowledge of the authors, and by identifying additional providers during the situation analysis and snowballing. Some providers used more than one approach. Criteria for selecting the models were that they used different approaches (e.g., telemedicine; eye camps for diabetics; mobile screening with or without training and treatment; screening in clinics for diabetics), and hospitals providing large community-based screening programs for DR, by the government and private facilities.

A team of senior community eye care physicians developed a framework and protocol for mapping and analyzing services in terms of human resources, protocols, methods used and validity of screening procedures, monitoring follow-up of those who failed screening and those referred for treatment, and initiatives to improve uptake. Site visits and interviews, as well as reviewing information presented, were undertaken for this question. Information was collected on the processes used in all steps of the program, from how diabetics were identified for screening through to policies about follow-up after treatment. Multiple approaches were used to assess the parameters outlined above. First, a range of closed-ended questions were administered, drawing on the published literature whenever possible, followed by a detailed observation checklist on service provision, manpower, infrastructure, governance structure, community outreach program, etc., was used to collect information. Finally, service providers were asked to rank their service on a scale of 1 (low) to 100 (high) for each parameter included in the assessment. Data were managed as above. The methods used for this component of the study are described in more detail in a separate paper.

Coverage

A total of 859 units were included in the study [Table 3], including 14 eye care providers managing programs for the detection and treatment of STDR, which was more than initially planned.

Discussion

In this study, a range of different types of facilities caring for diabetics and those with DR were assessed, and the perceptions of patients regarding diabetes and DR were gathered in 11 cities across India. Three further cities were included in the program evaluation component. This is the largest and most comprehensive study of its kind in India. Findings are being used to inform elements of a comprehensive integrated district model of screening and management of DR embedded in the Government health system. The Queen's Trust working in partnership with the Public Health Foundation of India is supporting some of these initiatives for DR in India, including models for the detection and treatment of STDR which are integrated into the government of India's program for the control of noncommunicable diseases.

Table 3: Distribution of units included in the study

City/town	Eye care units			Diabetic care units			Total
	Service providers	Patients	DR models in-depth interviews	Service providers	Patients	Counselors/dieticians	
Situation analysis of services and program evaluation							
Mumbai	8	17	1	10	24	1	61
Delhi	14	33	2	11	21	4	85
Kolkatta	6	32	0	2	27	0	67
Chennai	7	31	2	4	22	2	68
Bengaluru	9	48	1	6	30	4	98
Hyderabad	7	57	2	6	40	3	115
Ahmedabad	9	53	1	9	57	3	132
Pune	6	21	1	8	15	0	51
Surat	8	50	1	7	15	0	81
Jaipur	9	18	0	8	18	4	57
Bhubaneshwar/Cuttack	3	16	0	2	19	1	41
Program evaluation only							
Thiruvantha-puram	0	0	1	0	0	0	1
Noida	0	0	1	0	0	0	1
Madurai	0	0	1	0	0	0	1
Total	86	376	14	73	288	22	859

Conclusions

The findings of the study will be used to plan for need-based services for diabetic retinopathy in India.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

Perceptions and practices related to diabetes reported by persons with diabetes attending diabetic care clinics: The India 11-city 9-state study

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ABSTRACT

Background: India has the second largest population of persons with diabetes and a significant proportion has poor glycemic control and inadequate awareness of management of diabetes. **Objectives:** Determine the level of awareness regarding management of diabetes and its complications and diabetic care practices in India. **Methods:** The cross-sectional, hospital-based survey was conducted in 11 cities where public and private providers of diabetic care were identified. At each diabetic care facility, 4–6 persons with diabetes were administered a structured questionnaire in the local language. **Results:** Two hundred and eighty-five persons with diabetes were interviewed. The mean duration since diagnosis of diabetes was 8.1 years (standard deviation ± 7.3). Half of the participants reported a family history of diabetes and 41.7% were hypertensive. Almost 62.1% stated that they received information on diabetes and its management through interpersonal channels. Family history (36.1%), increasing age (25.3%), and stress (22.8%) were the commonest causes of diabetes reported. Only 29.1% stated that they monitored their blood sugar levels at home using a glucometer. The commonest challenges reported in managing diabetes were dietary modifications (67.4%), compliance with medicines (20.5%), and cost of medicines (17.9%). Around 76.5% were aware of complications of diabetes. Kidney failure (79.8%), blindness/vision loss (79.3%), and heart attack (56.4%) were the commonest complications mentioned. Almost 67.7% of the respondents stated that they had had an eye examination earlier. **Conclusions:** The findings have significant implications for the organization of diabetes services in India for early detection and management of complications, including eye complications.

Key words: Awareness, diabetes, healthcare utilization, India, perceptions

Introduction

Diabetes mellitus is one of the commonest noncommunicable diseases.[1] In 2013, The International Diabetes Foundation estimated the global prevalence of diabetes to be 382 million.[2] Eight percent of these individuals were thought to be in the low- and middle-income countries. India is home to the second largest number of people with diabetes.[3] With rampant urbanization and a drastic change in lifestyle, the prevalence of Type 2 diabetes (the most common form of diabetes in India),[4] is expected to increase from 51 million in 2010 to 100 million by 2030.[5]

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This will place an enormous burden on a health system that is ill-equipped to handle even the present scenario. A detailed analysis of the determinants of awareness and diabetic care practices of persons with diabetes attending diabetic care facilities in India will help promote a better understanding of the current epidemic and how it is being responded to. It will help us develop policies that will equip the health sector to effectively tackle the increased magnitude. This study in 11 cities across nine states in India was conducted to assess knowledge of diabetes and its complications among persons with diabetes and to explore their health-seeking behavior and challenges in managing their diabetes and/or in accessing services.

Methods

Detailed methodology has been described in a companion paper on methods used in the study and published simultaneously in this journal. Only a brief description of the methods is included here.

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.

Selection of health facilities

A two-stage systematic stratified random sampling was used to identify facilities to be included. In the first stage, cities were stratified based on their population with a larger number of health facilities being included in the more populated cities. In the second stage, a random sample was drawn from a list of hospitals/clinics in each city, which was prepared after listing the facilities from various sources. This included the list of 5000 clinicians who attended the evidence-based diabetes management certificate course in India and a web search of hospitals from the 11 cities.

Persons with diabetes were randomly sampled at Diabetes Hospital/clinics after obtaining permission from hospital administrators and the individual clients attending the outpatient clinics. At each diabetic care facility, 4–6 persons with diabetes were identified among those waiting for doctor's consultation, selecting an equal numbers of males and females. An equal number of persons with diabetes in each of the following age strata (≤50 years and >50 years) were interviewed by trained interviewers using structured, pretested questionnaires.

Data collection instruments

Pretested questionnaire schedules were administered to the persons with diabetes included in the study. All data collection instruments for respondents, and the information sheets and consent forms, were translated into the local language and translated back into English. The instruments were translated into eight Indian languages – Hindi, Telugu, Tamil, Oriya, Bengali, Gujarati, Marathi, and Kannada. Written informed consent was obtained from all respondents prior to being interviewed.

Stata 14 SE for Windows (Stata Corp., TX, USA) was used for statistical analysis. Frequencies of the variables were tabulated. *t*-tests were used for continuous variables and Chi- square for categorical variables.

Definitions used

For the purpose of this study the following operational definitions were used:

- Public-funded: Facilities which were financed by the national or state governments or statutory bodies financed and controlled by the national or state governments
- Private-funded: Facilities which were financed by organizations or individuals on their own. These included both the not-for-profit as well as the for-profit agencies/individuals
- More populated/Larger metropolitan cities: Cities with a population ≥7 million
- Less populated/Smaller metropolitan cities: Cities with a population <7 million
- Standalone facilities: Facilities which provide only diabetic care facilities, irrespective of the size of the facility. This could include single practitioner clinics or hospitals with a large team of human resources
- Multispecialty facilities: Facilities which provided many specialty medical services including diabetic care facilities. These included polyclinics and large hospitals with both outpatient consultation and inpatient facilities
- Teaching facilities: All facilities providing postgraduate residency programs recognized by the Medical Council of India (MCI) and National Board of Examinations (NBE) (MD/MS/DNB) or postdoctoral specialty fellowships
- Nonteaching facilities: Facilities without formal training programs approved by the MCI or NBE for medical graduates.

Results

A total of 285 individuals were interviewed. About 56.5% (n = 161) individuals lived in the most populated metropolitan areas with a population above seven million. Almost 54.7% (n = 156) of individuals attended private hospitals or clinics. Almost equal numbers of males and females were included in the study (50.9% vs. 49.1%) [Table 1]. The mean age was 54.2 years (standard deviation [SD] ±12.3) (55.0 ± 12.7 years and 53.4 ± 11.9 years for males and females, respectively [P = 0.3]). The mean duration since the diagnosis of diabetes was 8.1 years (SD ± 7.3) years, being similar for males and females (8.3 ± 7.6 years vs. 8.0 ± 7.0 years), respectively (P = 0.7). Half the participants (50.2%) had a family history of diabetes and 41.7% were hypertensive. Individuals living in more populated metropolitan cities were more likely to have hypertension than those in less populated cities (49.7% vs. 31.4%, respectively; P = 0.002).

The mean frequency of clinic visits was every 2.5 ± 2.7 months, being more frequent in the public-funded facilities than in the private-funded facilities (1.8 ± 1.8 months vs. 3.1 ± 2.6 months, respectively; P < 0.001) [Table 2]. In addition to clinic visits, 25% of patients also visited a general practitioner every 2.4 ± 2.3 months. Visits were more frequent among those living in more populated cities compared to those in the smaller cities (1.9 ± 1.4 months vs. 3.5 ± 2.2 months, respectively; P = 0.01). The proportion of individuals attending clinics at monthly or more frequent intervals was significantly higher in the public-funded compared with private-funded facilities (65.9% vs. 38.5%; χ^2 = 21.3; P < 0.001), which remained significant after adjusting for age, education, gender, city type, and occupation (adjusted odds: 3.52; 95%, confidence interval: 1.95–6.37).

The commonest reason for not attending a clinic at least every three months (n = 42, 14.7%) was because they were instructed accordingly by their treating physician (50%), or regularly attended another physician (21.4%) or perceived that their diabetes was stable (16.7%). Cost was rarely mentioned as a reason for attending less frequently (4.8%).

Among the respondents, 6.3% (n = 18) were on diet modification only (did not use oral medications or insulin) to manage their diabetes. Over three quarters of the patients overall were taking oral hypoglycemic drugs (79.6%), being more frequent among patients in more populated metro cities compared with smaller metros (83.8% vs. 74.2%; P = 0.04) [Table 3]. One-third of respondents (32.2%) were on insulin. Almost 41% reported taking exercise and 12% used traditional Indian medicines or yoga. Many reported using two or more treatment modalities. Of the 227 persons

Table 1: Characteristics of the Study Population

Parameter	Total	
	n	%
Sex		
Male	145	50.9
Female	140	49.1
Age groups		
≤40 years	39	13.7
41-50 years	70	24.6
51-60 years	77	27.0
61-70 years	77	27.0
≥ 71 years	22	7.7
Level of education		
Cannot read or write	85	29.8
Up to primary education	23	8.1
Up to secondary education	79	27.7
Beyond secondary education	98	34.4
Occupation		
Currently employed	117	41.0
Retired/unemployed	100	35.1
Housewife	68	23.9
Years since diagnosis of diabetes		
≤2 years	72	25.3
3-5 years	64	22.5
6-10 years	72	25.3
11-15 years	38	13.3
16-20 years	24	8.4
≥21 years	15	5.3

Table 2: Frequency of visits to physicians' clinics and general practitioners

Parameter	Total (*n*=285)	
	%	%
Visits to physicians' clinic		
Every month*	145	50.9
Every 2-3 months	89	31.2
Every 4-6 months	30	10.5
Visit clinic less frequently	12	4.2
No response	9	3.2
Mean interval between visits (months)	2.5±2.7	
Visits general practitioner (*n*=70)		
Every month	34	48.6
Every 2-3 months	21	30.0
Less than 3 monthly	15	21.4
Mean interval between visits (months)	2.4±2.3	

*Significant at P<0.05

Table 3: Treatment profile of responding persons with diabetes

Treatment modality	Total (*n*=285)	
	n	%
Oral medications	227	79.6
Diet modification/control	150	52.6
Insulin	92	32.3
Physical exercise	117	41.0
Traditional Indian medicines	17	6.0
Yoga	17	6.0
Don't take any treatment	5	1.7

with diabetes stating that they were taking oral anti-diabetic medications, 22.5% (n = 58) were also taking insulin. Five patients (1.7%) said they were not taking any treatment.

About 62.1% (177) of respondents stated that they received information on diabetes and its management through interpersonal channels, whereas 25% had received information leaflets from their treating physicians. An additional 24.9% (71) said that they had not received any information on diabetes from the clinics they were attending with significant differences between those attending public- and private-funded institutions (40.3% vs. 12.2%; χ^2 = 29.87; P < 0.001). Significant differences were also observed between clinics in more populated cities compared to less populated cities (34.8% vs. 12.1%; χ^2 = 19.3; P < 0.001) and those educated to beyond primary school compared to those educated up to primary school (29.4% vs. 17.6%; χ^2 = 4.98; P = 0.03). Overall, 84.3% (193) said they found the provided information very useful.

Overall, 61.4% (167) stated that they also sourced information on diabetes from other sources, principally from family/friends or neighbors (50.2%, 84), or 22.7% (38) from mass media sources (both print and visual media). Accessing information from other sources was significantly higher among those attending private compared to public-funded facilities (68.0% vs. 53.3%; χ^2 = 6.15; P = 0.013), those educated to below primary level compared to those more educated (54.7% vs. 72.5%; χ^2 = 8.56; P = 0.003) and those interviewed in smaller cities (71.7% vs. 53.3%; χ^2 = 9.55; P = 0.002).

Respondents were queried about what they perceived to be the cause of diabetes [Table 4]. Family history (36.1%), increasing age (25.3%), and stress (22.8%) were the commonest causes whereas 22.1% did not know the cause. None of the demographic factors such as age, gender, literacy, or occupational category were associated with any of the commonly reported causes.

Half the respondents (50.2%) stated that another family member was also a diabetic and 41.7% said they were hypertensive.

When they attended the clinic respondents had the following investigations every 2–3 months: Blood test for glucose (90.9%), lipids (36.8%), kidney function (36.8%), urine examination (69.1%), weight monitoring (74.7%), blood pressure measurement (85.6%), foot check (33.3%), and an eye examination (44.6%). Eye examination was repeated at a mean interval of 5.2 months (SD ± 7.9). Only 10% recalled meeting an optometrist or ophthalmologist when they came for routine follow-up to the clinic.

Only 29.1% (83) stated that they monitored their blood sugar levels at home using a glucometer. Self-monitoring was significantly more likely among those attending private-funded compared to public-funded facilities (39.1% vs. 17.0%; χ^2 = 16.63; P < 0.001) but was associated with any other variable, including literacy. Around 70% of respondents (n = 200) perceived their current glycemic control as adequate or well controlled whereas 26.7% (n = 76) perceived their glycemic control to be poor or very poor. Less than half (45.3%) stated that they understood good/adequate control to mean that their blood glucose or HbA1c measurements were within accepted limits.

Nearly three out of every 10 respondents (28.8%) stated that they did not face any challenges in controlling their diabetes [Table 5]. A total of 190 (66.7%) respondents mentioned one or more challenges, the commonest being modifying their diet (67.4%), remembering to take medicines regularly (20.5%) and cost of medicines (17.9%). Costs were a significant challenge as 25.8% (49) of those facing challenges mentioned cost of medicines/cost of investigations/loss of wages as an important cause.

About 76.5% of the respondents were aware of complications of diabetes. Kidney failure (79.8%) followed by blindness/vision loss (79.3%) and heart attack (56.4%)

Table 4: Perceived cause of diabetes reported by the respondents

Perceived cause	Total (n=285)	
	n	**%**
Family history	103	36.1
Increasing age	72	25.3
Stress	65	22.8
Don't know	63	22.1
Excess sugar consumption	35	12.3
Overeating	29	10.2
Lack of exercise	25	8.8
Being overweight	18	6.3
God's will	14	4.9

Table 5: Challenges reported in controlling diabetes

Challenges reported	Total (n=285)	
	n	**%**
Do not encounter any challenges	82	28.8
Reported facing some challenge	190	
Making modifications in diet	128	67.4
Remembering to take medicines regularly	39	20.5
Cost of medicines	34	17.9
Cost of investigations	25	13.2
Lack of time	25	13.2
Distance to clinic	24	12.6
Regularly visiting the diabetic clinic	23	12.1
Loss of wages	14	7.4
Found it hard to accept being a diabetic	11	5.8

were the commonest complications mentioned. A total of 103 persons with diabetes responded to what complication concerned them the most. Almost 65.0% were most concerned about loss of vision/blindness while 43.7% were most concerned about kidney failure [Table 6]. Respondents from less populated cities were significantly more aware of complications compared to more populated cities (84.7% vs. 70.2%; $\chi^2 = 8.18$; $P = 0.004$). None of the other factors such as age, gender, literacy, occupation, or funding status of the diabetic care facility showed any significant difference.

Two-thirds (67.7%) of respondents ($n = 201$) stated that they had an eye examination earlier with the mean duration since the eye examination being 10.5 months. Only 2.8% (8) reported that the eye examination was performed by the physician whereas 68.8% had been examined by an ophthalmologist. Almost 60.3% respondents stated that staff at the clinic where they were interviewed had advised them to undergo an eye examination.

Discussion

Age is an important risk factor for diabetes,[3] and there is evidence that Indian Asians develop diabetes at a younger age than their Caucasian counterparts,[6] as demonstrated in an analysis of 900,000 adults from seven Asian countries. The authors of this study postulate that this could be due to the earlier age of onset of substantial weight gain among younger adults as well as genetic factors.[7] The mean age of participants in our study was older than in other studies from India,[3,6,8] which is probably because ours was a facility-based study of known diabetics whereas most other studies were community based where detection of diabetes was included in the study protocol. In this study, a striking finding is that the mean duration of diabetes among the youngest age group (≤40 years) was over 5 years, suggesting a likely early age of onset compared to other countries. An early onset of diabetes was also reported from a population-based study from three cities in South India,[8] where more than a third of the diabetics were below the age of 44 years.

The prevalence of diabetes has increased in India from 5% to 15% in urban areas and from 2% to 5% in rural areas over two decades (1990–2010).[6] The higher prevalence in urban areas probably reflects a higher incidence combined with better control through better access to affordable care and hence longer life expectancy than in rural areas. Even in urban areas, there is a socioeconomic differential in mortality,[9] as diabetics of low socioeconomic status can spend at least a quarter of their income on treatment of their diabetes.[6] Our study shows that nearly one in five individuals was from a lower socioeconomic group, as evidenced by their literacy and occupational status.

As stated already, we observed that over half of all patients reported attending the diabetic clinic on a monthly basis, being significantly higher in public-funded clinics. There are several possible explanations for these findings. Firstly, in a cross-sectional study, individuals who attend more frequently would have a higher probability of being interviewed than those who attend less often, but this selection bias does not explain differences between the public- and private-funded facilities. Secondly, in India public-funded services are free at the point of delivery of care, but some medications have to be purchased by patients (out-of-pocket expenses). Cost was rarely reported as a barrier to attendance. Thirdly, in India it is unusual for prescriptions to be issued for more than 1 month's supply of medication, necessitating frequent visits to clinics, especially in public-funded institutions where diabetes medicines are provided free on specified days. Monthly visits to the physician are not required if there are no complications and control is adequate, and the costs of care both for the provider and the persons with diabetes could be reduced by more optimally spaced visits, as monthly visits by each person with diabetes in India translates into 40 physicians working full time, every day just to manage diabetics [Table 7].

Table 6: Respondent awareness of complications of diabetes

Complications	Aware of one or more complication (*n*=218)		Mentioned Complication of most concern (*n*=103)	
	n	%	*n*	%
Kidney failure	174	79.8	45	43.7
Blindness/loss of vision	173	79.3	67	65.0
Heart attack	123	56.4	21	20.4
Foot ulcers	77	35.3	13	12.6
Losing a limb	34	15.6	13	12.6
Stroke	33	15.1	6	5.8
Numbness of feet	26	11.9	5	4.8

Table 7: Estimated requirement of physicians for monthly consultations of persons with diabetes

The need	Persons with diabetes in India	Indian population	DM/million population	Diabetic physician need
	65,000,000	1,300,000,000	50,000	
Services needed	DM/million population	Number of visits per year if each person attends monthly	Number to be seen per day (300 working days per year)	Number of physicians needed per million population to see 50 diabetics every working day of the year
	50,000	600,000	2,000	40

The study shows that lifestyle modification is not a common practice among persons with diabetes in India with oral hypoglycemic medications being the commonest treatment modality. A few studies have shown equivalent benefits in relative risk reduction in control of glycemia in the management of diabetes with lifestyle modification, metformin, or both.[10] Lifestyle modification can play a major role in not only preventing diabetes,[5] but also preventing the progression of diabetic retinopathy.[11] Recent studies have shown that persons with diabetes with eye complications have significantly lower rates of physical activity and exercise.[12] A meta-analysis demonstrated that exercise significantly improves glycemic control and reduces visceral adipose tissue and plasma triglycerides (which are critical risk factors for diabetic retinopathy) in persons with Type 2 diabetes.[13] Lifestyle modification, followed effectively, can also help reduce the cost of care. Unfortunately observations from our study show poor compliance with lifestyle modification.

Previous studies have found that a family history of diabetes and hypertension are significant risk factors for diabetes.[14-16] In North India, it was shown that in middle-class urban areas, the age-adjusted prevalence of hypertension in people with diabetes was 72.1% compared with 26.5% in nondiabetic individuals.[17] It has also been shown that up to 75% of patients with Type 2 diabetes mellitus have a family history of diabetes.[14] In our sample half had a family history of diabetes and 41.7% also had hypertension. Although the numbers are probably lower in our sample (owing to differences in study design and sample population), the prevalence is still high. Hypertension is a modifiable risk factor and studies show that reduction of blood pressure reduces the risk of vascular complications in diabetes mellitus.[18,19] It is thus prudent to encourage good blood pressure control in persons with diabetes so that the risk of complications like retinopathy can be reduced.

Dietary modification was highlighted as a major challenge to managing their diabetes across the 11 cities in India, as has been reported in other countries in Asia.[20] A recent study from China could not identify any specific determinants at the individual level like literacy or household income for good dietary practices.[21] This could be due to the chronic nature of diabetes because of which people with diabetes may not directly appreciate a cause-and-effect relationship. Therefore educational interventions and counseling activities need to constantly reiterate the importance of avoiding high-calorie diets and how to change dietary practices.

Costs of medications and investigations and loss of wages were critical challenges in our study. Indeed, another study in India reported that a significant proportion of diabetics perceive that they are an economic burden on their families due to the ongoing cost of care,[22] and lowering the cost of medicines may play an important role in improving adherence to oral hypoglycemic agents.[23] In a country like India where health insurance is almost nonexistent, it is imperative that the cost burden for a chronic condition like diabetes is reduced so that persons with diabetes can be motivated to adhere to the medications prescribed.

Persons with diabetes who participated in the present study highlighted renal and visual complications of diabetes as the ones they were aware of and most concerned about, followed by heart and foot complications. Eye and kidney disease were also highlighted by persons with diabetes in other studies.[24,25] A nationwide study in India on persons with diabetes observed that the commonest complications were foot (32.7%), eyes (19.7%), cardiovascular (6.8%), and nephropathy (6.2%).[26] As in our findings, studies in Gambia and Turkey also observed that 67–88% of the persons with diabetes highlighted the eye complications in diabetes.[27,28] There is a consistency in what has been observed by examination and what is perceived by persons with diabetes in the present study regarding complications of diabetes although the frequency of reported complications may differ. It is thus important to realize the critical role that health education can play in augmenting the awareness of populations by focusing on controlling complications that concern them the most.

Most of the available literature shows that literacy is associated with awareness and practices in diabetes.[27,29,30] However, we did not find literacy to be associated with awareness of diabetes and its complications, nor practices like self-monitoring or dietary modification. Whether this was because we conducted the interviews in a hospital setting or whether this is because of poor educational interventions and information available on diabetes in general, is hard to say.

Our study had some limitations. Since our study was a hospital based, it may not be representative of all diabetics. The data were collected using a questionnaire schedule and therefore recall and selection bias are likely to be present. Lastly, we did not study the rural population and hence our findings cannot be extrapolated to a rural scenario. However, our rationale for the present study was that if gaps exist in diabetic care practices in urban areas, it is likely that the situation could be the same or worse in rural areas.

This multi-center study helped in identifying the health behavior and health-care access patterns in urban India. Such information is needed to plan need-based services at diabetic care facilities to improve the control of diabetes and reduce the risk of complications. Further research into the same will enable us to target core issues that hinder awareness of diabetes and its complications, and compliance to treatment.

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Conflicts of interest

There are no conflicts of interest.

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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%) (χ^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%) (χ^2 = 4.19; P = 0.04), those with higher educational attainment (80.8%) compared to those who were less educated (66.9%) (χ^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%) (χ^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%; χ^2 = 18.7; P < 0.001), among those interviewed at exclusive/stand-alone eye hospitals compared to multispecialty hospitals (54.6% vs. 39.5%; χ^2 = 7.25; P = 0.007), among the better educated (56.1% vs. 37.8%; χ^2 = 11.72; P = 0.001), persons with known diabetes of more than10 years (57.6% vs. 44.0%; χ^2 = 6.78; P = 0.009), those who regularly self-monitored their glycemic status (62.1% vs. 44.0%; χ^2 = 10.83; P = 0.001) and among those who perceived their glycemic control as adequate (100.0% vs. 18.3%; χ^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%; χ^2 = 6.48; P = 0.01); private versus public-funded facilities (38.1% vs. 24.4%; χ^2 = 6.88; P = 0.009); stand-alone eye facilities compared to eye units in multispecialty eye facilities (36.6% vs. 27.2%; χ^2 = 3.17; P = 0.07), higher versus lower educational attainment (41.2% vs. 18.2%; χ^2 = 19.4; P < 0.001), longer versus shorter duration of diabetes (52.1% vs. 19.6%; χ^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%; χ^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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Original Article

Is India's policy framework geared for effective action on avoidable blindness from diabetes?

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ABSTRACT

Background: The growing burden of avoidable blindness caused by diabetic retinopathy (DR) needs an effective and holistic policy that reflects mechanisms for early detection and treatment of DR to reduce the risk of blindness. **Materials and Methods:** We performed a comprehensive health policy review to highlight the existing systemic issues that enable policy translation and to assess whether India's policy architecture is geared to address the mounting challenge of DR. We used a keyword-based Internet search for documents available in the last 15 years. Two reviewers independently assessed retrieved policies and extracted contextual and program-oriented information and components delineated in national policy documents. Using a "descriptive analytical" method, the results were collated and summarized as per themes to present status quo, gaps, and recommendations for the future. **Results:** Lack of focus on building sustainable synergies that require well laid out mechanisms for collaboration within and outside the health sector and poor convergence between national health programs appears to be the weakest links across policy documents. **Conclusions:** To reasonably address the issues of consistency, comprehensiveness, clarity, context, connectedness, and sustainability, policies will have to rely more strongly on evidence from operational research to support decisions. There is a need to involve multiple stakeholders from multiple sectors, recognize contributions from not-for-profit sector and private health service providers, and finally bring about a nuanced holistic perspective that has a voice with implementable multiple sector actions.

Key words: Chronic disease, diabetes, diabetic retinopathy, health policy, India

Introduction

The growing prevalence of diabetes as a silent killer in the past two decades has contributed to global cognizance of its public health importance and of its complications, including diabetic retinopathy (DR).[1-3] Globally, 1.85 million people go blind due to DR,[4] and one in five persons with diabetes in India suffers from DR.[5] Currently, DR is the leading cause of avoidable blindness in the high-income countries and by 2035, it could also be a leading cause of avoidable blindness in low- and middle-income countries, where 80% of the global diabetic population is expected to reside.[6] India is already one of the diabetes epicenters of the world, projected to have 109 million diabetics in the next 20 years.[7]

Evidence suggests that good glycemic control may arrest the progression of DR.[8] Early detection and treatment can reduce the risk of blindness from DR by 90%.[9] The big question is: Is India's national policy architecture geared to combat the mounting challenge of DR? Delving into policies may highlight

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existing systems, trajectory of approaches, and levers to advance game-changing actions to tackle blindness due to DR.

Materials and Methods

A desk review was conducted, which involved identification of documents from a keyword-based Internet search. Key officials at administrative Ministry/Institution(s) were consulted to broaden the scope of the review. Two reviewers independently assessed, retrieved policies, and extracted contextual and program-oriented information as per the following:

Inclusion criteria

- Documents/monographs produced and circulars/notifications issued or ratified in the last 15 years (since 2000) when noncommunicable diseases (NCDs) received global attention from the World Health Organization (WHO)
- Provide "policy," "strategy," "program," "plan," "guidelines," and "working group recommendations" with reference to DR
- Keywords or reference to "DR," "diabetes complication/s," "NCD," "chronic disease," "blindness," "vitreo-retina (VR)," "medical retina," "cardiovascular disease," "modifiable risk factor/s," "lifestyle," "National Blindness Control Programme," "National Programme on Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS)," and "5-year plan (hereafter referred to as nth plan)."

Exclusion criteria

- Studies (journal articles and gray literature)
- Reports/operational guidelines from national and international private for-profit service providers, Non-Government Organizations (NGO) and hospitals, health clinics, or programs that provide health services
- Evaluation and audit reports (as their focus is on implementation, rather than the policy environment).

Using a "descriptive analytical" method, the results were collated and summarized as per themes to present status quo, gaps, and recommendations for the future.

Results

A total of 50 documents were reviewed (15 global; 35 national) to assess the policy environment for operationalization of quality, diabetic eye care. The following findings suggest that there is scope to strengthen India's approach:

Wide angle: The landscape for India's policy vision on diabetic retinopathy

In a nutshell, national policy priorities to accelerate reduction in DR prevalence are largely reflected in the realm of NCD and blindness prevention, detection, and control.

Early wins: Taking initiative through national programs

The WHO has led agenda setting and stewardship of global plans and programs for NCD and eye health. India has remained in-step and in some cases preempted World Health Assembly resolutions to confront the range of NCDs and diabetes and eye care [Table 1].

India was the first country in the world to launch a National Programme for Control of Blindness (NPCB) in 1976, before the WHO Programme for the Prevention of Blindness was announced.[10] The National Diabetes Control Programme was rolled out as a pilot (1985–1990) prior to global, landmark resolutions of 1989.[11,12] In 2010, an integrated NPCDCS was approved close on the heels of the WHO Action Plan for Prevention and Control of NCDs in 2008 which called on member states to establish national programs.[1]

Principal strategies for comprehensive, diabetic eye care and management

Structures, systems, and services to tackle DR as per the current policy framework are predominantly extended via the NPCB and NPCDCS in India. The National Rural Health Mission (NRHM) subsumed the NPCB in 18 states when it came into existence.[13]

Although it was not an intense part of the original mandate, NRHM, now National Health Mission (NHM) includes the NPCDCS. NPCDCS is currently operational in 152 districts,[14] whereas NPCB is operational across all 640 districts.[11]

Services at each level of care are described below.

Connecting the dots of primary care

At all Primary Health Centres, Vision Centres are being established and manned by Para-Medical Ophthalmic Assistants (PMOA)/Ophthalmic Officer (PMOO) to screen and maintain Diabetic Registers (trained to work with fundus photographs). Community Health Centres (CHCs) under NPCB focus on early detection through vision testing and refraction, referral, Information Education and Communication (IEC), and involving the community. In 2010–2011, sanction was provided to 7000 CHC and District Hospitals to create NCD Clinics to screen, diagnose, and manage chronic diseases, including complications.[14]

Table 1: Areas for action on DR as reflected in policy documents at the global and national level

Areas	Level	1970s	1980s	1990s	2000s	2010s
Health	Global	Health for all by 2000 Primary health care	Health promotion Healthy cities	Intersectoral approach Task-shifting Community participation	Health systems Healthy lifestyle Renewal of primary health care	Universal health coverage Health systems
Non-communicable diseases	Global		Lifestyle targets World Health Assembly resolution on NCDs	1st World Health Report on NCDs	Minimize risk factors (2000) Life course approach to health Establish national programmes (2008)	Integrating NCD services into primary health care Health systems strengthening Surveillance and monitoring
	National			9th plan (1997-2002)- Integrated NCD programme	NPCDCS approved (2010) 11th plan (2007-2012)- establish national guidelines for NCDs; holistic systems for NCDs	Integrated and comprehensive interventions (based on pilot results)
Diabetes	Global	Expert meetings for treatment/ technology	Establish national diabetes programmes (WHA, 1989)	Diabetes prevention, control and management World Diabetes Day established (1991)	Diabetes Action Now Your eyes and diabetes (2002) Epidemic rates	Pandemic proportions of NCDs
	National		7th plan (1985-90) - National Diabetes Control Programme as a pilot	8th plan (1992-97)- pilot NDCP under state scheme 9th plan (1997-2002)- diabetes is a major public health problem	10th plan (2002-2007) - Merge the central sector scheme of pilot diabetes control programmes with central institutions	NPCDCS Operational guidelines Revise Indian Public Health Standards
Eye care (where DR is mentioned specifically)	Global	Primary eye care WHO Programme for the Prevention of Blindness initiated (1978) Establish national programmes	Detection of eye problems and referral algorithms WHA resolution on blindness	The right to sight for the elimination of avoidable blindness (Vision 2020 document underway and 1st Action Plan, 1999)	Global Action Plan Joint provision of services with diabetic care World Sight Day (2002).[13] Scale up of Vision 2020 to include DR	Universal eye health Eye health workforce Integrating eye health into national health plans and health service delivery (2013)
	National	National Programme for Control of Blindness established (1976)	Focus on traditional eye conditions	9th plan - Include 'other' causes of blindness	Adoption of VISION 2020 in 2001 10th Plan (2002-2007) - NPCB included screening for DR 11th Plan (2007-2012) - DR under 'other' eye diseases Proposed Grant-in-aid for DR (2008).[14]	12th plan (2012-2017) - grant-in-aids, patient eligibility, for overall eye care

NCDs: Non-communicable diseases, DR: Diabetic retinopathy, NCD: Noncommunicable diseases, WHO: World Health Organization, WHA: World Health Assembly, NDCP: National Diabetes Control Programme, NPCDCS: National Programme on Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke, NPCB: National Programme for Control of Blindness

Auxiliary Nurse Midwives (ANMs) and Multi-purpose Health Workers (MPWs) are to support detection and referral for NCDs at Type B sub-centers.[15] Field health workers under NPCB, also conduct house-to-house surveys, awareness generation, and referral.[16]

Strengthening secondary eye care

Traditionally, district hospitals, notified as base hospitals provide eye care through an out-patient department, dedicated ophthalmic operation theater, and a separate eye ward. NCD clinics have been established at identified district hospitals to provide daily emergency care, screening, counseling, and management of diabetes. District hospital upgradation has also been charted, wherein multipurpose Medical Intensive Care and Stroke Units may be built.[17,18]

The state/union territories are required to develop a referral protocol for cases from the district hospital to tertiary care.

Transforming tertiary eye care

Twenty Regional Institutes of Ophthalmology (RIO) provide comprehensive and advanced patient eye care, research, and training at tertiary level.[19] Four RIOs specialize in VR and/or medical retina. Strengthening Government Medical colleges to provide specialized tertiary care facilities, resource centers for training and research in NCDs is an aim of the Ministry of Health, Government of India.[15]

Critical appraisal of policies to support diabetic eye care

For clarity of purpose and to commence impactful action on DR, there is a need for elaboration of components within the health systems response, such as clinical guidelines, information systems, quality assurance, manpower planning, and public awareness generation. Only publications from the last decade included measures that address a combination of program components. Salient features for diabetic eye care were examined across interplay of relevant program components [Table 2].

Integrated service delivery: Shall the twain meet?

Clear treatment guidelines for DR are required. The NPCDCS provides scope for inclusion of management of DR as a complication. While the WHO-Indian Council of Medical Research has developed guidelines for diabetes, including its complications, they have not been updated or adopted nationally.[20] Neither do they provide details for screening and referral for the treatment of DR. The Vision 2020: Right to Sight initiative in India has recently published a visually-rich manual of clinical guidelines for comprehensive management of DR in India,[21] building on International Council of Ophthalmology guidelines developed in 2008.[22] Both of these are a step in

Table 2: Components relevant to diabetic eye care delineated in national policy documents

Component	Number of policies	% reviewed	Comprehensive-ness (in at least one policy)	Areas for strengthening	Relevant National Policy reference
Clinical guidelines	3	0.8	*	Need to be formally adopted Lack recommendations on patient education and advice, prevention, family care and longer-term management	[20-22]
Targets	1	0.03	†	DR-related targets absent in most documents (1.2 lakh cases mentioned in 2013) State and district plans lack detail	11
Human resource	10	0.3	‡	Planning, skills upgradation and training require attention (especially for NCDs)	[19,22-30]
Health Management Information Systems (HMIS)	6	20	*	Centrally-driven model, with limited feedback mechanisms on reporting formats Emphasis on computerization and standardization, less on types and volumes of information flows or 'who' requires training	[15,19,23, 24,28,31]
Monitoring and Evaluation	10	33.3	*	Implicit focus on fund and infrastructure utilization and verification of private sector/ NGO grants External evaluation by private bodies and project management require detail NCD Cells at all levels expected to plan and review, including complications	[11,15,22, 25,27-29,31-33]
Convergence	14	46.7	*	NPCDCS guidelines lack mechanisms to build convergence While partners are mentioned the exact role requires detail	[11,17-19,23,24,26-29,31,32,34,35]
Quality assurance	6	20	†	Most documents highlight problems in quality of services and medicines; need to establish procedures and step-by-step guides to operationalize the same (revision of Indian Public Health Standards) Training of PMOAs and surgeons as next steps	[11,18,23, 24, 26,27]
Equipment	6	20	*	Need to standardize what equipment for Vision Clinics and NCD Clinics may be procured to screen and RIOs for VR surgery	[11,19,22, 25,28,32]
Advocacy	0	0	†	No explicitly identified issues for advocacy, but coverage, quality of services, affordable care, convergence, health promotion, and cross-disciplinary research need to be on the agenda	
Health education	13	43	*	A clearly articulated national health promotion and communication strategy for diabetic eye care	[11,14,15, 17,22-26, 28,29,31,32,36]
Budgetary allocation	1	0.3	*	Additional allocations to support Rs. 18 cr to DR (as 8% of total blindness under recurring expenditure) and Rs. 22.5 cr for VR surgery State Health insurance plan like Aarogyasri cover Retinal procedure	[11,37]
Evidence used	5	16	†	Majority of documents cite no evidence Surveys and population-based studies of limited scale provide prevalence data on avoidable blindness and NCDs, but not diabetic eye care	[15,23,25, 28,29]
Identification of good practice	5	16.7	†	Integrated NCD services recommended to continuously monitor all diabetics at the primary level (Aravind rural primary eye care centres and LVPEI/ICARE Mudhole experience) Limited information about Kerala, Tamil Nadu and Bihar models	[17,23,24, 31,38]

*Basic contours and mechanisms are outlined. †Mention of the word or statement of need. ‡Responsibilities for action are described. NCD: Noncommunicable diseases, NPCDCS: National Programme on Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke, DR: Diabetic retinopathy, NGO: Non-Government Organizations, PMOA: Para-Medical Ophthalmic Assistants, RIO: Regional Institutes of Ophthalmology, VR: Vitreo-retina; LVPEI: Lakshmi vara prasad eye institute, ICARE: International centre for advancement of rural eye care the right direction, featuring assessments, equipment, patient education, specialist support, and timing of follow-up, but require to be owned by both ophthalmologists and physicians.

The goal of collaborative care remains to be fully conceptualized and detailed across the primary, secondary, and tertiary levels of care. Better coverage and follow-up rates for DR are achievable only when eye care is provided jointly with diabetic care at the same healthcare facility. However, while the same facility offers eye and NCD services in India, each package under NPCDCS and NPCB is a stand-alone package, without information-sharing or a defined intra-facility or clear inter-facility referral pathway from the ophthalmologist to the physician or the endocrinologist and vice versa. A literature-based mapping of DR-relevant service delivery points and referral linkages are presented [Figure 1].

Human resource management

Establishing national coordinating mechanisms at health ministries and development of an eye health workforce, including paramedical professionals and community health workers has received global emphasis.[25,26] In India, adequacy and competency of overall human resources for comprehensive eye care is questionable.[27] A clear system to plan supply of human resources, particularly for NCDs is required. While manpower guidelines prescribing minimum requirements have been articulated for contractual doctors and staff,[25,27,28] skills and competencies of various health workforce cadres are lacking.

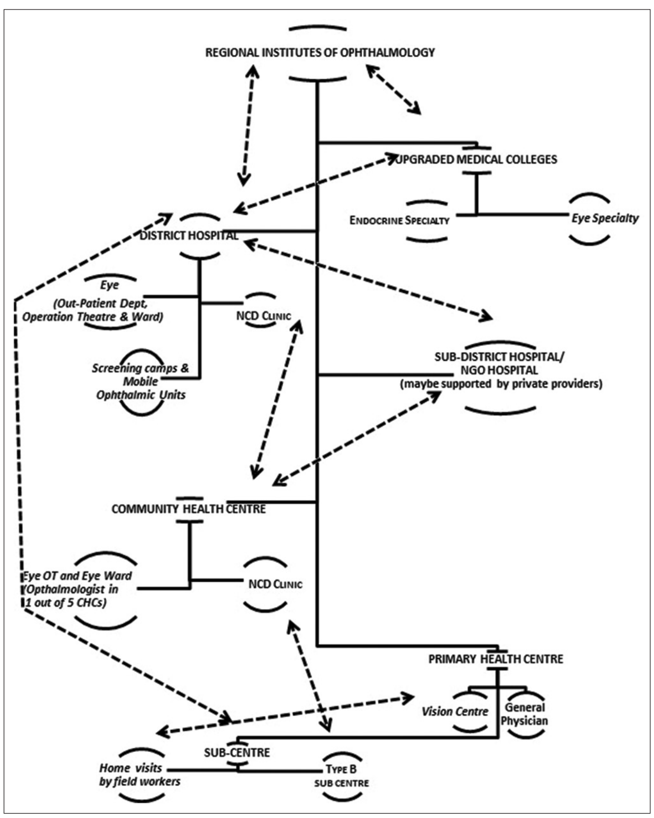

Figure 1: Eye care and diabetic care across levels of health service delivery in India

Affixing responsibilities for DR care is required. For example, CHCs are required to facilitate intensive glycemic control, retinopathy screening, and photocoagulation, but the "when" "how" "by whom" and "where" are not provided. NPCDCS operational guidelines bear only slightly more detail regarding staffing and roles within the NCD Cell as in the National Programme for Health Care of the Elderly.

Capacity building

Building a cadre for primary eye care, comprising surgeons, nurses, and requiring refresher training for PMOAs/PMOOs, Medical Officers, Accredited Social Health Activist (ASHA), and integrated child development scheme (ICDS) workers and one for NCDs, comprising 32,000 district physicians, nurses, and consultants has been recommended.[15]

Consolidation of curricula from the NHM, NPCB, and the NPDCS is necessary to lend structure to continuing education and skills development programs relevant to DR. Health services research and strengthening existing national and local training institutions on priority (RIOs, medical colleges, and district and sub-district hospitals) may facilitate more effective training programs.

Task-shifting emerges as a strong undercurrent, with training also being suggested for counselors, social workers, practitioners of Indian Systems of Medicine, Registered Medical Practitioners, ANMs, MPWs, and other locally available human resources.[25] Since 2009, efforts to equip the ASHA as a "lay diabetes facilitator" are ongoing, but evidence has not translated into policy directions.[39-41]

Infrastructure and equipment

There is a shortfall in equipment for the treatment of common eye diseases as well as surgical services.[16] Policy debates highlight challenges in the availability of good screening and diagnostic equipment, need for modern surgical tools and intraoperative patient care, full asepsis at all levels to prevent postoperative infection, and high quality presterilized drugs and surgical consumables.[42]

Guidelines and norms for assistance under NPCB have shown some inconsistencies. For example, fundus cameras are available at Vision Centres in the NGO sector, but there is no mention of the same under relevant documents for grants-in-aid or NRHM Programme Implementation Plan (PIP).

Real-time surveillance, health management information systems and monitoring

Reliable and timely consolidation of information from NPCB and NPCDCS at national, state, and district levels may potentially strengthen planning of DR programs. Global calls to establish monitoring mechanisms and coordinating agencies date back to the World Health Assembly resolution of 2003 in eye care,[43] through the Moscow Declaration in 2011 for NCDs.[44] Risk factors, outcomes, social and economic determinants of health, and health system responses should ideally be surveyed.[45-47]

The last two 5-year plan sketch a number of disparate mechanisms, but what would be most useful is to suggest how they may work together [Table 3].

Table 3: Monitoring and surveillance mechanisms mentioned in national policy documents

Mechanism	Task
Integrated Surveillance Project (IDSP)	Collect risk factor and morbidity prevalence on NCDs in seven states. No information on mortality, complications or expenditure
Sentinel Surveillance Units	Monitor, survey and study ocular morbidity
NCD Cells	Gather data for an epidemiological database on NCDs
Technical Resource Group (TRG)	Provide dedicated oversight and independent evaluation
Nutrition monitoring	Identify trends and initiate interventions on diabetes
Disease Registry	Collect secondary data related to specific diagnosis, condition, or procedure
Involve medical colleges	Operational and evaluation research
Health Impact Cell	Proactively understand the health impact of policies
Community-based Monitoring Committees	By Panchayati Raj Institutions (PRI), community based organizations (CBO), voluntary organizations (VO) and NGOs

NCD: Noncommunicable diseases, NGO: Non-Government Organizations

While the NHM is designed to monitor all programs under a single administrative system, its separation of accountabilities (design of the standard formats/software and training of management information system staff at the center, analysis of performance and expenditure by states, and compilation of data and monitoring of performance at the block level) does not provide sufficient tools for information-sharing, joint planning, and coordination or concurrent monitoring.

Promoting outreach activities and public awareness

The key messages, approaches, and arrangements for IEC are embedded in policies as an overlapping, fluid menu of options [Table 4]. Development of application-oriented strategies, that take a life course approach and tailor different approaches to varied contexts and target groups would further their utility. Vision 2020 has conducted workshops and roundtable meetings to develop an action plan in this realm.[48]

Global policies envision a leadership role for an adequately staffed and funded health promotion unit within the Ministry of Health,[1] but this is yet to be realized via the Central Health Education Bureau or a new National Institute for Health Promotion and Control of Chronic Diseases.[17] They may explore inclusion of NCD and blindness control activities into primary health care as aligned to the Moscow Declaration, potentially via Village Health Sanitation and Nutrition Committees and other avenues.

Budgetary allocations

There is nearly a 6-fold jump in NPCB allocations since the Ninth Plan and close to a 5-fold jump in NPCDCS funding in a short span since 2010–2011 [Figure 2]. NPCDCS funding has increased on account of increasing geographical coverage. As a proportion of the total healthcare budget,

Table 4: Salient features of health promotion relevant to DR from policy documents

Key message/ communication goal	Approaches	Intervention partners	Relevant National Policy reference
Primary and secondary prevention Early diagnosis and prompt treatment of NCDs	Mass media Learning resource materials	-	[28]
-	-	Non-formal leaders	[23]
-	-	PRIs, user groups, and CBO/ NGO/ VO representatives	[24]
Increased physical activity Avoidance of tobacco and alcohol Stress management Knowledge of risk factors Self-management by patients	Opportunistic screening at camps Interpersonal communication (IPC) Materials (posters and banners) Mass media (radio, television, print media) Mid-media and locally prevalent folk media	Community, school and workplace settings	[17]
Prevent risk factors of NCDs and promote healthy life style habits	-	Peripheral health functionaries and NGOs to lead and PRIs and NGOs to support	[1,15,49]
Diabetic Retinopathy – symptoms and control of blood sugar levels	Posters in multiple languages World Sight Day Newsletter*	-	[1,9,50]

*No issues available online prior to October-December 2011. NCD: Noncommunicable diseases, NGO: Non-Government organizations, PRI: Participatory research initiatives, CBO: Community based organizations, VO: Voluntary organizations the NPCB allocations remain nearly at the same level whereas NPCDCS allocation has doubled.

The Twelfth Plan initiated bold interventions under NPCDCS up to the district level [Table 5]. This confirms the level of commitment accorded to blindness and NCD control activities. Data on the proportion of total outlay on diabetes are not available since the Eleventh Plan, after merger of pilot programs. A limited provision of INR 1500 for DR laser and INR 5000 for VR surgeries has been made. No strategies or incentive mechanisms have been devised for greater uptake of DR services at secondary care facilities. No provisions on financing for vulnerable populations were found.

Changes in the ratio of sharing between the Centre and State Government from 80:20 to 75 in the last two 5-year plan may influence fiscal planning. In addition, from 2013 to 2014, NPCB expenditure falls under the NCD flexi pool, under the recently approved NHM umbrella. The 2015 budget cuts in the health sector, attributed to large unutilized sums may impact these plans.

Interconnectedness with other policies

Global health resolutions call for strengthening partnerships, with a view to share responsibilities, coordinate for resource

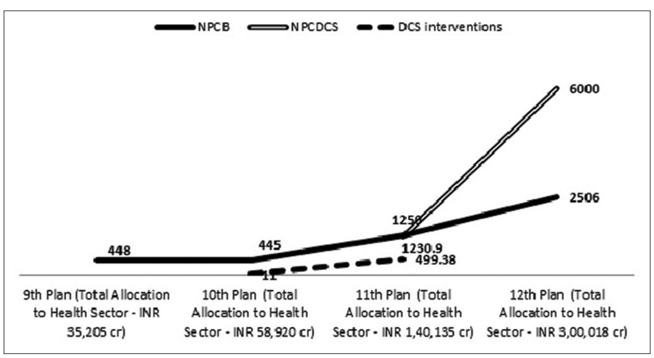

Figure 2: Outlays as per Indian 5-year plans (Indian Rupees in Crores)

Table 5: Significant budgetary initiatives relevant to DR in the Twelfth Plan

Area	Budget (in crore INR)	Remarks
Health education	12	Triple the previous amount
Target 1.2 lakh DR cases	18	Recurring expenditure (8% of total NPCB outlay @ Rs. 1,500 per case)
VR surgery for 0.45 lakh cases	22.5	Recurring expenditure (3% of total NPCB outlay @ Rs. 5,000 per case)
Assistance for RIOs	30	Five times the previous amount
Mobile Ophthalmology vans	2506	First-time investment

DR: Diabetic retinopathy, RIO: Regional Institutes of Ophthalmology, VR: Vitreo-retina, NPCB: National Programme for Control of Blindness, INR: Indian Rupee

mobilization, advocacy, capacity building, and collaborative research. They highlight the importance of intersectoral policies, regulations, and appropriate measures to minimize the effect of the major risk factors of NCDs. India's plans echo this sentiment. However, the nature and extent of engagement among multiple stakeholders, especially at the state and local level remains to be fleshed out.

Many national policies from nonhealth sectors have an impact on DR, through modification of lifestyle-related risk factors, and the interplay of social determinants of health and built environment for diabetes. Opportunities to incorporate prevention of diabetes, blindness, and visual impairment in schemes for the development of women and children, nutrition, National Urban Renewal Mission, school health programs, transportation, tobacco control, poverty reduction strategies, and relevant socioeconomic policies have been initiated and show promise. Policies must move beyond the usual suspects to apply across sectors, such as agriculture and food safety, finance (pricing and taxation), trade, environment, education, disability, alcohol, youth and sports, and local governance vide Panchayati Raj Institutions, Civil Society Organizations, and self-help groups.

The fine print: Policy commitments of direct relevance to diabetic retinopathy

Only a handful of national documents, out of the 35 reviewed, bear details for public health action on DR care and management.[11,15,19,24,25] The Ninth Plan (1997–2002), issued while "VISION 2020" was being prepared, was the first to call for inclusion of other causes of blindness. The Tenth Plan squarely stated that NPCB would tackle DR, following Vision 2020's inclusion of it as a priority eye condition.[9] The plan provided for screening of diabetics for retinopathy estimated the prevalence of DR at 20% among diabetics. Prior to the Tenth Plan, it appears that strategies for reduction in the prevalence of cancer were given greater priority vis-à-vis other NCDs.

Budgetary guidelines relevant to DR were developed by NPCB from 2008 onward. Recurring grant-in-aid sums were established for complete treatment of DR by voluntary organizations, NGOs, or private practitioners in fixed facilities and for VR surgery.[27] Patient eligibility, evidence, maintaining a DR register and submission of monthly reports on cases screened, treated, and operated in prescribed formats, and payments are mentioned, but without details.

For nonrecurring grant-in-aid for the development of mobile ophthalmic units with tele-ophthalmic network and fixed tele-models (up to maximum of INR 0.6 million), at least one eye surgeon in the base hospital is required to be experienced in DR. Currently, the PIP for 2013–2014 includes active DR screening of the population above 50 years at eye camps and transportation of operable cases to care facilities.

Conclusion

The policy literature is unanimous on the importance of strengthening functional linkages among primary, secondary, and tertiary care centers for integrated treatment of diabetes mellitus, hypertension, and heart disease. However, "universal eye health" as a backdrop for the systems' response and governance structures suggests that there are many ways to significantly improve early detection, treatment, and management of DR in India.

Recommendations of the World Health Report in 2008 on primary health care sought to breathe life into the aims of the Alma Ata Declaration, translating public policy for health systems strengthening and governance at the lowest level. India's policies have begun to shape a stronger primary eye care infrastructure and cadre, such that patients with simple eye conditions do not require to access services at secondary or tertiary hospitals.

A lack of focus on building sustainable synergies and sketchy details appear to be the weakest links across policy documents. Many of them lack the "how to" mechanisms for collaboration within the health sector and with other sectors. Operational research is required to identify mechanisms of convergence between NPCDCS and NPCB programme activities. To reasonably address the issues of consistency, comprehensiveness, clarity, context, connectedness, and sustainability, policies will have to rely more on evidence to support decisions and present essential actions. Current policies also need to expand their view of contributions by the not-for-profit sector and private health service providers to holistically address the situation. At the moment, limited innovations and voices are reflected.

There is a growing recognition of the need for multi-sectoral actions, if the commitment to tackle DR is to be adequately reflected in the policy realm. This is evident from reflections on policy formulation processes through working group notes and active revisions in the last decade. This is, especially crucial as the key tasks to prevent and control DR include improving dietary intake, reducing high levels of stress and lack of physical activity, as well as managing rapid urbanization and concomitant lifestyle change. As Vision 2020 is less than 5 years away, it is these factors and a responsive, nuanced policy architecture that may pave the way for vital change.

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Conflicts of interest

There are no conflicts of interest.

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Original Article

Estimating the proportion of persons with diabetes developing diabetic retinopathy in India: A systematic review and meta-analysis

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ABSTRACT

Background: Available evidence from India shows that the control of diabetes is poor in majority of the population. This escalates the risk of complications. There is no systematic review to estimate the magnitude of diabetic retinopathy (DR) in India. **Materials and Methods:** A systematic literature search was carried out in Ovid Medline and EMBASE databases using Mesh and key search terms. Studies which reported the proportion of people with diabetes with DR in a representative community population were included. Two independent reviewers reviewed all the retrieved publications. Data were extracted using a predefined form. Review Manager software was used to perform meta-analysis to provide a pooled estimate. Studies included were assessed for methodological quality using selected items from the STROBE checklist. **Results:** Seven studies (1999–2014; $n = 8315$ persons with diabetes) were included in the review. In the meta-analysis, 14.9% (95% confidence interval [CI] 10.7–19.0%) of known diabetics aged ≥30 years and 18.1% (95% CI 14.8–21.4) among those aged ≥50 years had DR. Heterogeneity around this estimate ranged from $I^2 = 79–87\%$. No linear trend was observed between age and the proportion with DR. The overall methodological quality of included studies was moderate. **Conclusions:** Early detection of DR is currently not prioritized in public health policies for noncommunicable diseases and blindness programs. Methodological issues in studies suggest that the proportion of diabetics with DR is underestimated in the Indian population. Future research should emphasize more robust methodology for assessing diabetes and DR status.

Key words: Diabetes, diabetic retinopathy, India, meta-analysis, screening

Introduction

Worldwide, the number of persons with diabetes is expected to increase exponentially, and 80% will be living in low- and middle-income countries (LMICs), particularly in India and China.[1] In 2000, 31.7 million people were reported to have diabetes in India, and this number is expected to rise to 79.4 million by 2030.[2] Between 1989 and 2005, a two-fold increase in the prevalence of diabetes was observed in urban areas (from 8.3% to 18.6%) with a more than a three-fold increase in rural populations (from 2.2% to 9.2%).[3] It has been estimated that 50–70% of diabetics in India

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have poor glycemic control, which increases the risk of complications such as diabetic retinopathy (DR).[4,5]

Worldwide, DR is a leading cause of vision loss in middle-aged populations,[6] and globally 34.6% of diabetics are estimated to have DR, i.e., approximately 93 million people worldwide.[7] However, there is no regional or country specific estimate for India which could be used to inform health policies and service delivery. Our preliminary search for published reviews conducted in PubMed Medline database used the following search terms(((“Diabetic Retinopathy” [Mesh]) AND (“Prevalence” [Mesh] OR “Epidemiology” [Mesh])) OR (“Review” [Publication Type] OR “Review Literature as Topic” [Mesh])) AND “India” [Mesh]), found only one narrative review that inadequately reported the prevalence of DR in the Indian population.[8] Recent global reviews of DR neither presented country-specific estimates nor assessed the methodological quality of the prevalence studies.[7-9] Therefore, we first systematically searched the literature and synthesized the data reporting rates of DR among persons with diabetes in Indian studies. Second, data from the Indian studies was pooled to estimate the overall rate of DR among persons with diabetes. Third, a detailed quality assessment was performed to report major methodological limitations.

Materials and Methods

We conducted a systematic review and meta-analysis in accordance with the Preferred Reporting Items for Systematic Reviews statement.[10] A review protocol was developed which included the search strategy, inclusion and exclusion criteria, data extraction form, plan for analysis, and outline of evidence synthesis.

Identification of studies

The search for studies in electronic databases was conducted on May 01, 2015. Studies were identified through the following strategy:

- A search for literature was conducted in Ovid Medline and EMBASE databases to identify studies reporting rates of DR among diabetics in the Indian population. The search terms used are described in Appendix 1. No start date was specified
- Cross-referencing of eligible articles to identify additional studies that met our inclusion criteria was done
- Key informants (i.e., known DR experts, including authors of the eligible studies) were contacted to identify other studies that could be included in our review
- Bibliography of recent papers on DR[11] was hand searched to identify studies that may have been missed through the electronic database search.

Inclusion criteria

- Population-based cross-sectional studies that provided information on the number of persons with type 1 and 2 or other forms of diabetes as well as the number of diabetics with DR
- Studies conducted among adults aged 20 years and above
- Studies which reported DR regardless of the modality used for diagnosis of DR were included.

Exclusion criteria

- Facility based studies or studies of participants recruited through screening camps
- Studies which did not describe the study design or method of enumeration or base-population (denominator).

Data collation and extraction

Initial screening was performed by two reviewers (NL and SN) independently to identify papers for inclusion and data extraction. Titles and abstracts of each citation were identified and inspected with reference to the inclusion and exclusion criteria. Relevant full-text papers were then assessed and reviewed by the two reviewers independently. Any disagreements were resolved by consensus and when this could not be reached, a third reviewer (ATJ) adjudicated. The quality of the studies included was assessed using the STROBE checklist. Corresponding authors of all papers were contacted to retrieve any additional or missing information.

Data extraction

Data were extracted on the following parameters: Year of study, setting of the study (urban and rural), region, study design, sample size and sampling frame, characteristics of participants, number of persons diagnosed with DR, and methods used to diagnose diabetes and to assess and grade DR.

Assessment of methodological quality of studies

Parameters used for quality assessment were sample size, whether peer-reviewed or not, participant response rate, study measurement, methods. The studies which mentioned these parameters clearly are categorized as at low risk of bias. Studies which mentioned these parameters vaguely and unclearly are categorized as at high risk of bias and unclear risk of bias, respectively.

Data analysis

Meta-analysis was performed using Review Manager Version 5.1 (Cochrane Informatics and Knowledge Management Centre, London, UK) and “metan” command in STATA Version 13 (Stata Corp, Texas, US). The I^2 test was used to measure statistical heterogeneity across studies. A random–effects model was used when substantial heterogeneity was observed.[12] The uncertainty around heterogeneity was explored using subgroup analyses. Confidence intervals (CIs) for the prevalence estimate were calculated using the following formula (95% CI = prevalence ± 1.96 × standard error).[13] When standard deviations for the mean age were not reported, these were calculated using the formula (maximum − minimum/4).[14]

Results

Search results

After removing duplicates, the electronic search identified 358 studies. Seven studies fulfilled the inclusion criteria [Figure 1].[11,15-20]

Study characteristics

Five of the seven studies were conducted in an urban population, particularly in the South of India [Table 1]. Five out of the seven studies were conducted in an urban population.[11-15,18,20] One study recruited both urban and rural populations,[17] and another recruited a semi-rural population.[16] Three studies were conducted in Tamil Nadu: two in urban Chennai[19,20] and one in Theni district.[17] Another two studies were conducted in the state of Maharashtra; Mumbai[11] and Nagpur.[16] The other studies were from Hyderabad, Telangana,[15] and Palakkad, Kerala.[18]

Study design

All studies were population-based cross-sectional surveys. Four of the seven studies used a two-phase study design [Table 1].[11,17,19,20,21] In phase 1, potential and known diabetics (KD) were identified and invited for phase II, when a detailed retinal examination was performed. In two studies, both phases were conducted in a community setting,[17,18] whereas, in three studies, phase II evaluation took place in hospital settings.[11,19,20] In a further study free transport was arranged for all eligible participants to the base hospital for phase I and II clinical examinations. One study conducted phase I and phase II evaluations at temporary clinics established in the study catchment area.[15]

Characteristics of participants

Three of the seven studies recruited participants aged 30 years and above.[15,17] Two studies recruited those aged 40 years and above,[11,19] and the remaining studies recruited participants aged 50[18] and 20 years and above [Table 1].[20] The proportion of female participants ranged from 47.3% to 55.5%. One ongoing study did not provide information on the gender distribution.[17]

Diagnosis of diabetes

Diagnostic measurement and classification of diabetes varied greatly among studies [Table 2]. Most recruited both KD and newly detected diabetics (NDD). Five studies asked about a medical history of diabetes and tested blood glucose levels for those unaware of their diabetic status.[11,16,17,19,20] One study included only KD.[18] Another study assessed diabetes status only for participants whose

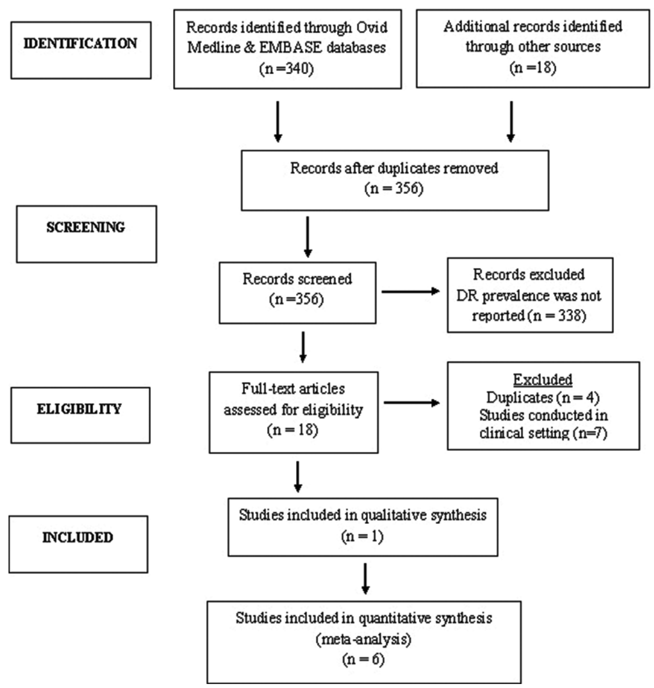

Figure 1: Preferred Reporting Items for Systematic Reviews flowchart

Table 1: Characteristics of studies included in the review

Reference	Study period	Region	Settings	Type of survey	Total sample	Age, (mean age)	Female %
Mohan, 2005	2001/2	Chennai (urban), Tamil Nadu	Community (Phase-I) and Hospital (Phase-II)	Two-phase	26001	≥ 20 (52±11) years	55.5
Raman, 2009	2003/6	Chennai (urban), Tamil Nadu	Community (Phase-I) and Hospital (Phase-II)	Two-phase	5784	≥ 40 (56±10) years	47.6
Narendran, 2002	2001	Palakkad district (urban), Kerala	Community/study centre	One-phase	5212	≥50 (61.7±8) years	47.3
Dandona, 1999	1996/7	Hyderabad (urban), Telangana	Clinical setting	One-phase	2522	≥30 (54±13.7) years	55.5
Namperumalsamy, 2009	2005/6	Theni district (urban and rural), Tamil Nadu	Community (Phase-I and II)	Two-phase	25969	≥30 (47.0±12.7) years	52.1
Sunita, 2014	2011/4	Mumbai (urban slum), Maharashtra	Community (Phase-I) and Hospital (Phase-II)	Two-phase	14739	≥40 years	NA
Jonas, 2013	2006/9	Nagpur (semi-rural), Maharashtra	Hospital setting	One-phase	4711	≥30 (49.1±13.2) years	53.5

fundus examination indicated the presence of DR.[15] Except one,[16] all the other studies mentioned the criteria for the diagnosis of diabetes. Study participants who reported a medical history of diabetes and were using drugs (either oral or insulin) were categorized as KD. For NDD, five of the seven studies performed fasting blood glucose (FBG) test using glucometer,[11,15,17,19,20] and of these, three studies conducted additional biochemical investigations, for example, oral glucose tolerance test, glycosylated hemoglobin estimation to confirm the diagnosis of diabetes.[11,19,20] In three out of seven studies, participants with FBG level ≥126 mg/dl were categorized as NDD;[11,17,20] whereas another study used FBG ≥110 mg/dl as the cutoff.[19] In one study, FBG was measured after the DR diagnosis and, fasting glucose level of more than 120 mg/dl was used to confirm the diagnosis.[15] One study mentioned that diabetes status was assessed by a blood glucose test and glycosylated hemoglobin, but cut-points were not presented.[16] Five out of seven studies used digital fundus cameras,[11,15,16,19,20] and two other studies used direct and indirect ophthalmoscopy alone for DR diagnosis.[17,18]

Methodological quality of studies

Overall, the methodological quality of the studies was moderate [Figure 2]. All included studies provided details of the sampling frame and sampling method used. In three studies the sample size calculation was unclear.[16,18] Two studies assessed FBG using a glucometer, and no further confirmatory investigations were performed for those who were not previously diagnosed as diabetic.[15,17] Another study applied self-reported information for diagnosis.[18] Two studies that applied direct and indirect ophthalmoscopy were rated as unclear for risk of bias.[17,18] In two studies, information on nonparticipants was not mentioned clearly and so were rated as having an unclear risk of bias.[11,15,16] External validity was discussed in all studies. However, in two studies, the findings were generalizable only to the study participants: One recruited participants from an urban slum,[11] and another recruited participant from an undefined catchment area that may not be representative of the target population.[18]

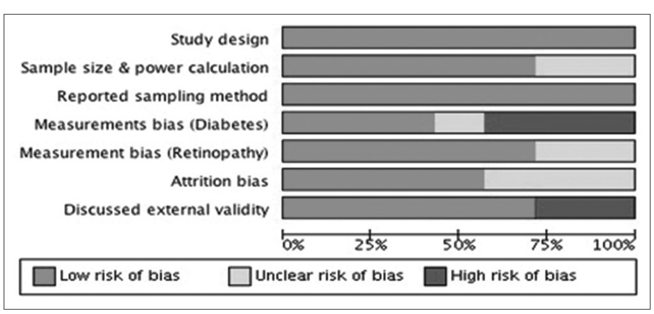

Figure 2: Risk of bias summary: Review authors' judgment about risk of bias

Proportion of diabetics with diabetic retinopathy

It was observed that between 9.6% and 26.8% of participants with diabetes had some degree of DR [Table 1]. Rates of DR were high among adults aged over 50 years, but there was no linear association of DR with age [Figure 3]. The prevalence was slightly higher among males as compared to females.

Although age eligibility criteria differed among studies, most presented data by age group, allowing data to be pooled in the meta-analysis. About 14.9% (95% CI: 10.7–19.0%) of the diabetics aged 30 years and above had DR compared with 16.7% (95% CI: 14.2–19.2%) of those aged 40 years and above, and 18.09% (95% CI: 14.8–21.4%) of those aged 50 years and above [Figure 4]. High heterogeneity was observed around these estimates $I^2 = 79–87\%$.

Discussion

The pooled prevalence of DR among known or NDD was 14.8% in persons aged 30 years and older, 16.7% in persons aged 40 years and older, and 18.1% in persons aged 50 years and older in the Indian population. We also observed sizeable variations in the prevalence of DR reported in these studies. Putative reasons for observed heterogeneity include differences in sample size, data collection methods, the definition of diabetes used, duration of diabetes, and procedure followed for diagnosis of retinopathy.

Our review found that the overall prevalence of DR among persons with diabetes in India to be lower than in high-income countries and other LMICs.[9,22,23] The DR prevalence is influenced by the risk factors such as poor control of blood glucose, undiagnosed diabetes, and high rates of blood pressure.[1] Although these risk factors are equally or highly prevalent in the Indian population,[24,25] interestingly, Indian studies found low prevalence. One possible explanation could be the difference in life expectancy of the population; the other could be the methodology issues in the Indian

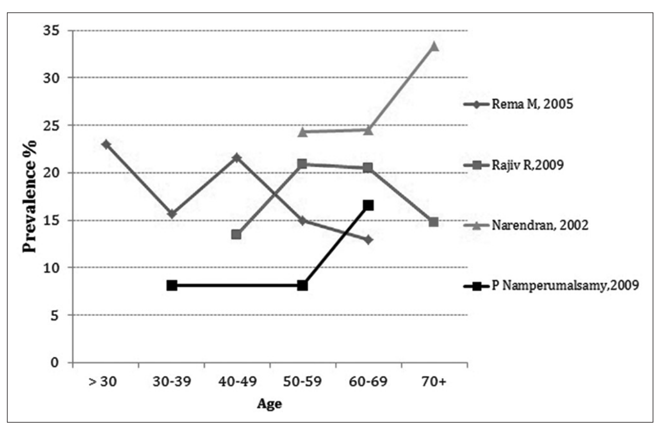

Figure 3: Proportion of diabetics with diabetic retinopathy by age group

Table 2: Methods used to aascertain diabetes and diabetic retinopathy

Reference	Ascertainment of diabetes	Ascertainment of diabetic retinopathy	Proportion of diabetics undergoing eye examination
Mohan, 2005	Fasting capillary glucose (glucose meter) and oral glucose tolerance test (OGTT)	Four-field stereo colour retinal photography performed by trained and certified photographers	90.4% (1382/1589)
Raman, 2009	Fasting capillary glucose (glucose meter) and biochemical analysis (blood)	Four-field stereoscopic digital photography and seven field stereo digital pairs for those with evidence of DR	85.6% (1563/1816)
Narendran, 2002	Self-reported (current use of insulin to control diabetes)	Direct and indirect ophthalmoscopy using 20D lens after dilatation of the pupils	92.0% (5212/5666)
Dandona, 1999	Self-reported (history of diabetes), Random and Fasting capillary glucose (using glucose meter)	Indirect ophthalmoscopy using 20D lens after pupil dilatation and stereoscopic photographs of macula/optic disc (fundus camera)	85.4% (2522/2953)
Namperumalsamy, 2009	Fasting capillary glucose (glucose meter), test strips, and history of diabetes	Direct and indirect ophthalmoscopy using after dilatation	87.4% (2448/2802)
Sunita, 2014	Fasting capillary glucose (glucose meter) and biochemical analysis (blood and urine)	Indirect ophthalmoscopy using 20D lens after pupil dilatation and stereoscopic photographs of macula/optic disc (fundus camera)	Ongoing
Jonas, 2013	Biochemical analysis (blood and urine)	Slit-lamp bimicroscopy after pupil dilation and retro-illuminated photographs using telecentric fundus camera	96.6% (4551/4711)

DR: Diabetic retinopathy

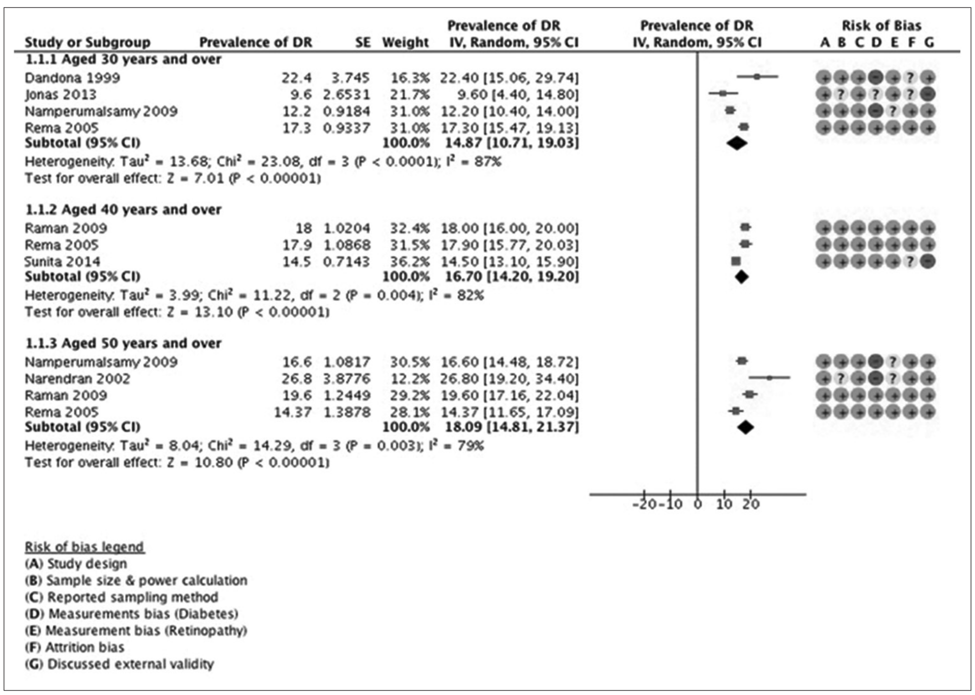

Figure 4: The meta-analyzed data showing the overall proportion of diabetics with diabetic retinopathy

studies. It will be useful to identify the methodological issues so that better estimates can be generated.

We observed two major methodological problems in the Indian studies: (a) Accuracy of measurement of diabetes and (b) study design.[26,27]

Accuracy of measurement of diabetes

Blood glucose testing using a glucometer (which was used in the majority of studies), is recommended as a monitoring tool but not as a screening device. This is unlikely to achieve 100% sensitivity and specificity.[28,29] Low sensitivity will result in false negatives who would not be assessed for DR regardless of the study design, whereas low specificity will result in the assessment of those who are not diabetic. Low sensitivity and low specificity will, therefore, be likely to bias the studies of DR, with low specificity leading to an underestimation of the proportion with DR.

Study design issues

Two-phase versus one-phase design

A two-phase study design was common among the studies included in this review where a large random sample is first screened for diabetes, with referral for detailed eye examination of those known to be diabetic/newly diagnosed as diabetic. Although there are logistical advantages to this approach, there are important limitations. The main limitation is that not all those identified as diabetic will attend for ophthalmic examination. Indeed, in the studies included in the review response rates were lower in studies using a two-phase study design (range 85.6–90%) compared with those using a one-phase design (92% and 96%). If those that do not attend differ from those who do in relation to risk factors for DR, then estimates of the proportion with DR will be biased. This seems likely, as those with other complications of long-standing, poorly controlled diabetes, such as heart disease, amputations, or renal failure are less likely to attend but more likely to have DR. Indeed, those already blind from DR may see little value in attending for ophthalmic examination. A two-phase approach is, therefore, likely to underestimate the proportion with DR. At least 10% of negatives should be invited for phase two assessment, and in case, DR is detected in 10 false negatives that number should be weighted back to the composition of the base population for precise prevalence estimates.

In phase one, none of these studies invited persons scoring negative according to the screening test in the phase one. They should have been invited for phase two clinical and laboratory examination to confirm the diagnosis of diabetes and DR. None of the included studies adequately assessed the diabetes status. In this case, the denominator, number of persons with diabetes, is imprecise: Prevalence estimated in these studies may be underestimated.

Accuracy of diabetes diagnosis

All the DR studies in the review were subject to measurement bias. We noticed two main measurement issues: (a) Self-reported assessment and (b) use of glucometer for diabetes assessment.

Studies measuring diabetes status by self-reported information are likely to yield higher prevalence of DR. In India, 20% of patients with type 2 diabetes have retinopathy at the time of diagnosis and prevalence of undiagnosed diabetes range from 4.2% to 10.5%, which is two times more than KD.[30,31] One study, recruiting only KD by self-reporting, observed a higher prevalence of DR than other studies of the same age group.[18] Possibly, in this study, self-reported assessment could have yielded only diagnosed cases; hence, the denominator (number of persons with diabetes) is likely to be smaller and result in an overestimation of DR prevalence for persons aged 50 years and older.[18]

Estimation of DR prevalence among persons with diabetes requires the inclusion of all persons with diabetes (denominator). Inaccuracy in ascertainment of diabetic status might result in either overestimating or underestimating the prevalence of DR among persons with diabetes. In four of the seven included studies, FBG was measured using a glucometer for first line screening or to confirm the diagnosis of diabetes.[15,17,19,20] Several studies which have tested the efficacy of a glucometer for diagnosis of diabetes have reported a low sensitivity and specificity as compared to the measurement of plasma glucose concentration using venous samples with enzymatic assay techniques.[32,33] Technically, a screening test that produces a considerable number of false positives or negatives would pose a major problem for prevalence estimation. In the case of DR, precise estimation of prevalence depends on an accurate denominator (total number of persons with diabetes). Hence more than sensitivity, the specificity of a screening test is arguably important. A study conducted in a South Indian population applied the WHO fasting plasma glucose (FPG) ≥110 mg/dl criteria and found that sensitivity and specificity of FBG measured by glucometer were 62.8% and 62.9%.[34] Both sensitivity and specificity were even lower (58.3% and 58.6%) for the American Diabetes Association criteria for diabetes FPG ≥100 mg/dl.[34] In another study, participants classified as having provisional diabetes using a glucometer were reassessed by a laboratory venous sample at the base hospital. Surprisingly, one-third participants received nondiabetic value in the laboratory investigations.[35] Although the impact of a diagnostic test on the prevalence of DR is difficult to judge, it is possible that DR is underestimated in the Indian population as no studies assessed false negatives.

Limitations

The literature search was conducted only in electronic databases, and we did not attempt to retrieve gray literature (university thesis, conference proceeding, and unpublished reports from services organization). Second, a database search was restricted to Ovid Medline and EMBASE databases, and other electronic databases were not extensively searched. However, expert's group consultation provided reassurance that no published eligible studies from India were excluded in this review. Third, we could not perform meta-regression (as the number of studies was <10) to explore factors contributing to heterogeneity around the prevalence estimate.

Conclusions

India is experiencing an unprecedented health transition as well as a demographic shift. A major public health concern is the increasing magnitude of noncommunicable diseases, which already account for 80% of the global burden of disease.[36] While cancer and heart disease mainly contribute to mortality, conditions such as diabetes and blindness increase the number of years lived with disability.[37] In 2013, it was estimated that 20% (35.5 million) of world's population with undiagnosed diabetes live in India.[38] Compared to type 1 diabetes, people with type 2 diabetes can remain undiagnosed for many years and remain unaware of the complications caused by the disease. Therefore, early detection and management of diabetes and DR among persons with diabetes are quintessential for attenuating adverse consequences. Simultaneous efforts to bring changes at multiple levels in the health system and effective health education needed for diabetic patients would result in early detection of both DM and DR, thereby reducing the blindness due to DR.

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Conflicts of interest

There are no conflicts of interest.

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Appendix 1: Search terms

1. Retinopathy.mp.
2. Exp diabetic retinopathy
3. Diabetic retinopathy.mp.
4. (diabet$ adj3 retinopath$).tw.
5. (preproliferative adj3 diabetic adj3 retinopathy).tw.
6. (proliferative adj3 diabetic adj3 retinopathy).tw.
7. Or/1-6
8. exp prevalence/
9. exp mass screening/
10. exp vision screening/
11. exp visual acuity/
12. Epidemiology.mp
13. Exp cross-sectional study/
14. Exp epidemiological studies/
15. Exp population surveillance/
16. Or/8-15
17. India.mp. or exp India/
18. 7 and 16 and 17
19. Limit 18 to human
20. Limit 19 to (comment or editorial or letter)

Original Article

Strengthening diabetes retinopathy services in India: Qualitative insights into providers' perspectives: The India 11-city 9-state study

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ABSTRACT

Context: There is a lack of evidence on the subjective aspects of the provider perspective regarding diabetes and its complications in India. **Objectives:** The study was undertaken to understand the providers' perspective on the delivery of health services for diabetes and its complications, specifically the eye complications in India. **Settings and Design:** Hospitals providing diabetic services in government and private sectors were selected in 11 of the largest cities in India, based on geographical distribution and size. **Methods:** Fifty-nine semi-structured interviews conducted with physicians providing diabetes care were analyzed all interviews were recorded, transcribed, and translated. Nvivo 10 software was used to code the transcripts. Thematic analysis was conducted to analyze the data. **Results:** The results are presented as key themes: "Challenges in managing diabetes patients," "Current patient management practices," and "Strengthening diabetic retinopathy (DR) services at the health systems level." Diabetes affects people early across the social classes. Self-management was identified as an important prerequisite in controlling diabetes and its complications. Awareness level of hospital staff on DR was low. Advances in medical technology have an important role in effective management of DR. A team approach is required to provide comprehensive diabetic care. **Conclusions:** Sight-threatening DR is an impending public health challenge that needs a concerted effort to tackle it. A streamlined, multi-dimensional approach where all the stakeholders cooperate is important to strengthening services dealing with DR in the existing health care setup.

Key words: Diabetes, diabetes retinopathy, health system response, India, providers perspective

Introduction

There is a global epidemic of diabetes. About 382 million people live with diabetes (8.3% of the world's adult population in 2013) and by 2035, this will have increased by 55% to 592 million.[1] Many emerging economies contribute to this global epidemic. According to a study conducted by the Indian Council for Medical Research in 2011, India has 62.4 million people with type 2 diabetes.[2] It is further projected by the International Diabetes Federation that by 2030, this will increase to 100 million.[1]

Studies in different parts of the country reveal a high and increasing prevalence in both urban and rural areas, with a higher prevalence being reported from urban areas. Most of this evidence comes from South and Central India. In

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South India, the prevalence of diabetes among adults is estimated to be around 20% in urban areas and nearly 10% in rural areas.[3] As the epidemic matures and diabetics live longer, the cardiovascular, renal, and ocular complications will increase, imposing a burden on health care facilities.[4]

Diabetic retinopathy (DR), a major microvascular complication of diabetes, has a significant impact on the World's Health Systems. According to an estimate, the number of people with DR will grow from 126.6 million in 2010 to 191.0 million by 2030. If this is not addressed appropriately, it is further projected that sight-threatening DR (STDR) will increase from 37.3 million to 56.3 million.[5]

An estimated 6 million diabetics in India have STDR. If the proportion of diabetics STDR remains the same over time, the number will increase to over 10 million by 2035.

The broad aims of the study were to understand the provider perspective on the delivery of health services for diabetes and its complications, specifically the eye complications in India. This paper focuses on providers' perspectives on diabetes and DR and strengthening health systems responses.

Materials and Methods

Ethics

The study was granted ethics approval by the Institutional Ethics Committee of Indian Institute of Public Health (IIPH), Hyderabad, and the London School of Hygiene and Tropical Medicine, UK.

Study design

The study was conducted in the most populated cities across India, representing different geographic regions of the country. Sampling entailed a two-stage process. Initially, cities were ranked in descending order of population size (2011 census) and the 10 most populated cities Ahmedabad, Bengaluru, Chennai, Delhi, Hyderabad, Jaipur, Kolkata, Mumbai, Pune, and Surat - were selected. To address lesser representation from Eastern India, Bhubaneswar was added, making the sample a total of 11 cities.

Detailed methodology adopted is described in a companion paper in this issue.

After obtaining approval from senior managers, semi-structured interviews were conducted with clinicians, counselors, and dieticians working in these hospitals. Semi-structured interviews were conducted by a team of investigators from IIPH Hyderabad. Interviews were recorded after taking consent from the respondents.

Data analysis

All the interviews were transcribed into English. Thematic analysis was conducted with the data from the semi-structured interviews [Figure 1]. Initial apriori codes were developed from the interview guide. The codes were refined in discussions with the researchers who conducted the interviews. Nvivo 10 software (QSR International, Melbourne, Australia) was used to code the interview transcripts. Emergent codes were identified through an iterative engagement with the data.

Results

The results presented here are from the analysis of 59 interviews conducted with senior physicians and endocrinologists across the study sites. The data were classified as 9 primary codes and 40 secondary codes. These codes were organized into 3 themes: (1) Challenges in managing diabetes patients; (2) current patient management practices; and (3) strengthening DR services at the health systems level. An overview of primary codes and their frequency is presented in Table 1, and illustrative quotes for the three themes and respective codes are presented in Table 2.

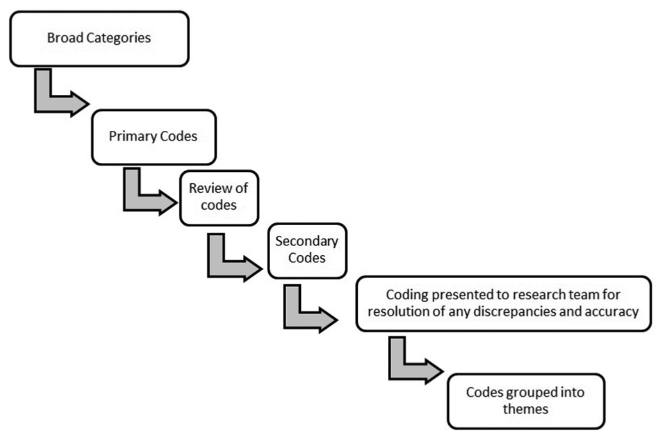

Figure 1: Method of developing codes and thematic content

Table 1: Frequency of primary themes and codes

Primary themes	Category	No. of coding references
Patient awareness	Challenges-management of diabetes	217
Compliance	Challenges-management of diabetes	166
Self-monitoring	Challenges-management of diabetes patients	260
Health system issues	Current patient management practices	120
Human resources	Current patient management practices	341
Level of awareness of DR	Strengthening DR services	300
Existing DR services	Strengthening DR services	140
Collaboration with ophthalmologists	Strengthening DR services	368
Training need	Strengthening DR services	291

DR: Diabetic retinopathy

Table 2: Tabulation of primary themes and codes with illustrative comments

Primary theme/codes	Illustrative comment
Challenges in managing diabetes patients	
Patient awareness	
Lack of awareness (*n*=50)	*"Majority of the patients are not aware of the complications of diabetes …they not understand the importance of the good glycemic control …these are the major problem we face and the patients are not properly educated."* (Diabetologist, Ahmedabad)
Fear of complications (*n*=10)	*"Fear of complications people do not want to come and face the situation, they know that diabetes may produce blindness and things like that but they don't want to come and get it tested for." (Senior Physician, Bangalore)*
Misconceptions about the causes and complications (*n*=8)	*"First it is compliance then lack of awareness. Patient always say I have been taking more sweets and last week I have taken sweets so that's the reason I got diabetes."* (Diabetologist, Surat)
Treatment delay (*n*=20)	*"Patients don't want to start medication and also after control of diabetes they consult some allopathic doctors and homeopathic doctors and then start their medication and then also after one month or two months complain again with high sugar level."* (Diabetologist, Surat)
Socio-economic status (*n*=37)	*"In our government hospital they are poor they come from very poor social economic background they are illiterate and uneducated so our main challenge is the patient's ability to know the diseases and since they are poor and cannot afford much and the next challenge is their medication."* (Endocrinologist, Mumbai)
Educational background (*n*=37)	*"Most patients are illiterate and uneducated kind of people so our main challenge is the patient ability to know the disease."* (Endocrinologist, Surat)
Need to create awareness (*n*=44)	*"The awareness of the patient should be increased. Along with the patient, if awareness is created among family members, it will be helpful in creating social support and better control of diabetes. I think this also helps in primary prevention."* (Diabetologist, Surat)
Primary prevention of diabetes (*n*=51)	*"Creating awareness among patients and their family members will help in primary prevention."* (Diabetologist, Hyderabad)
Increased awareness among patients (*n*=44)	*"Now it's better compared to ten years back because if awareness in public media like TV, Newspapers and other things, it is little better but I don't think it's enough."* (Senior Diabetologist, Mumbai)
Translation into Behavior change (*n*=30)	*"Challenge is to convert knowledge into practice. There is no dearth of information, whether from me or institution or diabetes educator, dietician, press, internet and so on."* (Senior Endocrinologist, Chennai)
Life style changes (*n*=38)	*"I am afraid that [challenges] will be more because people are not changing their habits. They are not changing their lifestyles and this is going to be one of the very challenging point for the govt. as well as all the practicing physicians. And the worst thing that I am seeing is that it is basically the young generation. The productive part of the population that is getting affected and that should be a concern for everybody because it is unlike the west where diabetes is diagnosed in the later stage. In India we have patients who are 20, 25 years and if they go to 30 and 40 years, they will have all these complications."* (Diabetologist, New Delhi)
Compliance	*"The main challenge is compliance, nothing more than that."* (Diabetologist, Mumbai)
Follow-up visits (*n*=45)	*"I should put compliance to follow-up visits to around 30% because we get patients from far places also and so many patients coming from Assam and Calcutta, it is very difficult for them to come every three months so I encourage them to come at least once in a year. Compliance from local people is highest and far people are less relatively."* (Diabetologist, Hyderabad)
Compliance to treatment (*n*=44)	*"Unfortunately compliance to treatment is 30% only. Despite our persistent motivation orally or by displaying visual aids."* (Diabetologist, Surat)
Compliance to physical activity (*n*=10)	*"..Poor compliance is regarding the exercise, it's the worst compliance. Very few people do exercise. If you say they tell they will give up one more idly but they will not do."* (Diabetologist, Hyderabad)
Excessive reliance on drugs (*n*=20)	*"People just keep on taking drugs and they think that it will be under control. it becomes very difficult for us to explain that drugs are not the main stay of treatment but diet and exercise are."* (Diabetologist, Ahmedabad)
Self-medication (*n*=1)	*"Patients are always doing self-medication. They increase or decrease the dosage of medicines or insulin."* (Diabetologist, New Delhi)
Age (*n*=22)	*"Age is a problem for compliance. Those who are young physically take care, they can go for walk, exercise, older people who are having knee problems and do not bother about what happens are difficult."* (Diabetologist, Surat)
Gender (*n*=4)	*"For women, the fees and the time they have to spend impact their compliance. A woman has to be accompanied by a man, when we have to explain her about the disease, a male member has to be present along with her.. but for a male patient, they don't need anybody."* (Diabetologist, Hyderabad)
Geographical variation (*n*=2)	*"Compliance is very poor, particularly in Gujarat. Majority patients do not follow guidelines regarding diet control. They can walk and exercise, but diet because here so many festivals are there and Guajarati's are really fond of sweets, so diet control is quite difficult."* (Diabetologist, Surat)
Psycho social counseling (*n*=19)	*"Having counselors helps a lot more than 50% of patients. they rely on them, we have a system in which we give our counselors phone numbers to the patients mobile numbers so any time of the day they will call, they can get immediate attention and whatever is needed next day they will call them here then give the proper way of advice either medically or socially or sometimes even emotionally."* (Senior Physician, Bangalore)
Self-monitoring	
Glucometers (*n*=8)	*"For 80% of our patients, we have glucometers. for those who cannot afford also sometimes we give free meters let them buy only the strips because that is the corner stone of the treatment for a diabetic patients who are on insulin- either type 1 or type 2 they must have a glucometer there is no other go."* (Senior Physician, Bangalore)

Contd...

Table 2: Contd...

Primary theme/codes	Illustrative comment
Provider-patient interaction (*n*=13)	*"…Depending on the physician how well he educates his patient how well he makes him understand about the aspects of diabetes is very important. If the patient understands well he follows well."* (Diabetologist, Mumbai)
Trust on the provider (*n*=4)	*"..Trust actually is most important. Whatever actually the information / advice I give to them, if he is having that trust on me he will be influenced by my advice only is possible."* (Diabetologist, Kolkata)
Health system issues	
Focus on treatment rather than on prevention (*n*=47)	*"..We are more oriented towards treating a patient rather than educating a patient."* (Senior Diabetologist, New Delhi)
Patient load (*n*=45)	*"There has been a big change in number of patients we are getting with diabetes nowadays. Even the person who is not practicing as a diabetologist's OPD around 80 to 90 per cent consists of diabetes patients."* (Senior Endocrinologist, Hyderabad)
Lack of community based outreach (*n*=46)	*"….Here, there are lot of drop-outs because we do not have community outreach program. So, a patient comes, drops out through a couple of months, re-appears when in a crisis; in the emergency gets re-admitted; or walks back into the OPD with high blood sugars and complications."* (Diabetologist, New Delhi)
Application of ICT (*n*=02)	*"The future of diabetes care, will be virtually. Patient from wherever can access the provider for an appointment and consultations."* (senior endocrinologist, Mumbai)
Human resources	
Insufficient staff (*n*=45)	"*With the level of human resources, the biggest challenge is building health literacy of the patients. So regular monitoring is not possible, though we do have a system here, which is located in another department other than the hospital where the patient has to go. At the point of care something should be available in every clinic."* (Diabetologist, New Delhi)
Trained staff (*n*=31)	*"In general hospitals huge load of patients is there, and diabetes care providers are less. definitely absence of diabetic care counsellors, diabetic care educators, health care professionals trying to focus on foot care and eye care, they are all not there in endocrinology OPD."* (Endocrinologist, Hyderabad).
Current patient management practices	
Dedicated team (*n*=15)	*"I am sure that diabetes management needs teamwork and until and unless we work in a team we cannot achieve the goals."* (Diabetologist, Delhi)
Good patient provider relations (*n*=45)	*"Local language, local cultural way of understanding and make friendly relations with them and make them understand in a better way rather than talk by a physician so that way a kind of relationship happens then they understand better, then if not in the first visit next visit they try to follow up."* (Diabetologist, Kolkata)
Emphasis on patient education (*n*=46)	*"Any chronic non-communicable diseases like diabetics, asthma and psoriasis, we don't expect patients to 100% sure compliance, So we are making them more independent of hospitals and doctors, so, diabetics self-care is being propagated. Diabetic's skills and diabetics self-care are part of diabetic education, which we are all focusing now, because we don't want our patients to depend on a hospital or medical facility always. Which we don't have hope to achieve also. But at least we are trying that in direction of improving diabetics' self-care, skills and diabetic education."* (Diabetologist, Hyderabad)
Comprehensive package (*n*=14)	*"Number one we have the diabetic package most of the patients who come for the first time we encourage them to go for a package basically why we encourage them is its come to a lower price it includes the dietary consultation, diabetic educator, endocrinologist, eye, it is a comprehensive package there is one point where they will have contact with the ophthalmologist for the diabetic retinopathy."* (Endocrinologist, Chennai)
Documenting extensive case history (*n*=33)	*"In case diabetics it is not a one day disease, family histories important what all complications they had in the past and what treatment they had all are important, so we capture all those things then we make our own assessment and then we start with the treatment depending on the severity of the disease.* (Diabetologists , Hyderabad)
Strengthening DR services at the health systems level	
Collaboration with ophthalmologists (*n*=17)	*"After getting the patients, we refer these patients to the ophthalmologist., when the patient comes we know that the risk factors are there. So until and unless we take care of those risk factors, diabetic retinopathy is not going to be under controls in control the outcome will be always better."* (Diabetologist, New, Delhi)
Cross referral between diabetologist and ophthalmologist (*n*=9)	*"Our ophthalmology department is there they will do the screening at OPD levels they will check it regularly, every new patient comes is definitely referred to ophthalmologist. [Similarly] whenever they go for eye problem if they find Diabetic Retinopathy sometimes they will also refer these patients to us.* (Senior diabetologist, New Delhi)
Data sharing (*n*=14)	*"Yes we get referrals from ophthalmologist quite often we get, but there are no stringent guidelines. Somebody (patients) tells I will have check-up in private institute and they will go there, so in the private there are not maintaining proper data then again the system fails (in managing DR)"* (Diabetologist, Surat)
Awareness levels about DR among paramedical staff (*n*=45)	*"They don't know much. Some medical officers must be knowing otherwise nursing staff, lab technician, pharmacist they don't know regarding diabetic retinopathy, like or less for example regarding the risk factors of diabetic retinopathy all those kind of things, they would not know much of that, there knowledge regarding diabetic other complication of diabetes but they don't particular know about retinopathy."* (Physician, Ahmedabad)
Need for training	
Acceptability (*n*=46)	*"Yes, training would be a welcome. I would say this fundus camera thing, a kind of a cheap version if that's available or opthalmoscopy if doctors are trained."* (Diabetologist, New Delhi)
Willingness (*n*=46)	*"Definitely we are willing to be trained on DR."* (Diabetologist, Mumbai)

Key overlapping issues, such as change over time in various aspects of diabetes, are discussed in a separate section.

Theme 1: Challenges in managing diabetes patients

In this section, challenges faced by the health professionals regarding the treatment and management of diabetic patients are presented. The data are structured around 4 subthemes: (1) Patient awareness, (2) compliance, (3) self-monitoring, and (4) health system issues.

Patient awareness

Service providers emphasized the lack of awareness about diabetes and its complications as a key challenge for self-management among the patients. The level of awareness of the patients was related to socioeconomic and educational background of the patients. Awareness levels were lower among the poor and less educated patients. Lack of awareness included misconceptions about the cause and fear of complications caused by diabetes. Lack of awareness leading to fear of complications was identified as a deterrent for seeking early diagnosis and treatment for diabetes among most of the patients.

However, participants reported better awareness among patients from urban area resulting in better screening and treatment. Improving awareness among the patients and their family members were also identified as an important strategy for the primary prevention of diabetes. Respondents opined that increased awareness could translate into health behavioral change and create social support systems for coping with the condition. For example, one of the physicians stated: "Awareness of the patient should be increased. Along with the patient, if awareness is created among family members, it will be helpful in creating social support and better control of diabetes. I think this also helps in primary prevention."

Compliance

A majority of the practitioners identified compliance as a critical factor in self-management of diabetes and associated conditions. Socioeconomic background of the patients and misconceptions about diabetes resulted in poor acceptance of diagnosis and compliance with medication and lifestyle changes. According to one of the participants, "patients complied better with medication than with life style changes, such as dietary modifications and physical exercise."

Participating health providers identified the following factors that influenced compliance:

- Provider - patient interactions resulting in trust on the provider. According to a diabetologist, "trust influenced the extent to which the information received by the patient is translated into effective compliance and self-care"
- Socioeconomic status of patients impacts their ability to bear the costs of disease monitoring and making life style modifications. Compliance was found to be poor among patients dependent on daily wages for their livelihood
- However, some practitioners reported that compliance to medication was better among patients accessing government services. Practitioners in the private sector assessed the financial status of patients and accordingly prescribed medicines, as there is a large variation in prices of the diabetes drugs
- The age of the patient influenced lifestyle changes and motivation to manage their condition. Younger patients were more able to make life style modifications compared to older patients who had age-related musculoskeletal impairments
- The gender of patients also influences compliance with follow-up visits and care. Men who sought medication from the government sector had a problem complying with follow-up visits and treatment as the distribution of free drugs is during working hours. Therefore most men who work do not comply with follow-up visits and medication, whereas women, many of whom were home makers, could visit the hospital independently to collect their free medicines
- Costs associated with the follow-up visits, the need for a male to accompany them and time required for the tests affect female's management
- Compliance with dietary change is influenced by geographical location where culture specific dietary practices and varieties of food items consumed vary
- It was reported that compliance to follow-up visits is largely dependent on the distances patients travel to seek treatment.

Self-monitoring

To encourage compliance, some practitioners were promoting self-monitoring of blood glucose. Decreasing cost and ease of checking blood sugar levels with a glucometer are said to have changed the scenario of self-management of diabetes. Interventions such as psychosocial counseling and medical counseling by trained counselors who were accessible by phone and a 24-h help line and telephone were reported to have increased compliance.

Health system issues

Excessive focus on treatment rather than prevention was identified as a reason for low awareness about diabetes and its complications. A burgeoning middle class is contributing to an exponential rise in the number of diabetes cases in India. A lack of policy attention on the rise of the middle class and the changing disease pattern was highlighted.

Increasing incidence of diabetes was identified as a challenge for the health system as it increased the patient load on the burdened health system. Paucity of human resources and lack of understanding among the care providers were contributing to the burden on the health system.

Theme II: Current patient management practices

Varied sets of practices were reported across different facilities. Few salient findings were:

- Some hospitals reported efforts to establish good patient-provider relationship and patient management. They recruited a team of counselors, educators, and physician assistants who communicated with the patients in the local language and in a culturally sensitive way
- Some diabetologists and hospitals emphasized on patient education on holistic self-management rather than promoting dependence on only medical management
- Some hospitals in the private sector offered a comprehensive package to the 1st time patients, including consultation with an endocrinologist, dietician, and a health educator
- Documentation of extensive case history of the 1st time patients was mentioned to be very helpful in effective assessment and management of diabetes in the later stages
- High patient load in the government hospitals and shortage of human resources were identified as challenges for managing patients in a government setting. Staff nurses and councilors provided information to the patient on life style modifications required for managing diabetes. Patients collected free diabetic medication for every 15 days. Due to the patient load, consultation with a doctor was only possible once in 6 months. Most of the times complications related to diabetes were self-reported by the patients
- Some private clinics, due to the absence of dieticians and counselors focused on medical management of diabetes with some basic advice on lifestyle modification
- Practitioners were increasingly depending on technological aids such as glucometers for promoting self-management of diabetes. Some hospitals were providing these machines at subsidized rates and sometimes at free of cost for the benefit of patients who cannot afford them for a regular monitoring of the blood sugar levels.

Upon querying about diabetes management, respondents mentioned that it was important to innovate in managing diabetes. Some of the key findings on diabetes management among the patients were:

- Importance of a team approaches among the health professionals in managing diabetes
- Establishing a peer network among the patients
- Lifestyle modification was identified as an important factor in managing diabetes. Changing food habits due to westernization and other life style changes such as sleep pattern, physical activity, and lack of preventive outlook in Indian society impact diabetes management
- Owing to its asymptomatic nature, detection of diabetes is delayed in majority of the cases. Added to this, stigma and general reluctance of high-risk people with family history of diabetes are reasons for delay in self-screening
- Frequent shifting from one health provider to the other, increasing the number of both trained and untrained health practitioners claiming to be specialists in diabetes treatment were identified as emerging challenges in diabetes management.

Theme III: Strengthening diabetic retinopathy services

The extent of services provided for DR varied across the hospitals.

Some hospitals initiated a system where a general physician did the initial screening for DR. Later, a fundus camera was used to take images of retina in patients with advanced retinopathy. Then the ophthalmologist was consulted for further analysis.

In some hospitals, annual retinal check-up system was institutionalized to monitor the retina complications among the diabetic patients.

Some hospitals were using internet to send the pictures of the fundus to an ophthalmologist who then sent an email with his observation. Patient was given a printed report about the status of their eye for further follow-up.

To understand the services better, the findings are presented in the following sections.

Collaboration with ophthalmologists

To document the existing practices of collaboration between the diabetologist and ophthalmologists, respondents were asked about the referral practices:

- Some clinicians preferred to manage the risk factors before referring the patients to ophthalmologists as they thought it was critical to address these to control DR
- In some large hospitals with ophthalmology section, diabetologist and ophthalmologists cross-referred patients
- As not all diabetes patients require DR examination, some hospitals institutionalized need-based online collaboration with ophthalmologists.

Data sharing between the private and government hospitals were highlighted as a contentious issue that influenced collaboration and cross-referrals among diabetologists and ophthalmologists.

Existing level of awareness on diabetic retinopathy
Most practitioners mentioned that the awareness levels among the paramedical staff in the hospitals such as nurses, lab technicians, and pharmacists regarding DR were low.

However, some practitioners were not sure about the levels of awareness among the staff in their hospitals.

Training need: Respondents were of opposing opinions on the need for diabetic retinopathy training for the health staff

- Most of the practitioners interviewed mentioned that training the staff on DR is welcome. In hospitals where ophthalmology units were established, diabetologists were open to training as it helps them in screening patients
- Some physicians were of the opinion that the training will help them enhance their knowledge, but expert ophthalmologists should be consulted for more careful examination
- Some of the practitioners in the hospitals were reluctant to get trained on DR, citing reason that they are already trained and at most a short-term refresher courses could be organized for them
- Some practitioners did not think that diabetologists be trained on DR. They felt that Ophthalmology Department should take the lead on DR
- Some felt that additional training for diabetologists will add to their existing burden and hinder the provision of comprehensive care to the patients
- Some practitioners categorically denied any need for training the staff on DR as it was felt that it requires professional assessment
- Short-term training ranging 3–5 h was mentioned to be more effective than long-term training
- A streamlined, multi-dimensional approach where all the stakeholders cooperate in treating diabetes and complications was suggested to strengthening services deal with DR in the existing health care setup
- Education of the patients, health professionals including nurses and general physicians was suggested as a way forward to deal with the increasing number of diabetes students.

Discussion

This study presents the perspectives of health providers on the scope for strengthening DR services in India. It suggests that many factors influence the management of diabetes and its complications in India. These factors are in consonance with what has been described from India in the recent past.[6-8]

The diabetic care providers managing the treatment of persons with diabetes and DR opined that the socioeconomic background of the clients with diabetes and their awareness levels were critical determinants in their willingness and ability to comply with medications, lifestyle changes, and long-term follow-up required for effective management. Similar findings regarding the impact of socioeconomic status of clients on treatment compliance have been reported earlier.[8-10] Physicians suggested that the awareness should be created among the family members along with the patients for better management of diabetes.

Self-management was identified as an important prerequisite for dealing with diabetes and resultant complications. Lifestyle interventions are a key to management of diabetes and its complications.[11] A study from China has highlighted the role of awareness and practices of self-management on type 2 diabetes.[12] The need to move beyond conventional hospital based management of diabetes and complications was suggested. The role of diagnostic and technological advancements and enhanced access to glucometers, application of information and communication technology in the provision of care, nonmydriatic fundus camera were identified as important in the effective management of DR in the future. The use of fundus photography for screening has now found widespread acceptance in many countries.[13-15]

The awareness level of hospital staff other than the clinicians on DR was found to be inadequate. Though most of the respondents welcomed training on DR, it was felt that a team approach that includes an ophthalmologist would be more productive in providing comprehensive diabetic care to the patients.

The findings from this study provide insight into the provider's perspectives on the strengthening DR services in India. The selection of the providers from different institutes across key cities of the country, in-depth interviews and coding process are the strengths of this study. A key limitation is that a comparative analysis of perspectives from ophthalmologists was not conducted.

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Conflicts of interest

There are no conflicts of interest.

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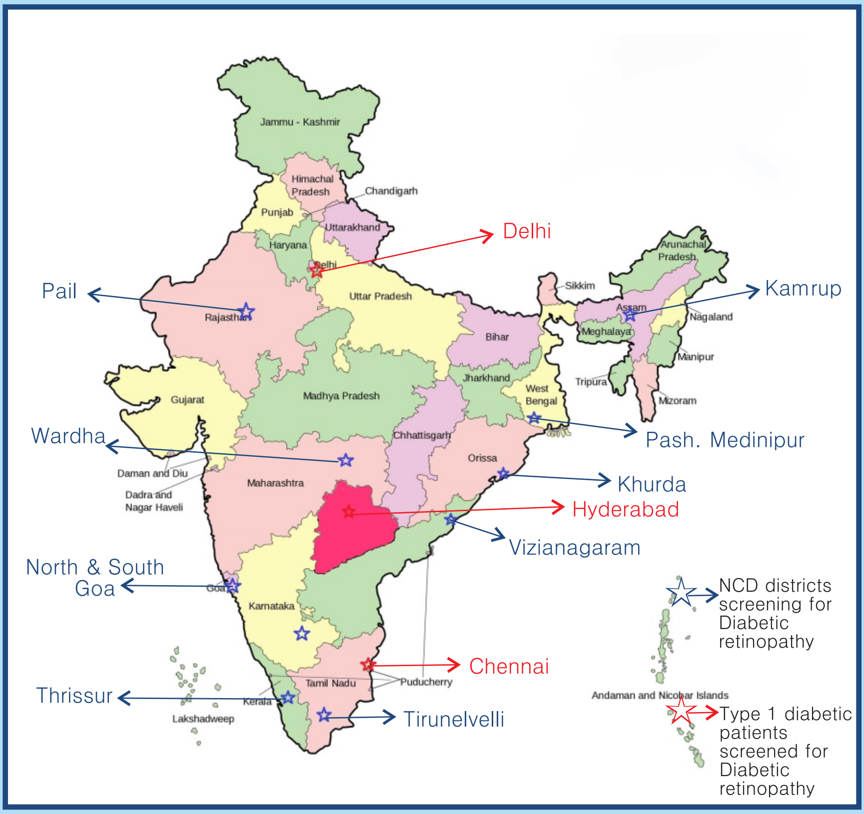

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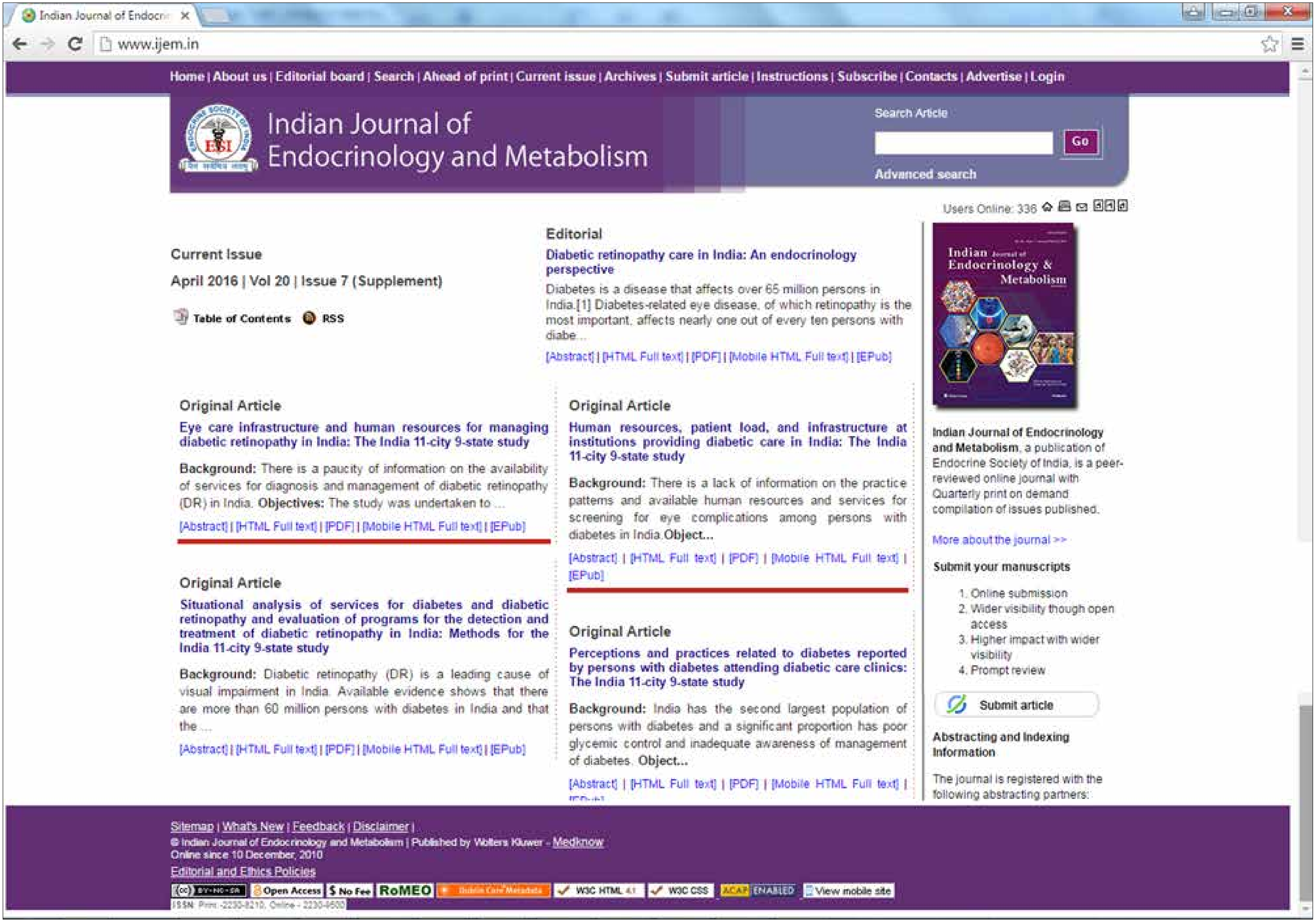

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