

Participation level of the leprosy patients in society

S Singh¹, AK Sinha¹, BG Banerjee¹, N Jaswal²

The present study examines the socio-demographic profile and participation restriction level of the respondents and the association of gender, socio-economic status (SES) and deformity status of the respondents with their respective participation restriction level. 245 leprosy patients have been selected for the present study. Socio-economic scale, participation scale and in-depth interviews were used for data collection. Data analysis was done by using statistical package for social sciences (SPSS). 57.1% belonged to poor SES followed by lower- middle (21.6%). Only 1.2% of respondents belonged to high SES. Out of 245 respondents, 32.20% had grade II deformity, 31.40% grade I and the rest 36.3% non-deformed. The results of the participation scale showed that 54.28% had no significant participation restriction and only 3.67% had extreme participation restriction. SES and deformity status of the respondents have shown significant differences with the level of participation restriction. The lower the SES and the severe the level of deformity of the respondents, the extreme is the level of participation restriction among them.

Key words: Leprosy, Participation restriction, Deformity, Socio-economic status

Introduction

Leprosy is a human disease. It usually starts with a non-itching patch or patches on the skin. These patches may appear on the non-visible parts of the body. Some parts of the skin may become anesthetic and loose sensation. These patches are prone to be neglected by a person. Unlike other diseases, patches in case of leprosy do not create any discomfort to a person. Similarly, no forewarning is experienced before the appearance of the patches. The neglect of non-itching, painless patches on the skin, loss of sensation in some parts of the skin and change in texture and colour of the skin, which are the early signs of leprosy, may help the disease to progress towards deformity.

In every society, there prevail aesthetic concepts of physical beauty. The beautiful and attractive people are admired by the society as is obvious from adoration received by the film actors and actresses. The idea of personal body image requires all the limbs of the body in right proportion and having a shape pleasing to the eyes. People thank God on the birth of child with a normal body and guard him/her from black magic by putting on charms round the neck or limbs of the body (Mutatkar 1979).

Though, leprosy is primarily a medical problem but it is a medical problem giving rise to many social problems. Medical problems like early signs leading to deformity and disability ends up in social problems of the people suffering from it.

S Singh, MSc, Research Scholar

AK Singh, PhD, Professor

BG Banerjee, PhD, Professor

N Jaswal, MA, Research Scholar

¹Department of Anthropology, Panjab University, Chandigarh, India

²Department of Psychology, Panjab University, Chandigarh, India

Correspondence to: S Singh **Email:** buntysen2k@gmail.com

These medico-social problems give birth to many misconceptions about the cause, spread, infectivity and the curability of the disease which are still prevalent in the minds of people. Some misconceptions like leprosy is a sin or a divine curse, hereditary in nature, highly infectious, disease of beggars, all leprosy respondents are deformed; it is an incurable disease and if a snakebites a leprosy patient the snake dies and so on, still exist even today.

Leprosy, although is like any other disease but strikingly differs from other diseases due to the peculiar psycho-social and economic problems it causes. The moment a person is correctly diagnosed as a leprosy patient, his roles in the society gets restricted and constrained in view of the socio-cultural norms of the society. This tends to isolate him, mentally and later physically when advanced symptoms of the disease like deformity sets in. Thus, he is subjected to an 'exile' into a leprosy colony and completely separated from ordinary social activities. In this new role, he soon becomes a 'non-person', and thus, starts his own 'premature social death' and is also blamed for his own sickness (Kurup 1991).

Activity is defined as 'the execution of a task or action by an individual' and participation is a person's involvement in a life situation. A life situation refers to a person's interaction and participation in wider aspects and areas of normal living or community life. These include the social, economic, civic, interpersonal, domestic and educational domains of daily living, most of which concern every person, regardless of their health, age, gender or caste. Problems experienced in participating in any of these 'life situations', are referred to as 'participation restrictions'. Participation restrictions are often referred to as 'social problems'. Causes of participation restriction include impairment, activity limitation, self-stigmatisation, money problems due to the ailment, absence of equipment, support/relationships, attitudes and systems, environment, policies or laws (van Brakel et al 2006).

The present study is an attempt to examine the socio-demographic profile and participation restriction level of the respondents and the association of gender, socio-economic status (SES) and deformity status of the respondents with their respective participation restriction level.

Materials and Methods

The present study is based on both qualitative and quantitative research to explore the different dimensions of problems under study. 245 respondents (195 who were seeking treatment from the leprosy clinics and 50 respondents staying in the Kushtha Ashram) were included in the study. The study was conducted in two phases. Quantitative data was collected in phase I and for this purpose, two standardized scales were used. Socio-economic scale by Aggarwal et al (2005) was used to determine the socio-economic status of the respondents. In order to study the level of participation restriction among the respondents, participation scale developed by van Brakel et al (2006) was used. The respondents with who were fall in the moderate, severe and extreme participation restriction level were selected in the second phase of the study i.e., the qualitative phase. In-depth interviews were conducted with the respondents selected in the second phase. *Chi-square* test was applied to study the significant differences between the socio-economic status, gender, residence, level of deformity and the participation restriction among the respondents. The respondents were interviewed by the researchers in the 4 leprosy clinics of Chandigarh: Postgraduate Institute of Medical Education and Research (PGIMER), Chandigarh; Government Multi-Speciality Hospital, Sector-16, Chandigarh; Community Health Centre, Sector-22; Civil Dispensary, Manimajra. In addition to this, the respondents staying in the Kushtha Ashram in and around Chandigarh were also interviewed. Verbal informed consent was taken from all the respondents.

Results

Majority of the respondents were males (69%) with females representing 31% of the group. The largest group of the respondents was between the ages of 31 and 40 (26.5%); while those in 21-30 years made up the second largest group (26.1%) and the third largest group was represented by those in 41-50 years (17.5%). Under the domain of religion, it was found that 61% of the respondents belonged to Hindu religion, 18% to Islam; 13% to Sikhism followed by 8% to Christianity. The marital status of the respondents revealed that 18% and 76.7% were unmarried and married respectively. 4.1% of females were widow and only one respondent was widower while 0.8% of the respondents were found to be divorced. Education wise, majority (32.7%) of the respondents had no formal education i.e. they were illiterate. 24.7% respondents studied up to primary level of education, 5.7% and 2.4% of them had education up to graduation and post graduation levels, respectively.

Socio-economic scale by Aggarwal et al (2005) was used to for the assessment of the socio-economic status of all the 245 respondents. It was found that 57.1% of the respondents belonged to poor socio-economic status followed by lower-middle (21.6%). Only 3 (1.2%) respondents had high socio-economic status. With regard to occupation, the majority 27.8% of respondents was unemployed and 26.1% did manual labour/work. Out of 245 respondents, only 4.1% respondents were in Government job. Out of 245 respondents, 158 respondents were migrated from the states like Andhra Pradesh (21), Bihar (23), Uttar Pradesh (13), West Bengal (26) and Orissa (28). Apart from these above mentioned states some respondents also migrated from the neighbouring states like Haryana (13), Punjab (14), Himachal Pradesh (9) and Uttaranchal (13).

Out of 245 respondents, 32.20% had grade II deformity whereas 31.40% and 36.3%

representing grade I and non-deformity respectively. Results from the participation scale showed that 54.28%, 20.40%, 11.24%, 10.23% and 3.67% respondents had no participation restriction, mild restriction, moderate restriction, severe restriction and extreme participation restriction respectively (Figure 1).

Deformity status and participation restriction

Chi-square test results showed that there were significant differences ($p < 0.001$) between the participation restriction and deformity status of the respondents. It was found that respondents suffering from grade I and grade II deformity were having participation restriction as compared to respondents who did not have any deformity. 6.53% and 2.44% of the respondents with grade I deformity and grade II deformity respectively had severe participation restriction. It was also seeing that 3.67% of respondents who had grade II

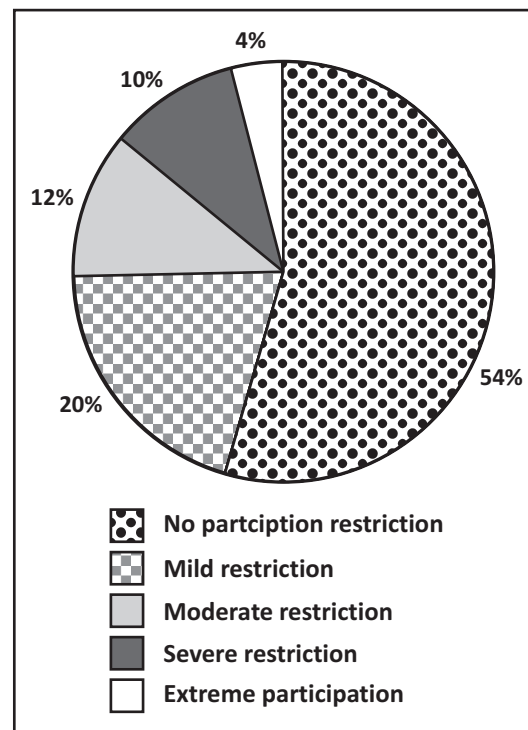


Figure 1 : Participation restriction level of the respondents

deformity had extreme participation restriction (Table 1).

The in-depth interviews were conducted with the respondents falling in the moderate, severe and extreme participation restriction category. During the in-depth interview with the respondents, it was found that they faced problems in different domains of the daily chores. During the in-depth interview with the respondents, it was found that the respondents with deformity when compared themselves with their peers, they realised that now they could not work as hard as their peer could do. One of the respondents narrated his own experience of extreme participation restriction as follows:

“Jab mujhe leprosy nahi thi tab main bahut zyada kaam karta tha, lekin jab se mujhe bimari ke baare me pata chala hai, tab se kaam karne ka mann nahi karta hai. Pehle main apne dost se bhi zyada kaam karta tha, lekin ab bahut kuch badal gaya hai. Leprosy ke kaaran mere haathon ki nase kamzor ho gyi hai. Mein ab zyada paise nahi kama pata hun aur na hi ghar me zyada paise de pata hun. Ab to mera kisi se baat karne ka bhi mann nahi karta hai. Sab mere munde hue haath ke bare me puchate hai. Mujhe sab se baar baar jhoot bolna padta hai. Main nahi chahta ki kisi ko meri bimaari ke bare me pata chale, main sab ko ye hi batata hun ke meri nason me problem hai”.

(I used to work a lot before I was infected with leprosy but after coming to know about my

disease, I no longer like to work. Earlier, I used to work more and harder than to my colleagues but now the things have changed entirely. The nerves of my hands have weakened due to leprosy. My earning capacity has lowered. I am not able to contribute to the household income. I even don't like to talk to anyone as everybody questions about my clawed hand. I have to lie time and again about my health status as I do not want to reveal about my leprosy status. Instead I tell them that I have some nerve problem in my hands).

It was very difficult for the respondents to hold things properly due to clawed hand and fingers as reported by them during the in-depth interviews. They felt that due to the leprosy their nerves became weak and they could not work as hard as they used to do earlier. One of the respondents narrated his experience as follows:

“Jab se mujhe kushtha rog hua hai, tab se main apna dhayaan nahi rakh pa raha hun. Main apne haath se chizon ko thik se pakad bhi nahi pata hun. Main apni daadhi bhi thik se nahi bana pata hun. Haath me sunpan hone ke karan main thande garam ka bhi ehसाas nahi kar pata hun, jis ke karan haathon me zakhm bhi ho jate hai. Main akela mehsus karta hun. Koi bhi mera pehle ke tarah dhayaan nahi rakhta hai”.

(I face difficulty in self-care since I have got leprosy. I cannot hold things properly with my hands. I am not able to cut my nails, shave my moustaches easily. I could no longer sense heat or cold due to numbness in my hands which often result in wounds and injuries. I feel aloof within a group as nobody now cares and shares the same way as it was done earlier.)

Socio-economic status (SES) and participation restriction level

Respondents from lower middle had to face various kinds of problems. It was found that majority of the respondents belonging to poor SES had severe participation restriction as compared to respondents belonging to upper middle and high SES (Table 2).

Table 1 : Association of deformity and participation restriction

Participation level	Deformity status		
	Grade I	Grade II	No deformity
No participation restriction	21	43	69
Mild restriction	17	20	13
Moderate restriction	16	8	4
Severe restriction	16	6	3
Extreme participation	0	9	0

15 out of 23 severe participation restriction respondents stated that their contribution to their family in terms of money had gone from leprosy. They admitted that they could not work with the same enthusiasm and capacity as they use to work with before. If ever they get work, they were not able to perform it well. Malfunctioning due to deformity is one of the major factors that affect the participation restriction level of the respondents. Experience narrated by one of the respondents support these findings as follows:

“Main car mechanic ka kaam karta tha, ghar ka guzaara thik chal raha tha, lekin jab se haathon ki nason me problem hui hai, tab se kaam karana bahut kam kar diya hai. Pehle maalik bhi khush ho kar zyada paise de dete the, lekin jab se bimari hui hai, tab se kaam thik se na kar paane ke kaaran paise bhi bahut zyada nahi milte hai, davai lene ke liye PGIMER me jana padhta hai. Vahan jaane ke liye ek din ki chutti leni padhti hai. Uske bhi paise kaat lete hai. In sab ke karan bahut kamm paise milte hai aur ghar mein bahut mushkil rozi-roti chalti hai”

(I used to work as a car mechanic to earn my livelihood. But, my working capacity has reduced due to nerve problem in my hands. Earlier my employer was happy with my works and used to pay me more but now lowering of working ability due to the disease yields me less. I have to go to

PGIMER every month for procuring medicines but I have to take one day leave for this and some amount deducted from my salary for each leave. This, in turn, affect my family income and creates problems for carrying out my livelihood).

The participation restriction level of the BPL respondents was found to be extreme. They were deprived of the work opportunities as compared to their peers. When these respondents were interviewed, it emerged that they always wanted to do work but they were not given work on the pretext of their deformity. They were facing two types of problems: one was that they were not getting any work which subsequently affected their income level and the other was that due to their very poor SES, they could not take care of themselves. The respondents could not seek treatment regularly. Few of the EPR respondents (3%) were coming from far flung areas to seek treatment and most of the times due to paucity of money, they preferred not to visit hospital for procuring medicines. One of the respondents narrated his own experience as follows:

“Sahib kya kare, mera ghar yahan se 250 kilometer ki duri par hai. Mahine me ek din davayi lene ke liye hospital jane ka matalab hai ki aap aane-jane ke kharche ke liye 300-400 rupeye taiyar rakho. Muje to chalo concession bhi mil jata hai, lekin ghar se koi na koi saath zarur aata hai kyunki main akela nahi aa sakta. Itni door se do logo ka davayi lene ke liye aana bahut mehanga

Table 2 : Association of SES and participation restriction level

Participation level	Socio-economic status					
	Upper high	High	Upper middle	Lower middle	Poor	Very poor
No participation restriction	1	4	22	32	64	8
Mild restriction	3	1	1	11	32	5
Moderate restriction	0	0	0	8	19	1
Severe restriction	0	0	0	2	23	0
Extreme participation	0	0	0	0	2	7

padhta hai. Isliye kabhi-kabhi davayi lene nahi aata hun. Khana khane ke liye pehle hi paise nahi hote, kiraye ke liye kahan se lau. Bahut mushkil se guzara kar rahe hai. Koi bhi madad karne ke liye taiyar nahi hota”.

(What could I do, Sir? My home is at a distance of 250 km from here. Spending one day for getting medicines from the hospital means that you should keep Rs. 300-400 ready for travelling only. I may get the concession for it but somebody from the family always travel with me as I could not come alone. It costs a lot for two persons to visit hospital from such a big distance. Sometimes, I could not afford money for eating food, from where would I get for travelling. We are leading a difficult life and nobody is even ready to help us).

Majority of the very poor respondents stated that they did not feel comfortable in meeting new people. Few of them (2) also revealed that they felt guilty of themselves. As said by one of the respondents:

Ek to hum garib hai, ek time ka khana bhi badi mushkil se milta hai. Dusra apangta bhi ho gyi hai. Kushtha rog ko samaaj me acha nahi maante hai. Sab ghrina karte hai. Kisi ki madad bhi nahi le sakte kyunki yadi kisi ko pata chal jaye ki kisi viyakati ko kodh hai to sab us se ghrina karte hai or koi bhi uski madad nahi karta. Garibi, Kusht rog or Apangta ek saath hone se badi mushkil hoti hai. Itna bada parivar hai mera, bache bhi abhi chotte hai, bhala kese ye jeevan chalega? Kisi ko meri is bimari ka pata na chal jaye, isliye bahar bhi nahi jata hoon. Sab se milna bhi kam kar diya hai.

(One aspect of my life is that I am poor and could rarely afford one time meal. Secondly, I have got the deformity. Leprosy is not considered good in our society. Everybody hates leprosy. If anybody in the society comes to know about a leprosy patient, then he is looked upon with hatred and do not get any help from anybody. Onset of leprosy, deformity and poverty at the same time creates lot of problems. I have a large family and my children are also small, how would I cater the needs of everybody? I even do not visit or meet anybody just to conceal my leprosy status from people).

Discussion

Although no significant differences was found between the gender and participation restriction level of the respondents, yet gender-wise determination of the respondents's participation level revealed that males outnumbered females both in moderate and severe participation restriction level. The respondents with severe participation restriction revealed that leprosy hampered their earning capacity.

It was found that the respondents started restricting their participation in the society with the progression of the disease. They did not want anybody to know about his/her disease status. Due to the strong stigma attached with the leprosy in their socio-cultural settings, they tried to hide their diseased status from the society. Due to deformity and inability to work hard as compared to his/her peer, respondents did not participate in the daily activities. Under severe participation restriction, the respondents experienced difficulties in self care, visiting outside the town/city, moving around inside and outside the house and under extreme participation restriction, the problems faced were inability to work hard as peers do, decline in the level of contribution to household economy, lack of participation in the social gatherings, feeling uncomfortable on meeting new people and weakening of interpersonal relationship. The most commonly affected indoor activities were cutting nails (22%) washing clothes (16%) using scissors (17%) and tying a knot (18%). Among the outdoor activities cutting grass, digging, harvesting and milking a cow or buffalo were the most commonly affected ones (22%-26%) (Chitra 2006).

They feared that if anybody came to know about their disease status of being leprosy patient, what they would think about them. For them a person who had committed some wrong deeds in his/her past could only suffer from leprosy. Another important aspect of the finding was that with a rise in the deformity status of the respondent, his

economic productivity declines. Ghimire (2002) suggested that if people are from a lower educational and economic status, they have more chances of developing secondary deformities. This change leads to the enhancement of the extreme participation restriction among the respondents. Although timely access to MDT restricts the participant from falling a prey to deformity but the respondents who fail to get treatment on time develop deformity and as deformity increases, the level of participation restriction also increases.

It is concluded that the respondents with low SES and grade II deformity had to face extreme participation restriction. Financially viable approaches should be made pro-active for the empowerment of the leprosy patients with deteriorated economic circumstances resulting from deformity and stigma and for building their self-efficacy to enhance the participation level in the social activities.

References

1. Aggarwal DP, Bhasin SK, Sharma AK et al (2005). A new instrument (scale) for measuring the socioeconomic status of a family : preliminary study. *Indian J Commun Med.* **30**: 111-114.
2. Chitra W (2006.) Impairment of activities of daily living among leprosy patients. *Indian J Commun Med.* **31**: 115-116.
3. Ghimire M (2002). Secondary deformity in leprosy: a socio-economic perspective. *Asia Pac Disabl Rehabil J.* **13**.
4. Kurup AM (1991). Health, leprosy and society. Centre for Social Science Research on Leprosy, Gandhi Memorial Leprosy Foundation, Wardha, India.
5. Mutakar RK (1979). Society and leprosy, Shubhada Saraswat Prakashan, Pune, India.
6. van Brakel WH, Anderson AM, Mutatkar RK et al (2006). The Participation scale: measuring a key concept in public health. *Disabil Rehabil.* **28**: 193-203.