“Perceived quality of life of leprosy patients: A qualitative inquiry”

A Capstone Project submitted to
Johns Hopkins Bloomberg School of Public Health & IIHMR University
in partial fulfillment of the requirements for
the award of the degree of
Master of Public Health

by

Ritupreet Virk
MPH - Cohort III (2015-17)

Under the guidance of
Dr. J.P Singh

October 2016

ACKNOWLEDGEMENT

I would like to take this opportunity to give my most sincere gratitude to the following people. The first and foremost words of gratitude to my guide **Dr. J.P Singh,** Associate Professor, IIHMR University**,** for giving me the opportunity to work under their guidance and for motivating and supporting me in my project work.

I would like to express my sincere thanks to **Dr. Neetu Purohit**, Associate Professor, IIHMR University, who has provided me with guidance, insightful suggestions and advice.

I specially thank IIHMR University and all the faculty members of the University for having equipped me with the skills and the ability through their inputs, which assisted me in the completion of the project.

I am also thankful to **Dr. Nutan Jain**, Professor, IIHMR University, who has helped me with her valuable suggestions and guidance for Institutional Review Board (IRB) approval for primary collection of data for the study.

I am also extremely thankful to **Ms. Balbir Kaur**, auxiliary nurse midwife, and **Dr. Vivek Anand**, Medical Officer, District Hospital, SBS Nagar, for their kind co-operation and support. I also express my gratitude to the **members of Kusht Ashram,** SBS Nagar, who participated and gave their time and invaluable support during this project.

Above all, I express my deep gratitude to my almighty and my beloved **family members and friends,** without their help and moral support I could not have been in a position to complete my study who taught me great things in life.

Ritupreet Virk

Table of Contents

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

Leprosy is one of the oldest diseases that still prevails in our society. The prevalence of this disease has significantly decreased over the years with countries implementing control programs. India is one such country with one of the highest prevalent rates in the world. The National Leprosy Eradication Program (NLEP) curbed the disease to bring the prevalence rate to less than one per 10,000 population reaching an elimination stage. However, some states still continue to tackle the problem of elimination. Leprosy Affected Persons (LAPs) are still affected with this disease after treatment due to stigma and discrimination associated with it. This paper is a qualitative study that looks at the quality of life of LAPs at a Kusht Ashram in Shahid Bhagat Singh Nagar (SBS Nagar), Punjab and the involvement of the leprosy program. 21 LAPs at the Ashram and 2 health staff at a district hospital in SBS Nagar were interviewed to find out their views of the quality of life and the views of LAPs and the health staff regarding the leprosy program.

Our findings showed that all 21 LAPs had developed the disease at a young age (8-15 years) and were satisfied with the quality of life in all four domains. None of the LAPs were employed and had no means of livelihood. All except one of them had no knowledge about the disease such as the cause and the transmission of the disease. This finding was consistent with other studies with the LAPs having a limited knowledge of the disease and thus it prolonged the period of diagnosis resulting in deformities at an extreme.[5,8] This also suggests that it has resulted in delayed treatment of the disease. The health staff also stated that the delay in diagnosis led to severe consequences such as grade II disability/deformities and a burden on the economy of the state. They also believed that the horizontal leprosy program has greatly impacted the lives as the services are more accessible to LAPs. They also reported that only 12 new cases of leprosy emerge every year in SBS Nagar which is evidenced in 9 people who were migrants and 3 people from Punjabi descent. In comparison to high endemic states of India, Punjab is a low endemic state. Kerala follows a vertical program and has high proportion of child and grade II disability cases. This is in congruent with the feedback from the district hospital staff in Punjab that stated that the horizontal program is more effective.

Though the results of this study cannot be extrapolated to the state or country without studying the situation in detail, it highlights the need for more studies and involving LAPs in training programs implemented by the government, to repeal the laws that stigmatize and discriminate LAPs and also it would be beneficial to have a horizontal leprosy program in all the states as a standard protocol.

Introduction

Leprosy is a disease also referred as Hansen disease is communicable which is caused by bacteria (Mycobacterium leprae). It is also known as a poor man's disease and continues to prevail in some endemic areas of the world in the 21st century. It causes damage resulting in impairment of daily activities as it affects the skin and peripheral nerves thus forming deformities of the hands, and feet.[1] Such visible deformities led to discrimination against people affected with leprosy. The British Raj passed the "Lepers Act, 1898" to manage the spread of it.[2] This Act also mentions to arrest people who would employ people affected with this disease. This may have initiated the stigma and discrimination against leprosy affect persons (LAPs) which had developed a long time ago and still continues to this day. Also the Hindu Marriage Act 1955 specifically mentions "….. allows divorce on a petition presented by either spouse on the ground that the other party – has been suffering from a virulent and incurable form of leprosy."[3] In 2015, The Law Commission of India undertook the task of identifying laws which can be repealed and a report was submitted to the government on eliminating discrimination against persons affected by leprosy.[4] This report highlighted the purpose behind the inclusion of it which was to control the spread of the infection to the unaffected spouse. But as it is recognized that leprosy is no longer incurable and can be treated and thus the repeal of such provisions have been recognized. However, such laws still continue to exist which stigmatize the people affected with the disease.

The Government of India (GOI) initiated the National Leprosy Control Program (NLCP) in 1955 to impart education and treatment of this disease.[5] With medical advancements in 1982, multi drug therapy (MDT) was recognized as the ultimate treatment for this disease.[5] Hence, World Health Organization (WHO) along with GOI initiated to eliminate leprosy at a wide scale by 2000.[2] With the combined efforts of GOI, WHO and the World Bank, the prevalence rate (PR) continued to decrease with

active searches of leprosy cases. According to National Leprosy Eradication Program (NLEP) 2008-2009 report, the prevalence rate was 0.74 per 10,000 in 2008-2009 with 0.87 lakh cases and in 2014-2015 report, the prevalence rate was 0.68 per 10,000 with 0.86 lakh cases.[6,7] The progress report of NLEP shows the trends from the years 1991-2009 and 2004-2015 in India as there is decrease in Prevalence rate (PR) and Annual New Case Detection Rate (ANCDR) (See Annexure - II).[6,7] Globally, India alone contributes for 60% of the total cases detected.[8] The Indian states of Bihar, Chhattisgarh, Jharkhand, Uttar Pradesh, West Bengal, Orissa and Maharashtra contribute to 66% of the country's cases of this disease.[2] However, Gupte et al mentioned in their research that the new case detection had declined over the years and India was one of the countries that has shown a great shift in this decline (See Annexure - III). [9]

GOI along with international partners catered to actively report and treat leprosy cases leading to research studies focusing on the perception, attitude of patients and the stigma in the community. A study done by Majumder (2015) analysed the poor socio-economic conditions of Leprosy Affected Persons (LAPs) such as stigma against the disease, being forced to live in leprosy colonies, practicing begging as a means of income and children of leprosy affected parents facing discrimination and denied admission in schools in a district in Jharkhand.[10] LAPs continue to face such challenges associated with the disease. This study focuses on inculcating WHO quality of life assessment (WHOQOL) to determine the quality of life among leprosy patients who have developed deformities due to the disease (See Annexure - VII).[11] This study also encompasses and documents views of the health staff treating the active cases of the disease.

Review of Literature

A study was done to monitor the performance of the project by NLEP by Indian Institute of Health and Management Research (IIHMR), Jaipur in 13 states during February-May 2005.[12] Their findings showed a significant decrease in prevalence rate (PR) which reduced from 3.74 per 10,000 population in March 2001 to 1.99 per 10,000 population in December, 2004.[12] Currently, the PR is 0.69 per 10,000 population, in April 2015.[7] In the year 2014-2015, the states of Chhattisgarh, Orissa, Bihar, and West Bengal (See Annexure - IV) have reported the highest annual new case detection rate (ANCDR).[7] The study by IIHMR University assessed the accomplishments that were done by NLEP-II. The study conducted focus group discussions, and case studies to assess the perception of the community on leprosy issues.[12] The case studies in this study showed that there were still misconceptions about the disease and were thought of "as a sort of divine punishment or result of past misdeeds."[12] Another study by Grewal et al (2013) showed poor levels of knowledge and negative attitude in the community in New Delhi.[13] Such a negative response from the community could be the reason for cases to still prevail in our society. Mankar et al (2011) assessed the quality of life in leprosy patients in comparison to control group and the results showed presence of stigma and attitude towards leprosy patients.[14] The control group also believed that leprosy patients should be segregated from the community and should have separate treatment facilities.[14] Another study by Joseph and Rao (1999) also found that the quality of life had decreased in LAPs in the state of Andhra Pradesh.[15] These studies over the years have recognized the importance of the quality of life among the leprosy patients and the stigma that is still associated with it. However, few studies have compared the perception of leprosy patients along with the perception of the health staff

post elimination of this disease. Thus, this paper focuses on qualitative data with discussion with LAPs and health staff treating the leprosy patients.

Rationale of the study

According to WHO weekly epidemiological record 2016, India, Brazil, and Indonesia, reported more than 10,000 new cases and accounted for 60% of new leprosy cases (See Annexure – V).[8] India is contributing a large amount of new cases of leprosy that are being reported. Even the low endemic states in India continually report leprosy cases and is still prevailing in the states of India. One such state is Punjab that has an estimated population of 2, 91,73192.[12] The prevalence of leprosy patients in Punjab in the year 2014-2015 is 0.18 per 10,000 population.[7] Shahid Bhagat Singh Nagar (SBS Nagar) is one of the low endemic districts of Punjab with an estimated population of 6,12,310 as per 2011 census and has a Kusht Ashram for leprosy patients catering to 35 families.[16] According to the district hospital data, currently there are about 12 active cases of leprosy in this district. It is a low endemic state but due to high migration from other states, the cases are usually found in people from other states. There is still a high chance of the disease proliferating in the state. Therefore, LAPs continue to be housed in leprosy colonies and still have not integrated within the general population. This signifies the need for the government to continue to focus on eradicating the disease as its symptoms are visibly evident, by eliminating it from being secluded and segregating it patients from the society. This qualitative study was conducted in SBS Nagar as it had a Kusht Ashram with negative cases of leprosy still residing in isolated area away from the city. It is important to understand why these patients are still not integrated into mainstream society and if the stigma discrimination still exists. It is also important to analyze how effective NLEP has been and its impact on these patients.

Objectives of the study

- To gather perceptions of leprosy patients on their quality of life (physical, psychological, social and environment domains).
- To document views of health staff on the leprosy incidence and management – transition from vertical to horizontal- post elimination era.
- To summarize the status of leprosy patients and leprosy as a disease.

Methodology

The study has been conducted in Kusht Ashram in SBS Nagar in the state of Punjab. It is a residential facility solely for leprosy affected families. The Ashram comprises of 35 built up houses. The residents have developed deformities due to the disease and their lives continue to be impacted even after post-elimination era. The study will assess their quality of life using WHOQOL questionnaire (See Annexure - VII) through four main domains: physical, psychological, social and environmental to assess whether their lives have improved through the program initiated by the Government of India.[11] By assessing the quality of life, we can identify the issues that they are still facing and how they could be addressed to resolve such issues. There is a district hospital with an assigned district leprosy officer who will be coordinating to assist in the matters of resolving any medical / health issues.

The study was done through voluntary participation. 21 LAPs were interviewed for 8 days and questionnaires were filled out. A detailed interview of each individual and his/her family members was done to collect the data pertaining to their quality of life. The questionnaire was in English and Punjabi. In case an individual was illiterate, the health worker along with the researcher assisted the individual to fill the form on their behalf. Two health staff (Leprosy Medical Officer and Auxiliary Nurse Midwife) were interviewed to assess their views regarding the leprosy patients and the program. (See Annexure – VIII).

Study type – This study uses qualitative data gathered from patients and the health staff.

Study setting – Kusht Ashram and District hospital in Nawanshahr District SBS Nagar (Punjab).

Sample size – A sample of 21 LAPs and 2 health staff who have been treating the patients at the District hospital.

Data collection techniques – A questionnaire using WHOQOL questionnaire (See Annexure - VII) was prepared to assess the quality of life of patients and also document views of health staff regarding this disease and the leprosy program.(Annexure – VIII). The parameters that were included were physical, environmental, psychological and social domains for the leprosy patients that were interviewed.

Ethical considerations

In the case of recognition of ethical concerns, the approval from Institutional Review Board (IRB) was done (See Annexure – I). A health worker along with the researcher coordinated to get the necessary care that may be required such as consulting a doctor regarding any medical issues.

For ethical issues that may arise, the following steps were taken:

- A retired skin dermatologist who has worked as a District Leprosy officer will be consulted for concerns regarding deformities in the participants of the study and if any assistance can be provided.
- In case if further medical issues arise during interview, the participants will be provided with contact details of public doctors to resolve issues such as depression, stress or counseling etc. The cost may be minimal for transportation

and hospital charges which can be borne by the individual and if required by the leprosy colony. A request to the doctor to waive his/her fee charges can be done.

- Auxiliary nurse midwife was involved in this study who was already assigned to Kusht Ashram for any assistance required by the patients.

Results

Data was gathered from 21 former leprosy cases. Majority of the patients responded positively towards the quality of life after being affected with the disease. Table 1.1 shows the social demographic profile at Kusht Ashram Colony in SBS Nagar. Only 1 LAP was educated at a graduate level and the rest were illiterate to primary level education. Table 1.2 shows the data regarding the knowledge levels of 21 LAPs about this disease. Table 1.3, 1.4, 1.5 and 1.6 shows the overall response of LAPs in regard to physical, psychological, environmental and social domains.

Table 1.1 Demographic Profile at Kusht Ashram, SBS Nagar, Punjab

Demographic Profile – 21 Leprosy Affected persons (LAPs)			
Sex	Male	Female	Total
	10	11	21
Education level			
Illiterate	2	8	10
Primary	3	1	4
Secondary	2	1	3
High School	2	1	3
Graduate	1	0	1

Table 1.2 Knowledge regarding the leprosy disease among Leprosy affected persons (LAPs)

Knowledge about the disease					
	Male	Female		Male	Female
What is the cause(s) of leprosy?			**What are the symptoms of leprosy?**		
Infectious disease	1	0	Skin patches	8	8
Punishment	0	0	Skin patches with loss of sensation	2	3
Curse of God	0	0	Deformities of hands/feet/face	0	0
Hereditary	0	0	Don't know	0	0
Don't know	8	11	Others	0	0
Others	1	0			

Table 1.3 Physical health domain

Physical Health Domain	Not at all	A little	A moderate amount	Very much	An extreme amount
To what extent do you feel that physical pain prevents you from doing what you need to do?	17	4	0	0	0
How much do you need any medical treatment to function in your daily life?	21	0	0	0	0
Do you have enough energy for everyday life?	0	0	4	16	1
How well are you able to get around?	0	0	2	17	2
How satisfied are you with your sleep?	0	0	0	20	1
How satisfied are you with your ability to perform your daily living activities?	0	0	0	20	1
How satisfied are you with your capacity for work?	0	0	2	18	1

Table 1.4 Psychological domain

Psychological domain	Not at all	A little	A moderate amount	Very much	An extreme amount
How much do you enjoy life?	0	0	5	16	0
To what extent do you feel your life to be meaningful?	0	0	12	9	0
How well are you able to concentrate?	0	0	1	19	1
Are you able to accept your bodily appearance?	0	1	12	8	0
How satisfied are you with yourself?	0	0	2	18	1
How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	0	17	4	0	0

Table 1.5 Social relationships domain

Social Relationships	Not at all	A little	A moderate amount	Very much	An extreme amount
How satisfied are you with your personal relationships?	0	0	1	19	1
How satisfied are you with the support you get from your friends?	0	0	2	18	1

Table 1.6 Environmental domain

Environmental domain	Not at all	Slightly	A moderate amount	Very much	Extremely
How well are you able to concentrate?	0	0	1	19	1
How safe do you feel in your daily life?	0	0	0	20	1
How healthy is your physical environment?	0	0	1	19	1

Health staff views of the program

A leprosy medical officer (MBBS, Dermatology MD) and Auxiliary nurse midwife (ANM) were interviewed to gather information regarding their perception of the program (See Annexure – VIII). Both stated that the program was very effective in case detection initially as door to door surveys were done. However, now the program is

merged horizontally, the impact is negative and hence it is still in elimination phase rather than eradication. Every year at least 12 new leprosy cases and majority of them are from the migratory population were reported. However, such patients come to the hospital to avail the services rather than health staff actively searching for such cases.

Discussion

To gather the perceptions of leprosy patients on their quality of life based on physical, psychological, social and environment domains.

The results for all the four domains for analyzing the quality of life after the impact of leprosy showed that majority of the patients had a positive response in respect to the quality of life now. Majority of the patients were able to attend to day to day household activities but only to a certain extent as the deformities of hands and feet have impaired the level of work that they can do. All LAPs expressed that they did not face any discrimination regarding school admissions for their children but instead had full support of the local government school motivating them to send their children to school. One LAP also has her son enrolled at a graduate college. The results also show poor knowledge of leprosy disease (see table 1.2) among the LAPs with only one LAP who knew that leprosy is an infectious disease. Studies as discussed earlier Majumdar (2015) and Grewal (2013) have had similar results of LAPs having a limited knowledge of the disease and thus it prolonged the period of diagnosis resulting in deformities at an extreme.[10,13] This also suggests that it has resulted in delayed treatment of the disease. Poor knowledge of the disease also highlights the importance to strengthen the aim to eradicate this disease by actively searching for positive cases through door to door surveys. There is a need for education among former LAPs on the disease, routes of transmission and preventive measures to prevent future cases.

The district hospital at SBS Nagar has regular camps at the hospital to create awareness in the community and patients are continuously followed up by the ANMs even if one follow up at the hospital is missed. They are contacted on a regular basis for a follow up with the district leprosy officer at the hospital. All 21 LAPs interviewed had contracted the disease at 8-14 years of age suggesting that children are also vulnerable to this disease which is consistent with another study done by Majumder.[10] This signifies that it is important to continuously actively screen children for early detection of cases. Late detection is a double edge sword that simply adds economic burden on the country as later they develop deformities thus impairing them in their productive years.[1] Also all 21 LAPs who were interviewed were not employed and have no means of livelihood. However, the Ashram is supported by the local community through donations and free medications are provided for minor injuries. All 21 LAPs who were interviewed also mentioned that the leprosy program has reduced the stigma over the years and also the burden of the disease with support from the government.

To document views of health staff on the leprosy incidence and management – transition from vertical to horizontal- post elimination era.

The district leprosy officer and ANM were interviewed who have been treating leprosy patients at the district hospital in SBS Nagar. The ANM reported on the current status of the disease and on the cases registered at the hospital. The current cases registered at the hospital were 12 in 2015-2016 which were in an age group of 15-23 years which are the productive age group with 9 cases from the migratory population and 3 cases of Punjabi descent. Although a small number, it still has a negative impact and puts a burden on the economy of the state. These findings were also consistent with the study by Bhat and Chaitra (2012) where they found that the disease was evidenced in 15-60 years of age.[1] It is also consistent with the data from the Kusht Ashram at SBS Nagar as they had also developed the disease at a young age and were all migrants. Every year there

are about 12-15 new cases that have been reported for the last 5 years in SBS Nagar. Again, even with such low incidence of cases being reported in SBS Nagar if not detected early, it would still hamper the current efforts to eradicate the disease as deformities such as grade II disability will reduce their productive years and will be dependent on the government services due to no employment.

In comparison to other Indian states, Punjab has a low incidence of leprosy cases. Table 2 below shows that PR and ANCDR from 2010–2015 were declining in Punjab, but the proportion of new leprosy child cases and deformities have increased in 2013-2014 due to active increased search for cases as stated in the progress report of NLEP.[6,7,17,18,19,20,21]

Table 2. Trend of Leprosy indicators in Punjab (2010-2015) [6,7,17,18,19,20,21]

			New case profile		
Reporting Year	PR/10,000	ANCDR/100,000	No	Child	Grade II Disability
2010-2011	0.24	2.96	819	-	55(6.7)
2011-2012	0.24	2.48	695	23(3.3)	41(5.9)
2012-2013	0.21	2.46	700	28(4.0)	10(1.4)
2013-2014	0.18	2.25	648	84(12.9)	33(5.1)
2014-2015	0.18	2.13	620	45(7.3)	41(6.6)

During the year 2014-2015, the reason for drop in the numbers of child cases is unknown and one could speculate whether it is a true decrease or if the efforts to track new cases had also decreased. Punjab is maintaining PR at 0.18 per 10,000 population (2014-2015) with horizontal program.[7] However, a study by Pandey and Rathod (2010) found that in Kerala, leprosy patients were still dependent on specialists for diagnosis and treatment thus still continuing with the vertical program.[22] In Kerala, in the year 2014-2015, the PR was 0.21 per 10,000 population.[7] However, Punjab was maintaining the prevalence rate at 0.18 in the year 2014-2015 with horizontal programming

continuing in the state.[7] This study reported a higher proportion of deformities in new cases in Kerala which indicates that the cases were diagnosed very late and the proportion of new cases in children was reported high which may suggest that the disease is still persisting and spreading within the population.[22] Table 3 shows that PR and annual new case detection rate (ANCDR) are declining from 2010-2015 however the proportion of new cases increased in child and grade II disability. Thus, one would speculate whether zero cases for grade II disability is a true decrease or if the efforts to track new cases had also decreased in the year 2014-2015. (See table 3).

Table 3. Trend of Leprosy indicators in Kerala (2010-2015) [6,7,17,18,19,20,21]

			New case profile		
Reporting Year	PR /10,000	ANCDR/10 0,000	No	Child	Grade II Disability
2010-2011	0.27	2.79	931	-	-
2011-2012	0.26	2.57	861	100(11.6)	43(5.0)
2012-2013	0.24	2.47	832	107(12.9)	73(8.8)
2013-2014	0.25	2.31	782	85(10.9)	66(8.4)
2014-2015	0.21	1.95	663	60(9.0)	0(0.0)

Chattisgarh, Orissa and Bihar had the highest PR in the year 2014-2015 respectively. (See tables 4, 5 and 6). Chhattisgarh and Orissa still face the challenge of reaching the elimination level of PR of less than 1 per 10,000 population. The proportion of child cases and disability rates continue to rise at an alarming rate which may be due to continuous door to door surveys that were carried out by NLEP. In comparison to high prevalent states of leprosy cases in India, Chhattisgarh has the highest prevalent cases however the proportion of child and disability cases is higher in Kerala. (See tables 2, 3, 4, 5, and 6). This may suggest the persistent transmission of the disease at an early age

that still continues and delay in disease diagnosis and treatment as suggested in a research by Pandey and Rathod (2010).[22] This suggests that children with grade II disability could have been diagnosed earlier. This is also suggestive that the delay in diagnosis can be linked to the functioning of the program at a vertical level. As Pandey and Rathod (2010) found that Kerala still continues to function as a vertical programme with the diagnosis and treatment given by specialists and district hospitals and a limited staff is trained in the general health system.[22] This may be the reason as to why Kerala has such a high proportion of child and grade II disability cases.

Table 4. Trend of Leprosy indicators in Chattisgarh (2010-2015) [6,7,17,18,19,20,21]

			New case profile		
Reporting Year	PR /10,000	ANCDR/100,000	No	Child	Grade II Disability
2010-2011	1.94	28.91	7383	-	-
2011-2012	1.69	26.85	6999	482(6.9)	378(5.4)
2012-2013	2.13	30.50	8115	545(6.7)	464(5.7)
2013-2014	2.10	31.38	8519	543(6.4)	607(7.1)
2014-2015	2.14	31.93	8847	590(6.7)	10(0.11)

In comparison to Chattisgarh - Orissa and Bihar have the highest proportion of child cases (see tables 4, 5 and 6). In the year 2014-2015, the proportion of child cases in Orissa were 8.9% and Bihar had 14.2%.(See tables 5 and 6).[7] This may suggest that the disease is still persisting to transmit within the population and also the cases are detected later and thus the treatment is given at a later stage of the disease. In both the cases of Orissa and Bihar, the grade II disability has dramatically dropped in the year 2014-2015. Both these states had integrated their leprosy programs and has been successful in early detection of new cases. (Table 5 and 6).

As table 3 shows that Kerala has a higher proportion of grade II disability among children as compared to Chhattisgarh, Orissa and Bihar. This is suggestive of the vertical program being less effective as cases are detected later leading to a higher proportion of grade II disability cases. This is in congruent with the feedback from the district hospital staff in Punjab that stated that the horizontal program is more effective.

Table 5. Trend of Leprosy indicators in Orissa (2010-2015) [6,7,17,18,19,20,21]

			New case profile		
Reporting Year	PR /10,000	ANCDR/10 0,000	No	Child	Grade II Disability
2010-2011	0.85	16.07	6742	-	-
2011-2012	0.99	19.56	8312	776 (9.3)	254(3.1)
2012-2013	0.98	19.10	8226	711(8.6)	265(3.2)
2013-2014	1.47	24.40	10645	908(8.5)	449(4.2)
2014-2015	1.23	18.11	8004	712 (8.9)	17(0.21)

Table 6. Trend of Leprosy indicators in Bihar (2010-2015) [6,7,17,18,19,20,21]

			New case profile		
Reporting Year	PR /10,000	ANCDR/10 0,000	No	Child	Grade II Disability
2010-2011	1.12	19.79	20547	-	-
2011-2012	0.89	16.77	17801	2667(14.9)	334(1.9)
2012-2013	1.20	20.27	22001	3493(15.9)	510(2.3)
2013-2014	0.91	16.39	18188	2828(15.5)	513(2.8)
2014-2015	0.91	14.84	16848	2392(14.2)	77(0.45)

To summarize the status of leprosy patients and leprosy as a disease.

The NLEP progress report for the year 2014-2015 states that 34 states/UTs had prevalence rate of less than 1 case per 10,000 population, Chhattisgarh and Dadra and Nagar Haveli has prevalence rate of 2 to 5 cases per 10,000 population and proportion of child cases was more than 10% of the new cases detected in 8 states/UTs. With the results mentioned by NLEP, a great number of new cases have decreased over the years. However, the integration of a vertical to a horizontal programme has also evidenced the consequences of it. There are still problems with leprosy services and its integration

with the health system. As seen in research by Pandey and Rathod (2010), very few medical officers were being trained for diagnosing leprosy in Kerala whereas in the case of Chhattisgarh, the medical staff along with multi-purpose workers was being trained for diagnosing and treating such cases.[22] This may be the reason we see a high proportion of child cases in Kerala as compared to the child cases in Chhattisgarh. A trained staff along with medical officers and an earlier detection of the leprosy cases can lead a better quality of life. Similarly, the ANM and leprosy medical officer at district hospital in SBS Nagar stated that they had been trained and with the program being horizontal which is spread across primary health centres (PHCs) has added advantage to detect more cases. Early detection of leprosy cases is the key to a better quality of life as disability/deformities can be prevented. The patients who were interviewed at the Kusht Ashram also stated that majority of them were diagnosed in their childhood and did not develop deformities due to early detection and treatment. Their quality of life was impacted by immediate detection and thus resulted in positive change in their lives. With the reports of NLEP analysed over the years, there is still a long pathway to go in order to eradicate this disease. Analysis of NLEP reports 2009-2015 in comparison to the new cases detected in high and low endemic states signifies the need to record such data. However, due to continuous stages of active searches going on various states dilutes the purpose of finding out the actual cases.

Deformities and physical disabilities were the severe consequences due to leprosy. Due to deformities and disabilities, the percentage of patients with such adverse outcomes of the disease is chosen to indicate the burden of the disease.[1] As seen in SBS Nagar which is a low endemic area, they still continue to track patients and submit the report regularly to the Ministry. Some states continue to report a high PR not reaching the elimination level. It indicates an alarming point for the country as this disease continues to transmit and the current health system has not been able to effectively eradicate it.

Limitations of the study

The study is limited to a small sample and thus is not representative of the entire population. However, our results were consistent to some of the studies that were already done in other states of India.

Recommendations

In order to eradicate leprosy, stigma plays an important role that impacts the lives of LAPs. This study revealed that all 21 LAPs were satisfied with the quality of life after impact of the disease. However, all 21 LAPs living at the Ashram were not employed and had no means of livelihood and thus add burden to the economy of the state. They did express that though the stigma due to disease has reduced in our society but it still prevails. They were not integrated into the general population and were still living in secluded colonies. This highlights the issue of stigma still persisting in our society. A recommendation to curb such stigma would be to involve LAPs in training programs implemented by the government. LAPs can sensitize the program and the staff on social issues and share their own experiences which would be beneficial for the staff when diagnosing and treating leprosy patients. Also LAPs could be incorporated into the team of trainers and could be compensated for it. This could also motivate other leprosy patients to involve themselves with the program by looking at LAPs already working with staff to remove the stigma of the disease.

Another recommendation is that all states should follow the standard protocol of horizontal program for easy accessibility of services rather than a vertical program. Through the analysis of progress reports of National Leprosy Eradication program, it does imply that a horizontal program is able to target the newly diagnosed cases and provide immediate treatment. As people migrate from one state to another due to the

stigma still associated with the disease, a horizontal program could curb this problem by detecting them at an earlier stage of the disease. Also more in depth study of the human resources that are required and trained for diagnosing leprosy cases at the primary health centres should be done along with the perception of the leprosy patients regarding the services. Another recommendation is early detection of child cases is the key to eradication of this disease. Early detection curbs from resulting to severe disability thus securing the productive years of the child. Early detection also results in early treatment and precautionary measures taken to reduce the spread of the disease. Even with such low incidence cases in some states, the health staff should still continue to actively search for leprosy cases for early diagnosis and treatment of the disease. More studies are required to calculate the Disability Adjusted Life Years (DALY) to estimate the years lost due to disability which could help in planning and evaluating disability prevention programs.

Conclusion

By assessing the quality of life of LAPs, this study has found that LAPs living in the Ashram in Punjab were satisfied their lives. However, they have no employment and depend on the health system and donations from the community. Thus, it leads to addition to the burden on the economy of the country as their productive years were lost. The study was consistent with other studies as all 21 LAPs had developed the disease at a young age signifying the importance of child transmission and early detection. The health staff that was interviewed also mentioned the importance of early detection and treatment of the disease. However, due to continuous stigma and discrimination, it results in LAPs still living in secluded colonies and were not able to integrate with the general population. In comparison to the NLEP progress reports from 2009-2015, we find an increase in child and grade II deformity cases in high prevalent states of India. This may suggest that the health system in such states is not actively

searching for cases. There is still delay in the process of detecting cases resulting in possibly the existence of vertical program such as in the case of the state of Kerala.

References

1. Bhat RM, Chaitra P. Profile of new leprosy cases attending a South Indian referral hospital in 2011-2012. ISRN Tropical Medicine. 2013 Jan 15;2013.

2. India. Lepers Act 1898. [Internet]. [cited 2016 September 1] Available from http://www.rfhha.org/images/pdf/Hospital_Laws/Lepers_%20act_1898.pdf

3. India. Delhi High Court. [Internet] The Hindu Marriage Act, 1955. [cited 2016 September 3] Available from http://www.delhihighcourt.nic.in/library/acts_bills_rules_regulations/The%20hindu%20marriage%20Act,%201955.pdf

4. India. Law Commission Report. Report No. 256.[Internet] On Eliminating Discrimination against Persons Affected by Leprosy.[cited 2016 September 3] Available from https://indiankanoon.org/doc/187916748/

5. Sardesai VR. Leprosy elimination: A myth or reality. Journal of neurosciences in rural practice. 2015 Apr;6(2):137.

6. India. Directorate General of Health Services. NLEP – NLEP Progress Report for the year 2008-09 ending on 31st March 2009. New Delhi: Central Leprosy Division; 2009.

7. India. Directorate General of Health Services. NLEP – NLEP Progress Report for the year 2014-15. New Delhi: Central Leprosy Division; 2015.

8. World Health Organization. Weekly epidemiological record: relevé épidémiologique hebdomadaire. WHO; [Internet] .2016 Sept. [cited 2016 Sept 15] 91: 405-420.

9. Gupte MD, Pannikar V, Manickam P. Health Administrator Vol: XVIII Number 2: 28-36, pg.

10. Majumder N. Socio-Economic and Health Status of Leprosy Affected Person: A Study in Jharkhand. Indian journal of leprosy. 2014 Dec;87(3):145-54.

11. WHOQOL-BREF, Questionnaire, June 1997, Updated 1/10/2014. Available from: http://tinyurl.com/jcotx9m

12. India. Indian Institute of Health and Management Research (IIHMR). Independent Survey to Monitor Performance at Close of Second National Leprosy Elimination Project. Ministry of Health and Family Welfare. 2006.

13. Grewal I, Negi Y, Kishore J, Adhish SV. Knowledge and attitude about leprosy in Delhi in post elimination phase. Indian Journal of Leprosy. 2013; 85(3): 123-127.

14. Mankar MJ, Joshi SM, Velankar DH, Mhatre RK, Nalgundwar AN. A comparative study of the quality of life, knowledge, attitude and belief about leprosy disease among leprosy patients and community members in Shantivan

Leprosy Rehabilitation centre, Nere, Maharashtra, India. J Global Infect Dis [serial online] 2011 [cited 2016 Jul 17];3:378-382. Available from: http://www.jgid.org/text.asp?2011/3/4/378/91063

15. Joseph GA, Sunder Rao PS. Impact of leprosy on the quality of life. Bulletin – World Health Organization. [Internet]. 1999 Jun [cited 2016 Aug 4] ;77:515-7. Available from http://www.who.int/bulletin/archives/77(6)515.pdf?ua=1

16. District Shahid Bhagat Singh. [Internet] [2016 cited August 3] Available from http://www.nawanshahr.gov.in/html/about_district.htm#area

17. India. Directorate General of Health Services. NLEP – NLEP Progress Report for the year 2009-10 ending on 31st March 2010. New Delhi: Central Leprosy Division; 2010.

18. India. Directorate General of Health Services. NLEP – NLEP Progress Report for the year 2010-11 ending on 31st March 2011. New Delhi: Central Leprosy Division; 2011.

19. India. Directorate General of Health Services. NLEP – NLEP – Progress Report for the year 2011-12 ending on 31st March 2012. New Delhi: Central Leprosy Division; 2012.

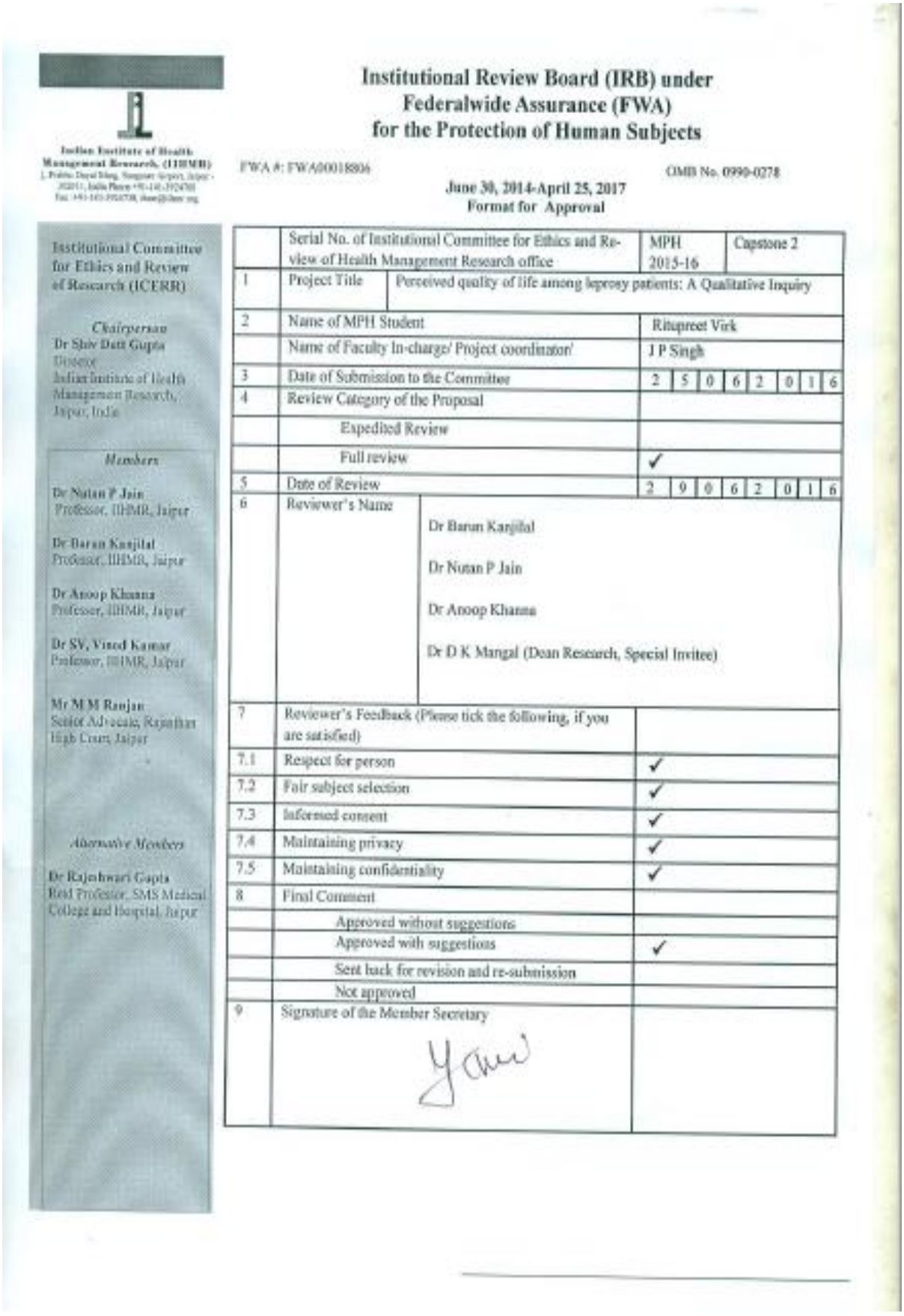
20. India. Directorate General of Health Services. NLEP – NLEP – Progress Report for the year 2012-13 ending on 31st March 2013. New Delhi: Central Leprosy Division; 2013.

21. India. Directorate General of Health Services. NLEP – NLEP – Progress Report for the year 2013-14 ending on 31st March 2014. New Delhi: Central Leprosy Division; 2014.

22. Pandey A, Rathod, H. Integration of leprosy in general health system vis-à-vis leprosy endemicity, health situation and socioeconomic development: Observations from Chhattisgarh & Kerala. Leprosy Rev. [Internet] 2010 [cited 2016 Aug 3]: 81(2): 121-128. http://www.leprahealthinaction.org/lr/June10/Lep121-128.pdf

Appendices

Annexure I - Institutional Review Board Approval



Indian Institute of Health Management Research, (IIHMR)

Institutional Committee for Ethics and Review of Research (ICERR)

Chairperson
Dr Shiv Datt Gupta
Director
Indian Institute of Health Management Research, Jaipur, India

Members
Dr Nutan P Jain
Professor, IIHMR, Jaipur

Dr Barun Kanjilal
Professor, IIHMR, Jaipur

Dr Anoop Khanna
Professor, IIHMR, Jaipur

Dr SV, Vinod Kumar
Professor, IIHMR, Jaipur

Mr M M Ranjan
Senior Advocate, Rajasthan High Court, Jaipur

Alternative Members
Dr Rajeshwari Gupta
Retd Professor, SMS Medical College and Hospital, Jaipur

Institutional Review Board (IRB) under Federalwide Assurance (FWA) for the Protection of Human Subjects

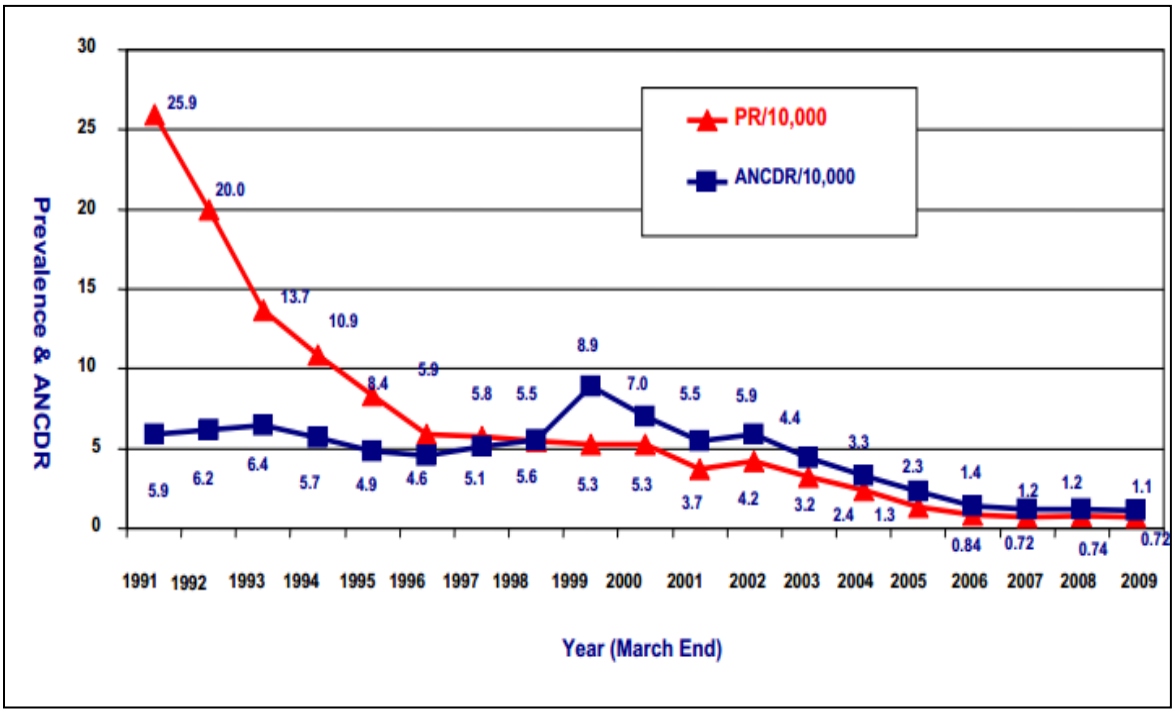
FWA #: FWA00018806 OMB No. 0990-0278

June 30, 2014-April 25, 2017
Format for Approval

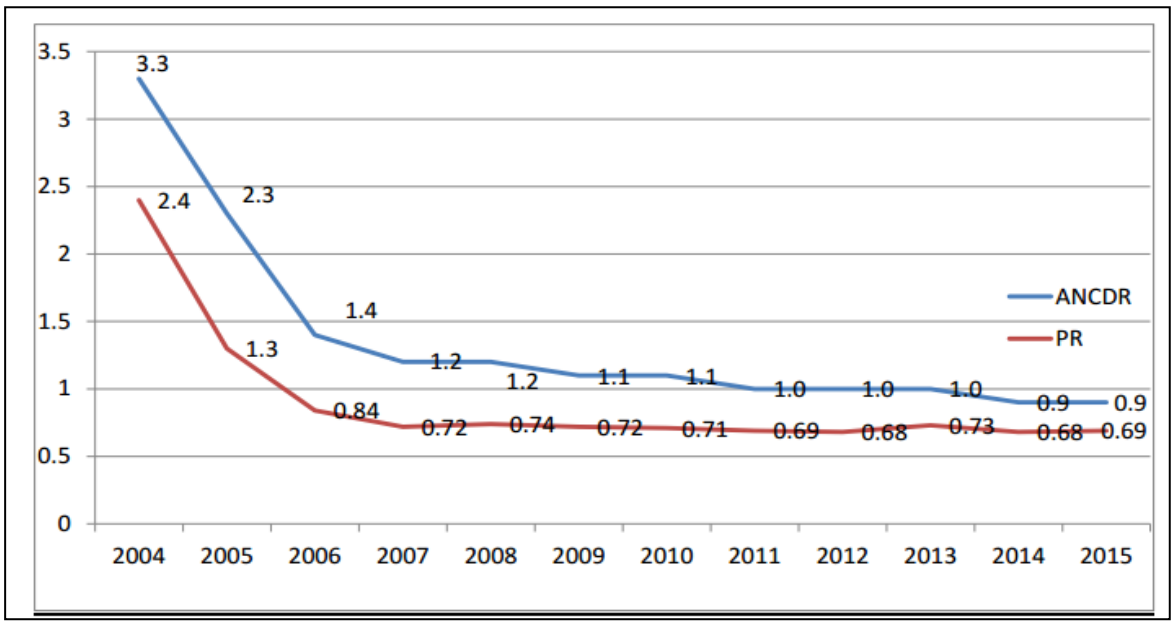
	Serial No. of Institutional Committee for Ethics and Review of Health Management Research office	MPH 2015-16	Capstone 2
1	Project Title	Perceived quality of life among leprosy patients: A Qualitative Inquiry	
2	Name of MPH Student	Ritupreet Virk	
	Name of Faculty In-charge/ Project coordinator	J P Singh	
3	Date of Submission to the Committee	2 5 0 6 2 0 1 6	
4	Review Category of the Proposal		
	Expedited Review		
	Full review	✓	
5	Date of Review	2 9 0 6 2 0 1 6	
6	Reviewer's Name	Dr Barun Kanjilal Dr Nutan P Jain Dr Anoop Khanna Dr D K Mangal (Dean Research, Special Invitee)	
7	Reviewer's Feedback (Please tick the following, if you are satisfied)		
7.1	Respect for person	✓	
7.2	Fair subject selection	✓	
7.3	Informed consent	✓	
7.4	Maintaining privacy	✓	
7.5	Maintaining confidentiality	✓	
8	Final Comment		
	Approved without suggestions		
	Approved with suggestions	✓	
	Sent back for revision and re-submission		
	Not approved		
9	Signature of the Member Secretary		

Annexure - II

Trend of leprosy through Prevalence rate (PR) and Annual New Case Detection Rate (ANCDR) from the years 1991-2009 in India

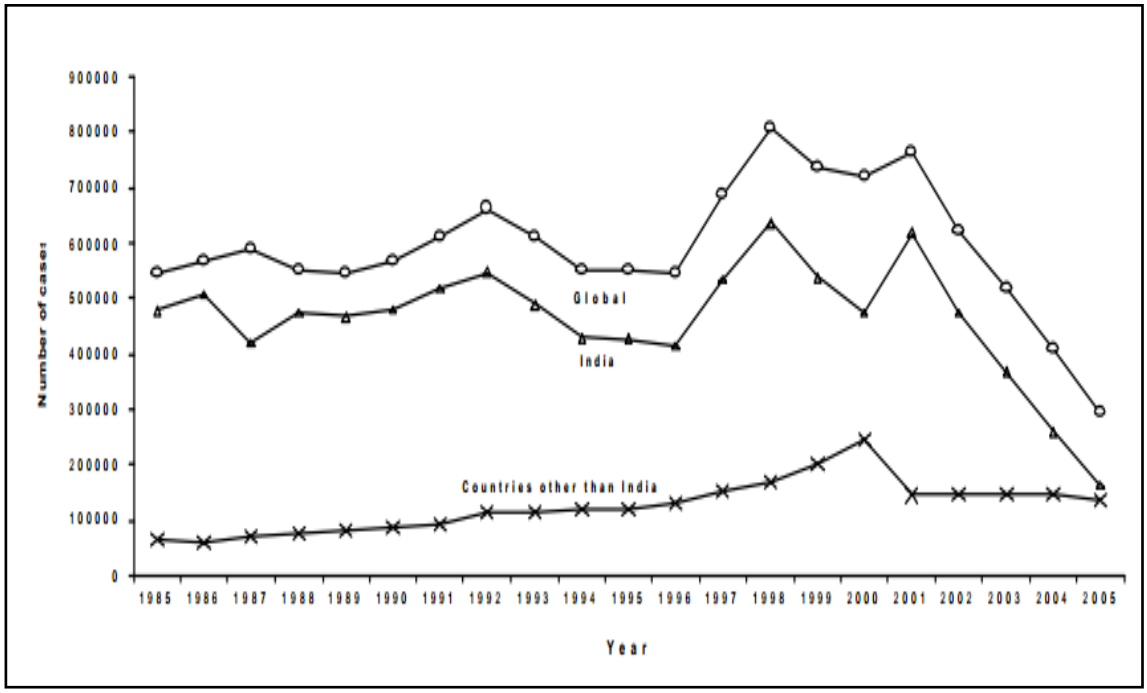


Trend of leprosy through Prevalence rate (PR) and Annual New Case Detection Rate (ANCDR) from the years 2004-2015 in India



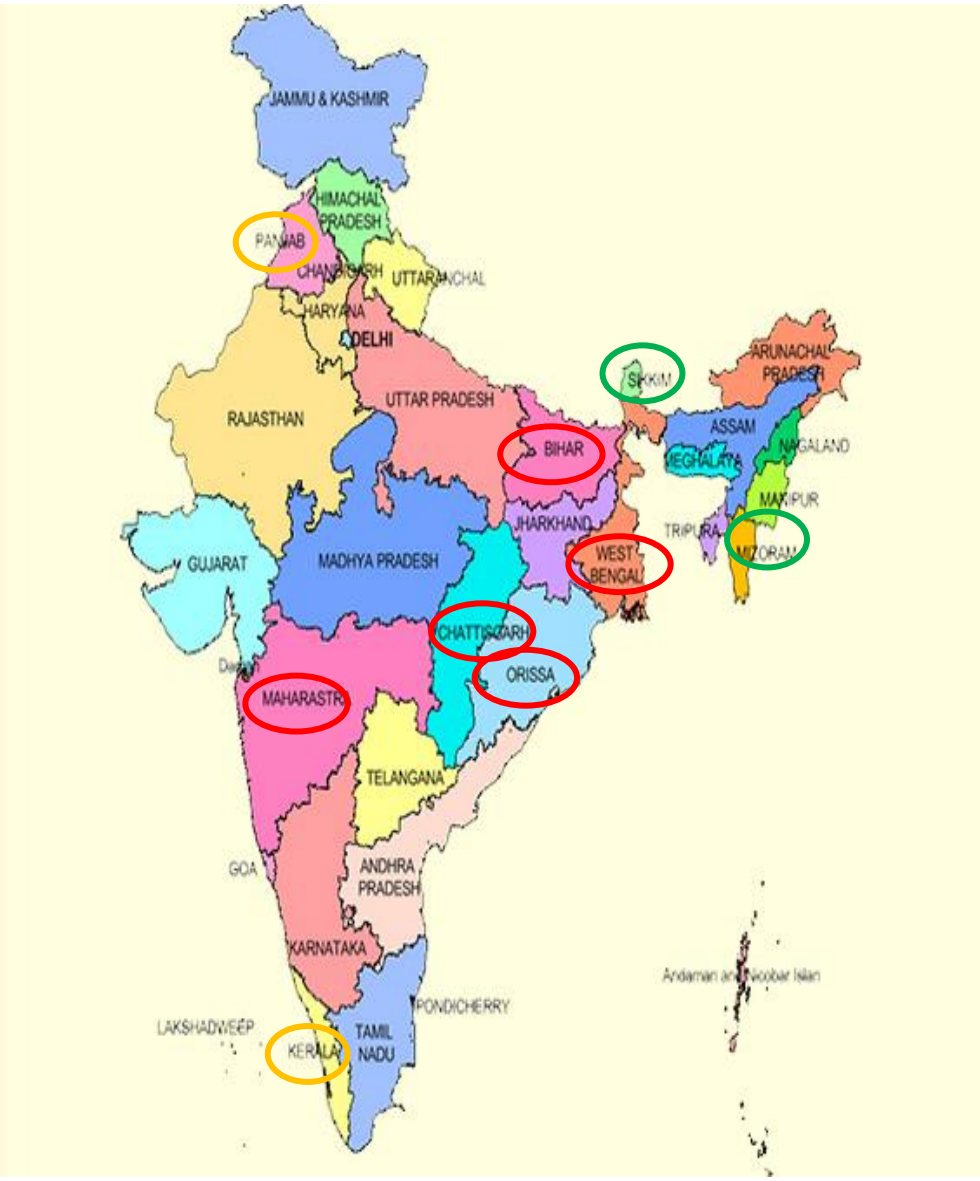
Annexure – III

Trends in new case detection by globally, countries other than India and India 1985-2005



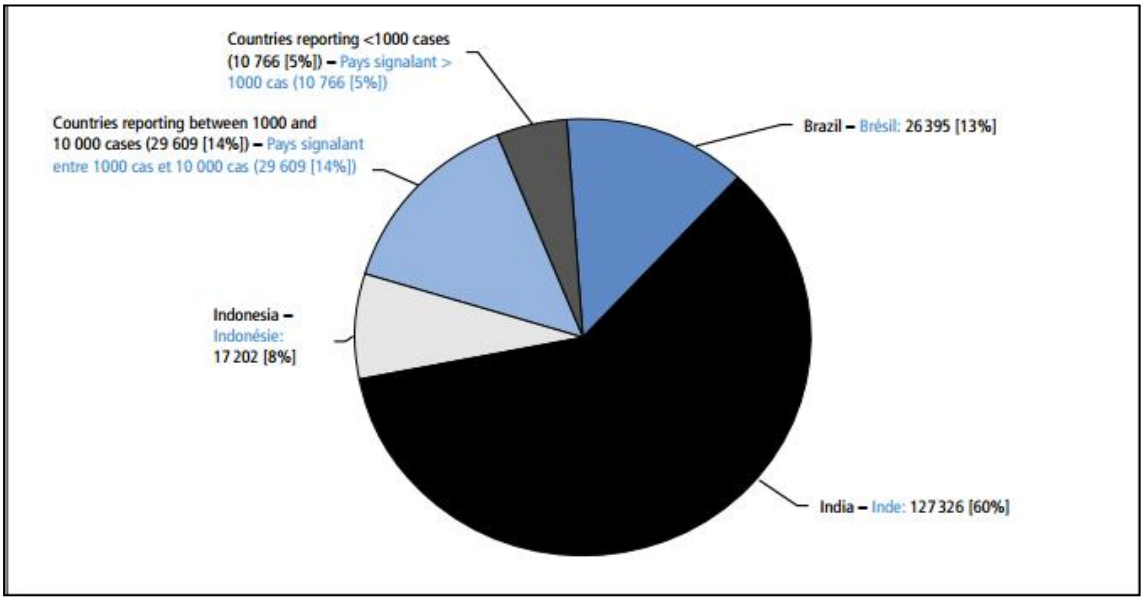
Annexure -IV

Figure 2. States with lowest (marked in green circles) and highest (marked in red circles) Annual New Case Detection Rate (ANCDR) of leprosy in India



Annexure - V

Geographical distribution of new cases in 2015, by country



Annexure - VI

INFORMED CONSENT FORM

This Informed Consent form for men and women with leprosy disease who are living in Doaba Kusht Ashram, Nawanshahr District, Punjab and who we are inviting to participate in this research. The title of our research project is "Perceived quality of life of leprosy patients: A qualitative inquiry"

[Name of Principal Investigator] – Ritupreet Virk
[Name of Organization] – Doaba Kusht Ashram
[Name of Sponsor] – N/A
[Name of Proposal and version] - "Perceived quality of life of leprosy patients: A qualitative inquiry"

This consent form comprises of the following:

- **Part I: An information sheet to provide information about the research project to participants**
- **Part II: Consent for participation by taking signatures if the participants fill the survey**

PART I

Introduction

I am Ritupreet Virk, studying at Indian Institute of Health Management Research (IIHMR), Jaipur, Rajasthan. I am undertaking the study as a part of Master in Public Health course. I am doing a research on leprosy disease which continues to impact the lives of leprosy patients post its elimination. The results will be used for academic purposes only. I am going to provide the information for you to decide whether to be a part of this survey or not. You can speak to anybody about the research and then decide if you would like to be a part of it or not.

If you have any difficulty in understanding the information that is provided, please do inform me and I can take the time to give you the information in the best possibility.

Purpose of the research

Leprosy still continues to impact the lives of many in the 21st century. Though this disease has been eliminated in many parts of the country but still it is limiting a portion of our population from doing daily activities. The reason of this research project is to identify the issues in terms of physical, psychological, social and environmental domains through a questionnaire. By using these domains, we can identify the quality of life of people suffering from this disease and how these issues could be resolved.

Type of Research Intervention

It will involve a questionnaire to assess the knowledge and quality of life of people suffering from leprosy.

Participant selection

All men and women suffering with leprosy residing at Kusht Ashram are encouraged to participate in this research. The participation is voluntary.

Procedures

We are asking you to help us learn more about leprosy and the impact it has on your day to day activities. You are invited to voluntary participate in this survey. If you accept, you will be asked to fill a survey regarding your knowledge, perception and quality of life with this disease. The survey will be given by Ritupreet Virk and collected by Ritupreet Virk. You can also fill out the survey yourself, or it can be read to you and filled out by the researcher. If you do not want to answer some of the questions, you may skip them. All the information gathered is kept confidential and no one else except Ritupreet Virk will have access to your survey.

Risks

Personal information may be gathered through this survey which you may be uncomfortable to share. We do not want this to happen. You may leave this survey if you are uncomfortable in answering the questions.

Benefits

There is benefit in filling out this survey as it will help us to assist people suffering from leprosy. We will be able to identify the issues still faced by leprosy patients and through community efforts address such issues. It would benefit the individuals as well as the community.

Sharing the Results

The information shared through the survey will not be shared with anybody outside the research team. The results will be used for academic purposes only.

Right to Refuse or Withdraw

You have the right to refuse to be a participant of this survey at any point. You may choose to review your answers at the end of the survey and can change or remove your responses if you wish to do so in case if I did not understand your response correctly.

Who to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact: Ritupreet Virk, B-6/16 Mota Singh Nagar, Nawanshahr, Punjab Pin – 144514.

This project has been reviewed and approved by Institutional Committee for Ethics and Review of Review of Research (ICERR), which makes sure that the participants of a study do not suffer in any form from the research that is done. If you wish to find about more about the IRB, contact **Institutional Committee for Ethics and Review of Research (ICERR)** IIHMR University, 1 Prabhu Dayal Marg, Near Sanganer Airport, Jaipur- 302029. India.

Part II: Consent for participation

I am participating in this research about the quality of life among leprosy patients. This study involves the participation of leprosy patients by answering questions in a survey.

I have been informed about the information that is required in order to participate in this survey. I also had the opportunity to ask questions and I am giving my consent voluntarily to be a participant in this study.

Full Name of Participant_____

Signature of Participant _____

Date _____

If illiterate [1]

I am the witness and the information has been accurately provided to the participant. I am giving my consent that the participant has understood and has given approval to participate in this study.

Print name of witness_____ **Thumb print of participant**

Signature of witness _____

Date _____
Day/month/year

Statement by the researcher/person taking consent

The information has been accurately provided to the participant to the best of knowledge and have asked questions if there are any doubts:

1. A written survey will be given at the Kusht Ashram to assess the knowledge, perception and quality of life of leprosy patients

2. Consent will be taken from each participant.

3. The participant can refuse to not be a part of the study at any time.

I have given the participants an opportunity to ask questions if there are any doubts and have also answered any queries that they had. The participants are participating voluntary and have the right to leave the study at any time.

Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____

Date _____

Day/month/year

[1] *A literate witness must sign (if possible, this person should be selected by the participant and should have no connection to the research team). Participants who are illiterate should include their thumb print as well.*

Annexure - VII

Questionnaire for Leprosy cases

1.	Name of State (ਸਟੇਟ ਦਾ ਨਾਮ)		
2.	Name of District (ਜ਼ਿਲ੍ਹਾ ਦੇ ਨਾਮ)		
3.	Sex (ਲਿੰਗ)	Male (ਮਰਦ)……..1 Female (ਔਰਤ)…...2	
4.	Age (ਉਮਰ)	_____years	
5.	Marital status (ਵਿਵਾਹਿਕ ਦਰਜਾ)	Unmarried (ਅਣਵਿਆਹੇ) Married (ਦਾ ਵਿਆਹ) Divorce (ਤਲਾਕ) Separated/ spouse left (ਵੱਖ / ਸਾਥੀ ਨੂੰ ਛੱਡ)	1 2 3 4
6.	Education level (ਸਿੱਖਿਆ ਦਾ ਪੱਧਰ)	Illiterate (ਅਨਪੜ੍ਹ) Primary (ਪ੍ਰਾਇਮਰੀ) Secondary (ਸੈਕੰਡਰੀ) High School (ਹਾਈ ਸਕੂਲ) Graduate (ਗ੍ਰੈਜੂਏਟ)	1 2 3 4 5
7.	Occupation (ਕਿੱਤਾ)	Labourer (ਲੇਬਰ) Service (ਸੇਵਾ) Farmer (ਕਿਸਾਨ) Sedentary work (ਸੁਸ ਕੰਮ ਦੀ)	1 2 3 4
8.	How long have you had this disease? (ਕਿੰਨਾ ਚਿਰ ਤੁਹਾਨੂੰ ਇਸ ਦੀ ਬਿਮਾਰੀ ਸੀ, ਕੀਤਾ ਹੈ ?)	_____	
9.	Where did you take the treatment from? (ਤੁਹਾਡੇ ਤੱਕ ਦਾ ਇਲਾਜ ਕਿੱਥੇ ਸੀ ?)	Sub health centre (ਸਬ- ਸਿਹਤ) PHC (ਪ੍ਰਾਇਮਰੀ ਹੈਲਥ) CHC (ਕਮਿਊਨਿਟੀ ਹੈਲਥ) Hospital (ਹਸਪਤਾਲ) NGO Others (Specify)_____ ਹੋਰ (ਨਿਰਧਾਰਿਤ)	1 2 3 4 5 6
10.	Are any of the children suffering from this disease? (ਇਸ ਬਿਮਾਰੀ ਨਾਲ ਪੀੜਤ ਬੱਚੇ ਦੀ ਕਿਸੇ ਵੀ ਹਨ?)	Yes (ਜੀ) No (ਕੋਈ)	1 2
11.	Are any other relatives suffering from this disease? (ਕਿਸੇ ਵੀ ਹੋਰ ਇਸ ਬਿਮਾਰੀ ਨਾਲ ਪੀੜਤ ਦੇ ਰਿਸ਼ਤੇਦਾਰ ਹਨ?)	Yes (ਜੀ) No (ਕੋਈ)	1 2

Knowledge about leprosy among leprosy patients

			Yes	No
1.	What is the cause of leprosy? ਕੋੜ੍ਹ ਦਾ ਕਾਰਨ ਕੀ ਹੈ?	Infectious disease (ਛੂਤ ਦੀ ਬੀਮਾਰੀ) Punishment (ਸਜ਼ਾ) Curse of God (ਪਰਮੇਸ਼ੁਰ ਦੇ ਸਰਾਪ) Hereditary (ਖ਼ਾਨਦਾਨੀ) Don't know (ਪਤਾ ਨਾ) Others (Specify)..... ਹੋਰ (ਨਿਰਧਾਰਿਤ)	1 1 1 1 1 1	2 2 2 2 2 2
2.	What are the symptoms of leprosy? ਕੋੜ੍ਹ ਦੇ ਲੱਛਣ ਕੀ ਹਨ?	Skin patches (ਚਮੜੀ ਪੈਚ) Skin patches with loss of sensation Deformities of hands/feet/face Don't know (ਪਤਾ ਨਾ) Others (Specify)..... ਹੋਰ (ਨਿਰਧਾਰਿਤ)	1 1 1 1 1	2 2 2 2 2
3.	How is leprosy transmitted? ਕੋੜ੍ਹ ਕਰਨਾ ਪ੍ਰਸਾਰਿਤ ਹੁੰਦਾ ਹੈ ?	Direct Contact (ਸਿੱਧਾ ਸੰਪਰਕ) Droplet Blood transfusion (ਖ਼ੂਨ ਚੜ੍ਹਾਉਣ) Sexual transmission (ਸੰਬੰਧੀ ਪ੍ਰਸਾਰਣ) Don't know (ਪਤਾ ਨਾ)	1 1 1 1 1	2 2 2 2 2
4.	Do you know that leprosy is curable? ਤੁਹਾਨੂੰ ਪਤਾ ਹੈ ਕਿ ਜੋ ਕੋੜ੍ਹ ਠੀਕ ਹੈ	Yes (ਜੀ) No (ਕੋਈ)	1 2	
5.	Do you know of leprosy patient(s) being discriminated in school? (ਤੁਹਾਨੂੰ ਕੋੜ੍ਹ ਮਰੀਜ਼ (ਹਵਾਈਅੱਡੇ) ਤੇ ਸਕੂਲ ਵਿਚ ਵਿਤਕਰਾ ਕੀਤਾ ਜਾ ਰਿਹਾ ਹੈ ਦੇ ਜਾਣਦੇ ਹੋ?)	Yes (ਜੀ) No (ਕੋਈ)	1 2	
6.	Were you discriminated against while studying in school? (ਤੁਹਾਨੂੰ , ਜਦਕਿ ਸਕੂਲ ਵਿਚ ਅਧਿਐਨ ਕਰ ਵਿਤਕਰਾ ਸੀ?)	Yes (ਜੀ) No (ਕੋਈ)	1 2	
7.	Do you know any leprosy patient(s) being discriminated against when applying for a job?(ਜੇਕਰ ਤੁਹਾਨੂੰ ਕਿਸੇ ਵੀ ਕੋੜ੍ਹ ਮਰੀਜ਼ (ਹਵਾਈਅੱਡੇ) ਜਦ ਇਕ ਨੌਕਰੀ ਲਈ ਅਰਜ਼ੀ ਦੇ ਨਾਲ ਵਿਤਕਰਾ ਕੀਤਾ ਜਾ ਰਿਹਾ ਹੈ ਨੂੰ ਜਾਣਦੇ ਹੋ?)	Yes (ਜੀ) No (ਕੋਈ)	1 2	

8.	Do you know any leprosy patient(s) being discriminated against while travelling in bus/train? (ਜੇਕਰ ਤੁਹਾਨੂੰ ਕਿਸੇ ਵੀ ਕੋੜ੍ਹ ਮਰੀਜ਼ (ਹਵਾਈਅੱਡੇ) ਜਦਕਿ ਬੱਸ / ਰੇਲ ਗੱਡੀ 'ਚ ਸਫਰ ਕਰ ਵਿਤਕਰਾ ਕੀਤਾ ਜਾ ਰਿਹਾ ਹੈ ਨੂੰ ਜਾਣਦੇ ਹੋ?)	Yes (ਜੀ) No (ਕੋਈ)	1 2	
9.	Do you know any leprosy patient(s) being discriminated against by relatives? (ਜੇਕਰ ਤੁਹਾਨੂੰ ਕਿਸੇ ਵੀ ਕੋੜ੍ਹ ਮਰੀਜ਼ (ਹਵਾਈਅੱਡੇ) ਤੇ ਰਿਸ਼ਤੇਦਾਰ ਨੇ ਵਿਤਕਰਾ ਕੀਤਾ ਜਾ ਰਿਹਾ ਜਾਣਦੇ ਹੋ?)	Yes (ਜੀ) No (ਕੋਈ)	1 2	
10.	Do you know any leprosy patient(s) being discriminated against by society? (ਜੇਕਰ ਤੁਹਾਨੂੰ ਕਿਸੇ ਵੀ ਕੋੜ੍ਹ ਮਰੀਜ਼ (ਹਵਾਈਅੱਡੇ) ਤੇ ਸਮਾਜ ਕੇ ਵਿਤਕਰਾ ਕੀਤਾ ਜਾ ਰਿਹਾ ਜਾਣਦੇ ਹੋ?)	Yes (ਜੀ) No (ਕੋਈ)	1 2	

OVERALL QUALITY OF LIFE AND GENERAL HEALTH

		Very Poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life? ਤੁਹਾਨੂੰ ਜੀਵਨ ਦੇ ਆਪਣੇ ਗੁਣਵੱਤਾ ਨੂੰ ਰੇਟ ਹੋਵੇਗਾ ?	1	2	3	4	5

		Very Dissatisfied	Dissatisfied	Neither Dissatisfied nor satisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health? ਤੁਹਾਡੇ ਨਾਲ ਕਿੰਨੇ ਸੰਤੁਸ਼ਟ ਹੋ ਆਪਣੇ ਸਿਹਤ ਦੀ ?	1	2	3	4	5

PHYSICAL, PSYCHOLOGICAL, SOCIAL AND ENVIRONMENTAL DOMAINS

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do? ਕਿਸ ਹੱਦ ਕਰਨ ਲਈ ਤੁਹਾਨੂੰ ਲੱਗਦਾ ਹੈ ਕਿ ਸਰੀਰਕ ਦਰਦ ਕਰ ਤੁਹਾਨੂੰ ਰੋਕਦੀ ਹੈ ਤੁਹਾਨੂੰ ਕੀ ਕਰਨ ਦੀ ਲੋੜ ਹੈ ਕਿ ਕੀ ਹੈ	1	2	3	4	5
4.	How much do you need any medical treatment to function in your daily life? (ਕਿੰਨਾ ਕੁ ਤੁਹਾਨੂੰ ਕਿਸੇ ਵੀ ਮੈਡੀਕਲ ਦੀ ਲੋੜ ਹੈ ਇਲਾਜ ਆਪਣੇ ਰੋਜ਼ਾਨਾ ਜੀਵਨ ਵਿਚ ਕੰਮ ਕਰਨ ਲਈ ?)	1	2	3	4	5
5.	How much do you enjoy life? (ਤੁਹਾਨੂੰ ਕਿੰਨਾ ਕੁ ਕਰ ਜ਼ਿੰਦਗੀ ਦਾ ਆਨੰਦ ?)	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful? (ਕਿਸ ਹੱਦ ਤੁਹਾਡੇ ਲਈ ਆਪਣੇ ਜੀਵਨ ਮਹਿਸੂਸ ਕਰਦੇ ਹੋ ਕਰਨ ਲਈ ਅਰਥਪੂਰਨ ਹੋ ?)	1	2	3	4	5

		Not at all	Slightly	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate? (ਤੁਹਾਨੂੰ ਚੰਗੀ ਧਿਆਨ ਕਰਨ ਦੇ ਯੋਗ ਹਨ ?)	1	2	3	4	5
8.	How safe do you feel in your daily life ? (ਕਰਨਾ ਸੁਰੱਖਿਅਤ ਤੁਹਾਨੂੰ ਆਪਣੇ ਰੋਜ਼ਾਨਾ ਜੀਵਨ ਵਿੱਚ ਮਹਿਸੂਸ ਕਰਦੇ ਹੋ?)	1	2	3	4	5
9.	How healthy is your physical environment? (ਨੂੰ ਸਿਹਤਮੰਦ ਆਪਣੇ ਸਰੀਰਕ ਵਾਤਾਵਰਣ ਨੂੰ ਹੈ ?)	1	2	3	4	5

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life? (ਤੁਹਾਨੂੰ ਰੋਜ਼ਾਨਾ	1	2	3	4	5

	ਦੀ ਜ਼ਿੰਦਗੀ ਲਈ ਕਾਫ਼ੀ ਊਰਜਾ ਹੈ?)					
11	Are you able to accept your bodily appearance? (ਤੁਹਾਨੂੰ ਆਪਣੇ ਸਰੀਰਕ ਦਿੱਖ ਨੂੰ ਸਵੀਕਾਰ ਕਰਨ ਲਈ ਤਿਆਰ ਹੋ?)	1	2	3	4	5
12	Have you enough money to meet your needs? (ਤੁਹਾਨੂੰ ਆਪਣੇ ਲੋੜ ਨੂੰ ਪੂਰਾ ਕਰਨ ਲਈ ਕਾਫ਼ੀ ਪੈਸੇ ਦੀ ਹੈ?)	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life? (ਕਿਸ ਉਪਲੱਬਧ ਕਰਨ ਲਈ ਤੁਹਾਨੂੰ ਜਾਣਕਾਰੀ ਹੈ, ਜੋ ਕਿ ਤੁਹਾਡੇ ਵਿੱਚ ਲੋੜ ਹੈ ਆਪਣੇ ਦਿਨ–ਪ੍ਰਤੀ –ਦਿਨ ਦੀ ਜ਼ਿੰਦਗੀ ?)	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities? (ਕਿਸ ਹੱਦ ਲਈ ਤੁਹਾਨੂੰ ਮਨੋਰੰਜਨ ਲਈ ਮੌਕਾ ਹੈ?)	1	2	3	4	5

		Very Dissatisfied	Dissatisfied	Neither Dissatisfied nor satisfied	Satisfied	Very satisfied
15	How satisfied are you with your sleep?) ਤੁਹਾਨੂੰ ਆਪਣੇ ਸਲੀਪ ਨਾਲ ਕਿੰਨੇ ਸੰਤੁਸ਼ਟ ਹੋ ?)	1	2	3	4	5
16	How satisfied are you with your ability to perform your daily living activities? (ਤੁਹਾਨੂੰ ਆਪਣੇ ਰੋਜ਼ਾਨਾ ਦੇ ਰਹਿਣ ਦੇ ਕੰਮ ਕਰਨ ਲਈ ਤੁਹਾਡੀ ਯੋਗਤਾ ਨਾਲ ਕਿੰਨੇ ਸੰਤੁਸ਼ਟ ਹੋ ?)	1	2	3	4	5
17	How satisfied are you with your capacity for work? (ਤੁਹਾਨੂੰ ਕੰਮ ਦੇ ਲਈ ਆਪਣੇ ਦੀ ਸਮਰੱਥਾ ਦੇ ਨਾਲ ਕਿੰਨੇ ਸੰਤੁਸ਼ਟ ਹੋ?)	1	2	3	4	5
18	How satisfied are you					

	with yourself? (ਤੁਹਾਨੂੰ ਆਪਣੇ ਆਪ ਨੂੰ ਨਾਲ ਕਿੰਨੇ ਸੰਤੁਸ਼ਟ ਹੋ ?)	1	2	3	4	5
19	How satisfied are you with your personal relationships? ਆਪਣੇ ਨਿੱਜੀ ਰਿਸ਼ਤੇ ਦੇ ਨਾਲ ਤੁਹਾਨੂੰ ਕਿੰਨੇ ਸੰਤੁਸ਼ਟ ਹੋ?	1	2	3	4	5
20	How satisfied are you with the support you get from your friends? ਤੁਹਾਨੂੰ ਸਹਿਯੋਗ ਨੂੰ ਤੁਹਾਨੂੰ ਆਪਣੇ ਦੋਸਤ ਤੱਕ ਪ੍ਰਾਪਤ ਨਾਲ ਕਿੰਨੇ ਸੰਤੁਸ਼ਟ ਹੋ ?	1	2	3	4	5
21	How satisfied are you with the conditions of your living place? ਤੁਹਾਨੂੰ ਆਪਣੇ ਰਹਿਣ ਦੀ ਜਗ੍ਹਾ ਦੇ ਹਾਲਾਤ ਨਾਲ ਕਿੰਨੇ ਸੰਤੁਸ਼ਟ ਹੋ	1	2	3	4	5
22	How satisfied are you with your access to health services? (ਤੁਹਾਨੂੰ ਸਿਹਤ ਸੇਵਾ ਕਰਨ ਲਈ ਆਪਣੇ ਪਹੁੰਚ ਨਾਲ ਕਿੰਨੇ ਸੰਤੁਸ਼ਟ ਹੋ?)	1	2	3	4	5
23	How satisfied are you with your mode of transportation? ਤੁਹਾਨੂੰ ਆਵਾਜਾਈ ਦੇ ਆਪਣੇ ਢੰਗ ਨਾਲ ਨੂੰ ਸੰਤੁਸ਼ਟ ਹਨ	1	2	3	4	5

		Very Poor	Poor	Neither poor nor good	Well	Very Well
24	How well are you able to get around? (ਤੁਹਾਨੂੰ ਕਰਨਾ ਚੰਗੀ ਦੇ ਦੁਆਲੇ ਪ੍ਰਾਪਤ ਕਰਨ ਦੇ ਯੋਗ ਹਨ?)	1	2	3	4	5

		Never	Seldom	Quite often	Very often	Always
25	How often do you have negative feelings, such as blue mood, despair, anxiety, depression? ਨੂੰ ਅਕਸਰ ਤੁਹਾਨੂੰ ਅਜਿਹੇ ਨੀਲੇ ਦੇ ਮੂਡ , ਨਿਰਾਸ਼ਾ , ਚਿੰਤਾ , ਡਿਪਰੈਸ਼ਨ ਦੇ ਤੌਰ ਤੇ ਨਕਾਰਾਤਮਕ ਭਾਵਨਾ ਹੈ?	1	2	3	4	5

Name of interviewer_____ Date:_____

Annexure - VIII

Questionnaire for the health staff at the district hospital

How long have you been involved with the leprosy program?

How effective do you think that the leprosy program is?

What is your perception of leprosy cases from last 20 years in Punjab?

Do you think that leprosy patients have good quality of life? Can this be improved in any way?

Statistics of the current leprosy cases in the SBS Nagar – number of multibacillary and paucibacillary cases, grade 1 disability, had visible or grade 2 deformities, incidence of females and child cases.

At what age did the cases contract the disease? Are any of the cases employed?

Name of interviewer_____ Date:_____