Knowledge and awareness of diabetes in urban and rural India: The Indian Council of Medical Research India Diabetes Study (Phase I): Indian Council of Medical Research India Diabetes


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ABSTRACT

Background: Representative data on knowledge and awareness about diabetes is scarce in India and is extremely important to plan public health policies aimed at preventing and controlling diabetes. Aim: The aim of the following study is to assess awareness and knowledge about diabetes in the general population, as well as in individuals with diabetes in four selected regions of India.

Materials and Methods: The study subjects were drawn from a representative sample of four geographical regions of India, Chandigarh, Tamil Nadu, Jharkhand and Maharashtra representing North, South, East and West and covering a population of 213 million. A total of 16,607 individuals (5112 urban and 11,495 rural) aged ≥20 years were selected from 188 urban and 175 rural areas. Awareness of diabetes and knowledge of causative factors and complications of diabetes were assessed using an interviewer administered structured questionnaire in 14,274 individuals (response rate, 86.0%), which included 480 self-reported diabetic subjects.

Results: Only 43.2% (6160/14,274) of the overall study population had heard about a condition called diabetes. Overall urban residents had higher awareness rates (58.4%) compared to rural residents (36.8%) (P < 0.001). About 46.7% of males and 39.6% of females reported that they knew about a condition called diabetes (P < 0.001). Of the general population, 41.5% (5726/13,794) knew about a condition called diabetes. Among them, 80.7% (4620/5726) knew that the prevalence of diabetes was increasing, whereas among diabetic subjects, it was 93.0% (448/480). Among the general and diabetic population, 56.3% and 63.4% respectively, were aware that diabetes could be prevented. Regarding complications, 51.5% of the general population and 72.7% diabetic population knew that diabetes could affect other organs. Based on a composite knowledge score to assess knowledge among the general population, Tamil Nadu had the highest (31.7) and Jharkhand the lowest score (16.3). However among self-reported diabetic subjects, Maharashtra had the highest (70.1) and Tamil Nadu, the lowest score (56.5). Conclusion: Knowledge and awareness about diabetes in India, particularly in rural areas, is poor. This underscores the need for conducting large scale diabetes awareness and education programs.

Key words: Asian Indians, awareness, diabetes, Indian Council of Medical Research India Diabetes, India, knowledge, rural, South Asians, urban

INTRODUCTION

Diabetes mellitus is a major clinical and public health problem accounting for 4.6 million deaths annually world-wide.12 According to the International Diabetes Federation, around 366 million people globally are currently estimated to have diabetes, of which 80% live in low and
The paper discusses the prevalence of diabetes in India, noting that about 50% of those with diabetes remain undiagnosed. Although there have been small regional studies on the subject of diabetes awareness in India, there is no data at a national level or indeed even in a whole state of India on the awareness about diabetes. The study focuses on the level of awareness and knowledge of diabetes in the general, as well as the diabetic population in four regions of India based on the first phase of the ICMR-INDIAB study.

Materials and Methods

The methodology of the ICMR-INDIAB study has been published separately. Briefly, this is a cross-sectional national survey to estimate the prevalence of diabetes and its correlates in India. Men and women aged 20 years and above were recruited for the study. The study plans to survey all the 28 states in India, the two union territories (UTs) of Chandigarh and Puducherry and the National Capital Territory of Delhi in a phased manner. Phase I of the ICMR-INDIAB study was conducted from November 2008 to April 2010 and included three states randomly selected to represent the South (Tamil Nadu), West (Maharashtra) and East (Jharkhand) of India and one UT representing Northern India (Chandigarh). The regions included in phase I have a population of 213 million, which is roughly 1/6 of India’s total population of 1.2 billion people.

A stratified multistage sampling design was followed (similar to the National Family Health Survey-3). The primary sampling units (PSUs) were villages in rural areas and census enumeration blocks in urban areas. A three-level stratification process was carried out based on geography, population size and socio-economic status. The sample size was calculated to be 4000 per state (2800 rural and 1200 urban). Thus, the sample size for the entire study once completed would be 124,000 (28 states, 2 UTs and 1 NCR). Phase I of the study, which is presented in this paper, had a sample size of 16,000 individuals.

In both urban and rural areas, one individual was selected from the selected household following the World Health Organization KISH method. A total of 16,607 individuals (5112 urban and 11,495 rural) were selected from 363 PSUs (188 urban and 175 rural), of whom, 14,277 individuals consented to participate (response rate 86%) (Tamil Nadu – 3664, Maharashtra – 3920, Jharkhand – 3337 and Chandigarh – 3356 individuals). Of the total 14,277 study subjects, data on awareness were available on 14,274 subjects, which included 480 self-reported diabetic subjects. Approval of the Institutional Ethics Committee was obtained prior to study commencement and written informed consent was obtained in the local language.

Data was collected using a structured and pre-tested questionnaire which included details on demography, behavioral aspects, physical activity, dietary patterns and medical information. It included questions about knowledge and awareness of different aspects of diabetes. Specific questions were used to assess the subject’s knowledge regarding risk/causative factors as well as complications and prevention of complications. Knowledge on 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.

Questions used for obtaining data regarding knowledge of diabetes were 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/Don't know
3. Do you think diabetes can affect other organs? Yes/No/Don't know
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/Don't know
7. If yes, how can it be prevented? Diet/Exercise/Others (Specify).
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 ≥ 220 mg/dl were defined to have diabetes.[11]

A composite score for knowledge of diabetes, which has been described earlier, was used for this study.[2] The scoring was done as follows: (a) For closed questions, correct answers were graded as 1 and incorrect answers (inclusive of “don’t know”) as zero. (b) For causative factors for diabetes, the highest score of ‘4’ was awarded 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 × 100 = 75%.

**Statistics**
Statistical analyzes were performed using SAS statistical package (version 9.0; SAS Institute, Inc., Cary, NC). Results are expressed as frequencies (percentages) for quantitative variables. Chi-square test was used to test differences in proportions. A $P < 0.05$ was considered to be significant.

**RESULTS**

Figure 1a and b shows the region and gender wise awareness levels about diabetes in the four regions studied.

![Figure 1: (a) Knowledge about diabetes in the four regions studied - Region wise. (b) Knowledge about diabetes in subjects in the four regions studied - Gender wise](image)

Of the general population, 41.5% (5726/13,794) knew about a condition called diabetes. Figure 2 illustrates the awareness about diabetes among those in the general population ($n = 5726$) who had heard about a condition called diabetes and among the self-reported diabetic
Among the general population who knew about diabetes [Figure 2], 56.3% (3221/5726) were aware that diabetes could be prevented (Tamil Nadu [rural: 45.1% vs. urban: 53.4%, \( P < 0.001 \)), Maharashtra [rural: 45.9% vs. urban: 62.8%, \( P < 0.001 \)], Jharkhand [rural: 56.8% vs. urban: 78.4%, \( P < 0.001 \)] and Chandigarh [rural: 66.6% vs. urban: 77.9%, \( P < 0.001 \)]. Even among diabetic subjects, only 63.4% were aware that diabetes could be prevented. The 3221 subjects who stated that diabetes could be prevented received an open-ended follow-up question about the ways to prevent diabetes. Of these, 3.1% (101/3221) said that “exercise” could prevent diabetes, 36.8% \( (n = 1185) \) said “diet,” while 45.8% \( (n = 1474) \) said that both “diet and exercise” could prevent diabetes.

Regarding complications, 51.4% (2946/5726) of the general population who had heard of diabetes (rural: 44.4% vs. urban: 62.7%, \( P < 0.001 \)) knew that diabetes could affect other organs (Tamil Nadu [rural: 44.3% vs. urban: 59.3%, \( P < 0.001 \)), Maharashtra [rural: 40.7% vs. urban: 57.6%, \( P < 0.001 \)], Jharkhand [rural: 36.2% vs. urban: 66.0%, \( P < 0.001 \)] and Chandigarh [rural: 56.9% vs. urban: 73.3%, \( P < 0.001 \)]. However, this figure was much better among diabetic subjects where 72.7% \( (349/480) \) (urban: 75.6% vs. rural: 69.5%, \( P < 0.001 \)) reported knowledge about complications [Figure 2].

Knowledge of the organs affected by diabetes in the four regions is shown in Figure 3. Among the general population who answered in the affirmative for the question “Do you think diabetes can affect other organs?” \( (n = 2946) \), the most common organs reported were the feet (54.0%), eyes (52.3%), kidneys (36.3%), heart (33.6%) and nerves (18.7%). Other reported complications included lung problems (19.6%), brain diseases (26.6%) and stomach disorders (16.9%). Among diabetic subjects, the knowledge of diabetic complications was comparatively better (eyes – 73.5%, feet – 61.3%, kidneys – 47.9%, heart – 45.1% and nerve problems – 26.8%). It is disturbing that even among subjects with diabetes; this basic knowledge was still so poor.

The knowledge of the risk factors for diabetes in the four regions studied is shown in Table 1. The major causative risk factor for diabetes was stated as consuming more sweets by 59.8% (urban: 65.5% vs. rural: 56.3%, \( P < 0.001 \)), whereas overweight or obesity was listed only by 35.5% (urban: 45.7% vs. rural: 29.2%, \( P < 0.001 \)), family history of diabetes by 17.7% (urban: 25.1% vs. rural: 13.1%, \( P < 0.001 \)), high blood pressure by 23.2% (urban: 31.2% vs. rural: 18.1%, \( P < 0.001 \)), lack of physical activity by 16.5% (urban: 25.5% vs. rural: 10.8%, \( P < 0.001 \)) and mental stress by 12.2% (urban: 17.5% vs. rural: 8.8%, \( P < 0.001 \)) of the general population. Not surprisingly, the knowledge on risk factors for diabetes was better among the known diabetic subjects (Consuming more sweets – 52.5%; overweight – 50.4%; family history of diabetes – 28.3%; high blood pressure – 35.6%; lack of physical activity – 22.9%; and mental stress – 23.5%).

Table 2 provides the composite knowledge score of diabetes in the four regions studied. The mean composite score of the general population was 25.4 and that of self-reported diabetes was 61.2. Least score of “0” was obtained by 58.5% of the general population and 9.6% of the self-reported diabetic population. The maximum score of “100” was obtained by 2.8% of the general population and 10.4% of the self-reported diabetic population. Among the general population, Tamil Nadu (31.7) had the highest mean score, followed by Maharashtra (28.9), Chandigarh (23.6) and Jharkhand (16.3). However, among self-reported diabetic subjects, Maharashtra had the highest mean score (68.9), followed by Chandigarh (65.7), Jharkhand (62.4) and Tamil Nadu (56.5).

### DISCUSSION

This study is the first from India to report on the awareness and knowledge of diabetes on a representative sample of four regions of the country, representing a population of over 200 million people. The following are the significant findings: (1) Overall only about 50% of the population of the four regions of India studied have heard of a
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Condition called diabetes. (2) A significant disparity exists in the level of knowledge of diabetes between the different regions studied. (3) In rural areas, the awareness and knowledge about diabetes are significantly lower than in urban areas. (4) Females had low awareness rates compared with males in all regions except Chandigarh. (5) Not surprisingly, there is better knowledge of diabetes among the self-reported diabetic population compared with the general population in all four regions studied. (6) However, even among known diabetic subjects, knowledge levels are not satisfactory. (7) Based on a composite knowledge score, among the population studied, Tamil Nadu had the highest and Jharkhand the lowest score, while among self-reported diabetic subjects, Maharashtra had the highest and Tamil Nadu the lowest score.

These findings underscore the need for intensifying diabetes education measures to the community at large and to diabetic subjects in particular. Imparting knowledge about diabetes to the community is the first step in prevention and early detection of the disease and prevention of its complications. (12) The study results emphasize the need for better education measures among individuals who know they have diabetes, as over 50% of them were not even aware that diabetes could affect their nerves.

The ICMR-INDIAB study showed that the prevalence of diabetes in Tamil Nadu was 10.4%, Maharashtra, 8.4%, Jharkhand, 5.3%, and Chandigarh, 13.6%, and that overall 6.24 million people in India needed to reach diabetes awareness to people with diabetes in India.

It is worthwhile that, overall, only 41.5% of the general population reported that they knew about a condition called diabetes. The highest rates of awareness in Chandigarh were due to the extensive diabetes awareness activities in the city. A similar survey conducted in Chennai reported that only 25% of the participants had not heard of diabetes. These findings show that awareness levels vary significantly across different regions in India.

Table 1: Risk factors for diabetes reported by participants

<table>
<thead>
<tr>
<th>Perceived risk factors for diabetes</th>
<th>All four regions</th>
<th>Tamil Nadu</th>
<th>Maharashtra</th>
<th>Jharkhand</th>
<th>Chandigarh</th>
</tr>
</thead>
<tbody>
<tr>
<td>General population (n)</td>
<td>2211</td>
<td>351</td>
<td>5726</td>
<td>694</td>
<td>1345</td>
</tr>
<tr>
<td>Urban</td>
<td>1448 (65.5)</td>
<td>1978 (56.3)</td>
<td>3426 (59.8)</td>
<td>298 (42.9)</td>
<td>469 (34.9)</td>
</tr>
<tr>
<td>Rural</td>
<td>1011 (45.7)</td>
<td>1026 (29.2)</td>
<td>2037 (35.5)</td>
<td>266 (38.3)</td>
<td>269 (20.0)</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>137 (19.7)</td>
<td>113 (8.4)</td>
<td>163 (29.1)</td>
<td>131 (19.6)</td>
<td>141 (12.1)</td>
</tr>
<tr>
<td>Maharashtra</td>
<td>153 (22.8)</td>
<td>146 (12.5)</td>
<td>210 (35.2)</td>
<td>130 (25.2)</td>
<td>19 (4.9)</td>
</tr>
<tr>
<td>Jharkhand</td>
<td>108 (24.8)</td>
<td>16 (4.2)</td>
<td>175 (42.5)</td>
<td>70 (27.6)</td>
<td>43 (19.0)</td>
</tr>
<tr>
<td>Chandigarh</td>
<td>152 (22.7)</td>
<td>157 (13.4)</td>
<td>151 (22.8)</td>
<td>25 (7.9)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Urban</td>
<td>114 (49.1)</td>
<td>252 (52.5)</td>
<td>27 (30.3)</td>
<td>27 (7.9)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Rural</td>
<td>101 (44.7)</td>
<td>242 (50.4)</td>
<td>47 (52.5)</td>
<td>22 (5.5)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Tamil Nadu</td>
<td>134 (28.3)</td>
<td>20 (19.6)</td>
<td>17 (45)</td>
<td>15 (6.9)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Maharashtra</td>
<td>143 (45.7)</td>
<td>210 (52.5)</td>
<td>22 (5.5)</td>
<td>15 (6.9)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Jharkhand</td>
<td>170 (35.6)</td>
<td>33 (32.3)</td>
<td>22 (5.5)</td>
<td>15 (6.9)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Chandigarh</td>
<td>171 (35.6)</td>
<td>33 (32.3)</td>
<td>22 (5.5)</td>
<td>15 (6.9)</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Mental stress</td>
<td>70 (27.6)</td>
<td>43 (19.0)</td>
<td>110 (22.9)</td>
<td>15 (6.9)</td>
<td>1 (1.0)</td>
</tr>
</tbody>
</table>

*p < 0.001, **p < 0.05 for urban and rural comparison
Thus it will take massive efforts to teach the areas, obesity is rapidly replacing underweight as a health state level in India. Extremely important to plan public health policies aimed at preventing and controlling diabetes at the national and regions. Such data on knowledge and awareness levels are fragmented and not uniform across states/

<table>
<thead>
<tr>
<th>Composite score</th>
<th>Overall (population)</th>
<th>Tamil Nadu (population)</th>
<th>Maharshtra (population)</th>
<th>Jharkhand (population)</th>
<th>Chandigarh (population)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>480</td>
<td>13794</td>
<td>191</td>
<td>3471</td>
<td>80</td>
</tr>
<tr>
<td>0</td>
<td>46 (9.6)</td>
<td>8066 (58.5)</td>
<td>10 (5.2)</td>
<td>1432 (41.3)</td>
<td>5 (6.3)</td>
</tr>
<tr>
<td>1-24</td>
<td>10 (2.1)</td>
<td>448 (3.3)</td>
<td>8 (4.2)</td>
<td>189 (5.5)</td>
<td>1 (1.3)</td>
</tr>
<tr>
<td>25-49</td>
<td>67 (14.0)</td>
<td>1149 (8.3)</td>
<td>58 (30.4)</td>
<td>698 (20.1)</td>
<td>2 (2.5)</td>
</tr>
<tr>
<td>50-74</td>
<td>78 (16.3)</td>
<td>1225 (8.9)</td>
<td>37 (19.4)</td>
<td>377 (10.9)</td>
<td>16 (20.0)</td>
</tr>
<tr>
<td>74-99</td>
<td>229 (47.7)</td>
<td>2515 (18.2)</td>
<td>54 (28.3)</td>
<td>632 (18.2)</td>
<td>47 (58.8)</td>
</tr>
<tr>
<td>100</td>
<td>50 (10.4)</td>
<td>391 (2.8)</td>
<td>24 (12.6)</td>
<td>143 (4.1)</td>
<td>9 (11.3)</td>
</tr>
<tr>
<td>Mean score±SEM</td>
<td>61.2±1.3</td>
<td>25.4±0.29</td>
<td>56.5±2.1</td>
<td>31.7±0.57</td>
<td>68.9±2.6</td>
</tr>
<tr>
<td>Proportion of subjects with score≤50%</td>
<td>74.4</td>
<td>29.9</td>
<td>60.2</td>
<td>33.2</td>
<td>90.0</td>
</tr>
</tbody>
</table>

SEM: Standard error of mean

Chennai as part of the Prevention, Awareness, Counseling and Evaluation (PACE) Diabetes Project.[13] Indeed, the PACE project showed that it was possible to increase awareness of diabetes in the whole of a large city like Chennai (with a population of nearly 6 million people). This points to the need for replicating such models such as the PACE project in other parts of the country.

Another matter of concern is that overall, 60% of the population was aware that diabetes could be prevented. Awareness of the major risk factors for diabetes, such as overweight, family history of diabetes, lack of physical activity and high blood pressure was poor. Unless the public knows that diabetes can be prevented and are aware of risk factors, primary prevention of diabetes is unlikely to become feasible in India. It is noteworthy that obesity was not reported as a risk factor for diabetes by majority of the participants. In a country where, until recently, under nutrition associated with poverty was a major problem, obesity is often considered a sign of prosperity and good health.[14] With rapid epidemiological transition in urban areas, obesity is rapidly replacing underweight as a health problem.[15-17] Thus it will take massive efforts to teach the population at large about the ill-effects of obesity including diabetes and this has emerged as a public health message from this study.

Based on the composite knowledge score, among the general population studied, Tamil Nadu had the highest and Jharkhand had the lowest score. However, the same trend was not seen among the self-reported diabetic subjects, where Maharashtra had the highest and Tamil Nadu had the lowest score. Results of the study reveal that currently knowledge and awareness about diabetes in India are fragmented and not uniform across states/regions. Such data on knowledge and awareness levels are extremely important to plan public health policies aimed at preventing and controlling diabetes at the national and state level in India.

The regional differences in level of awareness of diabetes could be attributed to differences in the education levels. In the present study, subjects with no formal education were found to have high unawareness rates compared with the educated group regarding diabetes, which is in agreement with previous studies.[18,19]

This study also emphasizes the need for comprehensive diabetes education through awareness programs for all diabetic subjects. Education about risk factors, complications, diet control, physical activity, regular checkups and screening will go a long way in achieving better control of diabetes and thus reduce the burden due to diabetes complications. The National Program for Control of Diabetes, Cardiovascular Disease and Stroke is presently being rolled out all over the country and this program can help improve diabetes awareness levels at a national level.[20] Two major nationwide efforts to train physicians (Certificate Course in Evidence Based Diabetes Management [CCEBDM]) and diabetes educators (National Diabetes Educator's Program [NDEP]) have helped in capacity building in diabetes education in India. The first program, CCEBDM was launched by Public Health Foundation of India and Dr. Mohan’s Diabetes Education Academy (DMDEA) with the fundamental objective of improving the treatment outcomes for patients by providing evidence based guidance to physicians and general practitioners.[22] More than 5000 physicians and general practitioners have been trained through this program so far. The second program, NDEP, is a certification course jointly conducted by DMDEA and the Indian Association of Diabetes Educators and 1054 diabetes educators have been trained from 78 cities in 18 states in India.[21]

In summary, the present study provides a snapshot of the current situation of knowledge and awareness of diabetes in four study regions in India. The study emphasizes the need for improvement in knowledge and awareness both among the general population as well as diabetic subjects in
order to achieve prevention and better control of diabetes and its complications.

ACKNOWLEDGMENTS

We gratefully acknowledge the support of Indian Council of Medical Research, New Delhi and the ICMR-INDIAB Expert Group for their valuable suggestions and scientific inputs for the study. We also thank the ICMR-INDIAB study Quality Managers, Quality Supervisors and the field team for smooth conduct of the study and the participants for their cooperation. This is the fourth paper from the ICMR–INDIAB Study (ICMR–INDIAB–4).

REFERENCES