ORIGINAL RESEARCH

Glaring incongruity in perception and practices regarding diabetes amongst patients, family and general population in India

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ABSTRACT

Background: The data regarding the perception and practices regarding diabetes among diabetics, their family members, and the general population is sparse in India, especially in recent decade

Aims and objectives: This cross-sectional study was carried out to ascertain the perception and practices of diabetes mellitus and to find the incongruities that exist in knowledge between the diabetic patients, their family members and the general population.

Material and Methods: A community-based cross-sectional study was conducted over 2 years across 3 centres. Data was collected using pretested structured face-to-face interviews after taking informed written consent, and respondents were selected via convenience sampling. A total of 4244 people were interviewed. The population was then divided into three groups' people with diabetes, their family members and the general population

Results: Only 51.8% of respondents had knowledge of diabetes, with glaring disparities between the three groups. Amongst the general population, only 27.4% had knowledge of diabetes. Similarly, the awareness of prevention, complications and risk factors of diabetes was much lower in the general population compared to diabetics and their families, and this group had a significantly lower composite knowledge score of diabetes.

Conclusion; About half of the population studied was found to have inadequate knowledge of diabetes. Even amongst the diabetics and their families, the perception and practices were poor. A greater emphasis on the dissemination of community education regarding symptoms, prevention and risk factors for diabetes is necessary.

Key Words- perception , practices , Diabetes, Population

Introduction

One-fifth of all adults with diabetes in the world live in the South-East Asia Region. Currently, estimated population data indicates that 9.1% of the adult population, or 463 million people have diabetes, of which 88 million live in India. This number will increase to 115 million by 2030 that is 12.1% of the adult population. A further 31 million people have impaired glucose tolerance, and this will also increase to 50 million by 2050. India has the second-highest prevalence of diabetes among adults at 9.1%.in the south East Asian region and about 1.1 million people die from diabetes-related illnesses in India each year. (1) It has been estimated that in India more than half (56.1%) of all people with diabetes, are undiagnosed(1) and even among known diabetes patients, less than one third have their diabetes under good control. (2)(3)Evidence suggests that poverty and poor access to health care, coupled with low education, are linked to a high rate of diabetes-related complications. (4),(5). Education remains one of the key measures in ensuring better treatment and control of diabetes. There is also evidence to show that increasing knowledge regarding diabetes and its complications can lead to an increase in compliance to treatment, thereby decreasing the complications associated with diabetes. (6),(7)

70 % of the Indian population still resides in rural areas and growing urbanisation and changing lifestyle habits (e.g. higher calorie intake, increasing consumption of processed foods, sedentary lifestyles) contribute to the increasing prevalence of type 2 diabetes at a societal level. While the global prevalence of diabetes in urban areas is higher, this

gap is closing, with rural prevalence on the rise. (1) There is evidence to suggest that diabetes mellitus and its related complications show a threefold rise in rural areas. (8) While there have been studies on the subject of diabetes awareness in India, there is a paucity of studies from the rural area and most of these studies were conducted at the hospital level rather than population level thus may not truly reflect the population data. There is a need to assess the perception and practices among participants living in rural areas to aid in the future development of awareness programs and techniques for effective health education and patient counselling. Identification of lacunae of knowledge amongst diabetic individuals will help us in providing better insight in further management and education.

Thus, with this study, we aimed to ascertain the perception and practices in the rural population and to find the disparities that exist in knowledge between the diabetic patients, their family members and the general population.

Material and methods

The present study was conducted in rural areas of delhi andwestern Uttar Pradesh for the duration of 1st January 2022 to 31st December 2023 (over 2 years) to ascertain the practices and perceptionof diabetes i. The institutional ethics committee approved the study for all three participating centres.This study was part of our ongoing project on the evaluation of prevalence of Diabetes and its complications .After excluding non-responders, a total of 4244 participants were recruited in the study via the health camp approach i.e. Non-probability or Convenience Sampling. Local panchayats , religious leades, RWA heads village heads were consulted to ensure maximum participation. After written or verbal informed consent was obtained, Data was collected using a structured and pre-tested questionnaire used previously in the ICMR-INDIAB study (10) after taking permission from the research group. Specific questions were used to assess the subject's knowledge regarding risk/causative factors as well as complications and prevention of complications. Knowledge of causative factors and complications of diabetes was assessed using open-ended questions. The questionnaire was translated into the local language and administered by a trained interviewer. The questionnaire and calculation of Knowledge composite score is shown in Appendix 1

Individuals diagnosed by a physician and on antidiabetic medications (self-reported) and/or those who had fasting capillary blood glucose ≥126 mg/dl and/or 2-h post-glucose value ≥200 mg/dl were defined to have diabetes.

Statistical analysis

Sample size was calculated from a previous study (9).Statistical analysis was carried out using SPSS for Windows (SPSS 24.0, SPSS Inc., Chicago, IL, USA). Data were presented as numbers (%) and mean (±SD). Quantitative variables that followed normal distribution were compared using ANOVA to compare the three groups. A p-value of <0.05 was considered to be significant.

Results

A total of 4244 participants were included in the study of which 2328(54.85%) were male and 1916(45.15%) were females. Amongst these 341 (8.03%) were diabetics, 598(14.1%) were their family members (non-diabetic) and the remaining 3305 were part of the general population. The mean age of diabetics(51.6years) was higher than the other two groups. Table 1 summarizes the data regarding the demographic profile and awareness regarding diabetes amongst the study participants.

Overall total of 1713(51.8%) participants reported that they knew about the condition called diabetes. However, on including only the general population, just 907(27.4%) reported that they knew about diabetes. Even amongst the family members of diabetics, 133(22.2%) did not know about diabetes. Amongst those who had heard about called diabetes in the general population, 59. 8% thought that more people were being affected by diabetes, 55% answered that diabetes can affect other organs and 48.6% reported that diabetes could be prevented. Corresponding no. for the diabetic groups were 95.8%, 71.2% and 52.5%, while amongst the family members the nos. were 85%, 61.9% and 60.2% respectively. Interestingly more participants family members thought that diabetes could be prevented as compared to the other two groups.

The knowledge of the risk factors for diabetes in the participants reporting that they knew about diabetes studied is shown in Table 2. The major causative risk factor for diabetes was stated as consuming more sweets by 71.7% whereas overweight or obesity was listed by 49.8%, family history of diabetes by 38.1%, high blood pressure by 29.3%, lack of physical activity by 21.8% and mental stress by 15.2% of the general population. Not surprisingly, the knowledge on risk factors for diabetes was better among the known diabetic subjects (Consuming more sweets – 84.2%; obesity – 60.2%; family history of diabetes – 54.6%; high blood pressure – 56.2%; lack of physical activity – 51.6%; and mental stress – 41.2%). Amongst the family group percentage of participants reporting lack of physical activity and family history was significantly higher than the diabetes group(67.3% and 65.2% respectively, p=0.001 for both)

Among the preventive factors, the diet was reported by 65.2% diabetics and exercise by 58.1%. There was no significant difference between the distribution of participants reporting exercise as a preventive measure amongst the three groups amongst those who reported that diabetes was preventable.

Knowledge of the organs affected by diabetes is shown in table 3. Among the general population who answered in the affirmative for the question "Do you think diabetes can affect other organs?" (n = 498), major organs reported were the feet (18.6%), eyes (32.6%), kidneys (45.3%), heart (17.8%), nerves (18.7%), lung (1%), brain (11.2%) and stomach (3.6%). Among diabetic subjects, the knowledge of diabetic complications was comparatively better (eyes – 61.5%, feet – 48.9%, kidneys – 68.9%, heart – 23.5% and nerve problems – 55.3%). It is disheartening to see that even among subjects with diabetes; this basic knowledge was still so poor. Among family members, the knowledge of diabetic complications was comparatively better than the general population (eyes – 53.4%, feet – 36.5%, kidneys – 41.2%, heart –12.6 % and nerve problems – 41.2%) possibly because they have seen their family members suffer from the complications affecting these organs.

Table 4 provides a comparison between the composite knowledge score of diabetes amongst the three groups studied. The mean composite score of the general population was 17.9, family members were 45.2 and diabetics had a significantly higher score of 68.2(p=0.001). The least score of "0" was obtained by 72.6% of the general population and 22.2% of the family members. The maximum score of "100" was obtained by 2.7% of the general population and 10.2% of the diabetic population and 8% of the family members.

Table 1. Demographic features and awareness regarding diabetes of the study participants

	Diabetics(n=341)	Family(n=598)	General population (n=3305)	P value
Age distribution(in yrs)				
18-30	8.2%	17.4%	25.7%	
30-39	9.4%	19.2%	22.2%	
40-49	22.6%	21.1%	19.6%	
50-59	29.3%	19.2%	18.1%	
60-69	21.7%	17.6%	10.8%	
>70	8.8%	5.5%	3.4%	
Mean age	51.6yr	43.8yr	38.9yr	0.001
SEX				
Male	50.7%	48.2%	56.5%	
Female	49.3%	51.8%	43.5%	
Awareness				
Have you heard of a condition called diabetes?	341(100%)	465(77.8%)	907(27.4%)	0.01
If yes, do you think in general more and more people are getting affected with diabetes nowadays?	327(95.8%)	395(85%)	542(59.8%)	0.001
Do you think diabetes can affect other organs?	243(71.2%)	288(61.9%)	498(55%)	0.02
Can diabetes be prevented?	179(52.5%)	280(60.2%)	441(48.6%)	0.01

Table 2: Risk factors and preventive factors of diabetes as stated by the participants

Risk factors	Diabetics(n=341)	Family(n=465)	General population(n=907)	P value
Consuming sweets	84.2%	78.8%	71.7%	0.011
Family history	54.6%	67.3%	38.1%	0.004
Obesity	60.2%	54.9%	49.8%	0.014
Hypertension	56.2%	38.5%	29.3%	0.003
Lack of physical activity	51.6%	65.2%	21.8%	0.03
Mental stress	41.2%	39.6%	15.2%	0.001
Preventive factors	N=179	N=280	N=441	
Balanced diet	65.2%	69.4%	52.6%	0.01
Exercise	58.1%	60.2%	58.9%	0.321

Table 3: perception about organs affected by diabetes

	Diabetics(n=243)	Family(n=288)	General population(n=498)
Eyes	61.5%	53.4%	32.6%
Kidneys	68.9%	46.8%	45.3%
Nerves	55.3%	41.2%	22.3%

Hands	45.8%	19.3%	12.5%
Lungs	2.5%	1.0%	1%
Stomach	6.8%	2.6%	3.6%
Feet	48.9%	36.5%	18.6%
Brain	7.9%	6.5%	11.2%
Heart	23.5%	12.6%	17.8%
Any other relevant answer	2.1%	1.2%	3.8%

Table 4: Composite knowledge score of diabetes

	Diabetics	Family	General population	P value
Mean score(±SEM)	68.2±2.9	45.2±1.8	17.9±0.9	0.001

Appendix 1. Questionnaire and Calculation of KAP composite score (Reproduced with permission from ICMR-INDIAB with permission)[10]

The Interview Schedule consisted of 7 questions which were closed or semi-closed as follows:
1. Have you heard of a condition called diabetes? Yes/ No
2. If yes, do you think in general more and more people are getting affected with diabetes nowadays? Yes/No
3. Do you think diabetes can affect other organs? Yes/No
4. If yes, which organs? Eyes/Heart/Lungs/Stomach/Kidneys/Feet/Brain/Hands/Nerves/ Others (Specify)/Don't know
5. What are the risk factors for diabetes? Overweight/High blood pressure/Family history of Diabetes/Consuming more sweets/Lack of physical activity/Mental stress/Others (Specify)/Don't know
6. Can diabetes be prevented? Yes/No/
7. If yes, how can it be prevented? Diet/Exercise/Others (Specify)

A composite score for knowledge of diabetes was used for this study. The scoring was done as follows: (a) For closed questions, correct answers were graded as one and incorrect answers (inclusive of "don't know") as zero. (b) For causative factors for diabetes, the highest score of '4' was awarded to subjects who ticked obesity, high blood pressure, lack of physical activity or family history of diabetes, '3' was given to those who ticked "consuming sweets," '2' to those who ticked "mental stress" and '1' for any other answer which made sense or was close to the above answers, while all other answers were scored '0'. (c) Thus the least possible score was '0' if all answers were incorrect, and the maximum score was '8' if all answers were correct. (d) A composite score in percentage was then derived by dividing each individual's score by the maximum score possible. E.g., if an individual's score was '6', then the composite score would be $6/8 \times 100 = 75\%$. Questions 4 and 7 were not included in the score.

Discussion

In the current study, we assessed the perception and practices amongst 4244 participants with the help of a prevalidated questionnaire. Previously a few studies regarding knowledge of diabetes have been reported from India, but most of these studies are hospital-based. There is a paucity of data from rural India. The major finding in the study is the lack of perception of diabetes among the rural population with just over half (51.6%) knowing about diabetes, and what is more worrisome is that 72.6% of the general population is unaware of diabetes itself. This is worrying in the context of the fact that India has a mostly rural population, and an estimated 56.1% of the diabetics in India are undiagnosed. Even amongst the family members of diabetics, 22.2 % did not know about diabetes. ICMR-INDIAB(10) study reported a 36.8% awareness of diabetes in the rural areas with no. ranging from 55% in rural Tamil Nadu to 16.5% in rural Jharkhand. This is in contrast to findings reported by Islam et. al who reported much higher no. at 93% in rural areas of Bangladesh. (11). Deepa Mohan et. al (2) also reported a higher awareness of diabetes, albeit from an urban area in India. A lower score in our study could be a reflection of the low literary rate in rural areas

Another finding of great public health importance was that even amongst knew about diabetes only 59.8 % of the general population reported that there was an increasing prevalence of diabetes and less than half amongst these (48.6%) said that diabetes was preventable and even lower no. were aware of major risk factors of diabetes. Even in those who thought diabetes was preventable only 58.9% were aware of the effect of exercise and 52.6% were aware of the effect of diet for prevention of diabetes. The people will transform their behaviour and attitude regarding diabetes only if they think themselves to be at high risk. Even amongst diabetics, only 52.6% reported that that diabetes is a preventable disease despite evidence for the same having being reported by many studies such as the Finnish Diabetes Prevention Study(12) and the Diabetes Prevention Programme(13). This points towards a need to ensure robust participation of the population under the already undergoing The National Program for Control

of Diabetes, Cardiovascular Disease and Stroke, and this can help improve diabetes awareness levels at the rural level.

In the diabetic population, the knowledge regarding preventive and risk factors and complications of diabetes was higher than both the other groups, but it stills paints a dismal picture. Among the risk factors, obesity was considered by most(60.2%), while diet as a preventive measure was reported by only 65.2 %. Amongst the diabetic complications, renal involvement was reported maximum at 68.9%. This reflects a poor attitude towards patient counselling and education regarding various aspects of diabetes. It should be well understood that diabetic care involves intensive education and counselling along with medical management. This forms a strong basis for recommending the presence of a diabetes educator at each centre that caters to diabetics.

On considering the composite score, the disparities between the diabetic group and the general population come to the fore with a vexatious difference of 68.2 vs 17.9. This reveals an unsettling knowledge gap regarding diabetes in the general population. Such data gives an indication of the various levels at which public health policies need to be planned and aimed at preventing diabetes at the rural level.

The strengths of our study are its large sample size and representation of data from a usually poor represented population. There are a few limitations of our study. Being a questionnaire-based study has its own disadvantages. Respondents may try to guess answers and verbal ability also becomes a factor. While a health camp-based approach may be convenient, it does not ensure accurate representation of the population.

To summarize, this study provides a glimpse of the current status of perception and practices of diabetes from rural India. There is an increasing need to provide diabetic awareness activities in the rural population which can be done via public talks, use of mass media and use of local resources such as leaders, religious assemblies and door to door campaigns to increase awareness regarding diabetes.

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Conflicts of interest

There are no conflicts of interest

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