

Health literacy on tuberculosis amongst vulnerable segment of population: special reference to *Saharia* tribe in central India

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Background & objectives: Health literacy on tuberculosis (TB) is an understanding about TB to perform activities with regard to prevention, diagnosis and treatment. We undertook a study to assess the health literacy on TB among one of the vulnerable tribal groups (*Saharia*) in central India.

Methods: In this cross-sectional study, 2721 individuals aged >15 yr from two districts of Madhya Pradesh State of India were interviewed at their residence during December 2012-July 2013. By using a short-form questionnaire, health literacy on cause, symptoms, mode of transmission, diagnosis, treatment and prevention of TB was assessed.

Results: Of the 2721 (Gwalior 1381; Shivpuri 1340) individuals interviewed; 76 per cent were aged <45 yr. Living condition was very poor (62% living in huts/*katcha* houses, 84 per cent with single room, 89 per cent no separate kitchen, 97 per cent used wood/crop as a fuel). Overall literacy rate was 19 per cent, and 22 per cent had >7 members in a house. Of the 2721 respondents participated, 52 per cent had never heard of TB; among them 8 per cent mentioned cough as a symptom, 64 per cent mentioned coughing up blood, and 91 per cent knew that TB diagnosis, and treatment facilities were available in both government and private hospitals. Health literacy score among participants who had heard of TB was <40 per cent among 36 per cent of respondents, 41-60 per cent among 54 per cent and >60 per cent among 8 per cent of respondents.

Interpretation & conclusions: The finding that nearly half of the respondents had not heard of TB indicated an important gap in education regarding TB in this vulnerable population. There is an urgent need to implement targeted interventions to educate this group for better TB control.

Key words Health literacy - *Saharia* tribals - tuberculosis - vulnerable tribal groups

Poor health literacy is common among people who have low educational attainment, immigrants, elders and racial and ethnic minorities¹. Research from developed countries demonstrated that the level of health literacy expected was the constellation of skills, the ability to perform basic reading and tasks required to function in the health care environment

such as reading labels on drug bottles, interpreting the test results, dosing of drugs, educational brochures or informed consent documents. This was studied in disease specific literacy level like type 2 diabetes, hypertension², asthma³, and AIDS⁴. However, in developing countries similar studies are not available.

Tuberculosis (TB) is a major global health problem and India remains as one of the most TB affected countries in the world. As per census of India 2011, the scheduled tribe (vulnerable population) population in India comprises nearly one tenth of the country's population⁵. Any development programme initiated by the Government of India will take time to reach this segment with limited access to health care services due to isolation, low social status and weaker economic position. Studies undertaken by the National Institute for Research in Tribal Health (NIRTH), Jabalpur, Madhya Pradesh, estimated the magnitude of TB among particularly vulnerable tribal groups (PVTGs) and reported a high burden of TB among *Saharia* tribes (1518/100000) which is one of the PVTGs in India^{6,7}.

We undertook this study to assess the disease specific literacy on TB among this tribal population in terms of their awareness on symptoms suggestive of TB, preventive measures, mode of transmission, availability of diagnostic, and treatment facilities.

Material & Methods

Study area: The areas of habitation of *Saharia* population in Madhya Pradesh are Gwalior, Datia, Morena, Sheopur, Bhind, Shivpuri, Ashoknagar and Guna. This study was carried out in two selected districts namely, Gwalior and Shivpuri, considering the operational feasibility, rapport with community and support by district authorities. Community survey done among *Saharias* in these districts by NIRTH showed that most of them were labourers with annual family income of < ₹10000. Majority were illiterate and they resided in *Kachcha* houses/huts with no separate kitchen in houses. In these districts as per the RNTCP (Revised National Tuberculosis Control Programme) quarterly reports, 2014, the total case detection rate (CDR) was (144/100,000) less than the expected 216/100,000 population and new smear positives CDR was 61 as against the expected 80/100,000 population⁸.

Study population: This study was carried out between December 2012 and July 2013, and the data from each district were collected by two independent teams during the same period. Both male and female individuals aged >15 yr were included in this study. Considering the prevalence of risk to develop TB (50%), level of confidence (95%), precision (5%) and design effect (3), the required sample size to assess the health literacy was estimated to be 1200 from each district. All the villages were arranged in descending order of the tribal population and those villages with more than

80 per cent tribal population were selected. A village was considered as a sampling unit and required number of villages was selected using probability proportional to the size of each block in the district in order to cover the estimated sample size.

Data collection: Semi-structured, pre-coded, pre-tested questionnaire was used for data collection. The interviews were conducted at home in their local language (Hindi) by trained field investigators. The interview included household identification, demographic and socio-economic characteristics of respondents. In addition, data on health literacy on TB such as cause of TB, signs and symptoms of TB, mode of transmission, diagnosis and treatment and preventive measures were also collected from the individual respondents at their residence available at the time of survey. The interview teams were supervised by trained supervisors during data collection. All the filled forms were sent to NIRTH, Jabalpur, to check for correctness and completeness, any incomplete forms were sent back to field for corrections within 15 days.

Overall health literacy about TB was assessed based on the following items: (i) symptoms of TB (persistent cough for 2 or more weeks, sputum with blood, chest pain, weight loss, loss of appetite, fever, and night sweat), (ii) recognize TB as a transmissible disease, (iii) enumerate correct mode of transmission of TB (cough/sputum from infected persons), (iv) TB is treatable, (v) TB diagnosis tests, (vi) effective allopathy treatment for TB, and (vii) correct preventive methods for TB (covering nose/mouth while sneezing/coughing, not spitting everywhere, BCG vaccination). Total 20 questions and score of one (1) was given to correct responses and zero (0) for incorrect/do not know responses. Only respondents who had ever heard of TB were asked these questions. Responses were added together for each respondent to generate a literacy score (converted to percentage) ranging from minimum of zero to maximum of 100. The composite score was categorized into three grades low, medium and high using cut-off value of <40, 41-60 and >60. The similar methodology was used by World Bank to compile the Knowledge Economy Index⁹ and by Tobin *et al*¹⁰ to assess the knowledge and attitude to pulmonary tuberculosis in rural Edo state, Nigeria.

Data management and analysis: Data entry was done by using the Census and Survey Processing System (CSPro) software package version 5.0 (*cspro.software.informer.com/s.o*, USA). Data entry format was

developed with logical expressions and conditional statements used to minimize the errors in data entry. Data were analysed using Statistical Package for Social Sciences (SPSS/PC version 20.0; SPSS Inc., Chicago, IL, USA) package. In univariate analysis, Chi square test was used to compare the level of health literacy on TB with their demographic, socio-economic characteristics and tested for statistical significance. Multiple regression analysis was performed to find out the factors independently associated with the level of health literacy.

The study protocol was approved by the Institutional Ethics Committee of NIRTH, Jabalpur, and respondents were interviewed after obtaining voluntary, written informed consent.

Results

Of the 2721 persons enrolled in this study, 1381 (51%) were from Gwalior district and 1340 (49%) from Shivpuri district. Demographic and socio-economic characteristics of study subjects are shown in Table I. Mean age of respondents was 39 yr and majority (74%) belonged to the age group of less than 45 yr. Regarding their housing conditions 21 per cent lived in huts, 41 per cent *kachcha* houses, 84 per cent in a house with single room, 89 per cent did not have separate kitchen (cooking either in living room or outside the house) and 97 per cent used wood or crop residuals as a fuel, overall literacy rate was 19 per cent; (11% completed primary and only 3 per cent completed High School and above). Family size indicated that 22 per cent of the study participants lived with more than seven members in a house.

Health literacy on TB: Of the 2721 respondents participated, nearly half (n=1306, 48%) had not heard about TB. It was observed that majority were females (55%); illiterates (54%) and unemployed/housewives (50%) or farmers/labour (48%) (Table I). Respondents having heard of TB were asked to response 20 questions on TB. Table II indicates health literacy on TB in each item as reported by the respondents.

(i) Symptoms of TB - Considering the total population, 44 per cent of the respondents mentioned that cough for more than two weeks as a symptoms of TB. Other symptoms mentioned by the respondents included cough with blood (33%), fever and chest pain (15%), weakness (13%) and only a few reported weight loss, breathlessness, loss of appetite and night sweats.

(ii) TB transmission - Forty eight of the respondents stated TB as transmissible disease and 46 per cent Sated

coughing/sneezing from infected person as a mode of transmission.

(iii) TB diagnosis - About literacy on TB diagnosis 47 per cent answered that TB was diagnosed by sputum examination and 40 per cent by X-ray.

(iv) TB treatment - Overall, 82 per cent of the respondents knew TB as a treatable disease. Further, majority (92%) reported that diagnosis and treatment facilities were available in both government and private hospitals.

(v) TB prevention - Respondents were asked about the prevention of TB infection by three questions; 29 per cent were aware that TB infection could be prevented by covering nose/mouth while sneezing or coughing. Only two per cent knew about BCG vaccination and less than one per cent reported that 'not spitting everywhere' could also prevent TB.

Overall score for 'Health Literacy on TB': Twenty questions on TB were used to assess the level of literacy on TB and 52 per cent participants who had ever heard about TB were interviewed to answer these questions. Of the 1415 respondents, 36 per cent scored less than 40 per cent, 54 per cent scored between 41-60 per cent and only 8 per cent scored more than 60 per cent. Health literacy scores according to respondent's demographic and socio-economic characteristics are given in Table III. The average score was significantly higher among males compared to females (42 vs 39; $P=0.002$), among literates (44 for primary & middle schooling, 46 for high school and above) as compared to illiterates (38; $P<0.001$). Students had significantly higher score (50) as compared to farmer/labourers (41) and unemployed/housewives (39). Multiple regression analysis was performed to find out the factors independently associated with health literacy on TB and, general education was the only factor independently associated with health literacy on TB.

Discussion

The objective of the study was to assess TB awareness with respect to disease symptoms, transmission, diagnosis, treatment and prevention among the tribal group. From the public health perspective health literacy may represent an important variable explaining the prevalence of poor health outcomes. In our sample, 52 per cent of respondents had heard about TB. This is low as compared to the national average of 88 per cent¹¹. But among those who had heard of TB, the most significant finding that

Table I. Demographic and socio-economic characteristics of population (n=2721) those who had heard of TB (n=1415) and not heard of TB (n=1306)

	Total No. (%)	Heard about TB No. (%)	Not heard about TB No. (%)	<i>P</i> value
Age (yr)				
<25	699 (26)	328 (47)	371 (53)	0.010
25-34	746 (27)	385 (52)	361 (48)	
35-44	580 (21)	310 (53)	270 (47)	
45-54	379 (14)	217 (57)	162 (43)	
55+	317 (12)	175 (55)	142 (45)	
Sex				
Male	1255 (46)	760 (61)	495 (39)	0.000
Female	1466 (54)	655 (45)	811 (55)	
Family size (members)				
≤4	1043 (38)	549 (53)	494 (47)	0.506
5-6	1071 (39)	563 (53)	508 (47)	
7+	607 (22)	303 (50)	304 (50)	
Type of housing				
Hut/Thatched	574 (21)	259 (45)	315 (55)	0.000
<i>Kachecha</i>	1127 (41)	634 (56)	493 (44)	
Semi-pucca	763 (28)	363 (48)	400 (52)	
<i>Pucca</i>	257 (9)	159 (62)	98 (38)	
No. of rooms in the house				
1	2292 (84)	1178 (51)	1114 (49)	0.342
2	373 (14)	206 (55)	167 (45)	
3+	56 (2)	31 (55)	25 (45)	
Main fuel for cooking				
Wood/crop residuals	2633 (97)	1371 (52)	1262 (48)	0.702
Others	88 (3)	44 (50)	44 (50)	
Cooking place				
Living room	1990 (73)	986 (50)	1004 (50)	0.000
Separate room	305 (11)	184 (60)	121 (40)	
Outdoor	426 (16)	245 (58)	181 (42)	
Education				
Illiterate	1936 (81)	888 (46)	1048 (54)	0.000
Primary	300 (11)	196 (65)	104 (35)	
Middle	143 (5)	112 (78)	31 (22)	
High School & above	342 (3)	219 (64)	123 (36)	
Occupation				
Farmers/Labour	2019 (74)	1053 (52)	966 (48)	0.043
Unemployed/Housewives	562 (21)	279 (50)	283 (50)	
Student	40 (1)	29 (73)	11 (28)	
Others	100 (4)	54 (54)	46 (46)	

Table II. Health literacy on TB among those who heard about TB (n=1415)

Question No.	Question to assess health literacy on TB	No.	%
1	Cough	1195	84
2	Cough with blood	906	64
3	Fever	402	28
4	Chest pain	398	28
5	Weakness	362	26
6	Weight loss	171	12
7	Breathless	128	9
8	Loss of appetite	56	4
9	Night sweats	34	2
10	TB is a transmissible disease Mode of transmission	678	48
11	From infected persons cough/ sneezing	648	46
12	TB is treatable Knowledge on TB diagnosis tests	1163	82
13	Sputum examination	665	47
14	X-ray	572	40
Places for TB diagnosis			
15	Private & Government hospital	1288	91
Knowledge on TB treatment			
16	Modern treatment	1091	77
Places for TB treatment			
17	Private & Government hospital	1297	92
TB prevention			
18	Covering nose/mouth while sneezing/coughing	410	29
19	BCG vaccination	23	2
20	Not spitting everywhere	3	0.21

emerged from this study was 84 per cent knew cough as a TB symptom.

In this study, 48 per cent subjects had not heard of TB. This deficiency in health literacy on TB may hamper their treatment seeking behaviour and contribute to delay in diagnosis and treatment adherence leading to the high TB burden reported constantly in this segment of population^{6,7}. Another significant finding was that among those who had heard about TB only a few

respondents knew all the symptoms of TB and only one third mentioned any one preventive measure. In an earlier study the main reasons for not taking action were lack of awareness on TB (40%) and poor socio-economic condition (36%)¹². Many of the lower socio-economic groups are not aware the risks associated with long standing cough. *Saharia* is not exceptional; they live in remote areas, not well connected through road/bridge network and lack of exposure to modern life has left *Saharias* economically weak tribe¹³.

Our findings corroborated with a study on TB done among sandstone quarry workers (83% were Scheduled Caste and Scheduled Tribes) which reported low literacy on TB¹⁴. The Patient Protection and Affordable Care Act¹⁵ has enlightened health literacy as the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions. Research indicates that nearly nine out of 10 adults have difficulty using the everyday health information that is routinely available in our healthcare facilities, retail outlets, media and communities¹⁶. Without proper information and an understanding of importance of information, people are more likely to skip necessary medical tests, end up developing the disease¹⁷. Care seeking behaviour^{18,19} and delay in diagnosis of TB have been studied extensively in India and in other countries among general population^{20,21} and in TB patients¹⁸. It was found that lack of education on TB symptom was one of the reasons for delay in diagnosis of TB²²⁻²⁴. A study conducted in 2003 by Indian Institute of Health Management on accessibility and utilization of RNTCP services by Scheduled Caste/Scheduled Tribe population in Madhya Pradesh reported that 18.9 per cent were unaware of the place to seek treatment²⁵. In order to reach out to the particularly vulnerable group, an evidence-based and focused communication strategy has to be adopted to improve standards of care among these groups and to form scientific evidence based communication and social mobilization strategy^{26,27}.

The Government of India with Danish assistance to the National Tuberculosis Programme (DANTB) has done an information, education, communication (IEC) project in Odisha to develop innovative approaches and strategies as well as making use of successful experiences with health communication from other health programmes²⁸. The innovations include patient provider interaction meetings; interactive stalls at weekly markets; a wide range of folk media;

Table III. Health literacy score on TB by demographic and socio-economic characteristics of study subjects (n=1415)

Characteristic	Total No.	Heard about TB No.	Health literacy (TB) score		P value
			Mean	SD	
Age (yr)					
<25	699	328	40	17.7	1
25-34	746	385	40	16.5	0.781
35-44	580	310	41	16.1	0.984
45-54	379	217	42	17.3	0.485
55+	317	175	41	17.0	0.787
Sex					
Male	1255	760	42	16.9	1
Female	1466	655	39	16.6	0.002
Family size (members)					
≤4	1043	549	40	16.5	1
5-6	1071	563	41	17.1	0.491
7+	607	303	40	16.9	0.897
Type of housing					
Hut/Thatched	574	259	42	16.6	1
<i>Kachcha</i>	1127	634	40	15.9	0.971
<i>Semi-pucca</i>	763	363	42	18.2	0.880
<i>Pucca</i>	257	159	41	17.5	0.687
No. of rooms in the house					
1	2292	1178	41	16.8	1
2	373	206	39	16.8	0.285
3+	56	31	39	17.9	0.453
Main fuel for cooking					
Wood/crop residuals	2633	1371	41	16.9	1
Others	88	44	44	12.6	0.207
Cooking place					
Living room	1990	986	41	16.9	1
Separate room	305	184	42	15.8	0.530
Outdoor	426	245	39	17.1	0.127
Education					
Illiterate	1936	888	38	16.7	1
Primary	300	196	44	15.8	0.000
Middle	143	112	44	15.0	0.001
High School & above	342	219	46	16.9	0.000
Occupation					
Farmers/Labour	2019	1053	41	16.9	0.004
Unemployed/Housewives	562	279	39	15.8	0.000
Student	40	29	50	15.3	1
Others	100	54	44	19.2	0.173

involvement of *panchayat raj* institutions, self-help groups and community-based organisations; as well as locally-designed IEC materials. Odisha became an IEC laboratory with involvement of villagers, DOT providers, former patients, health staff at all levels and non-government (NGOs) and voluntary organisations as laboratory technicians. This Odisha model of communication involved seven strategic elements: Universal right to know, Cultural sensitivity, Gender sensitivity, Community participation, Multi-level partnership, Appropriate media mix, Research, Monitoring and evaluation. These approaches can be utilized to increase health literacy in tribal areas.

There were some limitations of this study. A detailed questionnaire was used to collect information from tribal population. There might be a problem in the comprehension of the questions since most of the respondents were illiterate. Also health literacy from non-tribal population in the area was not compared. The questionnaire did not include data on 'prior exposure to this disease either in self or in the family'. This valuable information was not collected.

In conclusion, the findings of this study indicate the need to develop working strategies to provide 'Universal Access' to TB care, especially among the tribal and socially vulnerable populations. Based on recommendations, working strategies could be framed for improving health literacy on TB among PVTG such as *Saharia* and incorporated in the ACSM (Advocacy, Communication and Social Mobilization) tribal plan for TB control in the country.

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