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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