

Dehabilitation among Leprosy Affected Persons and Lived Experiences: A Mixed-Method Study

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Despite advancements in medical sciences, leprosy is still a public health challenge in a country like India. Leprosy results not only in physical problems but also has psychological, social, and behavioural consequences. Stigma related to leprosy leads to restrictions in participation and causes emotional harm. The combination of all these leads to the dehabilitation of leprosy-affected persons. This study aimed to assess leprosy-affected persons' social participation and understand their lived experiences, treated at their homes in the Haridwar and Dehradun district areas of Uttarakhand. A sequential mixed-method study included participants who had leprosy in the past three years and were on treatment or treated at their homes. Participants were interviewed with the help of a structured questionnaire including a participation scale. Fifteen participants were interviewed about their lived experiences with leprosy. Quantitative data was analysed using proportion and chi-square tests. For qualitative, inductive codes were generated from transcripts and analysed with a thematic approach. A total of 108 participated in the study. Thirty per cent had mild to moderate restrictions on social participation. Those with visual disability were found to have a comparatively higher score on the participation scale than those with no disability. Six themes generated were delayed diagnosis, coping mechanism, change in daily routine, health problems, perception and stigma related to the disease. One-third had mild to moderate restrictions, but they were related to physical health problems, not social exclusion. Many cases reported delayed diagnosis due to misdiagnosis. Participants felt supported by their family members. Some participants had perceived fear and stigma of the disease, but none of them had experienced the stigma till date. Some spoke about the disease to others, while few were seeking alibis.

Keywords: Leprosy Affected Persons, LAP, Perceptions, Dehabilitation, At Homes.

Introduction

Leprosy (Hansen's disease) is one of the world's oldest diseases caused by the slow-growing bacteria *Mycobacterium leprae*. In 1966, WHO reported 10,786,000 cases which remained stable through 1972, and 1983 and declined significantly in 1991 due to the introduction of Multidrug therapy (MDT), strengthened

control activities, and natural declining trends (Noordeen et al 1992). In 2021, new cases were detected globally 127,558, including 8,629 cases among children below 15 years old (WHO Source – Penna 2022). India achieved elimination in 34 states/ Union Territories (U.T.s) out of 36 States / U.T.s in March 2011-12 (Rao & Suneetha 2018). In 2020, before the start of COVID-19 pandemic

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in India, the Annual New Case Detection Rate (ANCDR) was 45.6 per 100,000 population (WHO 2022a). The post-elimination ANCDR has been higher in a few states such as Chhattisgarh, Bihar, Jharkhand, and Orissa than the national average. In Uttarakhand, 275 new cases were detected in 2020-2021. In Haridwar, a district of Uttarakhand, leprosy is quite common among Sadhus and beggars (NLEP- NIC Uttarakhand State Unit 2022).

Leprosy has been associated with stigma, particularly in the presence of visible deformity. Leprosy was considered a hereditary disease, a curse, or divine punishment. During the Middle Ages, persons with leprosy had to wear special clothes, and a ring bell to warn others that he was nearby, and treatment occurred in separate hospitals and the colonies. Affected people continued to face problems like social exclusion that further led to psychosocial problems such as depression, low self-esteem, anxiety, and withdrawal. Discrimination, stigma, prejudice, and negative attitude toward leprosy were the major barriers to early detection of leprosy (WHO2022b). Physical impairments and social stigma led to dehabilitation i.e., loss of social role /participation, ultimately impacting the quality of life.

Community-based rehabilitation (CBR) was first started in 1970 to provide services for persons with disabilities and then in 1980s it started focussing on people and community development. India had shifted its focus in 2001 from institution-based care to Community-based rehabilitation (CBR). Since 2004, the CBR approach has evolved from healthcare service delivery to community development, which preserves the rights of people affected by leprosy to access local support and services to improve their quality of life and ensure they can participate as equal members of society (Khasnabis et al 2022).

The present study focuses on the dehabilitation

of leprosy-affected persons (LAPs) and their lived experiences while getting treatment /treated in their homes. All the studies in India were done on institutionalised leprosy patients (Singh et al 2012). We could not find any published study among those treated at home in Uttarakhand and India. There is a need to know the status of dehabilitation (level of social participation) when leprosy is on the verge of eradication. It is also necessary to explore the lived experiences of people affected with leprosy, their perception of the disease, the associated stigma, and how it has affected their overall well-being so that suitable interventions can be made for helping them achieve the optimum levels of happy and healthy lives.

Objectives of this study are:(i) To assess the status of dehabilitation (level of restriction to social participation) among leprosy-affected persons treated /undergoing treatment at their homes, (ii) To find the association of the level of restrictions with age, gender, type of case and grades of disability and (iii) To explore the lived experiences of the leprosy-affected persons.

Methodology

Study design:

The study was conducted in two phases. The first phase was a community-based cross-sectional study with a quantitative component. The second phase involved a qualitative component using descriptive phenomenology. The study was conducted in Haridwar and Dehradun, covering a total of 174 leprosy patients. Haridwar had 75 registered patients, while Dehradun had 99. The study lasted for six months, from December 2021 to May 2022, with the participation of individuals aged between 18 to 60 years who had completed their treatment within the past three years and were currently residing in their homes. Participants who were either on treatment or had been treated at their respective homes were

included. However, those who were not willing to participate, unable to respond or understand the questions, or critically ill at the time of the interview were excluded.

During phase 2, we included individuals who had a clear understanding of the illness process and could effectively communicate their experience of living with the disease, in addition to meeting the previously mentioned eligibility criteria.

The sample size for phase 1 (Quantitative) consisted of 108 participants who were recruited using purposive or snowball sampling, based on their ability to travel.

For phase 2 (Qualitative), we initially planned to interview participants in the lowest quintile of the participation scale. However, upon analyzing the data from Phase 1, we found that no participants were under severe restriction while three were facing moderate restriction. As a result, we invited participants who were willing to speak about their experiences to obtain more comprehensive data. We conducted fifteen in-depth interviews, with twelve males and three females. Data saturation was achieved after ten interviews.

Study Tools:

In the 1st phase, the data collection tools used in this study were divided into three sections. The first part focused on sociodemographic information such as gender, age, education, marital status, family income, occupation before and after the disease. The second part dealt with clinical information such as the type of disability, treatment taken, and any complications. Finally, the third part assessed participation levels using three different scales. However, for this study, the 13-item Participation Scale was used due to its recent development in 2006, validation in English and Hindi, and its availability. The scale measures the ease of finding work, working hard, contributing economically, visiting outside

or festivals, participating in social activities, etc. using a five-point scale from 0 (no problem) to 5 (a large problem). The questionnaire was translated into Hindi and then pilot tested on eight educated leprosy cases attending OPD of our institute. The Hindi version was found to be coherent and understandable. The categories used to evaluate the level of restriction were no significant restriction (0-13), mild restriction (14-30), moderate restriction (31-50), and severe restriction (more than 51).

During phase 2 (Qualitative), we gathered data through in-depth interviews using a comprehensive guide. The interviews focused on the participants' experiences after being diagnosed with the disease, including how it affected them personally, their family, and community. Additionally, we explored any changes in their daily routine or job, any obstacles they faced in social participation due to the disease, and how they overcame these challenges (if applicable).

Data Collection:

- (i) For the first phase, structured questionnaires were used to collect quantitative data from identified patients. The contact numbers of the patients were obtained from District Leprosy Officer (DLO), CMO (Chief Medical Officer), and the Department of Dermatology at AIIMS Rishikesh. The investigator contacted the participants via phone and explained the purpose of the study. Verbal consent was obtained, and interviews were conducted through a structured questionnaire. The interviews lasted for 15-20 minutes, and privacy was always ensured. Those who were on treatment and living nearby were asked to visit the center for an interview, with the help of a managing officer (District Leprosy Officer), Health Educator (NLEP), and Block Manager.

(ii) In the second phase, in-depth interviews were conducted to gather qualitative data. Participants were identified by the Block officer, and informed consent was obtained before the interview. Privacy was maintained, and the interviews lasted for 40-45 minutes. All discussions were audio-recorded, and field notes were taken. The investigator summarized the relevant points, clarified doubts, and ended the interview with a thank you note. Counselling and referral services were provided if necessary. Interviews continued until data saturation was reached.

Data Analysis:

For the analysis of data of the **first phase** of study, mean and standard deviation were calculated for variables such as age, age at diagnosis, and participation score. Categorical variables were presented through frequency tables and proportions. The difference between two categories was determined using the Chi-square statistic, with a significant P-value being less than 0.05.

For the analysis of data of **second phase** of study, which was qualitative, each interview was transcribed and analyzed for words and phrases in the local language, Hindi. The data was analyzed thematically, with interviews being repeated until new information was obtained. The investigator recorded statements from all participants and read them repetitively to gain an in-depth understanding of the interview. Extracted meaningful statements and phrases were sorted into clusters of specific themes, with repetition eliminated. The result was integrated and validated by asking participants if they wanted to add something.

The textual description includes categories derived from each participant, transcripts of interviews, varied results from each participant, a

narrative story, and keywords found based on the interpretation of the investigator and researcher.

Ethics Approval:

This study was carried out after approval from the Institutional Ethical Committee of AIIMS Rishikesh (Letter No. AIIMS/IEC/21/699). Additionally, we sought approval from the CMO Haridwar and obtained permission from the author for the use of the participation scale. Privacy was ensured during the interviews and confidentiality will be maintained as per ICMR Ethical Guidelines (2017).

Results

Results are presented in Tables 1- 4 and Fig.1

The majority of those interviewed were males, accounting for 67.9% (74) of the participants. The average age of the participants at the time of diagnosis was 37.48 ± 11.84 years. About 86.2% (94) of the participants were Hindu, and 76.1% (83) were married. Most of the participants belonged to the upper lower class, representing 26.6% (29) of the participants. A significant number of the participants, 86.2% (94), lived in a nuclear family (Table 1).

Table 2 shows that most of the study participants were having multibacillary leprosy 101(92.7%). 72 (66.1%) of participants were currently on treatment and 10 (9.2%) were defaulters. Three participants had a family history of leprosy. Anaesthesia was reported by 46 (42.2%), while 7(6.4%) had patches and one (0.9%) had visible deformity.

Questions asked (Fig. 1) are as follows:

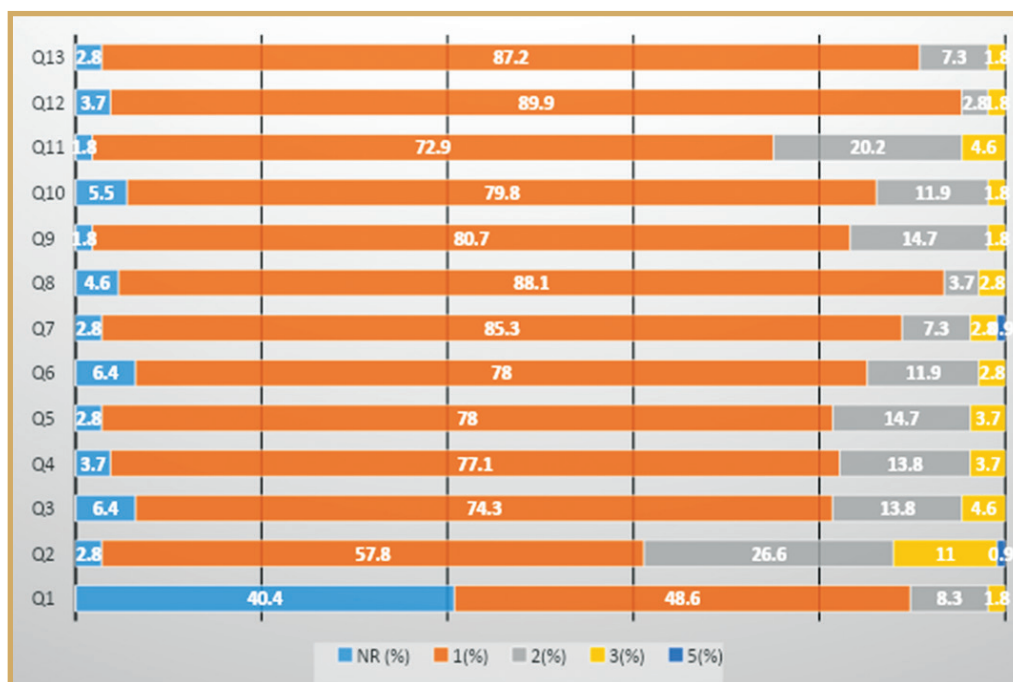
- Q1. Compared to others, how easy is it for you to find work?
- Q2. Compared to others, how easy is it for you to work hard?
- Q3. Compared to others, how easy is it for you to contribute to the household economically?

Table 1 : Socio-demographic characteristics of study participants.

Socio-demographic characteristics	Category	Count (N=108)	Percentage (%)
Age (in years)	<20	4	3.7
	21-30	34	31.2
	31-40	30	27.5
	41-50	22	20.2
	51-60	18	16.5
Mean (S.D.) years		37.48 (11.74)	
Gender	Male/female	74/34	67.9 /31.2
Religion	Hindu	94	86.2
	Muslim	13	11.9
	Sikh	1	0.9
Marital status	Married / Unmarried	83 /25	76.1 /22.9
Change of occupation after diagnosis	No	107	99.1
Type of Family	Nuclear/ joint	94/14	86.2/12.8
Family size	0-4	45	41.7
	5-8	53	49.1
	> 9	10	9.2
Socio-economic status*	Lower	5	4.6
	Upper Lower	61	56
	Lower Middle	29	26.6
	Upper Middle	10	9.2
	Upper	3	2.8

*According to Modified Kuppuswamy, Socio-economic classification year March 2022

- Q4. Compared to others, how easy is it for you to make visits outside your village/ neighborhood (e.g., bazaars, nearby villages)?
- Q5. Compared to others, how easy is it for you to take part in major festivals and rituals? (e.g. weddings, funerals, religious festivals)
- Q6. Compared to others, how easy is it for you to take part in social activities? (e.g. In sports, chat, dancing, meetings, religious or community activities)
- Q7. Compared to others, how easy is it for you to gain respect in your community?
- Q8. Compared to others, how easy is it for you to visit other people in the community?
- Q9. Compared to others, how easy is it for you to move around inside and outside the house and around the village/neighborhood?
- Q10. Compared to others, how easy is it for you to visit public places in your village/ neighborhood? (e.g., schools, shops, offices, market and tea/coffee shops)
- Q11. Compared to others, how easy is it for you to do household work?
- Q12. Compared to others, how easy is it for you to get people to listen to you in family discussions?



(N.R. – Not responded / Not applicable; 1% - No problem; 2% - Small problem; 3% - Medium problem; 5% - Large problem)

Fig 1 : Distribution of Response of participation-on-participation scale.

Table 2 : Clinical profile of study participants.

Clinical Profile	Category	Count (N)	Percentage (%)
Type of case	Multibacillary (MB)	101	92.7
	Paucibacillary (PB)	7	6.4
Family history of leprosy	Yes	3	2.8
	No	105	96.3
Treatment status	Currently on treatment	72	66.1
	Treatment completed	26	23.9
	Defaulter	10	9.2
Current symptoms	Patches	7	6.4
	Reactions	0	0
	Visible impairment	1	0.9
	Anesthesia	46	42.2
Grades of disability	Grade 0	61	56
	Grade 1	43	39.4
	Grade 2	4	3.7

Table 3 : Association of age, type of case, gender, and grades of disability with grades of participation.

Variables	Categories	Grades of participation			Chi square p value
		No restriction 74 (68.5%)	Mild restriction 31(28.7%)	Moderate restriction 3 (2.8%)	
Age (years)	≤ 20 (n=4)	3(75%)	1(25%)	0(0%)	df = 2 Chi-square = 4.91 p value= 0.085
	21-30 (n=34)	26(76.47%)	7(20.58%)	1(2.94%)	
	31-40 (n=30)	18(60%)	11(36.66%)	1(3.33%)	
	41-50 (n=8)	1(12.5%)	6(75%)	1(12.5%)	
	51-60 (n=18)	12(66.66%)	6(33.33%)	0(0%)	
Type of case	Multibacillary (n =101)	5(71.4%)	2(28.57%)	0(0%)	df = 1 Chi-square = 0.029 p value= 0.863
	Paucibacillary (n= 7)	69(68.31%)	29(28.71%)	3(2.97%)	
Gender	Male (n=74)	48(64.86%)	23(31.05%)	3(4.05%)	df = 1 Chi-square =1.45 p value = 0.22
	Female (n=34)	26(76.47%)	8(23.52%)	0(0%)	
Grades of Disability	Grade 0 (n=61)	47(77.04%)	13(21.31%)	1(1.63%)	df = 1 Chi-square =4.72 p value = 0.029
	Grade 1 (n=43)	26(60.46%)	15(34.8%)	2(4.65%)	
	Grade 2 (n=4)	1(25%)	3(75%)	0(%)	

Q13. Compared to others, how easy is it for you to meet new people?

When asked about the easiness of finding work, 44 (40.4%) participants did not answer this question because they didn't try to find a job as many were already working, few were homemakers, and others were already old aged to work. Approximately 48 % find no problem in working hard. More than two thirds of participants had no problems with the rest of the activities, as mentioned in Fig.1.

As summarized in Table 3, 28.7% of individuals experienced mild restrictions, while 2.8% experienced moderate restrictions. There was no notable disparity between gender and the level of restriction to social participation across all case types. However, individuals with grade 1 or 2 disabilities faced significantly more restrictions compared to those with grade 0.

Phase 2:

We conducted fifteen interviews, with males (12) and females (3). They all worked as farmers, shopkeepers, health workers, labourers or drivers. Four unemployed were students, and housewives, and one was unemployed due to illness. Four participants were educated up to high school, middle school, and graduation, respectively, and two were illiterate.

Various themes were identified during the interviews which relate to important aspects of lives of leprosy affected persons (Table 4)

Theme 1: Delayed diagnosis

One common theme among participants is a delay in diagnosis, usually one to two years. In our participants, the primary cause of this delay was found to be misdiagnosis by healthcare workers. Some participants were misdiagnosed with skin conditions such as psoriasis or allergy,

Table 4 : Themes generated during interviews related to lives living with leprosy.

Theme	Categories	Meaning condensed unit
Delayed diagnosis	Lack of awareness	Not aware of disease Not aware of sign and symptoms of disease
	Misdiagnosis	Health care worker not able to diagnose. Doctor Confused with psoriasis or allergy. Difficult to differentiate leprosy with other skin disease.
Coping mechanisms	Emotional support	Trust doctor and took help from counsel. Full support from family members. Share illness with trustworthy person only. Trust God completely.
	Acceptance	Feels lucky of taking full treatment and cured.
	Self-Blame	Feels ashamed, discarded
	Denial	Engaged self in the work of new home and not taken treatment Cannot have leprosy Not bothered of illness
	Changes in daily routine after diagnosis	Normally doing work
Health related problems	Physical problems	Work affected due to low physical strength Numbness in hands and itching all over body Not able to tolerate winter Loss of sensation, problems in fingers Bedridden Delayed wound healing, itching on the wound Difficulty in breathing, foul smell Weakness, low energy Nodules on ears Blackening and redness of skin
	Mental /Emotional problems	Feels depressed Feels life is stopped Feels like dying (suicidal thoughts) Fear that family's future is affected Fear of transmission of disease to others Family member got scared and upset of illness

Perception	Disease	Disease is not serious can be cured Now everyone is aware of the disease and no such stigma in the community. People know disease is not contagious
	Disease causation	Blood illness Got disease from water Covid vaccine aggravated the disease
	Treatment	Feeling weakness due to medicine Treatment cures the disease in 9 months
Stigma	Perceived stigma	Not open about leprosy to others in fear of stigma Fear no one will meet Fear of being separated from children, husband and family Fear of child's future Fear of marriage of daughter Seeking alibis - Told had allergies or psoriasis
	Disclosed disease status	Opened -up to everyone, no fear of stigma

while others were not aware of the signs and symptoms of leprosy. For example, one participant shared that when they went to the doctor for a checkup, they diagnosed them with psoriasis and prescribed medication which ultimately did not work. Another participant stated that if they had known earlier that their symptoms were related to leprosy, they would have sought treatment sooner.

Theme 2: Coping strategies

Individuals diagnosed with the disease utilized various coping mechanisms. Some sought emotional support from trusted family members and individuals. Others relied on their doctors, counsellors, and faith in God. On the other hand, some individuals denied the possibility of having the disease and engaged in other activities as a distraction.

"My family provided me with immense support.

They never asked anyone to avoid sitting or staying near me," shared a 38-year-old male participant.

Similarly, another participant shared, *"My children stood by me throughout my treatment. They took precautions and even provided me with warm water for bathing."*

However, one participant refused to acknowledge his leprosy diagnosis and claimed that his/ her symptoms did not match the disease, even though he/she received treatment and was registered for it.

Theme 3: Adjustments to daily routine post-diagnosis

Most participants continued to work as usual, with only one individual resigning due to foot inflammation and pain caused by leprosy. One participant, a 52-year-old male farmer, stated, *"I have my own land and continue to work as I did*

before my diagnosis.” Another 38-year-old male participant shared, “I used to drive a car before my illness, and I still do so now”.

Theme 4: Health-related problems

The fourth theme of the study related to health-related issues. It was found that almost all participants experienced weakness, loss of sensation, and delayed wound healing. Additionally, one participant struggled with the cold winter weather while another had difficulty breathing. One participant shared that he/she previously had concerns about his/her face becoming darker and experiencing bad breath, but both issues have improved. Another participant mentioned experiencing weakness that occasionally hinders his/ her ability to walk.

Theme 5: Perception

Each participant had a unique perception of the disease, its cause, and treatment. Some believed that contaminated water, allergies, or bad blood caused the disease. One participant even thought that the COVID-19 vaccine caused it.

“When I collected something from the water and consumed it, I thought I contracted the disease from water,” said a 38-year-old male.

“After receiving the COVID-19 vaccine, my illness worsened,” shared a 60-year-old female.

Some participants believed their illness was due to an allergy or bad blood, *“I thought that my blood had some kind of allergy that caused the disease,”* said a 38-year-old male.

During in-depth interviews, many participants expressed that community members had a negative attitude towards leprosy and avoided those with the disease. *“I will never disclose my illness to anyone. Nobody should know that I have leprosy,”* said a 24-year-old male.

Despite this, participants remained optimistic about their treatment and believed compliance

would lead to a cure. However, some participants reported that the medicine caused weakness.

Fortunately, some participants observed that the negative attitude towards leprosy had decreased, and people no longer discriminated or maintained distance from those with the disease. *“Nowadays, everyone knows about this illness and how it spreads. No one discriminates against those with leprosy,”* said a 32-year-old male.

However, many still felt that community members had a negative attitude towards those with the disease and avoided them. One participant even stated that he/ she would never reveal his/ her illness to anyone in his/ her entire life.

Theme 6: Stigma

None of the patients reported experiencing stigma, but most participants felt stigmatised due to fear of discrimination, separation from family, or other factors. Only one participant disclosed their disease status and hoped for help with their illness. Two participants were concerned about their children’s future, while one worried about their daughter’s marriage.

A 60-year-old male participant stated, *“I am not worried about anything else; I am only worried about my daughter getting married.”* Two participants did not disclose their status, including a field health worker who feared being forced to leave home, facing verbal violence, rejection, and people refusing to visit their home even after treatment.

One female participant shared, *“I have not told anyone in my family about my condition because I am afraid, they will not talk to me, harass me, or even throw me out of the house.”*

Participants sought alibis and told others they had skin conditions like psoriasis or allergies. Another participant claimed to be unaware of his/ her illness, and the doctor assured them that it would be cured.

Discussion

Our study revealed that a significant proportion of individuals, 28.4% and 2.8%, experienced mild and moderate limitations, respectively, in terms of social participation. This restriction was mainly due to physical health problems. Significant association was seen in grades of disability and participation restriction. As grades of disability increases, the participation restriction increased. Participants perceived fear and stigma of disease due to which some of them were suffering from depression and loneliness, but none have experienced the stigma to date. Family members supported the participants in all possible ways. Many participants were open about their disease to their near ones, which depict changing perception of disease and acceptance of leprosy case in the community.

A male preponderance of 67.9% was seen in the present study. Other studies also showed that leprosy in males was more frequent than in females (Singh et al 2012, Seshadri et al 2015, Dimri et al 2014). The reason for this was their outdoor activity and a higher chance of infection or because they have more access to the health care system. In the present study, most of the participants belong to 21-30 years (31.2%) age group; a similar finding was reported by Kumar et al (2020) in the Ujjain district of Madhya Pradesh (2020), where maximum number (40%) of participants belonged to 21-40 years age group. Most of the participants belonged to upper-lower (56.0%) followed by lower-middle (26.6%) socio-economic status; similar findings were observed in a study conducted by Seshadri et al (2015) in which (41%) of each belonged to the upper-lower and lower-middle socio-economic class (Seshadri et al 2015). More than 90% were multibacillary cases. A study conducted in Eastern India reported that 83% of cases were of multibacillary types (Ramasamy et al 2019). The NLEP reports of Assam and

Kerala mention that multibacillary (MB) type comprised of 79.1% and 63.1%, respectively, and overall, in India (2020-21), it was 58.1% (National Leprosy Elimination Programme 2021). Reporting of a high percentage of MB cases shows that early case detection and treatment are not taking place. However, in Uttarakhand there is a high proportion of multibacillary cases in cases treated at a tertiary care centre (Rawat et al 2017), possibly due to delayed diagnosis. This is higher than the national average (NLEP Annual Report 2015-16). Even a small percentage of default could have significant implications, given the country's population.

Approximately 40.4 percent of our patients had grade 1 and grade 2 disabilities. Grade 2 disability was higher than Haryana report 2020 and NLEP report 2020-21 (2.5%) (NLEP 2022) and lower than Kerala (2017-18) and Assam (2018-19) (9.6% and 7.9% respectively) (NLEP 2021, NHM Assam 2022). The higher percentage of Grade 2 deformity among new cases (visible deformity) is due to late detection detected in the community, and these cases may only be the tip of the iceberg. In the present study, anaesthesia was reported by 42%. Naik et al (2016) reported anaesthesia in 54.7%, Similar findings were also reported by Sharma et al (1996). The present study used the social participation scale (Hindi version) to assess the participation restriction (Participation Scale, P scale 2022). It was observed that 11% of participants found it very difficult to work because of the numbness and anaesthesia in their hands. 4.6% of participants had some difficulty contributing economically due to physical impairment.

In the present study, no association was found between the level of participation restriction and age, gender, and type of case. A study by Govindhraj et al (2018) in West Bengal reported that 15% and 10% of participants had mild to moderate restrictions, and 10% had severe

restrictions, respectively. It was observed that restrictions develop with the progress of the disease (Govindhraj et al 2018). The participants with grade 2 disabilities reported moderate to severe restrictions due to visible deformity and less physical strength to perform the routine roles and responsibilities.

Phase 2 confirms the result of Phase 1 that very few had restrictions. When enquired about their life with leprosy we came across six themes. These were delayed diagnosis, coping mechanisms, changes in daily routine after diagnosis, health-related problems, perception, and stigma.

It was seen that knowledge among leprosy-affected individuals was low and inadequate. Some delays were because of misdiagnoses by healthcare workers. Participants presented with some redness or allergy in their skin, while insensitive lesions were diagnosed quicker. Similar findings were seen in a study by Henry et al. in Brazil (Henry et al 2016). Mathuvel et al (2017) concluded that reasons for the delayed presentation were: poor awareness of leprosy symptoms, the first health care providers visited being private practitioners who were not aware of the provision of free leprosy treatment at public health care facilities, reduced engagement, and capacity of the general health care system in leprosy control.

The second theme was a coping mechanism. Persons with leprosy try to seek support from their family members and trusted doctors; they believe that they do not get discriminatory treatment from the community because their family supports them. A study by Nasir et al (2022) in Indonesia also had reported similar findings. Some participants believed that their family was under the shadow of leprosy. Another theme was health-related problems which were further divided into physical and mental/emotional problems. A similar finding was reported in a study in Nepal, which showed that 70% of the

patients treated with leprosy had neuropathic pain (Toh et al 2018). In the present study, one participant reported suicidal thoughts, van Dorst et al (2020) from Nepal have also reported mental depression among participants, and their family's future is affected (van Dorst et al 2020).

The present study reported no change in daily routine due to disease. There were misconceptions related to the cause of the disease. van't Noordende et al (2019) in a study from North India have also reported such misconceptions about the disease such as hereditary, transmitted by touch, unclean environment. One participant reported that people nowadays know the disease and accept the cases. Many were optimistic about the treatment and completed it timely.

No one experienced stigma in the present study. Some people have perceived stigma and did not want to disclose their illness to others to protect themselves from the community's negative attitude. Similar findings were observed in several other studies (Adhikari et al 2014). In a national sample survey, it was observed that compared with past stigma has been reduced and most of LAPs get support, however, self-stigma has been identified as an issue among 30% of leprosy patients which requires health education and counselling (Katoch et al 2017). Our study also shows good family/social support. They were seeking alibis by telling others they had some kind of allergy or a skin condition like psoriasis, so they do not get discriminatory treatment from the community. Agrawal (2022) identified stigma and Covid pandemic as impediments in leprosy programme. Pena (2022) also mentioned Covid having negative influence. These opinions imply that competing priorities at a particular moment of time thus can have negative impact on leprosy programme.

Strength

A mixed method approach used in this study not only assesses the level of restriction to social

participation but also examines the experiences of leprosy-affected people undergoing treatment /t at their homes. All the earlier studies were institutions based, we could not find the study among those treated at home in Uttarakhand and even in India. Thus, our observations add new information about the lives of leprosy affected persons specially from this state which has potential application to find solutions to these problems.

Limitations

Phase one was mostly conducted by telephonic interviews, so only those with mobile phones could be contacted. Some of the cases could not be traced due to changed mobile numbers. We could not ascertain their expression via voice call, so many were encouraged to connect via what's app video call. Insufficient time is the main drawback of a telephonic interview; however, we connected with participants 2-3 times if participants could not devote 15-20 minutes at one time. The sample size is insufficient to comment on the prevalence of social restriction apart from the studied population. Further research on social restriction is needed when CBR is now being promoted.

Conclusion

Approximately 30% had mild to moderate restrictions on social participation. Those with disabilities had higher restrictions on social participation compared to no disabilities. Individuals with leprosy faced physical and mental problems, and many emotional issues were due to perceived fear. Their family members make them feel comfortable so they can heal easily, which helps them to cope with the disease. It was also observed that participants felt that now the community's perception had changed, and many were aware of the disease, and at the same time, some respondents felt fear of being discriminated though no one had yet experienced it.

Recommendations

Efforts need to be made to motivate the participants to seek early health care. Health workers need proper training in diagnosis, patient education and counselling. Community needs to be aware of the cause, mode of spread and the importance of early diagnosis and treatment. Many patients/ leprosy affected persons still face social exclusion due to the stigma attached to the disease. There is a need to strengthen further CBR and referral services involving all relevant stakeholders. Besides a person having leprosy, family members also need to be counselled and supported.

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