

Is beggary a chosen profession among people living in a 'leprosy colony'?

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Summary Leprosy is a highly stigmatized disease that apart from the physical ailments and the deformities causes psycho-socio-economic problems to the people affected. As a result of social rejection, leprosy colonies were formed inhabited by the leprosy-affected families. With inadequate socioeconomic support and help, these people often have resorted to beggary as a way to earn their living. This study is an attempt to look into the lives of the leprosy-affected people living in the leprosy colony in Ambala City, Haryana, north-west State of India and who have accepted beggary as their source of income. The psychosocial impact of leprosy and the subjects' attitude towards beggary has been studied. The study comprised 21 families, including, 22 men, 21 women and 40 children. Seventy-one percent of the families came from Southern India. All the men and nine of the women were leprosy-affected. The proportion of people with deformity was 89%. Prior to contracting leprosy, all of the men were employed, mainly in agriculture and physical labour. At present, all are beggars. Of the 20 who were interviewed, 65% of those who beg and 83% of other adults were illiterate. Fifty percent of the children were in need of education. Due to leprosy, the social interaction of 85% of the interviewees was limited to within the colony and of 88% to only other leprosy-affected people. Through their own organized efforts, they raised welfare services and housing for themselves. None of them liked begging to start with but have accepted it as a source of income. If given a chance and support, 80% said they were ready to quit begging. They were concerned about the education of their children. The study highlighted the need to develop alternate avenues of income generation utilizing the existing desires and potential of the inhabitants.

Introduction

The global leprosy elimination programme aimed at eliminating leprosy as a public health problem, thereby reducing prevalence to less than one case per 10,000 population. Much

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emphasis is being given to early detection and treatment, and prevention of deformities and disabilities. Rehabilitation of the debilitated (former) patients, who have suffered the consequences of leprosy, both physically and socio-economically and who have become beggars, has not been given sufficient attention. A leprosy-affected person exhibiting deformities and begging on the roadside is a common feature in countries where leprosy is endemic. In India, in majority of places, beggars are seen to operate near places of worship and in crowded areas such as bus stands, railway stations, markets and more fairly close to people. A large number of them are leprosy-affected with characteristic deformities and ulcers. As beggars, they continue to perpetuate the stigma in society. As a result, leprosy continues to be identified with deformities and beggary despite the success of health education and effective treatment.

Legally, beggary is an offence in India. Under the Bombay Prevention of Beggary Act, 1959, beggary is defined as 'soliciting or receiving alms in a public place, whether or not under any pretence such as singing, dancing, fortune telling, performing or offering any article for sale, . . . exposing or exhibiting with the object of obtaining or extorting alms, any sore, wound, injury, deformity or disease whether of a human being or animal'. Leprosy is one of the types defined amongst the types of beggars.

A few studies have been done on leprosy cured beggars living in leprosy colonies. One study of 40 people in a leprosy colony in Mysore observed 93% illiteracy and 73% deformity rate, and found that, whilst all of the patients had been employed prior to settlement in the colony, following settlement, 65% had resorted to begging, significantly reducing their income.¹ Their common occupations prior to begging were agriculture and labour. Moreover, even some healthy male relatives were found to have left their jobs so that they could transport patients to places of begging. Similar observations have been made in another study.² Prasad *et al.*³ have reported a higher proportion of ex-leprosy patients becoming beggars in urban areas compared to rural areas. They were mainly from the leprosy colonies. The colonies were well organized and had registered societies. Persons living in such structures are usually elderly, from the pre-MDT era. Under the Rehabilitation programme, they received some monetary help and beggary was their additional income source. Since the monetary help under Rehabilitation Programme was not enough for them, they were reluctant to give up begging. An important question that comes to mind is whether beggary amongst the leprosy-affected people is a part of debilitation and as such unwanted or whether it is one of the means of income generation taken up on a voluntary basis.

This study seeks to understand the life of former leprosy patients living in a 'leprosy colony' who resorted to beggary and to find out their attitude towards beggary and related issues.

Materials and methods

ABOUT THE LEPROSY COLONY

The study has been carried out in the later part of 1999 in a leprosy colony, Pashupathi Kusht Ashram, in Ambala City, Haryana, north-west State of India. Pashupathi Kusht Ashram is a registered society. They receive monthly pension from the government along with ration card that help them procure basic food items and fuel for cooking at low cost. Through donations,

the inhabitants had built six houses, another 10 were under construction. They wanted to build houses for all the families living there. At the time of study, they were living in temporary housing structures, locally termed as 'jhuggies' or shants. They had common toilets and bathrooms in the colony. At the time of conducting the study, 25 families were living there, of which four had gone to their native place for a visit. All the adult men were beggars. They all go in a group singing together and begging. The women and children stay behind.

The study was descriptive and the participants were purposefully selected. The data were collected using semi-structured interview schedules (Appendix). In order to study the socio-economic background of the family, the process of disease and deformity, and the attitude towards beggary, three sets of interview schedules were made:

- to study the family details,
- to study the disease, deformity and debilitation process of the leprosy-affected person in the family, and
- to study the attitude towards beggary of those engaged in it.

The first questionnaire was used with the head of the family, the second was given to all the leprosy-affected persons in the family and the third was used to interview the leprosy-affected beggar/s in the family. All the interviews were conducted by two trained Social Workers from The Leprosy Mission, India, including one the main author. The observations made in the colony during the study were also recorded. The three-point system of grading severity of impairment, grade 0, 1 and 2, suggested by the Sixth WHO Expert Committee on Leprosy in 1988, has been used in the study.

Results

SOCIO-DEMOGRAPHIC PROFILE

In the colony, men who had had leprosy headed all the families. Of the total population of 83 people, including 22 men, 21 women and 40 children, all the men and nine of the women were leprosy-affected. Except for one woman who was on anti-leprosy treatment, all the others were treated. Although all children were reported to be healthy, a 6-month-old child had undiagnosed patches that had not been given medical attention. Eighty-one percent among those who had had leprosy had grade II deformity, and 8% had grade I impairments. Twelve percent had been treated and cured without deformity.

Leprosy was found to lead to not only physical deformities, but also to complex psychosocial and economic difficulties. None of the inhabitants belonged to Ambala. The majority (57%) came from Andhra Pradesh, followed by Karnataka (14%), Maharashtra (9%), Bengal (9%), Uttar Pradesh (5%) and Bihar (5%). Most (76%) were Hindus. For their prayers they had built a temple in the colony itself. A few were Muslims (19%) and one was a Christian (5%). The languages spoken were Telugu (52%), Hindi (24%), Kannada (14%), Bengali (5%) and Bihari (5%).

In the colony, all the male family heads (21) went begging, except for the one who was working as a temple 'pujari' (priest). Twenty of them were interviewed. Eighty percent had been begging for more than 5 years (Table 1), 35% had been begging for 11–15 years and 10% for more than 20 years. There were a few (10%) who started less than a year ago, only after coming to the colony.

EDUCATIONAL PROFILE

The majority of those who begged (65%) were illiterate (Table 2), 15% were just literate, 15% had had school education and one (5%) was a graduate. The majority of the other (non-leprosy) adults (83%) also were illiterate.

Amongst the 40 children of leprosy-affected parents, 22 were living with their parents in the colony, of whom only two were going to school. One of them, a girl, was studying in a private school, supported financially by the school itself. The other 20 were in need of education (Table 3). They included those children who were yet to attain school age and would need education in the near future. Others were either in a hostel (6), given for adoption (1) or were at their native place (11), either settled or studying in the normal society.

PSYCHO-SOCIAL AND ECONOMIC PROBLEMS RESULTING FROM LEPROSY

The respondents said that the decision to leave their family was not easy. However, they had been forced to leave due to the comments made by people in their neighbourhood, not only towards them but also towards their family. Because of their diseased state, the marriage of their children and or siblings was jeopardized.

One couple said that their son and daughter-in-law made them leave the house out of the fear of infection. After that they never wanted to live there.

One of the women who had had leprosy, and was abandoned by her husband, was living with her son, daughter-in-law and grandson. Her son was a treated case of leprosy and her daughter-in-law was the daughter of leprosy-affected parents. She said that the marriage had been purposely arranged in a family with a history of leprosy for better acceptance and adjustment by the girl. A girl from a non-leprosy background would not have lived with them.

PREVIOUS OCCUPATION OF LEPROSY BEGGARS

Before the onset of deformities caused by the disease, the present beggars were economically productive members of the society. They were engaged in different professions such as farming (35%), cattle rearing (5%), weaving (5%), skilled labour (10%) and unskilled labour (10%). Twenty percent were in service. For treatment, they were admitted in a leprosy hospital. Long-term hospital stays and the social experiences due to leprosy at their native places discouraged them to return home. They came to the colony looking for better acceptance and started begging due to physical disabilities.

SOCIAL PARTICIPATION (IN AMBALA) OF THE LEPROSY-AFFECTED PEOPLE

The interviewees said that to avoid any further embarrassment from their own people at their native place, they came to Ambala in search of a place where they would be socially accepted and could live in peace.

The interview revealed that leprosy and the deformities destroyed their self-image. They said they hesitated to mix with 'healthy people' and felt more comfortable living amongst people like themselves. The majority (85%) only interacted socially within the colony itself (Table 2). There were a few (15%) who had friends outside the colony. Only a few men (12%) mentioned non-leprosy friends. For most people (88%), social interaction was restricted to contacts with leprosy-affected people. In addition, they said they rarely went out for social

Table 1. Number of years in begging

No. of years	No. of persons	%
≤ 1	2	10
2–5	2	10
6–10	4	20
11–15	3	15
16–20	7	35
21–25	1	5
>25	1	5
Total	20	100

Table 2. Social interaction of leprosy-affected people (*n* = 26)

Social interaction	Response	Male (<i>n</i> = 21)	Female (<i>n</i> = 5)	Total (%)
Interaction within the colony only	Yes	17	5	22 (85)
Interaction both within and outside the colony	Yes	4	0	4 (15)
Total				26 (100)
Interaction only with the leprosy-affected	Yes	18	5	23 (88)
Interaction both with leprosy-affected and non-leprosy-affected	Yes	3	0	3 (12)
Total				26 (100)
Go out shopping	Yes	21	0	21 (81)
	No	0	5	5 (19)
Total				26 (100)
Go out to cinema	Yes	5	1	6 (23)
	No	16	4	20 (77)
Total				26 (100)

Table 3. Educational status

	Education	No. of persons	%
Leprosy beggars	Illiterate	13	65
	Just literate	3	15
	School education	3	15
	Graduation	1	5
	Total	20	100
Other adults	Illiterate	19	83
	Just literate	1	4
	School education	3	13
Total	23	100	
Children living outside the colony	At native place	11	27.5
	In hostel	6	15
	Given for adoption	1	2.5
Children living in the colony	In school	2	5
	Needing education	20*	50*
	Total	40	100

* Also includes children who will need education in future.

functions or entertainment such as shopping or cinemas. This was more obvious in the case of the women (Table 2).

SOCIAL ORGANIZATION

To survive, these former patients have struggled through together. They registered themselves as a Society. The Registered Society has a nominated committee or 'Panchayat'. The committee comprises a President (Pradhan), Secretary, Cashier, People's Representative (Public Member) and 'Kotwal'. The Public member brings forward the problems and/or needs of the inhabitants and the Kotwal distributes the donations received in kind (especially food items) evenly amongst the families. The 'Panchayat' pays the electricity bill out of the donation money. They have elections every year.

The inhabitants of the colony also collect donations to build houses for themselves. They take active part in procuring the building material required and supervising the building process. However, they do not participate as construction labour, in order to protect themselves from any further trauma to their anaesthetic limbs. They said they wanted to build houses for all the families. A temple has also been built, and a leprosy-affected 'pujari' (priest) appointed to carry out the religious activities. They raised all the income through beggary and donations. All the property belongs to the society and not to the families.

Through their efforts, they have gained welfare services for the beneficiaries. This included monthly pension for both the spouses, a ration card with an extra supply of kerosene to protect against burns by burning wood for fire, and railway concession to travel. All of them are actively involved in developing the society.

Rules and regulations have been set. All the men go begging in a group. Even the able-bodied beg. The amount collected is evenly distributed amongst the families. The women and children stay behind. Nobody is allowed to work or do separate business while living in the Ashram. Liquor, gambling and prostitution are prohibited. They also maintain the Ashram's security. Men from two of the families sit on guard at night. The Ashram is a form of organized group living. People follow the group norms that help in the acceptance and maintenance of peace in the colony.

ATTITUDES TOWARDS BEGGARY

All the leprosy-affected beggars said that in the beginning they never liked to beg. They felt ashamed and humiliated. However, in the absence of any other source of income and to meet their basic needs, they resorted to beggary. One of them said that they had to follow the colony rules, if they wanted to live there. Due to trauma, many of them already had lost much of their fingers and toes in their previous professions. They were reluctant to carry out any hard work with their anaesthetic hands and feet out of fear of damaging them further.

With continued begging and living in the colony, where donations were never short, they got used to begging. They said that they were comfortable living in the colony, since there was no stigma and enough donations to live without doing other work. Some still felt ashamed, but most of them were resigned to it.

More than one-third (35%) believed that begging was the only option left for them (Table 4). Still, the majority of the beggars (80%) said they were ready to quit beggary, if given a chance (Table 4). At the same time many could not think of any other work to do. They could only say that they would do any work that they would be able to do without

Table 4. Attitude of leprosy-affected beggars towards begging

Attitude towards beggary	Response	No. of persons	%
Begging is the only option	Yes	7	35
	No	13	65
	Total	20	100
Ready to quit begging, if given a chance	Yes	16	80
	No	4	20
	Total	20	100

harming their limbs any further. Some suggested poultry farming, goat rearing, weaving, candle making, soap making, gardening, tailoring, starting a small shop, etc. They longed for work opportunities and financial support. One of the beggars pointed out that they had to follow the rules of the colony, which do not allow other paid work.

IMPACT OF BEGGARY ON CHILDREN

The small children, when asked about their father, quickly replied that he had gone begging. One of the parents said that his children had asked him not to go begging anymore. They did not like it and he also felt ashamed, since the children were growing up and they understood the meaning of begging. One of the children, who attended a regular school, had expressed the desire to leave the colony. In one case, the grown-up son of a leprosy-affected woman, who also developed and was cured of the disease without any deformity, resorted to begging with the others. He said that because he is able-bodied, he helped to carry out various activities in the colony that others found difficult to do.

FUTURE ASPIRATIONS

The interviewees were not very sure of their future. Half of them said they avoided thinking about it. Amongst the others, two were thinking of having their own business and three about going back to their native place. Four of them would prefer to live in the colony itself, continuing the same life. Another specified that he wanted to live without begging.

The colony members might not be sure of their own future wishes, but almost all of them were concerned about the future of their children. Ten had small children and five had grown-up children who were settled in life outside the colony.

Amongst the small children, as mentioned above, six children from four families were living in a hostel, sponsored by the school itself. The rest of the families also would like their children to be educated, preferably on a sponsorship basis, with the children staying in a school hostel. They believed that the children would not be able to study in their current environment. They said they were not in a position to take up the responsibility of their education, meet their everyday needs of school uniform, books and notebooks, and take them to school every day. Some also complained that local government schools do not give admission to their children and that they cannot afford private school education.

Discussion

Leprosy seems to have gained recognition through the deformities caused by the disease. It has affected all aspects of life of affected patients, from the physical, psychological and economic to social life. Beggary is the social consequence of leprosy. The impact is so deep-rooted that despite the advancement of treatment and health education over the years, the negative community behavior is still prevalent. Even today persons affected by leprosy have to leave their own homes, families and villages, or are socially isolated. Social isolation of leprosy-affected people in leprosy colonies is the result. Some recent data from countries including India, Vietnam and China shows that there are many such leprosy colonies with significant number of persons living there.⁴

Leprosy colonies are a form of group living of people with common problems, who had faced similar social consequences and seek solace in each others' company. Beggary is their common profession in order to make ends meet. Dharmendra⁵ had stated that 'the beggar problem is a particularly difficult one in India as the money and institutions needed for them are not available. Some studies have explored the problems of leprosy among beggars.⁶⁻⁸ They have also been found to be the reservoir for transmission of infection.^{9,10}

A need analysis of leprosy settlements in Nigeria performed by Ogbeiwi and Nash¹¹ explored what leprosy-affected people believed to improve their lives. They emphasized mainly health care or drugs for their general ailments and financial resources. This in turn depicts their socio-economic situation. In the present study too, the leprosy-affected beggars raised the need for work opportunities and financial support for their rehabilitation.

Although both men and women face social isolation from the so-called 'healthy society', women are more isolated. Gender inequalities, both biological and social cultural, related to leprosy have been reported.¹²⁻¹⁴

Despite being mostly illiterate, the colony inhabitants were found to be well organized. They have a strong leadership and have set rules and regulations. Through planning and group living, they have been able to procure various services and facilities for their welfare. This shows that there is the motivation and potential to change.

Because of lack of opportunities and direction, they themselves may have accepted their present state of life, but they are strongly concerned about the future of their children. At present, many children are not getting the required education. Also, in the present situation of living in an environment with inadequate opportunities and role models, it would be difficult for the children to learn to seek other professions. Moreover, their social life too is restricted only to those having had leprosy. One such case, of a grown-up son of a leprosy-affected woman, who resorted to begging in the colony, has been reported. Their desire to quit beggary and their potential for planning and management should be utilized to develop alternate ways to reach economic sustainability. This would require training and support to develop alternate professions and avenues for the education of the children.

The final solution to the problem of rehabilitation lies in preventing the process of debilitation of patients from society. But at the same time, it is also important to rehabilitate those who have ended up as beggars. Both the processes should be simultaneously taken care of. It will build the confidence of those affected and also minimize the social stigma.

CONCLUSION

In the present study, the majority of the people living in the colony, both those who had had leprosy and those who had not, were found to be illiterate. The literacy status thus does not seem related to having had leprosy. Prior to settling in the colony, they were all engaged in productive occupations, mainly agriculture and labour that involved physical activity. Anaesthesia of the limbs due to leprosy and the trauma caused due to physical labour resulted in deformities. Because of the disabilities, they were no longer able to carry out their previous occupations. Due to lack of opportunities and restricted physical ability, they opted for beggary. Continuing for years, they have adopted begging as an alternate vocation. Despite this, we found that 80% reported to be ready to quit begging, if given a chance to start afresh. The need is to redirect energy towards productive living.

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Appendix

Interview schedule **Family No.**

Family information

Name of the Head of the family:

2a. Address—Present:

2b. Address—Previous (before the disease, if different):

Religion:

Caste:

Language spoken (mother tongue):

Family details:

Member	Relationship with Head of the family	Age	Sex	Education	Occupation		Income	Whether leprosy-affected	Living with the family
					Previous	Present			

Any other source of income: _____ Total income per month: _____

Whether receiving any pension/ benefit from the Government/ NGO/ Private?

- (1) Financial: (1) Yes (2) No
- (2) Service: (1) Yes (2) No
- (3) Treatment: (1) Yes (2) No
- (4) Any other: (1) Yes (2) No

About the disease and disability (To be asked to the leprosy-affected)

At what age did you first observe the symptoms of leprosy?

What were the early symptoms observed?

Have you ever received treatment for leprosy? (1) Yes (2) No

If yes, give details:

If no, why?

Deformity/disability status:

Deformity grade:

Deformity type:

Body parts affected:

Any other family member having leprosy? (1) Yes (2) No

If yes, how is he/she related to you?

Social life

Do you have:

- (a) Friends: (1) Yes (2) No
 If yes, (i) within the leprosy colony
 (ii) outside the leprosy colony
- (b) Neighbours: (1) Yes (2) No
 Do you visit them? (1) Yes (2) No (3) NA
 Do they visit you? (1) Yes (2) No (3) NA
 Do you face any discrimination from them? (1) Yes (2) No (3) NA
 If yes, explain.
 Whether they are: (1) Leprosy-affected (2) Normal (3) Both (4) NA

Other routine chores

Do you face any problem while going to the

- (1) Shop (1) Yes (2) No (3) Do not go
 (2) Tea stall (1) Yes (2) No (3) Do not go
 (3) Cinema (1) (1) Yes (2) No (3) Do not go
 (4) Temple (1) (1) Yes (2) No (3) Do not go
 (5) Any other place, mention: (1) Yes (3) Yes (3) Do not go

If yes, give details.

Do you face any problem using public transport (e.g. bus)? (1) Yes (2) No (3) Do not use

If yes or do not use, give details.

In your daily living, are you

- (1) Independent (2) Dependent on others

Marital/family relationships

Do you have a sexual relationship with your spouse/other regular partner?

- (1) Yes (2) No (3) Not applicable

If no, give reasons.

Did you have children after you got the disease?

- (1) Yes (2) No (3) Not applicable

Do you have a satisfactory relationship with your children?

- (1) Yes (2) No (3) Not applicable

Your relationship with other family members (parents, siblings, others)?

- (1) Normal (2) Strained (3) No relationship (4) Not applicable

Do you go out with your family on any social/ family function?

- (1) Yes (2) No (3) Not applicable

Do you love your spouse, children and other family members?

- (1) Yes (2) No (3) Not applicable

Do you receive love from your spouse, children and other family members?

- (1) Yes (2) No (3) Not applicable

Opinion on leprosy

What do you think about leprosy as a disease?

Can one prevent deformities to happen? (1) Yes (2) No

Whether the disease/deformity produces:

- Social disability
- Economic disability
- Any other
- No problem

Do you have any complaints against

- family
- society
- anyone else

Do you regret anything?

Is there anything that you would like to share?

Beggary practice (to be asked to those who are begging)

Area of beggary:

Who introduced you to beggary?

Since when have you been begging?

When you started begging, what were your initial feelings?

How do you feel now while begging?

Do you believe that begging is the only option left for you?

If given a chance, would you quit begging? (1) Yes (2) No

If no, why?

If given a chance, what would you like to do?

What help you need to quit begging?

How do you visualize your future?

How do you visualize the future of your children?