

Awareness and attitudes towards leprosy in urban slums of Kolkata, India

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Urban slums have proliferated in India with poor health and socio-economic status with no organized health system. They are at high risk for contracting communicable diseases including leprosy. In order to obtain reliable data on knowledge, attitudes and treatment of leprosy; a random sample cluster survey was done in Kolkata slums. House to house screening for leprosy was done in 6 representative random samples of slums, each with a population of at least 5000, using accepted methods for detection. Suspects were confirmed by medical officers. Intensive interviews were done by qualified male and female investigators. A majority had some knowledge of leprosy but hardly any knew early signs or symptoms or where to get proper diagnosis and treatment. Half the respondents felt leprosy must be treated separately from general patients but stated they had no hesitation in working with or visiting a leprosy patient. There were 11 suspects of which 9 were confirmed for leprosy and sent to nearest centre for MDT. Glaring gaps are noticed between knowledge and practice of slum population regarding leprosy. An integrated health program is needed urgently in urban slums to control leprosy and other diseases using a variety of resources including medical colleges.

Keywords: Urban slums, Awareness, Attitudes, Survey, Leprosy

Introduction

Urban slums in India have doubled in the last two decades and continue to grow (Census of India 2001). Kolkata "the city of joy" had a population of 5 million in the municipality and an extended population of 14 m in the urban agglomeration according to the national census 2001. One third of the inner city population of 5 m i.e. 1.5 m people live in 2011 registered slums and 3500 unregistered slums of Kolkata (Government of India 2009). Slum residents are usually poor, illiterate and mostly migrants with sub-standard environmental sanitation and poor housing exposing these people to malnutrition and communicable diseases including leprosy (Awasthi and Pande 1997, Gomber et al 1998,

Mathew et al 2002, Ghosh and Bharati 2003). In a prospective community based study of slums in Kolkata, there was a substantial burden of cholera with risk factors not easily amenable to intervention (Sur et al 2005). In such slum population, ignorance and superstition leads to delay in early reporting, resulting in premature mortality and in the case of leprosy to irreversible and disabilities (De Zoysa et al 1998). Improving the health of slum residents can be quite challenging requiring a political will, socio-economic development and integrated health approach (Pawar et al 2008).

Early detection of leprosy depends almost completely on voluntary reporting which implies awareness of the disease and its treatment

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facilities. Knowledge per se may not necessarily lead to positive attitudes or proper behaviour in seeking prompt treatment (Raju and Kopparty 1995) and relevant data on these aspects in urban slums are limited (Barkataki et al 2006).

Hence, it was proposed to carry out an epidemiological survey of Kolkata slums with focus on knowledge and attitudes to leprosy. It was also planned to identify untreated cases of leprosy and the reasons for not reporting earlier. In this paper, the findings are presented and the recommendations made for future guidance are given.

Materials and Methods

Kolkata, the capital of West Bengal state, is a megalopolis with an estimated population in 2006 of over 11.5 million. As in any other major city in India, Kolkata has spawned over 5000 slums scattered all over the city, only half of which are registered. The total population of all slums is estimated as over 20 lakhs.

From a geographic map showing all the slums, considering only those with over 5000 population, a representative random sample of 6 slums was chosen. The sample population was nearly 50,000. The Leprosy Mission Hospital located in one of the busiest areas of the city served as the nodal centre for the survey.

Interview technique and examination of suspects were adopted visiting each house. The head of the household was interviewed using a structured schedule which covered demographic details, knowledge of the cause, early signs and symptoms of leprosy, attitude to leprosy patients and an enquiry about skin problems. Two experienced leprosy health workers (a lady and a man) were recruited and given orientation to carry out the survey.

Results

Demography

A total of 600 persons of both sexes were interviewed, the majority (80 %) lying between the ages of 20 and 50 years. The educational status was very low with over 80 % having a low level of education, of whom 23 % were illiterate. Most were migrants from villages seeking a livelihood and worked as unskilled daily wage earners, domestic help, rickshaw pullers, small shop owners. A small proportion are working in private or government jobs. The occupational status is displayed in Table 1. Nearly 90% of men and 84% of women had been resident in the slum for 10 years or more. For medical care, 42.5% go to a Government hospital for medical help and one-third to a private practitioner. Another 12% visit the corporate clinics, 5.2% use both

Table 1 : Occupational status of respondent by sex

| Occupation | Male 299 | | Female 301 | | Total 600 | |
|------------------------------|-------------|--------------|---------------|--------------|--------------|--------------|
| | No. | % | No. | % | No. | % |
| Skilled daily wage earner | 34 | 11.4 | 6 | 2.0 | 40 | 6.7 |
| Un-skilled daily wage earner | 81 | 27.1 | 11 | 3.6 | 92 | 15.3 |
| Service | 69 | 23.1 | 14 | 4.7 | 83 | 13.8 |
| Domestic worker | 1 | 0.3 | 227 | 75.4 | 228 | 38.0 |
| Driver/Conductor | 28 | 9.4 | 0 | 0.0 | 28 | 4.7 |
| Small business | 58 | 19.4 | 11 | 3.6 | 69 | 11.5 |
| Unemployed | 27 | 9.0 | 30 | 10.0 | 57 | 9.5 |
| Student | 1 | 0.3 | 2 | 0.7 | 3 | 0.5 |
| Total | 299 | 100.0 | 301 | 100.0 | 600 | 100.0 |

Government and private practitioners, 4.2% use corporate clinics and private practitioners and the rest use other facilities.

Knowledge of leprosy

93.8 % did know something about leprosy but only a third mentioned that leprosy was caused by a micro-organism. The other reasons are shown in Table 2. There was hardly any one who knew of early signs or symptoms as seen from Table 3. However, 88% of men and 79% of women stated that leprosy was curable with proper medicines. Only 58% of men and 52% of women felt that deformities and ulcers can be prevented.

Treatment for leprosy

About 60% stated that leprosy treatment is available at Government hospitals or corporate clinics, 12% didn't know and only 7% mentioned TLM hospital. Nearly 80% mentioned that leprosy treatment is free of cost. When asked where they will direct leprosy patient for treatment, there was a wide range of places as given in Table 4. Most of them got this information from friends and through the radio. Less than 10% mentioned posters or banners or even newspapers.

Attitudes towards leprosy

Only 14% were personally acquainted with

Table 2 : Knowledge on causation of leprosy by sex

| How is leprosy caused ? | Male 299 | | Female 301 | | Total 600 | |
|-----------------------------|-------------|--------------|---------------|--------------|--------------|--------------|
| | No. | % | No. | % | No. | % |
| Micro-organism | 104 | 34.8 | 80 | 26.6 | 184 | 30.7 |
| Curse of God | 15 | 5.0 | 32 | 10.6 | 47 | 7.8 |
| Hereditary | 35 | 11.7 | 36 | 11.9 | 71 | 11.8 |
| Immoral life | 3 | 1.0 | 5 | 1.6 | 8 | 1.3 |
| Bad blood | 47 | 15.7 | 36 | 12.0 | 83 | 13.8 |
| Others | 8 | 2.7 | 2 | 0.7 | 10 | 1.7 |
| Don't know | 87 | 29.1 | 108 | 35.9 | 195 | 32.6 |
| Curse of God and hereditary | 0 | 0.0 | 2 | 0.7 | 2 | 0.3 |
| Total | 299 | 100.0 | 301 | 100.0 | 600 | 100.0 |

Table 3 : Knowledge on signs/symptoms of leprosy by sex

| What are the signs of leprosy | Male 299 | | Female 301 | | Total 600 | |
|-------------------------------|-------------|--------------|---------------|--------------|--------------|--------------|
| | No. | % | No. | % | No. | % |
| Deformity | 32 | 10.7 | 41 | 13.6 | 73 | 12.2 |
| Ulcers | 34 | 11.4 | 24 | 8.0 | 58 | 9.7 |
| White patches | 75 | 25.1 | 79 | 26.2 | 154 | 25.6 |
| Anaesthesia | 8 | 2.7 | 6 | 2.0 | 14 | 2.3 |
| Don't know | 51 | 17.0 | 53 | 17.6 | 104 | 17.3 |
| White patch and anaesthesia | 50 | 16.7 | 68 | 22.6 | 118 | 19.7 |
| Ulcer and anaesthesia | 4 | 1.3 | 5 | 1.7 | 9 | 1.5 |
| Deformity and ulcer | 31 | 10.4 | 16 | 5.3 | 47 | 7.8 |
| Deformity and white patches | 12 | 4.0 | 7 | 2.3 | 19 | 3.2 |
| Ulcer and white patches | 2 | 0.7 | 2 | 0.7 | 4 | 0.7 |
| Total | 299 | 100.0 | 301 | 100.0 | 600 | 100.0 |

Table 4 : Treatment for leprosy as are directed by sex

| Where would you send anyone who needed treatment for leprosy | Male 299 | | Female 301 | | Total 600 | |
|--|-------------|--------------|---------------|--------------|--------------|--------------|
| | No. | % | No. | % | No. | % |
| Government hospital | 207 | 69.2 | 202 | 67.1 | 409 | 68.1 |
| Private doctor | 11 | 3.7 | 14 | 4.7 | 25 | 4.1 |
| Corporate clinic | 23 | 7.7 | 33 | 11.0 | 56 | 9.3 |
| Missionary of charity | 7 | 2.3 | 0 | 0.0 | 7 | 1.2 |
| Corporate clinic | 0 | 0.0 | 1 | 0.3 | 1 | 0.2 |
| TLM | 9 | 3.0 | 9 | 3.0 | 18 | 3.0 |
| Health Centre | 24 | 8.0 | 16 | 5.3 | 40 | 6.7 |
| Temple | 0 | 0.0 | 1 | 0.3 | 1 | 0.2 |
| Don't know | 18 | 6.0 | 25 | 8.3 | 43 | 7.2 |
| Total | 299 | 100.0 | 301 | 100.0 | 600 | 100.0 |

anyone with leprosy. About 45% of both men and women felt that leprosy patients should be treated separately from patients of other diseases.

Nearly 40% think that people hide the disease, largely due to social stigma attached with the disease. About 90% of men and 84% of women replied that they would have no hesitation to visit a relative or friend with leprosy. However, only 58% of men and 52% of women would agree to their family members marrying into a family which has a leprosy patient. On the other hand, 91% of men but only 79% of women would agree to work with a leprosy patient.

Prevalence of leprosy in the slum

There were 11 cases of leprosy of which 9 were found to be untreated and referred to the nearest Government hospital or corporate clinic for treatment.

Discussion

The findings reveal glaring gaps between awareness and practices in seeking prompt treatment for leprosy. Similar divergences were reported regarding maternal and child health in an urban slum in Chandigarh (Kumar et al 2008). There is, therefore, an urgent need to capitalize on existing knowledge and use of appropriate IEC techniques to change behaviours and inculcate

proper attitudes to leprosy. Proper evaluations are also needed to ensure that the desired change has taken place or is happening to avoid false conclusions (Barkataki et al 2006). Such interventions must also be followed up through adequate surveillance mechanisms and other public health strategies (Sur et al 2005).

Improving the health of urban slum residents needs an integrated approach based on well-grounded understanding of both health and social determinants (Pawar et al 2008). Stigma is an obnoxious social parameter that needs to be addressed using community-based approaches and avoiding socio-cultural barriers and misconceptions (Raju et al 2008). It is the societal stigma that prevents early reporting for treatment and waiting till irreversible disabilities occur when the best treatment are rendered ineffective (Rao et al 2008). There seems to be several positive traits in the slum population and less severe discriminatory practices which can be used to reduce and eliminate stigma and promote early registration and complete treatment with MDT.

It is well known that comparable to the rural health system in India, there is practically no formal structure of health care in the urban areas including the slums. Poor people and those below the poverty line are forced to seek free care at

Government centres and may be at a disadvantage in being correctly diagnosed (Ganapati et al 2008). Since it is the complication such as recurring plantar ulcers or reaction that forces a patient to seek medical care at a low cost care, the diagnosis of leprosy may be completely missed unless proper diagnostic tools are used (Margery et al 2008).

It must also be noted that leprosy has an uneven geographical distribution, even in the slum populations (Kumar et al 2005). In studying the pattern and magnitude of leprosy and its determinants, a proper epidemiological approach is necessary and useful for planning suitable strategies (van Veen et al 2008). Such research can be exciting and profitable in national programmes for the eradication of leprosy (WHO 2008). Since most medical colleges are situated in or near metropolitan urban centres, the study of slums and developing an effective health and leprosy control programs can be one of their prime responsibilities. These studies can also provide new insights into the epidemiology of leprosy and suggest modern methods of control.

Conclusions

While most respondents felt that leprosy is curable and knew where to obtain treatment, a large percentage of the population do not know the early signs and symptoms of leprosy and the importance of early treatment. They are still wary of associating closely with leprosy affected persons. This may lead to a dangerous situation where those with leprosy delay reporting, and thereby endanger themselves as well as the community.

Urban health programs in general and leprosy control in particular is still primitive in India (Park 2009). Urban slums with its poor infrastructure, poor socio-economic status and grossly unhygienic environment will be the breeding ground for both communicable and non-communicable diseases and affect the national health very badly unless urgent and stringent actions are taken. Programmes similar to the

national rural health mission (NRHM) must be formulated on a priority basis at least for the urban slums and peri-urban areas. This calls for innovative research projects and involvement of the medical colleges in the area. A sustained IEC programme as well as periodic health screening is essential especially in underserved areas if we do not wish to lose all we have achieved so far.

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