

**REHABILITATION OF THE LEPROSY PATIENTS
IN DINDIGUL DISTRICT, TAMIL NADU
- A SOCIOLOGICAL ANALYSIS.**

Dissertation submitted to
**THE JAWAHARLAL NEHRU UNIVERSITY
NEW DELHI**

in partial fulfilment for the award of the Degree of
MASTER OF PHILOSOPHY

by
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NEW DELHI.**

1993

DEDICATED TO

THOSE LEPROSY PATIENTS
WHO ARE THROWN AWAY FROM THEIR HOMES
AND BEGGING AT THE PUBLIC PLACES



**CENTRE OF SOCIAL MEDICINE & COMMUNITY HEALTH
SCHOOL OF SOCIAL SCIENCES
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New Delhi-110067

CERTIFICATE

This is to certify that the dissertation entitled, "REHABILITATION OF THE LEPROSY PATIENTS IN DINDIGUL DISTRICT, TAMIL NADU - A SOCIOLOGICAL ANALYSIS", submitted by C. KUBENDRAN, is in partial fulfilment of the requirements for the award of the Degree of **Master of Philosophy** of this university. The dissertation has not been submitted for any other degree of this University or any other University, and is his own work.

We recommend that this dissertation be placed before the examiners for evaluation.

**Dr. S.K. SAHU
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&
Chairperson.**

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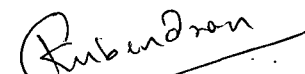
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DECLARATION

I, C. Kubendran, hereby declare that the dissertation titled, "REHABILITATION OF THE LEPROSY PATIENTS IN DINDIGUL DISTRICT, TAMIL NADU - A SOCIOLOGICAL ANALYSIS" submitted by me for the Degree of **Master of Philosophy** in Social Medicine & Community Health is a record of research work done by me during the period between 1992-93, and that the dissertation has not been submitted for any degree in any universities.

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ACKNOWLEDGMENT TO

- Dr. S.K. SAHU : My supervisor & chairperson, CSM & CH/SSS/JNU for his constructive guidance & encouragement in the preparation & my dissertation.
- Dr. PRABHA RAMALINGASAMY : Professor, CSM & CH/SSS/JNU for providing valuable ideas during many discussion I had with her.
- Sri. D.K. OZA : Vice-Chancellor, Gandhigram Rural University for his moral encouragement during my study period.
- Dr. S. GURUSAMY : Lecturer, Dept. of Sociology, G.R. University for having spared so much of his valuable time with me for many discussion.
- Dr. T. SURIYA KUMAR : Deputy Registrar, Gandhigram Rural University.
- Ms. V. SRIDEVI : Counsellor, DMSS, Dindigul who helped me to collect data from the female respondents in 27 villages.
- Mr. V. SELVARAJAN : Ph.D., Scholar in JNU, who helped me in collecting literatures in many institutions.
- The Library Staff of : JNU, DANIDA, VIHAI, NHIFA - Delhi.
DLO - Dindigul.
DMS - Madras.
GRI, IRH - Gandhigram.
M.K.UNIVERSITY - Madurai.
- The Staff of DLCC : for providing necessary documents related to case history of the patients.
- The Authors : From whose book, dissertations, publication I have drawn materials on informations to substantiate my empirical data.
- Dr. M.R. KUBENDRAN : Dept. of English, Gandhigram University who patiently went through my manuscript.
- The Staff of
- EXCELLENT COMPUTER LAND : Who have done an Excellent job in my Dissertation.
and
- All my respondents : who have given the backbone to my dissertation.


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CHAPTER II

INTRODUCTION

CHAPTER I

1.1 INTRODUCTION

1.2 DEFINITION OF LEPROSY & REHABILITATION

1.3 HISTORICAL & CULTURAL PERSPECTIVE OF LEPROSY

1.4 INCIDENCE OF LEPROSY IN INDIA AT VARIOUS LEVEL

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1.0 INTRODUCTION:

The moment we heard the word 'Leprosy' the picture of patients with severe deformities in the hands and feet begging at the public places or seeking alms at places of worship comes to our mind. When we wait at traffic signal we see the aged patient with depressed nose, blind eyes nodules in the earlobes and dirty cloths etc. They are all either thrown away by the society or they themselves rejected the society.¹

(Historical background of Leprosy - see Appendix-I)

According to National Leprosy control programme the programme carried out were such as survey, Treatment and Education, but Health education was neglected both to the patients as well as to the community. This fact and superstitious believes of the disease, and lack of scientific knowledge about the leprosy treatment have created problems to the patients for their habitation.² So the life of the patient was disturbed and he finds it difficult to live in the community as a normal person which leads to begging.

Basically the patient does not need pity. He is not just to be tolerated but he must feel wanted. He like any one else has skills ambitions and above all basic desires to live as a useful citizen with self respect. We must be able to look at the patient as a person and aim at a total care and restoration.

The community may accept the patients if convinced the patient is not public health risk as is a productive member of society and if his physical identity is no improve too much ; so leprosy is a disease not merely a medical problem, it is a bio-social disease in its true sense and it is to be handled on the basis of social dimension . To over-come this public health problem of leprosy. Government and Non Government organisations are taking several steps. Socio-economic rehabilitation may be regarded as hope for final eradication of leprosy. Studies show that patients economically independent are accepted by the society. Once he earns his living his social standing can be rebuilt and once his economic situation improves his own contacts will be re-established. So the philosophy of rehabilitation is to integrate disabled people in the society rather than create a special environment isolated from the remaining members of the society.

1.1 THE CONCEPT OF LEPROSY:

Leprosy is considered as the most dreaded one, largely owing to its socio-cultural dimensions. It knows no barriers, neither demographic or climates, unlike many others it is not a disease of modern civilization or industrialization nor is it the product of westernization. It is a disease which may lead to serious deformities and to pre-mature social death among patients, if not managed at an early stage.

Leprosy to-day can be defined as

"a chronic mildly contagious bacterial disease chiefly of skin nerves causing sensory lobe mainly of hands and followed by serious physical deformities, when not treated and detected early. ... If we see the views of Karl Marx, he says "If one person dies it is a tragedy and if millions die it is reduced to statistics". So, it is found duty of every one to transform this cold statistics of leprosy into a dynamic human issue. Gandhiji wanted science to be brought in leprosy. But he never wanted it to be dehumanized. He, in one of his sayings regarding leprosy, says "Leprosy work is not merely medical relief it is transforming frustration of life into joy of dedication, personal ambition into selfless service. If you can transform the life of a patient or change his values of life, you can change the village and the country.

T.K. Parthasarathy, describes 'leprosy' is not just a medical problem but a socio-economic one as well and had to be tackled on both the fronts.

So, leprosy, in this context is a disease, traditionally deep rooted than any other chronic disease. Because of lack scientific beliefs, people still think that leprosy is a punishment for the sin committed. In the villages, people who are uneducated and ignorant have the practice of scolding the criminals that they will be suffering from leprosy in future. So people think that leprosy is a punishment to the sin committed by an individual and leprosy will affect the individual or his generation.

The word leprosy is mentioned several times in the Bible.
 This word is translation of the Hebrew word ZARAATH.¹⁰

Vagbhata, a thinker of the 6th century A.D, considered that the word 'Kushta' has derived form "KUSHNATI" which in Sanskrit means "eating away"- a reference to limb obsorbtion. Early references of leprosy are noted also from China and Japan. One of the earliest Chinese Medical classics of the disease refer leprosy under the name 'Ma-Feng. The earliest Japanese reference to leprosy are also of the same period. In Japanese, it is called 'Rai'. It is called 'Judham' in Arabi, 'Aussatz' in German, 'Lepre' in French, and 'Prokaza' in Russian, It is believed that leprosy had spread to the other parts of the world from India. It is at present found all over the world in both Tropical and Sub-tropical countries.

1.2 REHABILITATION OF THE PATIENTS:

Rehabilitation is a word which is used by all to sort out any problem in the community or in the medical field or in case of natural calamity. In the recent context however it implies restoration of the cured individual to the physical, psychological, social and economic well-being. The main difficulty here in contrast to other handicapped persons lies in the prejudice that lies either overtly or in hidden manner in the society.¹¹

1.2.1 REHABILITATION:

There are two aspects of rehabilitation.

1) Re-establishing the economic productivity of the patient and

2) Re-assimilation in the society without either of these the rehabilitation is incomplete.

The national council on Rehabilitation, U.S.A has suggested the following definition for Rehabilitation of persons handicapped by cause other than leprosy..LM .5"

" The restoration of the handicapped to the fullest physical, mental, social vocational and economic fullness of which they are curable;

This definition however is incomplete as far as Rehabilitation of handicapped is concerned.

In this respect it is relevant to recall the definition of the WHO expert committee on leprosy in its second report ¹²

" By Rehabilitation is meant the physical, mental restoration as far as possible of all treated patients to normal activity, so that they may be able to resume their place in the home, society and industry. To achieve this, treatment of the physical disability is obviously necessary. But it must be accompanied by the education of the patients, his family and the public. So that not only can he take his normal place, but society will also be willing to accept him and assist in his complete Rehabilitation"...LM .0"

Restoration of the leprosy patients to normal life in his community in a precise definition of Rehabilitation. The Eighth All India leprosy worker conference held at Hyderabad in 1962 passed a resolution on the subject emphasising the increasing need for modern medical and surgical re-treatment of the disease. It goes on to say...

"Rehabilitation should be a attempt to keep in or send back the patient to his own normal environment. Attempts to give work and shelter for patient in a secluded environment, however worthy, results in strengthening prejudice against leprosy"

" The patient should be prepared for Rehabilitation right from the beginning of his treatment by suitable advice physio-therapy, craft training and building up of morale"¹⁴

"Rehabilitation in relation to leprosy patients should be linked up with the general Rehabilitation. Services for physically handicapped and the facilities, that are available through Government to other categories of handicapped, should be made available to those handicapped by leprosy "¹⁵

The United Nation reports mentions

"Although it may not be possible to do a great deal in the way of direct therapy and rehabilitation in countries which do not yet possess an organised hospital and school system, it must be forgotten that it is just as important to prevent or limited disability as it is to important to prevent or limit disability as it is to Rehabilitate and train those who are already disabled. From the view point of a nation total economy and well-being of maximum number of its citizens. Preventive efforts deserve the very highest priority. Campaigns to improve public hygiene and sanitation, to attack infective and injury deserve all possible encouragement and support".¹⁶

This would mean that in leprosy there is an urgent need for psychological, social and economic Rehabilitation. Unless there three basic criteria are fulfilled, no activity can really be called Rehabilitation for this purpose Education of the patients. Family and public and leprosy work is necessary. The social worker and organisation have to play a great role in the rehabilitation programme. Leprosy rehabilitation services have therefore to be planned in an integrated manner with the co-operation and co-ordination of various disciplines.

Paul Brond, the well known reconstruction surgeon has aptly said that in leprosy rehabilitation must an integral part of the programme of preventive and treatment and of final restoration of normal social relations. He has held the view without effective rehabilitation leprosy control programme would be a total failure.¹⁷ There is one more renowned leprologist Dharmendra, who has said that "Rehabilitation work is not a work wholly for the good of the handicapped persons, though they, obviously stand to gain by it. It should looked at in its overall perspective as corrective measures, In the interest of economic structure of the whole society instead of the handicapped persons remaining a load and economic track on the society, they can become any member of the society, and thus contribute to its, economic progress.¹⁸

As the definition, mentioned above, say about rehabilitation it is long drawn - out process requiring the co-ordinated activities of number of discipline the physician, surgeon, physiotherapist occupational-therapist, social worker, craft instructor, Industrialist and the like.

The definition of rehabilitations given by the WHO is criticised by one Author S.D. Gokhale by name, stated that this definition does not fully bringout the need for social assimilation a necessary complement to economic independence further it must be recognized that if the former 'Leper' are settled be as a separate group away from the society and vocations are provided to them there, they can only be considered as 'Vocationally settled' but not as rehabilitated.¹⁹

The criticism levelled against him is also partly correct, but at the same time this definition given by WHO envisages return of the person to his normal social environment after he has been adequately trained, mentally, and vocationally for the role he has to play.

The WHO definition is quite comprehensive one. If we analyse it carefully the basic concept behind rehabilitation can be listed as,

1. Any attempt to isolate the patients or to keep them permanently away from the normal social environment as a measure for rehabilitation is contament for failure of rehabilitation.

2. Rehabilitation means a restoration to economic productivity leading to economic independence such restoration therefore includes preparing him and are training him so as to enable him to be economically independent.

3. Rehabilitation as the WHO, definition assumes is a process of dispersal of leprosy patients away from colonies and asylums. "Rehabilitation Centre of Asylum for Rehabilitation would be a misnomer. This is because and asylum or institutions or a centre however ideally operated cannot be a substitute for normal social environment.

Rehabilitation training centre nevertheless would be quite consistent with the basic concepts. The stay of a patient in a training centre would be obviously limited and short. Such stay would enable him to acquire a new skill and learn a new work. In case he is not able to pursue his previous occupation, such training would help him in finding the nearest feasible alternative.

1.2.2 PRINCIPLES OF REHABILITATION:

As medicine may be defined as the diagnosis, treatment and prevention of disease, rehabilitation may be defined as the diagnosis, treatment and prevention of debilitation". In the context of leprosy, debilitation chiefly affects three areas of life the disease cause a patient to loss his family and place in the society, his work and means livelihood or his self-respect.

There are two aspects in rehabilitation.

1. Preventive rehabilitation is the surgical correction of deformity.

2. Active rehabilitation is concerned with providing work for patients assumes that if a patients become economically independent he can also keep his family and preserve his self-respect.

1.3 HISTORICAL & CULTURAL PERSPECTIVE OF LEPROSY:

From time immemorial leprosy has been associated with past sin divine curse, undesirable habits, immoral behaviour and tabooed sex relations. Leprosy had never been accepted merely as a disease. It has more often been recognized as a condition caused due to the wrath of super natural forces for a sin committed in the previous birth, and as a punishment for the sin, Virtually in every culture, leprosy has evoked vivid images of fear and fascination. Leprosy sufferers were historically cast out of society; in Europe buried alive or even burnt at the stake. Victims of this disease often suffer physical deformities and crippling, and even today are frequently stigmatized or condemned to social ostracism.

In culture strongly affected by Judeo Christian influence the stigma of leprosy spring from original Hebrew scriptures. Many other cultures impose severe measures on leprosy sufferers as those described in the old testament. To quote Saint Mark, in the first chapter of Lui Gospel, which read; And a leper came to him beseeching him, and kneeling, said to him, If you will, you can

make me clean; At this request Jesus stretched out his hand and touched him, and said to him, 'I, will be clean; And immediately he left him, and he was made clean'.²⁰

In the context of Hinduism, Mutakar says, "God is considered the embodiment of all perfection, virtues and bliss, including beauty. The Hindu aspires for moksha".²¹ The release of soul from the cycle of birth and rebirth. The release is possible only when the soul of person merges with the soul of almighty. The merging of souls is facilitated only if human soul acquired the quality of His Soul.

1.3.1 PERCEPTION OF THE COMMUNITY TOWARDS LEPROSY:

Contemporary society and its views are not much different from what they were nearly hundred years ago. Present day society is very much a product of the past. Our believes, values, tradition have not changed much. Prejudice of past have given birth to new ones. The attitude of public is that, once a leper is always a 'lepers' is very much in vogue even a today. People are afraid of this great disease due to alleged mental and social suffering resulting from disease. Since there are theories about transmigration of soul in many societies, People do not fear death,²² as much as suffering, which is considered as punishment. The change of identity of a person resulting from deformity is the root cause of fear. More ever, instead of enjoying bliss and sharing it with fellow men as per spiritual ideals, a leprosy patient is believed to infect others threatening deformity amongst them.

The attitude of the medical profession continuous to be very uniformed or unchanged and apathetic. No wonder the ugly social stigma of leprosy is very much part and parcel of our society also. The out moded laws which governed the social life of 19th century people are still in vogue dissolution of the Muslim marriage Act of 1937. and Hindu Marriage Act of 1955, still prevail over the innocent victims of leprosy, permitting divorce on grounds of incurability of the disease or the virulent nature of the disease.

The leprosy Act of 1898 and the Railway Act of 1890 were based on the assumption that leprosy was incurable. These laws were formulated during a period when we knew little about the true scientific aspect of the disease. The laws which reflected the general attitude of the society to the past still occasionally devoid fate of people in community today. Law is blind and the interpreters of the law often have not understood the need to change it.

The common man associated leprosy with gross deformities. It is true that leprosy affects skins, mucous membrane and destroys the peripheral nervous system leading to the loss of sensation and muscle weakness, many suffered from emotional disturbance, dreams and perpetual fear of abandonment by society. Acute consciousness of their deformities especially their facial deformities, made them to become highly neurotic.

1.3.2 SOCIAL STIGMA AND LEPROSY:

The socio-economic stigma on leprosy tends to vary in intensity in accordance with the type of society, community²⁴. Even within the single community for example, India social stigmatization appears in varying degrees in various parts. The tribal do not know much about leprosy in medical terms and in therefore in some aspect they are less fearful of it.

For the educated, while collared urban society, social stigmatization is more intense and acute. This difference is also visible in town and country.

The degree of stigma also depends on the prevalence of the disease. Those areas where the prevalence is low and patients are to be found in very few homes, Ostracism may also vary according to the impact of the disease.

In some areas, only patients with gross deformities may be ostracised while in other even an early skin patch could lead to ostracization if it becomes known.

Finally, the degree of stigma will depend considerably on the patients occupation. Generally agricultural workers are not²⁵ debilitated as early as white-collared work.

1.3.3 CONSEQUENCES OF SOCIAL STIGMA ON LEPROSY PATIENT:

Because of the ignorance of the people about the fact that majority of the leprosy patients are noninfectious, stigma develops. Even the law givers reveal their ignorance on their point. So, the nature of the disease, slow progress of scientific knowledge, ignorance and / or indifference of the law givers a stigmatised disease. A patient who reconciled to these extremes face economic, social or psychological impact of the debilitation.

After identifying the leprosy patients the society is afraid of the spread of disease, a social distance is created, it affects the patients and his family. Patients are thrown out of homes, even the doctors, leprosy worker do not look upon the patients as a human being desiring friendship and support, patients are beaten up by some irresponsible person on the street. They may not be able to eat in hotels or visit all places freely. They are denied civic facilities like public transport, educational and employment

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facilities. It is difficult to find a suitable marriage partner. Incidence of divorce between couples. There is an incidence where matrimonial alliances between families flounder on the rocks, when the news is broken. That the bridegroom had once leprosy but now has been completely cured and has his possession a medical certificate to the effect.

Many old woman have come out of their family and lead their life as maid servant in housing colonies of Bombay. The rate of migration from rural to urban increases which leads to several social problems. If the patients happened to be head of the family. An entire family becomes, rudderless all of a sudden.

Recently, the high court of Tamil Nadu had to direct the lower court to record the evidence of leprosy patients in their respective courts, the matter arose because one of the magistrate ordered the 'ex-leprosy patients' to go out of the court instead of recording their evidence as witness. The High Court referred to the conduct of the magistrate as responsible"

The agony and anxiety of the handicapped in leprosy are unimaginable, Number of new addition to leprosy colonies every year increase and number of percentage of leprosy beggars among total beggars increases every year.

So medical treatment and surgical correction should ultimately lead to vocational rehabilitation, which would make the person independent and self-reliant, which will help better integration and assimilation of the patient in his / her own social environment.

1.4.4 PERCEPTION OF THE PATIENT TOWARDS LEPROSY:

As soon as a person hears the diagnosis of leprosy; he gets a sudden violent shock. Even though he may have a mild form of the disease, and may be in early stages of the disease, the picture of an advanced case of leprosy with deformities and ulcers comes up in his mind. He considers himself as doomed. Then begins a chain of stressed and strains which leads to a number of psychological complexes, the intensity of fear of being disowned²⁷ and rejected by the family and society is very great indeed. This fear and anxiety sets up chain of psychological reactions.

He loses his confidence, may become depressed, withdrawn, apathetic, avoid meeting people develop an inferiority complex and even may not seek treatment or else he may become aggressive, anti social and hostile.

As a result of this attitude he may seek vengeance on the society, which he comes to consider as responsible for his miserable extense and social dis-location. It is said that these changes in personality traits are intensified by crippling deformities, patient considers himself guilty of some sin if not in the present life in past life. He does not find any other explanation for getting leprosy. He knows that he would generate in body and lose his limbs and nose. He feel certain that he would have to face problems of begging ²⁸. He therefore tries to hide the disease. He accepts fate as it presents itself to him. A person tries in vain to postpone social death by postponing treatment. Once isolated and caged in a colony he accepts his social condition and tries to mix with his disease - brother.

1.4. INCIDENCE OF LEPROSY IN INDIA AT VARIOUS LEVELS:

Leprosy is a burning problem in India and in a number of less developed countries in Asia, Africa and South America. Though WHO estimate is around 12/million. There are 15 million cases in the world, of all the countries, India has 63 % of the registered cases in the world. There are 19,96,310 cases on record and 18,29,990 cases are under treatment. ²⁹ About 3 lakh new cases are identified every year because of population increases and increase of life expectancy. It affects male more than female the ratio is 2 : 1. ³⁰ Almost 20 % of the sufferers use children, slum

dwellers, industrial labours and poor people. One out of every four patients is a child, and one out of every five physically handicapped individual in a child.

According to a survey conducted about five years back one percent of school going children of Bombay Municipal School were leprosy patients and one out of three industrial labour was a leprosy patients. The majority of the patients are those who live in slums and those who move abode bare footed. Bombay is said to be the "global city" of leprosy.³¹

Though the disease is found throughout the country it is not equally distributed in this sub-continent. There is wide variations in the prevalence. According to the prevalence of the disease. The country may be divide into three region.

TABLE 1.4.1 SHOWING THE ENDEMIC AREA OF LEPROSY IN INDIA:

High Endemicity	Moderate Endemicity	Low Endemicity
Tamil Nadu	West Bengal	Assam
Andra Pradesh	Bihar	Rajasthan
Orrissa	Himachalpradesh	Madhyapradesh
	Kerala	Hariyana
	Uttar Pradesh	Punjab

Of the 412 districts, in 76 districts the prevalence rate exceeds 10/1000 population which are considered as per hyper endemic and there are 125 other district of endemicity with prevalence rate between 5 and 10. The population of these 201 districts estimated to be around 435 million³² and they run the risk of infection. Thus, what is in store many times more than what we perceive.

1.4.2 LEPROSY IN TAMIL NADU:

Among all the states of India, Tamil Nadu has the highest prevalence rate.

According to October 1991 there are about 8,50,000 living cases of leprosy, in Tamil Nadu, of which 99,513 cases have been released from the control. After taking away 85,864 cases having inactive disease, there are 6,65,000 cases of the Tamil Nadu, of which 557,000 are under treatment of the 6,65,000 beggars suffering from leprosy.

As we have been in India. The prevalence of disease is not uniform. Tamil Nadu can be divided in to three region according to the prevalence of disease.

TABLE 1.4.2. SHOWS THE ENDEMIC AREA OF LEPROSY IN TAMIL NADU

High Endemicity	Moderate Endemicity	Low Endemicity
South Arcot	Ramanathapuram	Kanyakumari
North Arcot	Thirunelveli	Niligiries
Salem	Katta Pomman	
Madras		
Trichy		
Dindigul		
Thanjavur		

(Leprosy Infra structure facilities see Appendix II)

1.4.3 LEPROSY IN DINDIGUL DISTRICT:

Of all the districts of Southern part of Tamil Nadu, Dindigul District has the highest prevalence rate of leprosy.

(Dindigul District profile see Appendix III) Dindigul was one of the districts chosen by the Government of Tamil Nadu for the survey of leprosy to implement MDT. MDT was implemented in this districts in 1987. The total cases recorded as on 31.12.92 is about 2,744, and cases under treatment are 2,550. ³³ Dindigul districts may be divided in to prevalence of leprosy as we did at National level & state level.

TABLE 1.4.3. SHOWS THE ENDEMIC AREA OF LEPROSY IN DINDIGUL DISTRICT.

High Endemicity	Moderate Endemicity	Low Endemicity
Natham	Dindigul	Kodaikkanal
Nilakkottai	Vedasandur	Palani

1.5 ACTIVITIES UNDERTAKEN



1.5.1 INDIVIDUALS ON LEPROSY:

Before the Government and voluntary organisation under took various programmes for the control and eradication of leprosy- many individuals worked for it and devoted half their life for leprosy.

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There are many luminaries of last century for lighting the darkness in the dark age.

i) Dr. Armaur Hansen, who discovered a specific germ my co bacterioum which causes leprosy in Norway in 1873. Whose name is prefixed to the name of the disease (Hansen disease)

ii) Father Damien, who went to care for the ostracised people of the South pacific island of Molokai. In whose name many voluntary organisation are functioning ever now father Damien has set a shining example to us for self dedication and service to leprosy patients.

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iii) Wellesley Bailey a school master, out of compassion, and love for the victims of leprosy started to the lepers now known as the ³⁵ leprosy mission.

iv) Mahatma Gandhiji took special interest in leprosy through his life. He spoke about it right from his days in South Africa. In fact the entire anti leprosy work in the voluntary ³⁶ field owes its origin to Gandhiji's inspiration. All his life Gandhiji moved and mixed with leprosy patients fearlessly. While in Sevagram, Wardha, he allowed parchure Shastri, a leprosy patient to stay in his ashram. He included the leprosy victims among his chosen four brothers. To the inmates of a leprosy home he wrote; "I would like you not to feel sorry over your disease. I am ³⁷ sure that a diseased mind is worse than a diseased body" . Gandhiji's Constructive Programme included leprosy work.

Under Gandhiji's inspiration, his followers undertook the work as a labour of 'love', Manohar Dewan, Dr. Pat Wardha, Baba Aurte set up various institutions at Daltapar near Amaravathy, Varana, near Chandra pur, Maharogi Seva, Mandal, came into existence in 1940. The first effort to co-ordinate the activities of ³⁸ voluntary agencies was made by organisation first . The All India-leprosy worker's conference in 1947 which was addressed by Vinobaji received the blessing of Gandhiji.

1.5.2 THE ROLE OF N.G.O'S IN LEPROSY CONTROL :

The voluntary organisation have a special rote to play in the leprosy field. Organised leprosy work in India was being done by voluntary institutions for about 100 years before the Government stepped in a real big way. They have the advantage of a band of committed worker, a smaller and compact area to cover, facilities of constant and closer supervision and the flexibility in their approach where modifications or correction can be quickly introduced.

None will be of two views about definite place for the voluntary activity in any field of work, be it leprosy or social welfare. Some of the characteristics of the leprosy work are:

i) The beginning of voluntary efforts towards leprosy control is traceable to early 19th century, in Calcutta & Varanasi.

ii) Mission to lepers started in 1875 at Chamba in Himachala Pradesh had been by far the biggest single agency engaged in leprosy relief.

iii) The Belgian leprosy centre at Palavakkam, Madras.

iv) Ac worth-leprosy Hospital-Bombay was established as early as in 1890.

v) Mayzrbhani leprosy home, Baripada. Orissa in 1903.

vi) Saldoha leprosy Home & Hospital.v.s.kustha, Nivaran Sathi. Audhaura Rohtas in 1922.

vii) Shantipur leprosy Hospital, Rajpur 1922.

viii) In 1925 came the Indian Council of British empire Leprosy Relief Association that was later renamed Hind Kust Nivaran Sangh in 1947.

ix) Gandhi Memorial Leprosy Foundation Sevagram was created out of the Gandhi Memorial Trust in 1951.

After 1951, there occurred an extensive expansion of voluntary services for leprosy control all over the country. Presently 287 Voluntary agencies are functioning in the country as reflected in their reports to the Directorate General of Health Services.⁴⁰

International Agencies have also contributed significantly to the growth of public co-operation for disease control in India. Notable amongst them are:

i) Leprosy Mission which from a small nucleus in 1894 in Ambala has grown extensively over the years.

ii) The Leprosy Relief Association started at Chettipatti, Leprosy Relief Rural Centre in Tamil Nadu in 1957.

iii) The Swedish International Development Agencies (SIDA).

iv) Besides these, the major organisations supporting the Programmes are:

1) DANIDA

2) American Leprosy Mission

3) LEDRA Amecid: Roaul Fellereau (Italy)

4) DAMIEN Foundation and the German Leprosy Relief Association (GLRA)

Non-Governmental agencies engaged in leprosy have a common platform for sharing mutual experiences and mobilizing public participation. The National Leprosy Organisation (NLO), in India was established in 1965.

1.5.3 THE ROLE OF GOVERNMENT IN LEPROSY CONTROL:

By following the foot step of Gandhiji and other NGOs, the Govt. of India launched a National Leprosy control programme in 1955. But it began to receive high priority only after 1980.⁴¹ The control programme was redesignated as National Leprosy Eradication in 1983. It is being implemented by all the 32 participating States and Union Territories (UTs).

This programme was included in the 20 point programme of the Prime Minister with hundred percent assistance to the states/UTs since 1983 with the objectives of early detection and regular treatment and Multi Drug treatment. MDT to all the patients in a phased manner and education of leprosy patients, their families and communities and last, rehabilitation of cured patients with a view to make them economically self-reliant and socially acceptable.⁴²

An extensive infra-structure has been developed every year. Leprosy control unit and Urban leprosy centre of reconstructive surgery units have also been established. Special leprosy Eradication commission is responsible for policy making, and supervising the programme under the chairmanship of Union Health Minister. The Commission is assisted by the National leprosy Eradication Board which is looking after its planning and implementation.

Implementing MDT and Supervising the Training centres are the main components of NLEP. There are 3 research institutes in India and for health education, there is a central health education Bureau, which develops suitable health education materials.

i) ACHIEVEMENT OF NATIONAL LEPROSY ERADICATION PROGRAMME (NLEP)

At the end of September 1989, 3.34 million leprosy cases were on record and 3.06 million have been brought under treatment. 2.4 million cases had been discharged as cured/ migrated/ dead, since the inception of the programme. In 15 districts the prevalence of leprosy have been brought down to less than 5 per thousand population as a result of MDT. The relapse after MDT have been negligible. All the districts of the country are proposed to be brought under multidrug therapy by the year 1995.⁴³

ii) PROBLEMS FACED BY NLEP:

Though the programme has been in operation since 1955 still the main goal of the programme has not yet been achieved because of problems like

1. Inadequate priorities by the state resulting in a slow creation of infrastructure and operation of the programme.

2. Several sanctioned posts were vacant in some states.

3. 10-30 percent of the staff are working without training in some states.

4. Most of the state have yet to repeal the outdated lepers Act 1898.⁴⁴

1.5.4 LEPROSY CONTROL IN TAMIL NADU:

Leprosy work in Tamil Nadu before independence was carried out mainly by voluntary organisations in places like Pallampakkam, Thirumeni. The State Government created a state leprosy survey unit with one Health officer one Health Inspector, one Health Visitor. The Head Quarter of the unit was at Vellore. One district unit was created at Thirukovilur. These units collected particulars on the prevalence of the disease.⁴⁵

During the First Five year plan one leprosy treatment and survey unit was started as a pilot scheme for field study in South Arcot. During the later phase of First plan and second plan 13 Leprosy subsidiary centres were started. It gave training to 80 Leprosy Inspectors. In the Third plan 8 control unit were established, each with 11 leprosy Inspectors. 6 of the subsidiary centres were upgraded as control unit, 78 SET centres were established.

In the Fourth plan, the number of paramedical worker was increased to 15, each paramedical was in charge of a sub-centre and covered a population of 20-25,000.

During the Fifth plan 27 control units were added, each sub-centre of the control units had been divided into epidemiological survey areas and non-epidemiological survey areas.

A general population survey is conducted once in 3-4 years.

Urban leprosy centre were established with one leprosy Inspector to cover an area 80,000 population. In order to supervise the larger number of units created and also to intensity the health education Programme parts of DLO and health education were created, 13 DLO were sanctioned.

Subsequently every five year the infrastructure facilities of the programme and population covered has also increased. In 1987 MDT was introduced. With help of MDT the number of cases cured every year has increased.

According to October 1991 report the known cases are 1,60,778. (MB. 51,916 and PB. 1,08,862).pa

1.5.5 LEPROSY WORK AT DISTRICT LEVEL:

Dindigul is one of the five districts, chosen by the Govt. of Tamil Nadu for the survey of leprosy affected persons as the first phase of eradication of leprosy by 2000 A.D.

According to the above proposal MDT programme has been implemented in this district from 1.9.87 with the initiation of screening work.

i) Preparatory phase:

Before implementing MDT as a part of strengthening and standardising the infra-structure two more urban leprosy centres have been created at Kodaikkanal hills to cover the uncovered tribal population.

ii) Intensive Therapy:

This intensive therapy, after screening has been started on 11.12.87 in all the 6 units (both Govt & Voluntary) simultaneously in the first circuits. The intensive therapy in first circuit came to an end on 24.12.87.

The I.T. has been continued in other circuits successively. The I.T. of last circuit to an end in 88. During I.T. 351 M.B. cases have been treated among the 3791 MB cases fit for MDT.

iii) Puls Therapy:

It has been started on the 14th day of IT in each circuits and continued till now according to the guidelines issued by the Directorate General of Health Services (Leprosy Division) New Delhi.

iv) Tribal Coverage:

The so far unsurveyed population of Kodaikkanal Hills have been surveyed by dapping nearly sub-centres, leprosy Inspector in addition to the newly created V.L.C Kodaikkanal I.T.

Population enumerated	20758
Population examined	13534

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Immediately after the survey and screening, I.T has been started in Kodaikkanal in 1988. Pulse treatment has been started on the 14th day as per guidelines.

At present this District is having 3 leprosy control centres
4 Urban leprosy centre, 3 voluntary organisations to cover the
entire population of the District.

1.6 REHABILITATION PROGRAMMES:

Rehabilitation is an important aspect to eradicate leprosy. It is not enough to declare that the patient is bacteriologically negative. i.e. he is no longer infectious and that he may return to his family and to his work. When he is discharged from the hospital, he will have to face the loneliness of an outcast and the poverty of the beggar. His family may not take him. Many leprosy patients are forced to begging because he is not a useful member to his family or productive member and the community rejects the patients even after his complete cure.

In brief, he should be prepared for entry into the world again by training him in some crafts or trades so that he can become useful member of his family. Restoration to normal social life/ environment will depend upon several factors. Such as

Region in India

Socio-Cultural or economic background of the patients

Prevalence of leprosy in an area

Types of society (Tribal, Rural, Urban)

Class of society (Upper, Middle, Lower, educated etc)

But studies prove that, if the patient is economically independent he may avoid the danger of displacement both from his home and from the society. To save a leprosy patient from social death, which ultimately will help to eliminate the stigma, economic rehabilitation will pave the way for complete rehabilitation. So long as the patient is not accepted into the social stream of life as a normal individual, it can not be said that the patient is rehabilitated although he can work and earn in a secluded environment..PA

1.6.1 ROLE OF UNO IN LEPROSY REHABILITATION:

The UNO has helped for the control of leprosy, by establishing UNDP. The UNDP has approved a project for treatment and prevention of leprosy in India.

While the executing agency will be the world Health Organisation (WHO) the Government implementing agency will be the department of Science and Technology through the Bose Institute at Calcutta.

Technical skill and expertise generated by this programme will also showed by other developing countries, Ultimately the information gathered will be shared and transmitted to concerned authorities like the department of Health, Government of India WHO and UNDP.

The project acts as complementary to other research programme of UNDP, World Bank, and WHO in their special programme for re-
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search and training in tropical disease.

1.6.2 ROLE OF GOVERNMENT IN REHABILITATION:

It is unfortunate that the National leprosy Eradication programme (NLEP) of the Government of India did not consider rehabilitation as a part of the programme in the initial stages. Only after 25 years it was realised that if we are to control the disease, rehabilitation will have to form an important aspect of the total strategy. The Government of India constituted a committee to prepare a detailed scheme for setting up rehabilitation training centre for the cured symptoms free leprosy patients. In its report submitted to the ministry of Health and Family welfare, Government of India in 1982 had made the following Recommendation.

"Vocational training cum shelter work centre available for physically handicapped should also open their door to leprosy patients. In addition big leprosy homes, hospitals or colonies should have their own unit for vocational training and production. The leprosy rehabilitation promotion unit and research institutes can act as a nodal point for establishment of such vocational training and production centres by the social welfare or labour department or by a voluntary organisation to supplement the effort of rehabilitation at this medico surgical"

Government of India in its National strategy for elimination of leprosy did not give such importance to rehabilitation. Only during 1982 the strategy included disability and ulcer care services; in fact it has become essential components of quality care services. The Swaminathan committee (1982) firmly recommended that rehabilitation should become an integrated part of leprosy control programme. It felt that rehabilitation facilities be organised or created for all categories of the handicapped, including cures and non effective patients. They also recommended a joint action plan to be undertaken by the Ministry of health and social welfare, education, labour, and employment and others besides the ministry of health, acting as a nodal ministry. It was recognised that no rehabilitation programme could be successful unless public health and nutritional aspects were also addressed. This is particularly so fact that 'free' colonies and Jhuggi "Jhonpri" clusters which where often enough located near traditional leprosy homes and hospitals. The committee recommended that there there were suitable locations for the establishment of vocational training centre. ⁵⁰ It is difficult to accept the view that rehabilitation measures should wait until the patient has developed severe deformities and is unable to retain his job. So prevention developed severe deformities and is unable to retain his job. So prevention of dehabitation should be an important goal at the commencement of chemotherophy itself.

Prevention and control of leprosy has been receiving priority under NLEP, but socio-economic aspects have been receiving the similar attention by the voluntary organisation involved in lepro-

sy control activities. Greater and closer co-operation between voluntary organisation and NLEP is being aimed in the area of vocational and social rehabilitation of medical and social rehabilitation surgery units. The latest addition to their activities is the sanction of leprosy rehabilitation promotion units in highly endemic areas. It is planned to involve the Ministry of social Welfare for providing massive support in providing vocational training facilities for cured leprosy patients through voluntary organisations.

1.6.3 REHABILITATION PROGRAMME IN TAMIL NADU:

Every state wherever leprosy rate is high, has established leprosy homes for to take care of and to avoid the increasing trend of leprosy beggars in their state.

The Govt of Tamil Nadu has started 10 such homes at various districts like Chengalpet, south Arcot, Madurai. ⁵¹

These homes are mainly for beggars suffering from leprosy. They are admitted in the homes either voluntarily or by court order. It is said that a total number of 3425 inmates were being looked after by the ten homes put together, each home has a provision to admit about 40 inmates.

1.6.4 THE ROLE OF NGOs ON REHABILITATION - IN INDIA:

Knowing the importance of socio-economic rehabilitation many voluntarily organisation/ non Governmental organisation came forward to take certain rehabilitation programmes like Domiciliary, Tailoring, agricultural, carpentry and so on.

Today we have several such institutions of repute in the country, giving all round services, medical and social. To those suffering from leprosy like Mother Teresa, Baba Amte, Late Dr. Shivaji Rao Patwardhan. The work of Schiefelin leprosy research and training centre at Karigiri.

The services in the field of leprosy rehabilitation provided by the charitable trust entitled "Puna District leprosy committee" and Dr. Bandorawala leprosy hospital have all been recognised nationally and internationally.

The rehabilitation model called "Mehtha co-operative rehabilitation model", is co-operative movement in which cured leprosy patients have become members has shown one important methodology of rehabilitation applicable to industrialised areas. In this model, handicapped person not suffering from leprosy and able-bodied but socio-economically depressed individuals are also included in order to break the leprosy stigma.

The German leprosy relief association joined India's fight against leprosy in 1975 by starting Cheltipatti leprosy relief centres in Tamilnadu.

1.6.5 NGO's ON REHABILITATION ACTIVITIES AT NATIONAL LEVEL:

Though Government of India is doing a lot to control leprosy at National level, NGOs are doing commendable work in rehabilitation. Some selected NGOs are ...

i) Kusht Nivaran Sangh India Leprosy Association:

It is being the premier voluntary organisation in India, and having branches in almost all the states and territories is striving hard to supplement the efforts of the government.

ii) The Gandhi Kusht Ashram-Agra:

It was started in 1969 for beggars who migrated to Agra from various parts of India and begging on the banks of Yamuna river. It began with 25 families for which loans have been sanctioned for goetery unit in the Ashram with the help of bank. there are 150 goats at present. It is a kind of domiliary rehabilitation.

iii) The Vidarbha Maharogi Seva Mandal Mopavan (Maharashtra):

The mandal has a huge rehabilitation center in which leprosy programme are given training in carpentry, poultry, painting, handloom and power looms, weaving carpet making, iron smithy ect.

iv) The Maharogi Seva Mandal Tapovan(near Wardha)

There are over 2000 leprosy programme under its institutional care, some trades in which the programme are trainee are Tincan project, carpentry, printing, iron smithy water management training in electronics work, tailoring, spinning and weaving, leather craft (chappal shoes)

It has land of 300 acres where intensive modern is being done. This centre also maintains a dairy farms, poultry and goat and sheep rearing.

1.6.6 SOME SELECTED NGOs WORKING FOR REHABILITATION IN TAMILNADU

Compared to Govt of Tamilnadu, NGO's are doing better work for the rehabilitation of leprosy programme in Tamilnadu by offering various types of assistance, some of such organisation are:

i) The WORTH TRUST, Katpadi:

Now being a self supporting enterprise, provides employment for nearly 450 handicapped people, of which nearly 100 persons are engaged in poultry, light engineering, fabrication, production of wind mill pumps, tractor, tailoring, agriculture, dairy farming.

ii) The Salvation Army Cathrine Booth Hospital, Training centre for the physically handicapped, Aramboly, Tamilnadu.

This centre caters for 50 trainees at a time the training food accomodation are provided free for the trainees who stay for 2 to 3 years and develop knowledge and skill according to their aptitude and ability. The training such as high engineering, spray painting, electric gas welding, poultry rearing are also done in a small way are ex-leprosy patients or physically handicapped people.

iii) The Schi Leprosy Research and Training Centre, Karigiri near Katpadi Tamilnadu

Besides imparting training in several trades, it is experimenting on domiciliary rehabilitation of leprosy programme.

iv) German Leprosy Relief Association Rehabilitation Fund:

It has been working for the community based rehabilitation for the past 20 years. The basic principle of it is to encourage domiciliary rehabilitation programme without disturbing their natural environment. Training and placement to those who are young, educated and handicapped were referred for training to different training centres, shelter workshop has light engineering and plastic container making unit for the boys and tailoring unit for the girls. (List of NGOs working for the Rehabilitation program in Tamilnadu - See Appendix II)

1.7 REVIEW OF LITERATURE:

Dutt Chowdry(1965) observed a deformity rate of 43.5 percent in lepromatous and 19.7 percent in non-lepromatous causes. Noordeen etanel(1966) in a total population of 2,00,000 in 300 villages analysed male programme above 15 years of age, physically disability was found least in skilled light occupations and in agricultural work. Disability and worsening of economic status went together. Srinivasan et al(1966) observes that 19.7 percent, of deformities were(claw hands) absorption was present in 0.9 percent. Blindness was in 1.3 percent. 57.8 percent of labramatous case had hand deformities, deformities were more common in skilled heavy workers and weavers.

Noordeen at al (1969) in a study at Sriperumbudhur taluk of Chengalpet district observed a deformity rate of 19.4 percent. The deformity rate increased as the age increased. The mean duration

of leprosy for the deformed was 8.1 years and for the non deformed were 5.4 years. Male had a rate of 11.0 percent. Hand deformities were more common than foot deformities. Deformities involving multiple limbs were common than those living one limb alone.

Hassan (1977) In a study of 1,000 patients in Hyderabad city worked out deformity rate of 44.3 percent. This high rate may be because of selective migration of patients with deformities from rural areas. 66.4 percent lapromatous cases had deformities 29 percent of hands, 30.7 percent of feet and 5.2 percent of faces had deformities.

Sehgal and Sharma (1985) observed that the frequent occurrence of disabilities in illiterates and manual labourers. ⁵³

There were few attempts made on the empirical substantiation of socio-economic rehabilitation of patients. However there are few attempts made by some scholars like Pamle, Divwedi, Ramu, Christiane in different aspects which may not provide the sound basis for comparison. The problems of leprosy patients and institute engaged is Karat et al (1967) have similarly reported that agriculture work is quite safe for patients with anesthetic hands provided simple protective devices are provided to the patients and they are well-instructed in their use. ⁵⁴

Selvapandian et. al (1972) had conducted a study on attitude of people towards leprosy urban and Rural areas. A comparative study as apart of suggestion regarding suitable jobs which leprosy patients could not do any work, 12 urban and 16 rural subject had said that they did not know of suitable jobs and other had men-

tioned some jobs like peon, teacher, poultry keeping this was (study) carried out in the insected groups of urban respondents and 50 rural respondents. ⁵⁵

Thamas(1985) has conducted a study amongst 7,000 leprosy patients in the service area of Karigiri and reported 600 need surgical help, 600 need eye care and 600 need social help. ⁵⁶

R. Ganapathy et. al 1982 had conducted a study an domiciliary rehabilitation of leprosy patients in Bombay Slum community. This study showed that out of 82 leprosy patients 62 (75 %) patients continued their work like vegetable selling, tailoring etc., and 56 (66 %) patients were returning loan in installments regularly. Only 16 (20 %) did not return the loan. This study carried out over a period of about two years showed that domiciliary rehabilitation of leprosy is quite feasible in urban area an well accepted by the community.

Srinivasan (1983) noticed that rehabilitation is being practiced mostly in sheltered workshops and leprosy home in different corners in contrast experience with "Individuals" or Domiciliary rehabilitation in urban communities. ⁵⁷

Naik .et. al 1989-90 conducted a study on the problems and the needs of women leprosy patients in Bombay and Goa, the general pattern regarding assistance from out side agencies, the women in the younger age group needed financial assistance and guidance to initiate small business of their own, 29 % of them had requested that the need financial assistance to start some small scale

business like selling vegetables, pickles, fish, and starting
58 tailoring work.

1.8 PREMISES OF THE PRESENT STUDY:

Rehabilitation in leprosy should be comprehensive encompassing physical and socio-economic aspects. In the absence of social acceptance what ever is done for the patients towards his rehabilitation can only remain partial. Though the Government and NGOs working for complete rehabilitation of leprosy patients where endemicity is high and prevalence rate of leprosy is high and number of leprosy cured persons with deformity are high. Studies on the successful and failure aspects of rehabilitation of leprosy patients are scanty. This has necessiated the investigator to full up the gap in the form of undertaking the present study and investigate socio-economic rehabilitation in a systematic manner. In this regard it is well known that the NGOs are doing better job when compared to Government organisation, with a view to expose the good works done by NGOs and thereby high light the problems which they faced in process of rehabilitation as well as to bring it to the notice of Government organisation involved in Rehabilitation.

Present study was carried out in one of the blocks of Dindigul district where the high endemic was reported and more rehabilitation work is done.

The research work will be helpful in designing future strategies and planning appropriate programme for the total and comprehensive integration of rehabilitation of leprosy patients.

Chapterisation

This dissertation has been organised in terms of Five chapters for the purpose of presenting the whole research process in a easy understandable manner.

The first chapter presents the Introduction part covering the aspects such as concepts off leprosy & rehabilitation Cultural perspective, incidence of leprosy, acticties under taken by various agencies, Review of literatore and the present study

The second chapter deals with the research design covering conceptualisation of the problme, study area, selection of the respondents data collection, data analysis 2 limitations of the study.

The third chapter bringsout the data presentation, covering socio-economic, demographic particulars of the patients, treatment process and problem faced, knowladge of the patients about the disease, and opinion about various type of rehabilitation, case studies.

The fourth chapter presents the discussion and analysis of the empirical data.

The last chapter listsout the major findings, conclusion and suggestion to improve the present rehabilitation programme.

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CHAPTER III

RESEARCH DESIGN

CHAPTER II

2.0 RESEARCH DESIGN

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2.0 RESEARCH DESIGN

2.1 CONCEPTUALISATION OF THE PROBLEM

There has been research gap identified through reviewing literature on the leprosy cured patients which needs fulfillment in the form of an empirical investigation on the topic. The researcher has analysed the adequacy and inadequacy of the rehabilitation program undertaken through NGO giving emphasis on the consideration of leprosy rehabilitation programme in high, moderate and low endemic area.

Tamilnadu is being one of the high endemic area in the incidence of leprosy. The work of NGO in the field of rehabilitation is very much in progress. The investigator has chosen Dindigul District of Tamilnadu, where NGO is working for the rehabilitation of leprosy cured patients for this study and to carry out the field investigation.

In addition he has also discussed the problem with the leprosy cured patients and officials and the staff involved in rehabilitation programs in the study area and accordingly the problem was formulated for the study to fulfill the research gap.

2.2 OBJECTIVES OF THE STUDY

For the purpose of the present study the following objectives were formulated.

The first objective is to study the socio-economic condition of leprosy cured patients in the study area.

The second objective is to study the knowledge of the patients about the disease leprosy.

The third objective is to make a comprehensive analysis on the socio-economic rehabilitative measures carried out by N.G.O selected.

The fourth objective is to highlight various problems faced by the leprosy cured patients in the study area.

The fifth objective is to offer suggestion to strengthen the programs of rehabilitation.

2.3 SCOPE OF THE STUDY:-

The scope of the study specifically to focus on leprosy cured patients who are subjected to socio-economic rehabilitation through NGO selected in the study area.

2.4 OPERATIONALISATION OF THE TOPIC:-

1. LEPROSY:- -----

Leprosy is a disease caused by Microbacterium (a germ) in which the skin becomes rough and thick with small round hard, whitish, pieces, the flesh, and nerves are slowly destroyed and fingers, toes etc., drop-off.

After the patient was treated systematically and completely cured of leprosy, the problem of leprosy patient doesnot end when he goes back to home even his own near and dear refuse to accept him in the family in any spontaneous manner. Often deprived of their hearth and homes, and having no proper means to sustain their livelihood, many of the patients ultimately take to begging. It is therefore, necessary the rehabilitation in leprosy should be comprehensive encompassing physical and social aspects which makes better understanding and a human relational attitude towards the leprosy patients so that their social ostracism ends and they become a useful partner of the society.

(ii) REHABILITATION :-

To put back the disabled person into good condition. Rehabilitation is the process of making the leprosy cured patients able to live an ordinary life again by offering measures in the direction of socio-economic rehabilitation.

(iii) N.G.O:-

N.G.O is a non-government organisation and not profit making and it is a service agency to supplement the work of the government organisation by raising resources from own resources and from national and international level, organisation for undertaking rehabilitative activities.

2.5 PILOT STUDY:-

The problems of leprosy patient is not a new aspect, and problem of rehabilitation is existing in almost all organisation working for the rehabilitation of leprosy cured patients. The number of leprosy beggar increases every year in India, and migration from rural to urban takes place continuously among leprosy patients which leads to increasing number of leprosy colony in urban areas and responsible for various anti-social activities.

A preliminary study was carried out to get an early idea about various aspects of study area with the permission of the authority of the agency personnel. The investigator gathered information on the problems of leprosy cured person in the study area. Taking into account the various NGO organisation working for rehabilitation. A detailed list was prepared from the NGO working in Dindigul District for leprosy rehabilitation.

There were three NGOs

1. Christian Fellowship Leprosy Hospital, Ambilikai.
2. Poorna Sugam St. Joseph Hospital Dindigul.
3. Damien leprosy control centre, Nilakkottai

No other governmental agency was available for rehabilitation of leprosy cured patients. Of the three NGOs Damien Leprosy Control Center, Nilakkottai was found to be suitable NGO working for rehabilitation, since the organisation had a long history of experience in this as well as various types of rehabilitation programs were available to the leprosy and disabled patients for rehabilitation.

2.6 THE STUDY AREA:-

The area of the present study is Nilakkottai Taluk of Dindigul District of Tamilnadu in India. It is well known fact that India has the highest prevalence rate in the world. Of all the states in India, Tamilnadu is the high endemic state, of all the District in Tamilnadu Dindigul is one among the high endemic areas. Within Dindigul District, Nilakkottai is one of the 6 blocks where an NGO is working for rehabilitation of leprosy cured patients and having rich experience in that field in Dindigul District. Of the 8 Sub-centres, concentration of leprosy and cured patients who have got benefited are more in the two sub-centres namely Nilakkottai, Ammayanayakkanoor keeping all these in view 2 sub-centres were selected for the purpose of sociological analysis of Rehabilitation programme.

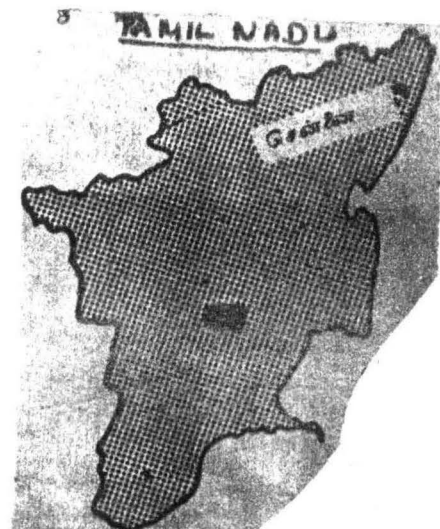
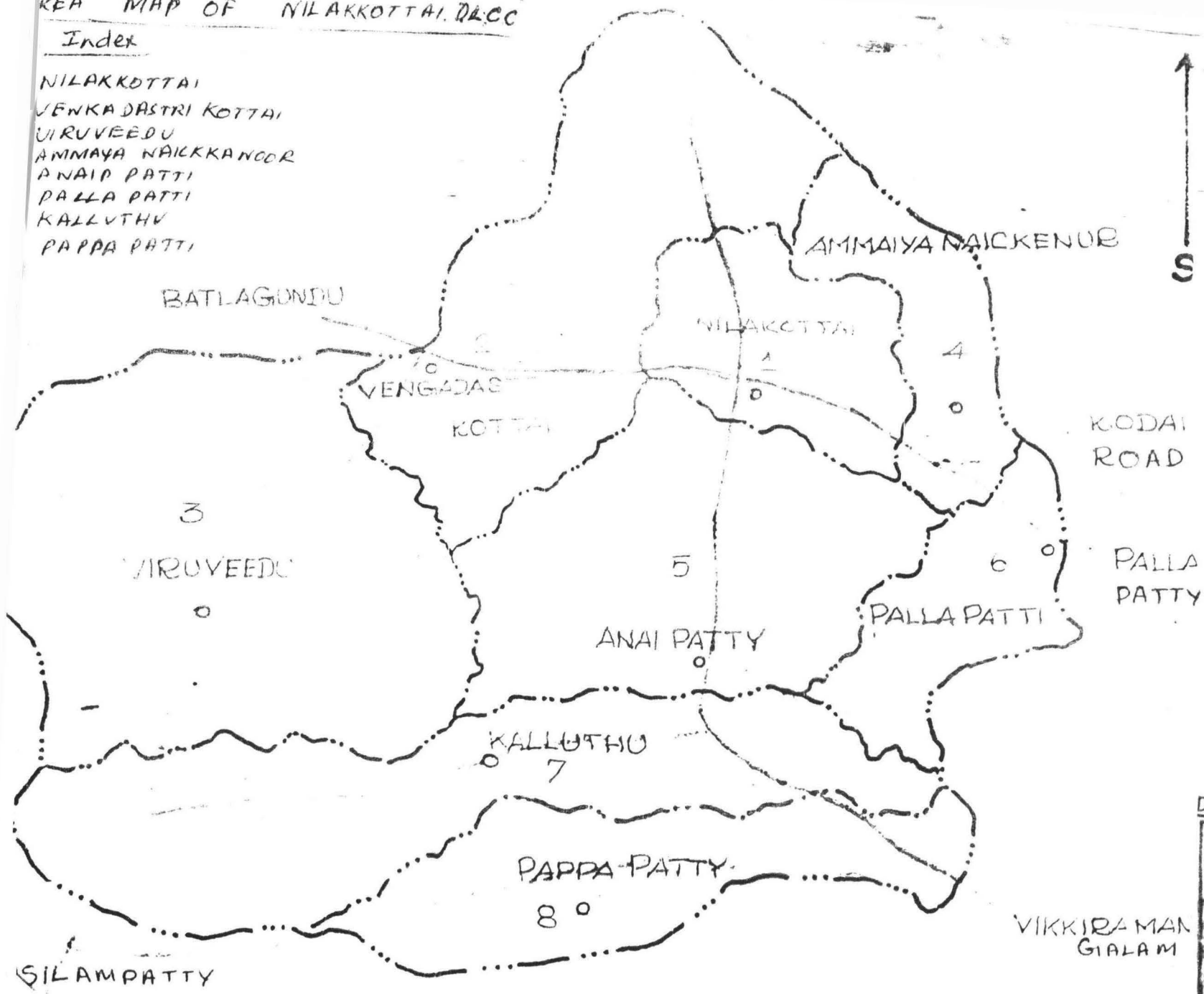
2.7 THE STUDY UNIT: DAMIEN LEPROSY CONTROL CENTRE(DLCC),NILAKKOTTAI:

Before the establishment of leprosy organisation Government and NGO, individuals were playing very important role in leprosy work. Father Damien was one such individual. In whose name a number of NGO's came into being in all over India. Damien Leprosy Control Centre, Nilakkottai is one such NGO working for leprosy control and rehabilitation of leprosy cured patients in Dindigul District. This centre has rich experiences as for as rehabilitation in concern, compared to the other two organisation working in the same District. (The actives of DLCC, see Appendix-No-v)

REA MAP OF NILAKKOTTAI Q&CC

Index

- NILAKKOTTAI
- JENKADASTRI KOTTAI
- VIRUVEEDU
- AMMAIYA NAICKANUR
- ANAI PATTI
- PALLA PATTI
- KALLUTHU
- PAPPA PATTI



DINDIGUL DISTRICT



KODAI ROAD

PALLA PATTI

VIKKIRAMAN GIYALAM

Care was taken in framing questions to seek relevant data on each on each aspects covered in the interview schedule to fulfill the objectives.

2.10 PRE - TEST:

To find out the applicability and validity of the schedule the research had tested it and interviewed a group of leprosy cured patients in the study area. The investigator has modified and deleted and added to ensure the reliability and validity of the schedule.

2.11 DATA COLLECTION:

Interview Schedule was cyclostiled in English and the investigation put the question by translating into the regional language that is in Tamil. The respondents were met with the assistance of staff working in the organisation selected and local leaders in each village.

In addition to the personnel interview schedule, observation and informal discussion on various aspects relating to the socio-economic conditions of the patients were also made.

2.12 SOURCE OF DATA:

i) Primary data: -----

It is collected from the field from the respondents by using constructed and pretested personnel interview schedule.

ii) Secondary data: -----

The investigation collected secondary data from the published sources like books, documents and government reports other unpublished documents like thesis etc., to substantiate the primary data.

2.13 VERIFICATION OF THE DATA:

Having collected the empirical data from the respondents related to rehabilitation programme. The researcher has cross checked the data into the officials working in the NGO selected like the Director of the NGO and social worker.

Case study was also used carried out by selecting two special cases from different types of rehabilitation to go deep into the problem, and to strengthen the qualitative findings of the study.

2.14 DURATION OF DATA COLLECTION:

The present study was carried out by the investigator from October 1992 to march 1993. The investigator stayed in the study area throughout the study period to get access to the living conditions of the respondents and the organisations selected for this study.

2.15 DATA ANALYSIS:

After the field investigation is over the data were processed and classified. The collected data were edited and checked for its completeness, correctness and consistency. Finally a master table was prepared with the help of primary data collected from leprosy cured and rehabilitated patients which were distributed under each heading. The classified data were then put in simple and cross tables manually. Analysis was carried out with respect to each type of rehabilitation under the study and presented separately. The data were also statically processed and simple statistical technics such as average and percentage were used in the analysis and discussed.

2.16 LIMITATIONS:

The study is being the sensitive one finding the socio-economic aspect of leprosy patients. The investigator found it difficult in the beginning of the study to elicit whole hearted co-operation from respondents on certain sensitive aspects covered in the schedule. Subsequently the rapport was established between the investigator and the respondents by frequently meeting at their family and work places. The investigator convinced the objectives of the study to the respondents. Thereafter it was easier to collect all possible data from the respondents. The number of respondents was 90 and were scattered in 27 villages of two sub-centres. There were some villages like, Agrahrapatti, 7km from Nilakkottai where the investigator had stayed having no road and bus facilities. The investigator covered those villages by bicycle. During the data collection natural calamity (flood) disturbed the life of the village for about 10 days also disturbed the routine visit of the researcher to the villagers. More number of the patients would have been interviewed the patients had migrated to some other places for their livelihood. The study was carried out for M.Phil Programme which is time bond in nature. Besides the resource was not available, however the researcher tried his best to assure the precision and reliability and validity of the data and analysis. Generalisation made out of the present study are subject to these limitations.

CHAPTER III

DATA PRESENTATION

CHAPTER III

3.0 DATA PRESENTATION

3.1 SOCIO-ECONOMIC AND DEMOGRAPHIC PARTICULARS OF THE RESPONDENTS

KNOWLEDGE OF THE PATIENTS ABOUT THE DISEASE

TREATMENT ASPECTS

NATURE OF THE REHABILITATION PROGRAMMES

CASE STUDIES IN THREE TYPES OF REHABILITATION.

AN INTERVIEW WITH SOCIAL WORKER

3.0 DATA PRESENTATION

According to the objectives of the present study the investigator designed the study to collect empirical data regarding the rehabilitation of leprosy patients benefited out of Damien Leprosy Control Centre (DLCC) functioning at Nilakkottai. The Rehabilitation programme of the leprosy cured patients was covered by Five types of programmes offered through this NGO. These five types of rehabilitation or 1) Domiciliary 2) Dairy 3) Tailoring 4) Housing and 5) Bank loan.

Out of 8 Sub-Centres functioning under this NGO, 2 Sub-Centres namely Nilakkottai and Ammaya Naikkanoor were picked up which are providing services to 27 villages having 118 leprosy cured patients in the programmes. Out of 118, in the study the investigator could cover only 90 respondents (leprosy cured patients). These 90 leprosy cured patients were distributed into 5 types of rehabilitations.

The rest of 28 could not be contacted because of migration of the respondents to the other places for their livelihood during the study period.

The detailed empirical investigation was carried out by the investigator for the 90 respondents in a period of 6 months.

These empirical data have been analysed and presented here according to

- 1) Socio-economic particulars of the patients.
- 2) Knowledge about the disease and treatment of the patients
- 3) An analysis on various types of rehabilitations, with case study of three types of rehabilitation programme.
- 4) An interview with a social worker working for rehabilitation in the selected organisation.

The table given below shows the distribution of the respondents according to the types of Rehabilitation.

Sl. No.	Type of Rehabilitation	N	(%)
1.	Domiciliary	64	(71)
2.	Dairy	10	(11)
3.	Tailoring	8	(9)
4.	Housing	5	(5)
5.	Bank loan	3	(3)
Total		90	(100)

It is clear from the above table that, of the total 90 respondents rehabilitated under five types of rehabilitation programme majority (71%) of the patients have been rehabilitated under domiciliary rehabilitation.

It is observed that the tailoring rehabilitation is meant for ladies, constituting eight patients. Number of patients assisted through banks are minimum in the selected two Sub-Centres.

TABLE 3.2 SHOWING THE SEX WISE DISTRIBUTION OF THE RESPONDENTS
IN DIFFERENT TYPES OF REHABILITATION

Sl. No.	Types of Rehabilitation	Sex				Total	
		Male n	(%)	Female n	(%)	n	(%)
1.	Domiciliary	46	(87)	18	(53)	64	
2.	Dairy	9	(16)	1	(3)	10	
3.	Tailoring	NIL		8	(24)	8	
4.	Housing	1	(2)	4	(12)	5	
5.	Bank loan	NIL		3	(9)	3	
	Total	56	(62)	34	(38)	90	100

Sex wise distribution of the patients in all types of rehabilitation is given in this table. The total Number of patients interviewed is 90. Out of which 56(62%) patients were male. The remaining 34(38%) were female respondents.

It is very clear from the above table that male patients are more in number. In tailoring and Bank loan rehabilitation all the patients are females.

TABLE 3.3 SHOWING THE AGE-WISE DISTRIBUTION OF THE RESPONDENTS
IN DIFFERENT CATEGORIES

Sl. No. Types of Rehabilitation	Age					Total
	11-20 n (%)	21-30 n (%)	31-40 n (%)	41-50 n (%)	above 51 n (%)	
1. Domiciliary	2 (28)	10 (77)	15 (94)	36 (72)	1 (25)	64
2. Dairy	NIL	NIL	NIL	7 (14)	3 (75)	10
3. Tailoring	5 (78)	3 (23)	NIL	NIL	NIL	8
4. Housing	NIL	NIL	1 (6)	4 (8)	NIL	5
5. Bank loan	NIL	NIL	NIL	3 (6)	NIL	3
Total	7 (8)	13 (14)	16 (18)	50 (56)	4 (4)	90

This table shows the age group of the patients rehabilitated under various types of rehabilitation programme. The age of the 90 respondents was categoried into 5 groups (11-20, 21-30, 31-40, 41-50, above 51) of the total patients. 7(8%) belong to the age group of 11-20. 13(14%) patients were under the age group of 21-30, and between 31-40 age group the number of respondents were 16(18%) and more than half of the 50(56%) patients belong to 41-50 age group and remaining 4(4%) had crossed the age of 50.

The inference drawn from the table is that more than half of the patients 50(56%) were under the age group of 41-50. It shows that more respondents who need rehabilitation are aged patients who delayed their treatment at early stage which lead to deformity. Deformity is higher among the aged people.

TABLE 3.4 SHOWING THE MARITAL STATUS OF THE RESPONDENTS
IN DIFFERENT TYPES OF REHABILITATION

Sl. No.	Types of Rehabilitation	Marital status			Total
		Single n (%)	Married n (%)	Widow n (%)	
1.	Domiciliary	3 (37)	60 (74)	1 (100)	64
2.	Dairy	NIL	10 (12)	NIL	10
3.	Tailoring	5 (63)	3 (4)	NIL	8
4.	Housing	NIL	5 (6)	NIL	5
5.	Bank loan	NIL	3 (4)	NIL	3
	Total	8 (9)	81 (90)	1 (1)	90

Marital Status of the patients in all types of rehabilitation is depicted in the above table which indicates, out of the total respondents, 8(9%) are single, (unmarried) 81(90%) have got married and there is only one widow patient.

In the Dairy, housing and bank rehabilitation all patients are married. Of the 8 unmarried patients, 5(63%) of the respondents are from tailoring rehabilitation.

From this table analysis, it is easy to understand that majority (90%) of the patients are married.

TABLE 3.5 SHOWING THE NUMBER OF FAMILY MEMBERS OF THE RESPONDENTS
FROM VARIOUS TYPES OF REHABILITATION

Sl. No.	Types of Rehabilitation	Family members			Total
		0-3 n (%)	4-7 n (%)	8--above n (%)	
1.	Domiciliary	12 (68)	51 (72)	1 (100)	64
2.	Dairy	2 (11)	8 (12)	NIL	10
3.	Tailoring	2 (11)	6 (8)	NIL	8
4.	Housing	2 (11)	3 (4)	NIL	5
5.	Bank loan	NIL	3 (4)	NIL	3
Total		18 (20)	71 (79)	1 (1)	90

Classification of the patients by family size is given in the above table which indicates the pre-ponderance of medium size (79%) with 4-7 members and 18(20%) of the patients having small size(0-3) and only one respondent accounts for large family with more than 8 members.

It is easy to understand that majority(79%) of the families of the patients are medium size.

TABLE 3.6 SHOWING THE TYPE OF RESIDENCE OF THE PATIENTS FROM
VARIOUS TYPES OF REHABILITATION

Sl. No.	Types of Rehabilitation	Type of Residence				Total
		Katcha with Roof n (%)	Tile Roof n (%)	Pucca n (%)		
1.	Domiciliary	35 (39)	27 (77)	2 (50)	64	
2.	Dairy	7 (8)	2 (6)	1 (25)	10	
3.	Tailoring	3 (3)	4 (11)	1 (25)	8	
4.	Housing	3 (3)	2 (6)	NIL	5	
5.	Bank loan	3 (3)	NIL	NIL	3	
	Total	50 (57)	35 (39)	4 (4)	90	

The above table explains the types of residence of the patients in the study area under various types of rehabilitation. There are 3 types of residence as shown in the table. Of the total 90 patients more than half of the respondents 50(57%) are living in Katcha with roof house followed by 35(39%) are in Tile roof residence and the rest of 4(4%) live in Pucca houses.

From this table we can conclude that majority 50(57%) are living in Katcha with roof house. It shows the poor housing condition of the respondents.

TABLE 3.7 SHOWING THE TYPES OF FAMILY OF THE PATIENTS IN
DIFFERENT TYPES OF REHABILITATION

Sl. No.	Types of Rehabilitation	Type of family					
		Joint		Nuclear		Total	
		n	(%)	n	(%)	n	(%)
1.	Domiciliary	2	(67)	62	(72)	64	
2.	Dairy	1	(33)	9	(10)	10	
3.	Tailoring	NIL		8	(9)	8	
4.	Housing	NIL		5	(6)	5	
5.	Bank loan	NIL		3	(4)	3	
	Total	3	(3)	87	(97)	90	

There are two major types of family in the study area.

1. Joint family 2. Nuclear family. Of the total 90 patients interviewed 87(97%) patients live in the nuclear family and only 3(3%) are living in the Joint family.

It is very clear from the table that the pattern of Joint family system is not in existence in the rural areas as before. It might be because of the leprosy, the joint families are disintegrated.

TABLE 3.8 SHOWING THE CASTE-WISE DISTRIBUTION OF THE
RESPONDENTS IN DIFFERENT TYPES OF REHABILITATION

Sl. No.	Types of Rehabilitation	Caste			Total
		BC n (%)	MBC n (%)	SC/ST n (%)	
1.	Domiciliary	12 (70)	19 (90)	33 (63)	64
2.	Dairy	3 (18)	NIL	7 (14)	10
3.	Tailoring	1 (6)	1 (5)	6 (11)	8
4.	Housing	1 (6)	1 (5)	3 (6)	5
5.	Bank loan	NIL	NIL	3 (6)	3
	Total	17 (19)	21 (23)	52 (58)	90

The caste of the patients in all types of rehabilitation is given in this table. There are three major castes in the study area namely BC, MBC, SC/ST. Of the total 90 respondents 17(19%) patients belong to BC category. In the MBC there are 21(23%) of the patients and the rest of the 52(58%) patients belong to SC/ST category.

It shows that majority (58%) are belonging to SC/ST categories, which include Pallar, Parayar and Sakkiliar. The findings of this study substantiate the findings of the study conducted by Dr. Rao, that among all the castes, SC are the most affected people by leprosy disease. The study area Nilakkottai is a reserved constituency of SC/ST who are numerically dominant. This may be a reason for more number of SC patients suffered from leprosy in this area.

TABLE 3.9 SHOWS THE RELIGIOUS WISE DISTRIBUTION OF THE
RESPONDENTS FROM DIFFERENT TYPES OF REHABILITATION

Sl. No.	Types of Rehabilitation	Religion			Total
		Hindu n (%)	Christian n (%)	Islam n (%)	
1.	Domiciliary	56 (71)	7 (63)	1 (100)	64
2.	Dairy	8 (10)	2 (18)	NIL	10
3.	Tailoring	7 (9)	1 (9)	NIL	8
4.	Housing	4 (6)	1 (9)	NIL	5
5.	Bank loan	3 (4)	NIL	NIL	3
	Total	78 (87)	11 (12)	1 (1)	90

The table presented above mentions the Religion to which patients belong in all types of rehabilitation.

Out of 90 patients interviewed 78(87%) of the patients are Hindus and 11(12%) Christians. Only one patient belongs to Islam, who is under domiciliary category.

It is concluded that patients of Hindu religion are more in number.

TABLE 3.10 SHOWING THE EDUCATIONAL STATUS WISE DISTRIBUTION OF
THE RESPONDENTS IN DIFFERENT KINDS OF REHABILITATION

Sl. No. Types of Rehabilitation	Educational Status				
	Illite. n (%)	Primary n (%)	Middle n (%)	High n (%)	Total
1. Domiciliary	42 (79)	15 (65)	6 (46)	1 (33)	64
2. Dairy	6 (11)	4	NIL	NIL	10
3. Tailoring	NIL	NIL	6 (46)	2 (67)	8
4. Housing	3 (5)	1	1 (8)	NIL	5
5. Bank loan	2 (4)	1	NIL	NIL	3
Total	53 (59)	21 (23)	13 (14)	3 (4)	90

Educational status of the patients is exhibited in the above table. Out of the 90 patients, more than 59% are illiterate and rest of the 41% are literate. Of 41% patients, who studied upto primary school are 21(23%), and 13(14%) have studied upto middle school and only, 3(4%) had gone upto high school.

From the table it is concluded that majority of the patients are illiterates. The high rate of illiteracy may be the reason for the deformity among leprosy patients in this area.

TABLE 3.11 SHOWING THE SOURCES OF WATER IN THE FAMILIES OF THE RESPONDENTS IN DIFFERENT TYPES OF REHABILITATION

Sl. No.	Types of Rehabilitation	Source of water					
		Well n	(%)	Hand pump n	(%)	Total n	(%)
1.	Domiciliary	55	(73)	9	(64)	64	
2.	Dairy	8	(11)	2	(14)	10	
3.	Tailoring	5	(6)	3	(22)	8	
4.	Housing	5	(6)	NIL		5	
5.	Bank loan	3	(4)	NIL		3	
	Total	76	(84)	14	(16)	90	

The table presented here reveals the sources of water in the study area. Out of 90 patients interviewed, majority 76(84%) of the respondents are using water from well and only 14(16%) respondents are using water from hand pumps.

It is clear from the table that in rural area, patients prefer well water than water from hand pump.

The investigator observed that the most of the patients feel well water more tastier than the water from hand pump.

TABLE 3.12 SHOWING THE TOILET FACILITIES IN THE HOUSES OF THE PATIENTS IN VARIOUS KINDS OF REHABILITATION PROGRAMME

Sl. No.	Types of Rehabilitation	Toilet facilities					
		Yes		No		Total	
		n	(%)	n	(%)	n	(%)
1.	Domiciliary	2	(50)	62	(72)	64	
2.	Dairy	1	(25)	9	(10)	10	
3.	Tailoring	1	(25)	7	(8)	8	
4.	Housing	NIL		5	(6)	5	
5.	Bank loan	NIL		3	(4)	3	
	Total	4	(4)	86	(96)	90	

Among the 90 patients interviewed, number of patients having toilet facilities within their houses itself are only 4%. The remaining 86(96%) are not having toilet facilities.

It is easy to conclude that majority (96%) are not having toilet facilities within their houses. Instead they uses the open grounds. Rural people do feel that, having toilets are luxury one and so they neglect it. Because of this lackness, lot of unhygenic and unsanitary conditions are prevailing around the villages.

TABLE 3.13 SHOWING THE TYPES OF FOOD IN THE PATIENTS FAMILY
IN DIFFERENT TYPES REHABILITATION

Sl. No.	Types of Rehabilitation	Type of food			
		Veg n	(%)	Non-Veg n	Total n (%)
1.	Domiciliary	1	(50)	63	(71) 64
2.	Dairy	NIL		10	(11) 10
3.	Tailoring	NIL		8	(9) 8
4.	Housing	1	(50)	4	(5) 5
5.	Bank loan	NIL		3	(4) 3
	Total	2	(2)	88	(98) 90

The types of food of the patients under various types of rehabilitation is given in the above table, vegetarian and Non-vegetarian. Of the 90 respondents, only 2(2%) of the patients consume vegetarian, and the rest of 88(98%) are consuming Non-vegetarian food.

Only one patient in Domiciliary on housing rehabilitation is vegetarian. It is clear from the above table that almost all the patients (98%) are Non-vegetarians.

The investigator found out in his routine observation in the respondents family that since the majority of the respondents belong to the agricultural labourers families, they were not getting sufficient food to eat. The two square meals were not available throughout the year for all members, a stark poverty and food deprivation was very much prevalent at majority of the levels. Though majority(98%) was non-vegetarian infact there was no sufficient Non-vegetarian food available to them, since most of them are hand to mouth. Severe poverty was observed in most of the households of leprosy patients.

TABLE 3.14 SHOWING THE SOURCES OF INCOME OF THE RESPONDENT'S
FAMILY IN DIFFERENT TYPES OF REHABILITATION

Sl. No. Types of Rehabilitation	Source of Income					Total
	Land n (%)	lives stock n (%)	Agl. labour n (%)	Busi- ness n (%)	other n (%)	
1. Domiciliary	8 (53)	12 (75)	36 (78)	6 (55)	2 (100)	64
2. Dairy	6 (40)	1 (6)	3	NIL	NIL	10
3. Tailoring	1 (7)	2 (13)	2	3 (27)	NIL	8
4. Housing	NIL	1 (6)	4	NIL	NIL	5
5. Bank loan	NIL	NIL	1	2 (18)	NIL	3
Total	15 (17)	16 (18)	46 (51)	11 (12)	2 (2)	90

Primary sources of income of the patients belonging to various types of rehabilitation are pictured in the above table. Out of the 90 respondents 15(17%) are owning land, 16(18%) have livestock as their sources of income and 46 (51%) are Agricultural labour, 11(12%) are Business men, and only 2(2%) are having other sources than the sources mentioned above, like pawn stalls, road side tiffin stall.

It is very clear from this table that almost half of the patients are agricultural labour.

The finding of this study substantiate the findings of study conducted in Bombay that majority of the patients working in the agriculture field, industry are more vulnerable to this disease. Because of their continuous work in those field, the disease becomes severe leading to severe deformity.

TABLE 3.15 SHOWS THE MONTHLY INCOME OF THE RESPONDENT'S FAMILY

Sl. No.	Types of Rehabilitation	Monthly income			
		0-300 n (%)	301-600 n (%)	601-900 n (%)	Total
1.	Domiciliary	22 (85)	39 (70)	3 (33)	64
2.	Dairy	2 (7)	7 (14)	1 (11)	10
3.	Tailoring	1 (4)	3 (5)	4 (45)	8
4.	Housing	NIL	4 (7)	1 (11)	5
5.	Bank loan	1 (4)	2 (4)	NIL	3
Total		26 (29)	55 (61)	9 (10)	90

Monthly income of the patient's family are shown in the above table. The income has been divided into 3 categories (0-300,301-600,601-900). Of the total 90 patient's, family earning of Rs. 300-600, are 55(6%) and the remaining 9(10%) are getting Rs. 601-900 per month.

It is observed from this table that the patient's family earning Rs 600-901 permonth are in all types of rehabilitation and more than half(61%) of the patient's family earn Rs. 301-600 per month.

It shows their standard of living and their poverty in their life. This poor economic conditions may be one of the reasons for not accessing the available medical facilities and having balanced food everyday.

TABLE 3.16 SHOWING THE KNOWLEDGE OF THE PATIENTS
ABOUT THE DISEASE

Sl. No.	Knowledge	Yes		No		Don't know		Total	
		n	(%)	n	(%)	n	(%)	n	(%)
1.	Is Leprosy a contagious?	62	(69)	7	(8)	21	(23)	90	(100)
2.	Are children more vulnerarable to leprosy than adults?	40	(44)	45	(50)	5	(6)	90	(100)
3.	Do you know two types of leprosy?	11	(13)	NIL	NIL	79	(87)	90	(100)

The above table shows that knowledge of the patients about the disease are not high. Nearly 62(69%) said that leprosy is a contagious, 45(50%) of the patients answered that children are not vulnerable to this disease and 79(87%) of the patients don't know of two types of leprosy.

It shows the ignorance or lack of scientific knowledge about the disease. Hence knowledge on leprosy should be given periodically to the affected patients and also to the public. Mass communication may be used in importing health education.

THE TABLE 3.17 SHOWS THE PERSON OF RECOGNITION OF THE DISEASE

Sl. No.	Disease Recognised by	No. of Resp.	
		n	(%)
1.	Self	8	(9)
2.	Leprosy Inspector	61	(68)
3.	Non-Leprosy Doctor	11	(12)
4.	Relatives / Neighbours	10	(11)
	Total	90	(100)

The table above shows the details about the person of Recognition of the disease in the first instances, it indicates the majority (68%) of the cases have been recognised by the Leprosy Inspector during his visit. But self-recognition of the disease is very poor (9%). It shows that the lack of knowledge about the symptoms of the disease in the initial stage of leprosy inspite of several indications through mass media also by the GOVT. and NGOs.

THE TABLE 3.18 SHOWS THE SYMPTOMS OF THE LEPROSY ANSWERED
BY THE RESPONDENTS

Sl. No.	Symptoms	No. of Resp.	
		n	(%)
1.	Patch	58	(64)
2.	Shining-Reddish	16	(18)
3.	Loss of sensation & sweating	7	(8)
4.	Wounding	5	(6)
5.	Swelling	2	(2)
6.	Watering in eyes	1	(1)
7.	Painful eye	1	(1)
	Total	90	(100)

The table exhibits the various symptoms of the disease of the patients from the table .It is understood that majority of the respondents (64%) had patches as the symptoms of their disease. Patch is the common and best symptom like Shining-Reddish wounds, swelling.

TABLE 3.19 SHOWING THE KNOWLEDGE OF THE RESPONDENTS ABOUT
THE CAUSE OF LEPROSY

Sl. No.	Causes of disease	No. of Resp. n	Resp. (%)
1.	God's curse to sin or violation of promise	9	(10)
2.	Pest bite	25	(28)
3.	Snake bite	16	(18)
4.	By wound	7	(8)
5.	Close association with other leprosy patients	9	(10)
6.	Un hygenic condition	6	(7)
7.	Immoral sex behaviour	4	(4)
8.	Heat temperature	12	(13)
9.	Heridity	2	(2)
	Total	90	(100)

The investigator collected the causes for the disease from the sample of 90 leprosy cured and rehabilitated patients (respondents) which are as shown in the above table. The table analysis conforms that patients are not known about the scientific medical name for the disease and it clearly shows their ignorance by saying that due to pest bite nearly 25% of the patients (majority among other causes of leprosy) are affected by this disease.

THE TABLE 3.20 SHOWING THE KNOWLEDGE OF THE PATIENTS
ABOUT DIFFERENT NAMES OF LEPROSY

Sl. No.	Names of the disease	No. of Respn	(%)
1.	Padai	5	(5)
2.	Themal	13	(14)
3.	Thozh viyathi	8	(9)
4.	Periya viyathi	25	(28)
5.	Kuttam	8	(9)
6.	Kustrogam	12	(23)
7.	Leprosy	21	(23)
	Total	90	(100)

The table 3.1.27 describes various names of the disease common in this rural area. Of the different names periya viyathi is commonly used by majority of the patients in Tamil.

"Periya" means "big", viyathi means disease. As the leprosy can't be cured easily and this is the biggest disease among other disease leading to severe deformity with ultimately lead to social isolation of the patient calling it as 'periya viyathi'. Patients consider the leprosy is the most dreaded disease of all diseases affecting human-being.

TABLE 3.21 SHOWING THE KNOWLEDGE OF THE PATIENTS REGARDING
THE SPREAD OF THE DISEASE

Sl. No.	Mode of spreading the disease	No. of Respn	(%)
1.	Physical contact	54	(61)
2.	By Air	16	(17)
3.	By water	20	(22)
Total		90	(100)

The table 3.1.28 exhibits the various names of disease replied by the patients under different types of rehabilitation.

Though there are different kinds of mode of transmission of the disease, according to the patients, majority 54(61%) of the patients think that direct contact is the main mode of transmission.

THE TABLE 3.22 SHOWS THE FEELINGS OF THE RESPONDENTS
AT THE TIME OF THE IDENTIFICATION OF THE DISEASE

No.	Feelings	No. of Resp.	
		n	(%)
1.	Sad to inform the family members	52	(58)
2.	Fear to be affected for a long time	16	(18)
3.	Death is the result	12	(13)
4.	Felt normal	10	(11)
	Total	90	(100)

The table manifests the feelings of the patients at the time of the recognition of the disease .

It is clear from this table that majority (58%) had felt sad to inform this disease to their family members and only 11% felt it normal about the disease attacked .

TABLE 3.23 SHOWS THE REACTION OF THE FAMILY MEMBERS
AFTER THE IDENTIFICATION OF THE LEPROSY

Sl. No.	Reaction of the family members	No. of Resp.	
		n	(%)
1.	Forced to go to the Doctor	28	(31)
2.	Keeping distance	16	(18)
3.	Hiding the disease to other members	30	(33)
4.	Took it normally	16	(18)
Total		90	(100)

The table illustrates the feelings of the family members of the respondents soon after the recognition of the disease of the patients. Of the total respondents 31% had been forced to go to hospital by their family members .18% of the respondents said that thier family members kept distance from them 33% respondents said that their family members hided the disease to the other members.Only 18% had taken it normally.

It is clear from the table that majority (33%) of the respondents had hided the disease to others, than family members.

TABLE 3.24 SHOWS THE STEPS TAKEN BY THE RESPONDENTS
IMMEDIATELY AFTER THE RECOGNITION OF THE DISEASE

Sl. No.	Steps taken	No. of Resp.	
		n	(%)
1.	Informed to family members	7	(7)
2.	Went to hospital directly	25	(28)
3.	Leprosy Inspector gave the tablets on the spot	51	(61)
4.	Self Healings	7	(7)
	Total	90	(100)

The table reveals the various steps taken by the patients soon after the recognition of the disease. Of the 90 respondents interviewed 7(7%) have informed the disease to their family members, 25(28%) had gone to the hospital directly and 51(61%) were given tablets by the Leprosy Inspector working under the NGO selected. The remaining 7(7%) had started self healing process. It is evident from this table that majority 51(61%) were given tablet by the Leprosy Inspector.

TABLE 3.25 SHOWS THE LIKING ASPECTS OF THE RESPONDENTS
IN THE HOSPITAL DURING THEIR TREATMENT

Sl. No.	Liking aspects in the hospital	No. of Resp.	
		n	(%)
1.	Free Food & Accomodation	14	(15)
2.	Kindness of doctors & Nurse	25	(28)
3.	Medical care & dressing	36	(40)
4.	Separate place	9	(9)
5.	Recreation	6	(7)
Total		90	(100)

The respondants have graded the facilities given by the NGO selected during their treatment.

The following is the order

- 1) Medical care & dressing.
- 2) Kindness of doctors & nurses during the treatment.
- 3) Free food & accomodation.
- 4) Separate place and cot.
- 5) Recreation facilities.

The inference drawn from this table is that the medical care and dressing in the hospital during their treatment is given first grade by majority (40%) of the patients which is more important.

TABLE 3.26 SHOWING THE PROBLEMS FACED BY THE RESPONDENTS
DURING TREATMENT

Sl. No.	Problems during treatment	No. of Resp.	
		n	(%)
1.	No security to family	19	(21)
2.	Reduacement of family income	21	(23)
3.	Publicity to Relatives about disease	22	(29)
4.	Hesitation of relatives to visit the patient in the hospital	8	(9)
5.	Separated even by family members	12	(13)
6.	Problems of the Son/daughter at the time of marriage	6	(7)
	Total	90	(100)

This table shows about 42% of the patients felt about their income and the publicity of the disease to other relatives. Hence the NGO should give financial assistance to the members of the patient during their treatment.

TABLE 3.27 SHOWING THE PROBLEMS OF PATIENTS IN GOING BACK
TO THEIR PREVIOUS JOB

Sl. No.	Problems	No. of Resp. n	Resp. (%)
1.	Can't do any work	15	(17)
2.	Don't like to go for cooly work	28	(31)
3.	Employer did not accept	38	(42)
4.	No problems	9	(10)
	Total	90	(100)

The table informs us the problems faced by the patients in going back to their previous job. Though there are four major problems, 38(42%) patients are ready to do their previous job as usual. But the employer didn't accept them to join.

It shows that there is still social stigma attached with leprosy in this area and only 10% of the patients said that they are willing to do their job without any problem. This might be probably the disease didn't affect them considerably.

TABLE 3.28 SHOWING THE PROBLEMS FACED BY DEFORMED
LEPROSY PATIENTS

Sl. No.	Problems	No. of Resp. n	Resp. (%)
1.	Seperate plate,cot inside the home	38	(42)
2.	Isolated from the home	32	(36)
3.	School drop-out	2	(2)
4.	No public contact	15	(17)
5.	Incidence of divorce	3	(3)
	Total	90	(100)

This table reveals the problems of the deformed patients identified in the study area. Though there are many problems like isolating the patients from their homes. Incidence of school drop out and instances of divorce, and unable to have public contact, nearly 38(42%) patients are partly accepted by their family members. The family members are supporting the patients for their lively hood but the separate plate and other utensils for their use will be given seperately. The social stigma is always with them.

The next table shows the various problems in the social acceptance of the patients in the study area.

TABLE 3.29 SHOWS THE PROBLEMS IN THE SOCIAL ACCEPTANCE
EVEN AFTER THE REHABILITATION

S1. No.	Problems in social acceptances	No. of Resp. n	Resp. (%)
1.	Prevalence of social stigma	35	(39)
2.	Fear of the spread of the disease	28	(31)
3.	Economically not useful	27	(30)
	Total	90	(100)

From the above table analysis it is understood that most of the patients are not accepted because of economically not useful and 28(31%) of the patients were not accepted because of the fear of the spread of the disease.

TABLE 3.30 SHOWING THE DESIRE OF THE RESPONDENTS
TO LIVE ALONE

Sl. No.	Desire to live alone	No. of Resp. n	Resp. (%)
1.	Yes	61	(64)
2.	No	29	(36)
Total		90	(100)

The table presented here portrays the desires of the patients to live alone. Out of 90 respondents interviewed, 64% of the affected and rehabilitated patients themselves like to live alone apart from their family. Only 29(36%) of the patients said that they don't need to live alone. This may be because the patients are not severely deformed.

TABLE 3.31 SHOWING THE FACTORS RESPONSIBLE FOR THE
ACCEPTANCE OF THE LEPROSY CURED PATIENTS IN THE FAMILY

Sl. No.	Factors	No. of Respn	(%)
1.	Economically useful	41	(46)
2.	More member in the family to take care of	14	(16)
3.	The patient is Head of the family	2	(2)
4.	The family has more cattle	5	(5)
5.	No symptoms at all	17	(19)
6.	The patient is a child	11	(12)
	Total	90	(100)

The table 3.31 illustrates the various factors that are responsible for the acceptance of the leprosy patients in the study area. Of all the factors, if the patients are economically useful to their family members one way or other, they will atleast partly be accepted by their family as stated by majority (46%) of the patients.

Followed by, patients will be accepted provided the families are having more members in their family. The investigator has observed that they need a seperate person to take care of the patients in assisting the patient to take bath and wash his clothes.

It is concluded from the above table that majority (46%) of the families want the patients to be economically viable. So, the NGO selected can generate some sources through which the families of the patient can accept the patients. Otherwise they will not be considered as one of the family member.

TABLE 3.32 SHOWING THE COMPLETION OF LOAN IN DIFFERENT
TYPES OF REHABILITATION

Sl. No.	Type of Rehabilitation	Completion of loan		
		Yes	No	Total
1.	Domiciliary	52 (76)	12 (57)	64
2.	Dairy	7 (10)	3 (14)	10
3.	Tailoring	5 (7)	3 (14)	8
4.	Housing	3 (4)	2 (10)	5
5.	Bank loan	2 (3)	1 (5)	3
Total		69 (75)	21 (25)	90

From the above table it is clear that majority (75%) of the patients have completed their loan under all types of rehabilitation.

It is observed that since the NGO selected had given loan to those patients who can repay the amount, majority of the patients have repaid their loan successfully.

THE TABLE 3.33 SHOWS THE DEPENDENCE OF THE PATIENTS
ON REHABILITATION

S1. No.	Dependence	No. of Resp. n	(%)
1.	Yes	23	(27)
2.	No	57	(63)
	Total	90	(100)

The table 3.1.35 shows whether the patients are mainly depending on this rehabilitation for their lively hood. Out of 90 respondents interviewed 57(63%) of the patients said that they were not mainly depending on the rehabilitation. They say that they can lead their lives even without the help of rehabilitation. They were selected for the rehabilitation because they are able to repay the amount of loan.

It shows that the organisation in the study area, has selected the patients according to their capability of repaying the amount of loan. And only 23(27%) have said that they mainly depend on the rehabilitation.

TABLE 3.34 SHOWS THE OPINION ABOUT THE TREATMENT

Sl. No.	Opinion about treatment	No. of Resp.	
		n	(%)
1.	Satisfaction	79	(87)
2.	Not Satisfaction	11	(13)
Total		90	(100)

The table presented here manifests, the opinion of the patients about the treatment process of the NGO selected. Of the 90 patients interviewed 79(87%) patients held the opinion that they were satisfied with the treatment provided to the respondents during their treatment. And the remaining 13% of the respondents were not satisfied with treatment.

It is easy to conclude that majority (87%) of the respondents were satisfied with the treatment offered to them.

TABLE 3.35 SHOWS THE SUGGESTION OFFERED BY THE
RESPONDENTS TO IMPROVE THE TREATMENT

Sl. No.	Suggestions	No. of Resp.	
		n	(%)
1.	No suggestion	7	(8)
2.	Establishment of Canteen	10	(11)
3.	Duration of treatment in the hospital may be shortened	73	(81)
Total		90	(100)

The table brings out the suggestions offered by the respondents. Out of 90 respondents 7(8%) respondents have offered no suggestions, 10(11%) respondents suggested to establish a canteen in the hospital and the remaining 73(81%) wanted and suggested that the duration of the treatment may be reduced.

It is evident from the table that, none has given suggestion on the treatment provided by the NGO, and most of them suggested to reduce the duration of the treatment.

TABLE 3.36 SHOWING THE OPINION OF THE RESPONDENTS
ON REHABILITATION

Sl. No.	Opinion about rehabilitation	No. of Respn	(%)
1.	Satisfied	28	(31)
2.	Not satisfied	62	(69)
	Total	90	(100)

The table 3.36 depicts the opinion of the patients regarding the rehabilitation under which they have been rehabilitated. Out of 90 patients in various types of rehabilitation 28(31%) of the patients opined that they are satisfied with rehabilitation and majority 62(69%) of the respondents are not satisfied with the rehabilitation programme.

Because, patients feel difficult to repay the loan, and the money sanctioned for the rehabilitation under various programmes of rehabilitation is not sufficient except tailoring.

Table 3.37 shows the Alternatives Rehabilitation measures as stated by the respondents

Sl. No.	Alternatives	No. of Resp. n	%
1.	Vegetable selling	23	(26)
2.	Carpentry work	6	(7)
3.	Horticulture	20	(23)
4.	Don't know of any work	18	(20)
5.	Can't do any other work	7	(7)
6.	Cycle rental shop	12	(13)
7.	Installation of telephone	4	(4)
	Total	90	(100)

The table presented above illustrates the various alternative measures to the rehabilitation programs offered at presently in the NGO selected.

It is observed from the above table that though there are many alternative programs, almost 26% of the patients suggested to vegetable selling followed by 23% of the patients wanted to work in the horticulture and only 4 patients wanted to operate telephone booth, who belong to Nilakkottai town. It shows the unsatisfaction of the patients towards the present rehabilitation measures offered by the NGO.

TABLE 3.38 SHOWING STEPS TO BE TAKEN BY GOVT. OR NGOs
TO ERACE THE SOCIAL STIGMA

Sl. No.	Steps to be taken	No. of Respn	(%)
1.	Documentary film	20	(22)
2.	Street play/drama	18	(20)
3.	Demonstration by Cine actor like polio	13	(14)
4.	By wall posters	4	(4)
5.	People themselves should change their attitude	23	(26)
6.	No idea	12	(13)
	Total	90	(100)

The table indicates the various steps to be taken by the Government or NGO to erase the social stigma attached with leprosy and the patients.

Though there are many steps as stated by the patients to erase the social stigma such as street cinema 22% and street play/drama (20%) and demonstration by cine actors like polio (14%), through wall posters. Majority (26%) of the patients suggested that people themselves should change their attitude towards the disease and the patients. 13% patients had no idea.

It shows that almost all all the patients directly or indirectly knowingly or unknowingly wanted that health education should be imported through mass media.

REHABILITATION PROGRAMMES AN ATTEMPT OF THE NGO

The NGO (DLCC, Nilakkottai) selected for the present study offers five types of rehabilitation programme for the leprosy cured patients. After having conducted the field study the major findings on all types of rehabilitation programmes are given in the table form.

TABLE 3.39 SHOWING THE SOURCES OF REPAYMENT OF THE LOAN IN ALL TYPES OF REHABILITATION

Sl. No.	Rehabilitation	Sources of repayments	No. of Resp. n	Resp. (%)
1.	Domiciliary (64)	Through Agricultural Cooly Cooly	42	(67)
2.	Dairy (10)	Through milk	6	(60)
3.	Tailoring (8)	Agricultural cooly	5	(63)
4.	Housing (5)	Agricultural cooly	4	(80)
5.	Bank loan (3)	Cooly/Petti shop/Cycle	3	(100)
Total (90)				

The above table reveals that the main source of repayment of loan for majority of the patients in domiciliary, tailoring and housing rehabilitation programmes is agricultural cooly works. In dairy rehabilitation the main source of repayment is yield through milch animal.

It is clear from the above table, the patients could not repay the loan through the income of tailoring.

TABLE 3.40 SHOWING COMPLETION OF LOAN IN ALL TYPES OF
REHABILITATION

Sl. Rehabilitation No.		Completion of loan n	(%)
1. Domiciliary	(64)	52	(81)
2. Dairy	(10)	7	(70)
3. Tailoring	(8)	5	(50)
4. Housing	(5)	3	(60)
5. Bank loan	(3)	2	(67)
Total		69	(75)

The table presented above shows us that the majority of the patients in each rehabilitation have repaid their loan successfully. Of the total 90 respondents (75%) have repaid during the study period.

It is clear from the above table that the majority of the patients are capable of repaying the amounts.

TABLE 3.41 SHOWING THE ADVANTAGES IN ALL TYPES OF REHABILITATION

Sl. Rehabilitation No.	Advantages	No. of Respn	Resp. (%)
1. Domiciliary (64)	Without interest	38	(59)
2. Dairy (10)	Without interest	5	(50)
3. Tailoring (8)	Free accomadation&training	5	(63)
4. Housing (5)	Without interest	3	(60)
5. Bank loan (3)	Low interest / No compulsory repayment	3	(100)
Total (90)			

The table here explains that without interest and low interest for the loan are the main advantages enjoyed by the majority of the patients in domiciliary, dairy and bank loan rehabilitation.

Free accomadation and training were the merits of the tailoring rehabilitation for majority 5(65%) of the patients.

TABLE 3.42 SHOWING THE PROBLEMS FACED BY THE PATIENTS IN
ALL TYPES OF REHABILITATION

Sl. Rehabilitation No.	Problems	No. of Respon	(%)
1. Domiciliary (64)	Amount is not sufficient	8	(59)
2. Dairy (10)	Fodder & veterinary facilities not available	5	(50)
3. Tailoring (8)	Not regular work	3	(38)
4. Housing (5)	Instalment basis loan	3	(60)
5. Bank loan (3)	Amount of loan is not sufficient	2	(67)
Total (90)			

This table describes us that the majority of the patients in domiciliary and bank loan are not satisfied with the amount of loan sanctioned. In dairy rehabilitation half of the patients feel the non-availability of the fodder and veterinary facilities for the cattle in their village is the main problem.

In housing rehabilitation, providing insufficient loan installments is the problem as stated by 60% of the patients.

TABLE 3.43 SHOWING THE SUGGESTION OFFERED BY THE PATIENTS IN
ALL TYPES OF REHABILITATION

S1. Rehabilitation No.		Suggestion	No. of Respon- n	Resp. (%)
1. Domiciliary	(64)	Amount of loan should be increased	31	(48)
2. Dairy	(10)	Fodder & Veterinary facilities should be made available	6	(60)
3. Tailoring	(8)	Establishment of cloth store guidance to contract work	6	(75)
4. Housing	(5)	Full amount should be given at once	4	(80)
5. Bank loan	(3)	Increase the amount of loan	3	(100)
Total		(90)		

The above table depicts that majority of the patients in domiciliary and bank loan rehabilitation suggested to increase the amount of loan. In dairy rehabilitation 50% of the patients wanted fodder and veterinary facilities for their cattle. In house rehabilitation majority (80%) wanted the amount of the loan should be sanctioned at once.

CASE STUDY - 1

I. DOMICILIARY REHABILITATION

A severely deformed patient, Perumal, by name, age of 51 who has been given loan under domiciliary rehabilitation was selected for the case study. Perumal was illiterate, agricultural cooly labour is his occupation in nature belonging to Scheduled Caste. He says that the symptoms of the attack of the disease leprosy was identified much earlier, ever before his marriage. Because of ignorance, and lack of knowledge about the disease, he didn't take it seriously As years passed the disease became visible. The Leprosy Inspector working in DLCC, identified the disease when he went for a regular visit. He was given tablets and asked to take treatment regularly. At the beginning he couldn't take regular treatment. He further says that many of his close friends avoided his close association with him. Even family members kept distance with him. But he had been in touch with the selected NGO (DLCC) and continued his treatment regularly because of his delay in treatment the severe deformity occurred before he coming to hospital for regular treatment. He stayed in the hospital for about 4-5 months and says.. "When I was under treatment (Some 20 years ago) the number of leprosy cases in the area was high, there were about more than 100 patients under treatment regularly and we were given treatment carefully, properly they gave us free accommodation and food and treatment. The doctors and the nurses were kind enough, the way they treated us was really appreciable. I will never forget those people till my death. This is the only hospital, know, the another hospital is in a long distance".

He was selected for domiciliary loan, 3 months after the discharge from the hospital, and given Rs. 500/- the money was not sufficient, so he added 50 more rupees to purchase a goat, since he can't do any heavy works which involves physical strain and none is ready to give any kind of job, he was looking after the goat. Hoping that he will get 2,3 goats every 6 months. He goes out side the village with that goat in the morning and come back in the late evening by which he avoids himself in meeting the people in the day time. After some months, the family members of the patient sold the goat and spent the money for some other purpose, when the researcher asked why did they sell, he replied that he had to spend the whole day for only one goat, if it is more than two, there is a point in spending a day. So, they felt it better to sell the goat.

Then they didn't repay the amount to NGO regularly. But now (during the interview) the NGO is compelling the patient to repay the amount by saying that he will be punished by police. The family members say that they are not responsible for the repayment of loan. So the patient can't repay it on his own and get second loan. Because second loan will be given only to those who have repaid the previous loan regularly. So now the patient is left with nothing. He himself is a burden to his family, he suffers a lot for his livelihood, there is none to help him from his relatives economically, even his wife and grand sons and daughters started keeping distance with him. He is not given full respect in his family. He further says ... if the present trends continues, he may leave his home and go to some other places where he can lead his life without disturbing his family members.

CASE STUDY: TAILORING

A lady by name Chitra of 18 years old belongs to SC Hindu family who was interviewed in detailed. She narrated her sufferings from leprosy in detailed. Her education was upto middle School. She was newly married lady by occupation she is landless agricultural labour and has income upto Rs. 300/- per month from tailoring and agricultural laboures. She has a family of 5 members. She was interviewed because she was a case for rehabilitation scheme by Damien Leprosy Centre (DLCC). In the house, there is a katcha house with one room. Her family was a joint family since she lives with her husband and her mother with two younger brothers. She fetches water from common well in the village and goes for the toilet in open areas. When she was interviewed for her sufferings in leprosy. She said she had no severe deformities. Only she developed some patches on her left hand which was identified by the Leprosy Inspectors during his periodical visit to her village. The inspectors directed her to take the treatment regular from the DLC. In the first instances she got shock to know that she was attacked by leprosy. She felt that if she becomes severely deformed patient then she would like to dessert her family and village like the other patients severely deformed. Her family members forced her to go to hospital (DLC) and take the treatment regularly since she was an unmarried young girl. She did as her family members said.

She knew that there was two types of leprosy and children are more vulnarable to this disease without knowing the age exactly. She believed that pest bite was the main cause for leprosy and she called it as "periya viyathi". She further informed the investigator that the direct contact with the leprosy patient is the main mode of transmission of the disease. Responding to the questions related to the problems of deformed patients in this area, she said that most of the deformed are isolated and kept outside the house and these patients are given seperate cot and tumbler and other necesseties.

Usually the villagers looked down upon the patients who have already cured, and these patients are not engaged for any job. If anybody becomes leprosy patients is economically useful then they don't dessert the family or village. She further informed the ivestigator that life becomes misserable when a leprosy patient does not have means to live or to get the treatment. After getting her regular treatment when she got cured from the disease she realised and hoped that leprosy is curable.

She further informed the investigator that she was suggested to under go tailoring training since she happends to be a unmarried girl. The DLC informed her that this training will provide her oppurtunity of future income to support her family after undergoing the training. She could learn the various types of stitching with the completion of the training. Oneday the DLCC in a special function invited her patients to the DLCC for

photograph and after the photograph was taken the DLCC provided her a sewing machine on loan which is repayable by her. When the question was raised why the photograph was taken, she narrated that since she was unmarried she may go out of her family after her marriage. In her absence, her mother or father would be liable to repay the loan towards the cost of sewing.

She further informed the investigator she does not get much work to earn substantial income to support the family because there is no cloth store in the village where she lives. And she does not know the stitching of the male garments and secondly since the village is nearby Nilakkottai town. People go to Nilakkottai for purchasing cloths and give the cloths for stitching in Nilakottai itself. As a result of this though she charges less than the charge of Nilakkottai she doesn't get much work and she gets low income from tailoring. The income she gets from tailoring is not sufficient even to repay the loan to DLCC. So, she had to go for Agricultural cooly work as a daily wage, with which she had repayed the loan and she has got married to a man who had some economic support.

She accepted that since there was no symptoms of leprosy on her body, she was married otherwise it would have been difficult to marry with symptoms of leprosy. Further she felt that unless the DLCC ensure the work and market the product after stitching the tailoring rehabilitation of DLCC would be meaningless. She continued saying that there is no problems in establishing a small shop for tailoring in this village itself. People also

maintain good relationship. Since this is a village gents are not allowed to come to my house for tailoring and I can't do any tailoring work for gents, which gives more income. So,if the DLCC assists to get contract work like school uniform or assisting to establish a small clothstore in my house itself. It will still be better and she further insisted that she is badly in need of second time loan for constructing a good house for her family since she does not have sufficient means.

Investigator found her to be very energetic and bold to reveal her sufferings and experiences for treatment for this severe disease.

CASE STUDY: HOUSING

The respondent namely Ponnaiyan age 55, belonging to Schedule Caste, Indian, severely deformed rehabilitated patient belongs to Agraharapatti. Agricultural labour by occupation received housing loan under the rehabilitation programme, he was attacked by leprosy 15 years back when he was diagnosed as a leprosy patient, because of lack of knowledge about the scientific knowledge about leprosy. He delayed and failed in taking regular treatment which lead to severe deformities. Now he has been sanctioned housing loan as a rehabilitation measures. He was selected for this types of rehabilitation because of his regularity and severe deformity, and economically poor but able to repay the amount and having no house. As a leprosy patient he has suffered a lot.

Answering questions what are the problems he faced. He told that he suffered social isolation from all corner including family member lost his self respect. He himself felt that because of his severe deformity and economically not useful. It is then he approached DLCC which offered loan for house construction. He thought that he will be atleast partly accepted by his family and retain his self-respect by contributing some amount of money for the construction of new house. Nevertheless he had faced some problems regarding the amount. He feels that the amount provided to him for house is not adequate. He further told that since the loan is for inproductive in nature, there arises the problem of repayment. In order to repay the amount he

has to find some other means that being a coolly work, he being a severely deformed patients depends on his family members to repay the loan. Though the loan is sanctioned for the patient to rehabilitate himself, that doesn't fall the purpose of making him independent on the other members in the family.

Mr. Fonnaiyan feels that the conditionalities attached with housing loan is rigid one like the second instalment will be released only after the amount given previously is spent fully for housing purpose. He further tells that the construction of the house has to undergo various stages and each stage requires a particular amount of money. For example, the construction of foundation which is first stage may require particular amount of money the construction of walls which may be considered as second stage may require more amount of money then the amount spent for foundation. Thus all stages of construction requires different amount of money but the loan amount given at every stage (installment) important of the different stages of construction. He further says that as result of which, construction of house can't be completed in time. In due course this case study Fonnaiyan also putforth some suggestions so as to make this programme more viable. Firstly the amount of loan has to be increased as well as it should be given at one time so that the construction work can be carried out without any hindurance. Secondly he suggested that since the nature of loan is not productive the repayment should be liberal. Finally he observed that along with the loan if the material required for housing construction may be provided. So that, he can reduce his work of ~~going here and there to collect the building materials.~~

Coming to the vexed issue of social stigma attached with leprosy patients he says the housing loan does not served the purpose of rehabilitation fully. The reason being the repayment of loan is taken care of by the patient and family members by way of cooly work or any other means. As already stated housing is inproductive one, though the family members accept the patient within the family to some extent for the reasons that he has contributed on amount by way of loan for the benefit of the family. But once the loan is received fully, the attitude of the family members towards him changes, the importance of the attached to the patient is gradually reduced.

He further says the repayment of the loan has to be made by the other members in the family, they feel that Mr. Ponnaiyan does not deserve the same respect he had during the requirement of the loan. He is being considered as burden to his family. Since he is deformed patient, he can't go for any other cooly work on his own. He continues saying that he is prevented from going outside the home and attend any social functions by his family members. Since recently he himself avoids going outside the house. He is given seperate plate and cot, he takes his path himself and washes his cloths, all his belonging are seperated outside the house. He feels that instead of being a burden to his family, it will be better to go out of home to a long distance where none my relatives could see him.

SOCIAL WORKER

Since a social worker from an NGO interacts very closely with leprosy patients he is bound to know the problems and needs of the leprosy patients. It is equally important for the investigator not only to get the responses from the patients but also from the social worker, who monitor the rehabilitation programme to cross-check the responses given by the patients.

Responding to questions of the nature of his work as a social worker in this hospital (DLCC), he said that he starts his work by field visit starting around 6'0 clock in the morning except on Monday and covers a wide area numberly 7 to 8 villages till noon. During his field visit he performs the following functions.

- 1) Assisting the mobile medical team to detect the new cases.
- 2) Approaching the local school to hide-out any new leprosy patients among the students.
- 3) Making a periodical visit to the rehabilitated patients a follow-up measures.
- 4) Recovering the repayment of loan of various types of rehabilitation from the patients or the family members of the patients.

In the afternoon he comes back to hospital and look after the repayment accounts. The investigator observed the many patients come to hospital directly to repay the amount in the afternoon to social worker.

When he was asked about the treatment of leprosy he ascertained that due to periodical visit to each village enables the social worker to detect the disease early. Moreover people are also aware of the symptoms of the disease and come forward for early treatment which helps early cure and to prevent the severe deformity. He further optimistically opined that by 2000 AD the incidence of can be eliminated with the help of MDT in this area, there may be one or two cases not none would be deformed.

Describing the problems in providing treatment he said that poor economic condition of the patients disallow the patients to go to the hospital periodically. The facilities for the treatment situated far away from the villages. So, the medical team goes to every village at least once a week. So patients access the facilities available. He further explained that since the duration of treatment takes a long period the patient get on impression that the disease is so serious that it may not cured completely.

When enquired about the problems faced by the officials in rehabilitating the patients the social worker answered that patients misuse the money given to them for rehabilitation programme and justifying the misuse by saying that the amount given is insufficient. Since, repayment of loan is compulsory, patients feel difficult to repay it, there are some cases, who did not repay it, some patients have migrated their villages to some other areas.

Answering to the questions why the DLCC does not provide fulfilled training in tailoring, he replied that tailoring rehabilitation requires more skilled person to teach all kinds of works in tailoring. Because of lack of skillful person in this they couldn't train the patients fully. Asking the question why not the amount of loan can be increased, he said that amount sanctioned for loan purpose is only Rs. 40,000/- with which they have to rehabilitate all the patients, which needs regular repayment. Coming back to the most important aspects of problems of leprosy rehabilitation patients, the social stigma attached with the patients has to be viewed very seriously. The social worker himself suggested some measures to remove this social stigma like organising leprosy awareness programme through education and mass media like cinema, T.V. programme, Radio as well as wall posters, street play etc. So as to make the common man to understand the problem in the right perspective in order to further strengthen the programme the social worker suggested.

- 1) More fund should be sanctioned for rehabilitation.
- 2) Types of rehabilitation may be increased.
- 3) Health education should be given high priority.

SUMMARY

In the empirical analysis of the rehabilitation programmes offered by the NGO selected, the tables are presented and discussed aspects such as socio-economic condition of the patients, family members of the patients' occupation and income of the patients' and their family, personal habits of the patients, facilities available in their houses. Knowledge of the patients on leprosy disease, feelings of the patients to leprosy problems faced by the deformed patients, factors responsible for the acceptance of the patients in the family and the community problem during their treatment, problems of the patients in going back to their previous job, opinion about treatment and rehabilitation and suggestion for both, alternative measures to the present programme and steps to be taken to erase the social stigma attached with the leprosy and an overview of the various types of rehabilitation programmes offered by the NGO.

The major findings of this empirical investigations are discussed in the next chapter.

CHAPTER IV

ANALYSIS AND DISCUSSION

CHAPTER 1V
ANALYSIS AND DISCUSSION

After having interpreted the tables on the rehabilitation taking into account the different background of the leprosy patients cured by the NGO as part of prevention, relief and rehabilitation. It is proposed to discuss certain issues emerging through such interpretation on relief and rehabilitation.

If a leprosy cured patient is sent back to his village, from the hospital, he is not fully accepted by either family or village. Still the concern family and village think that the disease is spreading over to the other people whomever is closely associated with him. Even there are instances cases that individual family keep the cured patient out of the mainstream of the family activities, providing separate bedsheet, (kanni bags) plate, tumbler, minimum utensiles for his daily needs.

The patient will find a berth in animal shed, or outskirts of the house boundaries so, the family thinks including the patient for the economic activities of the family will harm the health of the other family members. So he has been segregated by his own family members and also he would not be able to find employment sources outside the family too. It shows that he has been consider as a burden for his family and also he don't have any social activities to engage himself.

Under these circumstances, if any agency (Govt or NGOs) gives them any financial assistance or loan like maintaining poultry farm, or milch animal or sheep so on, he can look after and earn a considerable livelihood. Which will be helpful to him and his family.

For this purpose, Govt and NGOs are implementing programs of rehabilitation in Tamilnadu. The present study was carried out in Dindigul district of Tamilnadu selecting a NGO. To analyze the programs of rehabilitation and their effectiveness.

The discussion on the major findings of the present study conducted in the DLCC, Nilakkottai are given in this chapter, according to

- i) Socio economic particular of the patients
- ii) Knowledge of the patients on leprosy disease
- iii) The rehabilitation attempts of the NGO
- iv) Problems faced by the patients, and
- v) suggestion offered by the patients

i) THE SOCIO-ECONOMIC PARTICULARS OF THE PATIENTS

The study showed that out of the 90 patients interviewed male patients are more in number constituting 62%. The female are 38%. This finding shows the similarity of earlier studies conducted at National level.

With reference to the age of the patients though the symptoms of the disease leprosy detected much earlier even before their marriage, the severe deformity occurs only when the patients crosses the age of 40.

The reasons may be due to unawareness of medical facilities available to this disease and delay in getting treatment at early stage. Which ultimately leads to heavy deformities.

In some 20 years ago, in the study area soon after the leprosy attacked patients were enable to identify the disease. And approach the medical facilities for curing, the leprosy or some people also concealed the disease even from the parents and other member, in his family because of the prevalence of social stigma, which caused the delay in treatment, only after the laps of around 5 years or so people started coming to hospital, by the time, the disease will be at an advanced stage which will take years to control which will take years to control the disease but not fully cured.

Of all the rehabilitated patients majority (81%) of the patients have got married, of whom many patients knew the symptoms of the disease leprosy. Even before marriage but they had afraid of the disease to disclose. They feared they cannot get married if other members come to know it, they can never get married. some patients were unable to identify the symptoms of the disease

at early stage. Few years after marriage the disease become much visible and lead to severe deformities. The researcher observed two incidences of divorce because of the disease. So people started hiding the disease before marriage, and even after marriage they could not go to hospital for treatment. Because of this delay in getting treatment. It leads to severe deformities.

In the study area it was found that one of the respondents was leading a celibacy life on account of the stigma attached with leprosy disease.

As far as the types of family is concerned, there are only two types of family 1. Joint family, 2. nuclear family. Of which nuclear family is high in number representing 97%.

The family members of the patients rehabilitated under various types of rehabilitation showed that the average family size of the family is 5 constituting majority (70%) of the patients.

The study unfolded that of the 90 respondents interviewed, 57% of the patients live in katcha houses this shows the poor housing conditions of the patients. It is observed that many of the houses of the patient are one room model, without having separate kitchen, bath room.

Regarding the caste of the patients majority of them 58% belong to, schedule caste. The finding of this study coincides with the finding of DR.K.V.Rao, and poor hygienic conditions, may be the reason for more people being attacked by

leprosy.

Since the SC people are known for poor socio-economic condition. They were ignorant of the detection of the disease at early stage and avail curative medical care subsequently.

As far as the religion is concerned 87% of the patients belong to Hindu religion .Since the area selected for the present study is Hindu dominated area.

The educational status of the patients showed that 57% of the patients are illiterates. It is observed that majority of the children of the SC were not going to school, because of their illiteracy and unawareness they don't utilize the available medical facilities at the early stage of the attack of leprosy which lead to severe deformity.

Sources of income of the patients showed that 61% of the patient's family have agricultural cooly works as their sources of income. The finding of the study substantiates the finding of the study conducted in Bombay by Dr.K.V.Rao that agricultural labours and industrial workers are more prone to the attack of the disease .

In the study area there are no much big industries or even small scale industries. People in the area are left with no option. So the most of the people belonging to SC lead their life as a agricultural labours . Even the agricultural work is not a permanent one. The work in the agricultural field will be

seasonal work. During the off-season of the agriculture people face so many problems, their income will be reduced and most of the patients' (61%) family earn Rs 301-600 per month, which is not sufficient to lead their life without any problem. Because the average family size of the patients' is 4-7.

The worst affected section among the leprosy patients are agricultural labours, with low income, where the income do not allow, the patient to spend more money to avail the medical facilities. Another section go for a Siddha medicine and domiciliary treatment, which lead to severe attack of leprosy leading to the a severe deformity at later stage.

Regarding the toilet facilities available in the patients' home, Among 90 patients interviewed, majority (96%) of patients don't have toilet facilities within their house. people in the study area generally used to go for defecation in the open place or some ditch, or pushes or pond. And constructing a latrine in such village is considered as luxurious one and income of the patients and the types of house don't help the patients to construct a latrine. Because of non availability of toilet facilities in their houses, there is a lot of unhygenic condition found in and around many villages.

KNOWLEDGE OF THE PATIENTS ON THE DISEASE

i) Precedence of the disease.

When the patients were asked about the precedence of the disease in their family 64% of the patients answered negatively and the remaining 36% of patients answered affirmatively it shows that majority of the cases were not found in the same family for any of their close relatives. Data reveals that this disease is purely because of the personal habits of an individual, and nothing to do with heredity. If they had known that it is because of heredity the leprosy attacks, they would have taken preventive measures.

ii) The person who identified the disease

It is found that it is leprosy inspector working under DLCC, who identified the leprosy more than the other persons like non leprosy doctor, relatives and neighbours 68% of the cases of the rehabilitated patients were identified by the leprosy inspector during his periodical visits. The non_leprosy doctor has identified the disease when the patients approached the doctor for some other problem on their physic and directed to the leprosy hospital (DLCC). There were some patients who could not identify the symptoms of leprosy because of lack of knowledge about the actual symptoms of the disease. So their relatives, or neighbour who were knowledgeable identified the disease and directed the patient to DLCC.

It shows that majority of the cases were identified by the leprosy inspector during his periodical visit to each

village adopted by DLCC.

As padai(patch) was the (64%) symptoms and other kinds of symptoms are shining_reddish, loss of sensation & sweating, wounding, watering in eyes and painful eyes. It shows that though majority of the cases were identified by the symptoms of patch(first stage of the disease) only because of not taking regular treatment, hiding the disease inferiority complex of the patient, lead to sever deformity.

The researcher approached the leprosy cured patient to find out the in-depth knowledge about the leprosy .He wished to know how many patients are aware of the disease. If they were aware of the disease at early stage of the disease, if they could have tried to take treatment properly thereby prevented the severe defanity.

iii) Whether leprosy is contagious disease:

Responding to this questions out of 90 respondents 69% of the patients said that leprosy is contagious. The remaining patients said it is not.

Until 60s and 70s due to non-availability of medical facilities in rural sector and also drive campaign against leprosy not known to villages people, are of the opinion that leprosy is transmitted to one to another by birth, or direct contact.

iv) Whether children are more vulnerable than adults:

Asking this question to the patients half (50%) of the patients said, yes children are more vulnerable and the remaining half(50%) replied in negative. It shows the ignorance of the half of the patients about the most affected section of people. In fact children belonging to the age group of 4-15 are more vulnerable to this disease than adults. Patients believe that because of poor resistance power of the children they are prone to the attack of the disease.

Question is asked to test the knowledge of the respondent on this disease i.e. Do you know that there are two types of leprosy?

When they were asked this question 82% of the patients replied that they don't know of it. It shows that majority of the patients are not aware of the types of disease. Actually there are two types of leprosy i) Poucli bacillary (PB), ii) Multi bacillary (MB).

From this analysis it is easy to understand that the knowledge about the leprosy among majority of the cured and

rehabilitated patients are inadequate that necessitates health education

Regarding the causes of the disease the researcher found several causes for the prevalence of the leprosy. Of which around (majority) 25% of the patients said that type of pest bite could be the cause for leprosy and the 16% said that

snake bite was the cause for leprosy, followed by 12% of them said that hot temperature was the main cause of leprosy. Besides the above causes there were some more causes as stated by the patients like, God's curse to sin committed or violation of promise, by wound, close association with other patient unhygienic condition in and around the house and village, immoral sexual behaviour, and heredity.

This shows the lack of scientific knowledge about leprosy among majority of the patients. None has said the 'germ' caused leprosy. In fact it is a micro bacterium, a germ is the real cause of leprosy.

As far as the names of the leprosy, it is interesting to know that there are very many local names prevailing in the study area. The names are such as, Padai, Themal, Thozh viyathi, Periya viyathi, Kuttam, Kustrogam, leprosy. Of all the names of leprosy, majority call this disease as "Periya viyathi", they considered this leprosy disease as periya viyathi, (big disease) because it is most dangerous which is incurable in nature disease than any other common disease they knew. Because of severe deformity, long duration of the treatment and social stigma attached with leprosy and ugly appearance and separation from their home, neglected by even their own kith and kin which leads to begging.

It shows that patients are fully aware of the consequences of the disease at later stage and of all disease, leprosy is the

most dreaded disease, affecting all the human beings irrespective of sex, economic condition, social status etc. Regarding the mode of transmission of the disease, about 61% of the patients said that it spreaded over to other person by direct contact and 17% said that it spreaded through air, and the remaining 22% said through water.

It shows that majority(61%) of the patients are aware of the spreading of the disease by direct contact and 36% think that it spreaded to other through air, and water. In fact, the leprosy does not spread through either of this means, in fact only 25% of the cases are communicable (MB) that too through close associates with the leprosy affected patients.

The finding of this study showed that though the NGO selected, have conducted many awareness programme about leprosy, through drama, documentary etc, people still are unaware of the disease & its spread of the disease.

III) THE REHABILITATION ATTEMPTS OF THE NGO

The investigator wished to know the in-depth knowledge of various types of rehabilitation programme undertaken by DLCC and the merits and demerits of the programs and opinion of the patients towards the programme, and collected suggestions to strengthen the present offered programme.

There are five types of programs, which are discussed one by one.

i) DOMICILIARY REHABILITATION:

There are 64 patients interviewed under this programme. The amount of loan sanctioned under this programme is Rs.400.00. Patients were expected to repay it within 10 months, the amount of repayment per month is Rs. 50/-.

The loan was given for different purpose like for the purchase of goat and sheep, setting pettishop and cycle repairing shop. Of which majority of the patients have been benefited by purchasing goat/sheep constituting 75%.

When they were asked about the sources of their repayment of loan, 67% of them have repayed through earning by agricultural cooly. Because, the yield of a goat or sleek will take a long time, they could not repay the amount directly through the income of goat or sheep. So they repayed it by the agricultural cooly work in their villages. For the patients benefited through pettishop and cycle repairing shop repay the loan through their respective sources and 81% of the patients have repayed the loan at the time of interview.

It shows that most of the patients were in a position to repay it, because the DLCC have selected the patients according to their repayable capacity and it has been observed that the patients had known that if they repay the amount borrowed previously they can get second time loan for some other purpose, and it was said that only if the patients complete the loan regularly they could avail the medical facilities in DLCC

otherwise they will not be given any treatment for any other disease. There is only one leprosy hospital in this area so the patients have to come to this centre for any reasons. And repayment of loan is compulsory for availing for the medical services from DLCC. Patients are very particular in repaying the amount properly. So, the compulsion of the treatment for the purpose of availing treatment is not a proper way of getting the loan back.

It is found that of the 90 patients 61% of the patients have received second time loan and the some patient is given loan thrice when there are patients who is not given for not even a single time. It is because of his economic backwardness and inability to repay the amount.

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Regarding the advantages enjoyed by the patients in Domiciliary rehabilitation, 81% have said that loan without interest is the advantages. In the study area people can't barrow money even from the neighbours and relatives without interest. So patients have benefited to the extent of loan without interest making investment for gaining reasonable returns wonder this scheme only the interest free loan.

As far the problems faced by the patients, half(57%) of the patients felt that money sanctioned is not sufficient.

Patients feel that, it is difficult to purchase two goats\sheeps with Rs. 500/- and they have to spend the whole day for looking after them and many patients had added the additional

amount needed from their own source of income to purchase a goat.

And so, of the total 90 respondents 31% have suggested to increase the amount of loan in the domiciliary rehabilitation and adjustment in repayment is needed. It has been observed that at times the defaulters are threatened by harse words to ensure the prompt repayment.

ii) DAIRY REHABILITATION:

Sivaganapuram is the village where this programme was introduced for the first time. The DLCC has selected poor / cured patients they were given Rs. 4,000/- (each Rupees four thousand) with the repayment of Rs. 250/- per month the loan was given for the purchase of the milch animals. During the dry season, six other patients were selected, to equalise the income. All the milch animals are insured by the DLCC. The total number of beneficiaries at the time of interview was 14, the number of patients interviewed for the present study is 10. Of which except 40% all patient repayed the amount through yield of milch animals, Totally 70% of them have repayed at the time of interview. Regarding the merits of this programme half (50%) of the patients said that loan without interest, and financial assistance without security is the advantages.

Regarding the problems faced by the patients in this programme 60% said that non-availability of fodder and medical facilities are the major problems and the remaining 40% said that compulsory repayment is the problem.

The DLCC provides only loan for the purchase of milch animals but not only assistance to fodder and there is no veterinary facilities available in and around the village. Patients feel difficult in maintaining the milch animals without fodder and medical facilities for the cattle in this village.

So they (50%) suggested to provide medical facilities with fodder and the remaining wanted that there should not be repayment at all. When compared to assistance provided for the purchase of goat and subsequent problem in repayment the assistance provided for dairy is comparatively better as there is 70% of the repayment and the patient are satisfied with this development assistance provided for their rehabilitation.

iii) TAILORING REHABILITATION:

This programme is meant for ladies from poor family, cured patients or daughter of severely deformed patients unmarried. And the girls educated upto VIII std are given preference. There is a training centre in DLCC and the duration of the training is about 6 months. During this period they are provided with free accommodation and training. After the training is over they will be given a certificate and a machine costing Rs. 1250/-. The patients have to repay the loan at the rate of Rs. 50/- per month. The total number of patients benefited so far is 81. Of which 8 have been interviewed. Of which 5 patients have repayed the loan through agricultural cooly work in their villages only 3 patients could repay the

loan through the income of tailoring. It shows that it is very difficult to earn more money through tailoring work in the villages. It is a part time job, Most of the girls go to agricultural cooly work in the day time during agricultural season and during off season they have to depend mainly on tailoring. It was difficult for the poor girls to get more work in the villages. People in village generally go to the near by town and purchase cloth and give it for stitching there itself. So many girls feel that, if they establish a small cloth store in their house itself, it will be easy to have more work so that income through tailoring will be increased. Furthermore during the training stitching of gents (male) dresses are not taught, they are trained with only ladies items, so it is not a full-fledged training. If they had been given training for gents dress too, they feel that they could have earned more money which may be very much helpful to their family. So 75% of the girls have suggested to provide financial assistance to establish a small cloth store in their village itself.

It has been observed that, after the training was over, the parents or the guardians of the trainees were called by the DLCC officials and were asked to put a signature in the agreement that, they are responsible for the repayment of the loan (machine). They were snapped with the machine and the patients for security purpose. Since the girls are unmarried they may get married before the loan is completed even if they go out of their village after marriage their parents have to repay it. This is what the main purpose of calling the parents and getting the

signature and photo with them.

The investigator has observed that there are 2 cases of this kind in the study area where the parents are repaying the amount.

Since there are problems, experienced by the trainees, the intended purpose of the total rehabilitation of the patients' family is not fulfilled.

iv) HOUSING LOAN:

The loan programme was started in 1983, the total number of beneficiaries, are 27 in eight sub-centres. Every patient is given Rs. 10,000/- to 15,000/- for the construction of new house. Documents related to house and lands are pledged as a security. The loan is repaid through installments. The amount of the repayment Rs. 200/- per month in the case of Rs. 10,000/- and Rs. 250/- is for Rs. 15,000/-. Once the loan is repaid the documents will be returned to the patients.

Under this programme 5 patients have been interviewed. In this programme 4 patients have repayed the loan through agricultural cooly work in their village.

It is obvious that since the construction of new own house in the village is unproductive, they can't get any income from it. So they had to repay it through agricultural cooly work, Patients under this programme felt that getting Rupees 10,000/- to 15,000/- is not a imaginable amount in the village without interest. So, they felt it an advantage.

As regards the problems faced by the patients under this programme are, the loan sanctioned for housing is not given in lumpsum but in installments which hindrance the construction of the house without delay and the fixed amount of Rs. 10,000/- or 15,000/- is not sufficient to construct a house. Patients felt that they had again borrowed some money from their neighbours. Some times, construction of the house was stopped in the middle of construction because of the lack of money. So they want the money to be sanctioned at once.

v) BANK LOAN

DLCC has assisted three patients to seek financial assistance from some of the nationalised bank operating in the area, in addition to their programme of rehabilitation. This programme was started in the year 1986. Leprosy cured patients are given loan through Canara Bank and State Bank of India. The loan is used for the purchase of milch animal and goat for the establishment of pettishop. The patients are selected on the basis of their regularity in getting treatment during the attack of leprosy.

Under this rehabilitation programme, 3 patients were interviewed. Each patient was given Rs. 4,500, for the purchase of milch animal, setting of pettishop and running cycle repair shop.

Of whom 2 have repaid. One patient was about to complete (at the time of interview) the loan to the Bank. These patients are not given directly by the DLCC. But were

recommended and guided to the bank, and patients have received the loan through the banks. The DLCC are nothing to do with the repayment, and completion of loan.

Regarding the problems faced by the patients in these rehabilitation, 2 patients have said that the amount of the loan is not sufficient for the rehabilitation and one wanted that there should not be repayment at all.

It is observed that generally patients don't care about the repayment of the loan to the bank, because the bankers are not compelling the patients to repay it where as patients got loan from DLCC directly are threatened by the staff of DLCC. So, these patients (who received loan from the bank) are free from the clutch or the compulsion of the staff of DLCC. But they also wanted the amount of loan to be increased.

To sum up , the rehabilitation programme undertaken through DLCC, though yielded benefits, in the long run but considering the terms and conditions, the patients seem to struggle hard in the repayment of the loan assistance within the stipulated period. A part of their regular income earned through agricultural coolly work goes towards the repayment prior to reaping the actual benefits flowing through investment they made.

IV PROBLEMS FACED BY THE PATIENTS IN THE STUDY AREA

Though the leprosy patients are given free food accommodation and treatment. Still there are some problems identified with leprosy patients at various stage of their life because of the nature of the disease and the wrong notion of the public/society about the leprosy disease is general and the patient attacked by leprosy in particular.

1. Problems faced by the patients during the treatment.

As far as the problem faced by the patients during their treatment period. 23 % said that though they were getting tablets in the village itself they are expected. to be in the village to avail the .medical services during day time on the day of visit by the medical team of DLCC which reduces the income of the patient.

It shows how much the family depended on the patient's support, such a family can't offered to forgo the earning of the patient .

It is observed in some cases who were severely deformed and hospitalized, when they were hospitalized the burden of earning livelihood and looking after their family falls on the wife, Because of added responsibility the wife is forced to neglect visiting her husband as often she wants to. So, financial assistance to family members of the patients is essential during the treatment period.

As far as the feeling of the patient, at the time of the identification of the disease, 58 % have felt bad to inform to the other family members in his family. It is observed that patients felt comfortable with the doctors, leprosy inspector and social worker to talk about the disease and treatment but with family members and neighbours.

It shows the prevalence of social stigma from both patients and the public also. Immediately after the identification of the disease leprosy patients were given tablets from the leprosy inspector directly. As already started majority of the patients delayed treatment which head to serve deformity. But now the leprosy workers are very keen in making the patient to take treatment regularly. The patients were asked to take tablets in front of the leprosy Inspectors. In many cases, leprosy Inspector himself administered orally fearing that the patients may not take the tablets once they left. So that the default is prevented.

Regarding the reaction of the family members of the patients after the identification of the disease, majority (33 %) patients said that their family members had started concealing the disease to other members in the community and 30 % of the families had insisted them to go to hospital for treatment, 18 % of the patients said that their family members had taken it normally. It shows their awareness of leprosy and they felt that if we take regular treatment it can be cured, so, getting treatment regularly is very important. The awareness is mainly because of the regular visit visit and education by the NGO.

The fact is that majority of the family had started concealing the other members. Because they think that the society will ill-treat the family in various aspects not having connection with them and may not take and offer bride or groom to their family and neglecting the patient in an important social gatherings and the society will look at the patients and his family as dangerous and untouchables and they are much aware of social boycott in general.

ii) PROBLEMS OF THE SEVERELY DEFORMED LEPROSY PATIENTS

The main aim of rehabilitation is to integrate the patient in the family, or help him to go back to his home and lead his life as usual by providing some financial support. Unfortunately there are problems faced by the leprosy patients even after the rehabilitation.

The researcher collected information on various problems faced by the patients in the selected area. Of the total 90 respondents (patients) majority (42 %) of the patients said that patients are given separate plate, cot and other utensils for daily usage inside of their house 36 % of the patients said that patients are isolated from his home he can't have any close association with other family members in the family. And there are 2 cases of school - drop outs, and 3 incidences of divorce between the coupler, because of leprosy attack and the remaining have said that they could not have any public contact with others in and out side the village.

This shows that, people in their area still keep distance with leprosy patients fearing that, close association with patients would cause leprosy. The investigator observed that some patients quoted the incidence of the famous poet and patriot. Subramania Siva patriot, who fought for Indian independence, who was put into prison with severely affected leprosy patients later he was died by the attack of leprosy.

Some patients quoted that there is a film in Tamil "Rathakkanneer" The English translation of which is "Blood Tear". In which the hero was neglected by his close friend after the attack of leprosy After becoming severely deformed he was given separate place, and plate, cot, and other materials needed for his daily use, After some days when the deformity became more severe he himself goes out of his home, and suffered a lot without food, Beedi and so on . And nobody helped him during his last days. Finally he was died on the road. The theme of this film has impressed people negatively and it is known to almost 80 % of the people in Tamil Nadu either in terms of film or drama.

It is important to note that, mass media plays very important role to change the attitude, and generate awareness to the public, the film "Rathakkanneer" was screened almost all village in Tamil Nadu during festival season or else. Most of the people are known to the theme of this film, when even people see a leprosy patients, the image of the hero of "Rathakkanneer" comes to ones mind. The film projected the idea that the attack of the disease is due to sin committed by the individual. So the cause and mode of transmission of the disease and consequence of the severe deformity are all well known to the people through this film, which is deep rooted in the minds of the public. So it will take some years to erase to stigma attached with leprosy in their area.

It was observed by the investigator that there are boards hanging at the entrance of some small hotels that "Periya viyathiar (patients affected by leprosy) are not permitted .They were subjected to social discrimination in public places.

Quoting all these incidences people think that leprosy is a dangerous and communicable disease and patients are considered as inhuman in the society.

Regarding the problem of the patients in going back to their previous job (agricultural coolie work) in the villages after the attack of leprosy and cured, nearly half(42%) of the patients are needy to go back to their previous job and continue it as before. Since they are not attacked much, but they said that their employer did not allow them to join back fearing that the disease will attack other worker area.

Basically patients are daily worker, they have to work regularly so that they can lead their life, if they lose the work, the family incomes comes down, when the income of the family becomes low, obviously their life style, standard of living, will decrease leading to poverty unhygienic condition, Finally he migrates his village.

It is observed that the patients themselves feel inferior to attend any social factions in the community par with others. This means that the patients after cure are not completely rehabilitated though they are given some financial support of the family through different types of economic rehabilitation like domiciliary, Dairyetc., the social rehabilitation yet to take place among the patients since the DLCC has not done any sincere effort in this regard. The lack of education among villagers and because of high illiterate, social rehabilitation has not been possible in the study area along with

helpful employment and income source health education very much essential for social rehabilitation for the leprosy cured patients.

To understand the willingness of the patients to live in the midst of the family members or to live alone, a question was posed, According the response was only 36 % patients wanted to live alone. when they were asked the reasons why they wanted to live alone, majority of the severely deformed patients having psychological feeling that if they give much trouble in the form of mixing with family members. it might harm their survival in the family and they fear that they may loose self respect from their family members.

They further said that as long as they are away from their home, (nearly or outside the home) they will get due respect, due share of food for their survival.

This data establishes the fact the psychological strength has not been recognised by the rehabilitation programs, because, the rehabilitation programme offered by the NGO are a partial in nature. Developing the strength in the minds of the patients is very important. It can be developed on the basis of health education as well as rising educational status among the community.

FACTORS RESPONSIBLE FOR THE ACCEPTANCE OF THE CURED PATIENTS IN
THE FAMILY AND COMMUNITY

When the patients were asked about the factors that are responsible for the acceptance of the patients, almost half (46 % of the patients said that if the patients are economically helpful to his family he will be accepted, 17 % of them said that if there is no symptoms of leprosy on the body of the patients, he will be accepted and 2 % of them said that if the patients happened to be the head of the family, he will be accepted 11 % of the patients, responded that if the patient is a child, he will be accepted, apart from the above factors, there are another two factors such as if the family has more cattle, and family has more member in the family to take care of the patients, said by the 5 % and 14 % respectively.

It shows that majority of the people expect the patient to be economically helpful in any way. Economic status of the patients desires the acceptance of patients the community. The analysis shows that 14 % of the patient said that, patient will be accepted provided there are more members in the family to take care of the patients. Here it is important to note the observation made by the investigator that, severely deformed patients can't take his both on his own, and wash his cloth, and clean his utensils, he require a separate person to be looked after. It is difficult in the families where there are only 2 or 3, members. So they felt difficult to took after the patients timely regularly. Since the majority of the patients feel that

economic source is the main factors for acceptance of the patients, the patient should be in a position to earn and support the family from permanent employment.

iv) Dependency of the patients on rehabilitation Programme.

From the response of the respondents to this question, it is found that 63 % of the patients are not depending mainly on this rehabilitation programme. Only 27 % of the patients accepted that they are depending on it.

It clearly shows that, the majority of the patients selected for the rehabilitation programme are capable of living even without the help of this rehabilitation, it was observed during the interview that the organisation (NGO) had selected those patients who can repay the amount of loan. The organisation (DLCC) was very particular in getting the money back from the patients. As started earlier majority of the patients under various types of rehabilitation programs are capable of repayment.

The reason for not selecting the very poor patients are that if they are given loan, they may spend the money without the knowledge of the family members the family members will not repay the money borrowed by the patients or the severely deformed patient may migrate their village.

There is no guarantee for repayment, since he himself cannot do any work there is no possibilities of getting the money back. So the organization had selected the patients who have security to repay and capable of repayment.

Because of which many patients who are really in need of are not benefited under their rehabilitation programme. So, majority of the patients benefited under this programme are not mainly depending upon these programme alone.

QUALITY OF TREATMENT:

As far the quality of treatment provided to the patients is the hospital to cure the disease. Through there are different aspects impressed the patients, like free food and accommodation, kindness of the doctors & nurses, medical care and dressing, separate place and recreation facilities available the hospital, Majority (40 %) of the patients said that the medical care and dressing and regular supply of drugs, tablets cleaning of wounds were impressed them much.

It is observed that most of the patients appreciated the officials leprosy workers in the hospital, saying that they were treated the patients with a humanitarian touch. Further adding "Doing such ugly work without expecting any thing form the patients is really impressed the patients much and most of the patients considered the leprosy workers as a mobile God.

As far as the opinion about the treatment is the hospital majority (87 %) of the patients as highly satisfied with the medical care extended to them in the DLCC.

It shows that the treatment n DLCC were very kind and helpful and enthusiastic, and committed people to leprosy patients. So, the way the treated the patients during their treatment period is highly commendable, which is why majority of the patients are satisfied with treatment provided by the DLCC.

v) ALTERNATIVE REHABILITATIVE MEASURES :-

When the patients were asked to suggest some alternative measures to the present rehabilitation programs. 26 % of the patients suggested to give some financial assistance for vegetable selling and 23 % of the patients wanted to work in the horticulture 13 % of them wanted to establish cycle rental shop leprosy were and installation of telephone were suggested by 6 %, 4 % of the patients respectively 7 % told that they can't do any work and 20 % of the patients said that they don't know of any work.

Regarding the suggestion offered by the respondents to improve the treatment facilities. 81 % of the patients suggested that the duration of the treatment may be shortened, and 10 % wanted DLCC to establish a canteen within the premises.

It shows majority of the patients wanted the duration of the treatment for leprosy should be shortened. It is observed the patients generally felt difficult to continue the treatment for a long time, because of which they lose the confidence that the this disease will get cure completely If duration of the treatment is short, patients will be in a position to sustain the treatment until they get cured.

It has been seen that the MDT has developed a lot of confidence among the patient and the MDT has reduced duration and the rate of deformity among the patients.

It shows that majority of the patients like to sell vegetables. All the alternative measures to the present rehabilitation programme suggested by the patients are not involving heavy work. Which will not further cause deformity.

Suggestions to erase the social stigma attached with leprosy the responses of the patients were many such as, social stigma attached with leprosy can be erased through documentary film, through street play drama, Demonstration by cineactor (like polio) through wall posters, and people themselves should change their attitude towards leprosy and the patient affected by leprosy.

Though there are many means to erase the social stigma attached with leprosy. Majority of the patients said that unless people themselves change their attitude towards leprosy, no other measures could be erased this social stigma.

The result of this study, shows that, patients knowingly or unknowingly, directly or indirectly want the health education to play very important role in it.

So Health education, leading to community based rehabilitation should be introduced.

CHAPTER V

MAJOR FINDINGS

CONCLUSION

&

SUGGESTIONS

MAJOR FINDINGS, SUGGESTIONS & CONCLUSION:

The study on the topic, namely, " Rehabilitation of Leprosy Patients in Dindigul District, Tamil Nadu - A Sociological Analysis" is an attempt to investigate the major areas involved in leprosy cured patients and rehabilitation measured undertaken in the direction of total integration of patients in a society marked by strong influence of religious values norms, traditions and customary practices. The study attempted to study all these aspects pertaining to leprosy treatment cure and rehabilitation routed through the selected NGO.

The major objectives formulated for this purpose have been fulfilled through empirical investigation carried out on this aspect.

The first objective is to study the socio-economic condition of the leprosy cured patients in the study area.

The second objective is to study the knowledge of the patient about the leprosy disease.

The third objective is to make a comprehensive analysis and the socio-economic rehabilitative measures carried out by the NGO selected.

The fourth objective is to highlight various problems faced by the leprosy cured patients in the study area..

The fifth objective is to offer suggestions to strengthen the programs of rehabilitation.

The major findings of the present study have been presented here under.

1. The total number of patients interviewed under various types of rehabilitation is 90. Of whom majority (71%) of the patients belonged to domiciliary rehabilitation.
2. Of the total 90 patients interviewed male are more in number constituting 62%.
3. It is found out that of all the age group the severely deformed patients are in the age group of 40-51.
4. Regarding the marital stage 90% of the patients have got married.
5. The study showed that agricultural cools labors are the most vulnerable(61%) section of the deformed patients in the study area.
6. Of the 90 interviewed it is found that, of the families almost all 97% families (except 3%) are nuclear family.
7. Majority (79%) of the patients' family (47) maintain the average family size.
8. Regarding the types of residence majority (57%) of the patients live in a Katcha houses.
9. As far as caste is concerned of 90 respondents interviewed majority (58%) of the belonged to Schedule Caste.
10. Regarding the religion, of the total 90 respondents Hindus are more in number.(87%)
11. The educational status of the patients exhibited that majority (59%) of the patients are illiterates.
12. From the finding of the study it is understood that except 3 patients none have toilet facilities in their house itself.
13. The study unfolded that almost all the patients are taking non-vegetarian food in the study area.
14. The overwhelming number of the patients' family earn an average income is Rs.500/-per month.

15. It was inferred after the study that patch was the easily identifiable symptoms of leprosy at initial stage of the attack of leprosy as attributed by majority(64%) of the patient.
16. Early detection was done by the leprosy inspector in a majority (68%) of the cases .
17. Regarding the Knowledge of the patients about the leprosy it is found that 69% of the patients think disease that is a contagious one and exactly half of the patients (50%) have known that children are more vulnerable to this disease than the adults and most (81%) of the patients don't know the two types of leprosy.
18. It is interesting to know the finding of the study that regarding the cause of the disease leprosy, majority (28%) of the patients responded that Pest bite is the main cause of leprosy.
19. As for as the name of the disease in the area is concerned, majority (28%) of the patients call the disease as "Periya Viyathi" (Big disease).
20. Of all the ways attributed by the patients for the mode of transmission of the disease, Majority (53%) of the patients believed that direct contact is the main mode of transmission of leprosy.
21. Taking into account the desire of the patients if they liked to live alone from their house majority (64%)of the patients wanted to live alone. The main reason for which they wanted to live alone is to not to spread the disease to other members in the family.
22. The finding of the present study showed the factors that are responsible for the acceptance of the patients. Of all the factors most (46%) of the patients revealed that provided they are economically useful to their family.
23. The study showed that 63% of the patients(majority) are not depending mainly on the rehabilitation are not offered by the NGO selected because of the meager loan amount.
24. From the study it is observed that among all facilities available in the hospital the majority (46%) of the patients were impressed by the medical care and dressing work of the doctors and the nurses in the hospital.

25. Regarding the opinion of the patients towards the treatment offered by the NGO selected (DLCC) 87% of the patients are satisfied with the treatment given by the NGO selected (DLCC).
26. As for as the problems faced by the patients during their treatment period 23% of the patient have felt that their family income was reduced during the treatment in the hospital.
27. In the case of the feelings of the patient immediately after the identification of the disease(58%) of the patient felt very sad to reveal the attack of disease to their family members.
28. As regards the reaction of the family members after the attack of the disease, majority (33%) of the families have concealed the disease to the other neighbours/relatives.
29. Regarding the problems faced by the severely deformed patients in the study area, Majority of the patients felt that providing separate plate, cot and utensils inside or outside the house is the sign of keeping distance, which is Psychologically a big problem.
30. In case of the problems faced by the patient in going back to their previous job after getting cure of leprosy. The study showed that majority (42%) of patient are ready to go back to their previous job but the employer did not accept/permit the patients to continue their previous job. The patients find it difficult to go back to their previous job which they were performing previously.(Agricultural coolie work)
31. Taking into account the suggestion offered by the patients to strengthen the treatment process, Majority (81%) of the patient wanted the duration of the treatment should be reduced.
32. As for as opinion of the patients rehabilitated under various types of rehabilitation on their rehabilitation program 69% of the patient are not satisfied with the programs offered presently by the NGO selected.
33. In the case of an alternative rehabilitative measures, as stated by the patients, most (26%) of the patients are interested and they suggested that vegetable selling is the suitable alternative measures.

34. Regarding the steps to be taken by the Govt and NGOs to erase the social stigma attached with leprosy. Though there are different kinds of steps revealed by the 90 respondents interviewed, majority (26%) have believed that no other measures could be possible to erase the social stigma attached with leprosy unless the people themselves change their attitude towards leprosy and the patients in the society.
35. As far as the rehabilitation is concerned majority(69%) of the patients have rapid their loan in all types of rehabilitation.
36. The main sources of repayment of the loan under various types of rehabilitation is agricultural coolie work for majority (75%)of the patients.
37. Loan without interest and low interest are loan is the advantages of the majority of the patients enjoyed in domiciliary, dairy, housing and bank loan rehabilitation programs.
38. Free accommodation and training are the advantages enjoyed by majority(63%) of the patients in tailoring rehabilitation.
39. Insufficient of loan is the main problems of the patients in dairy and bank loan rehabilitation
40. Non availability of fodder and veterinary facilities for the cattle are the main problems of the half (50%)of the patients in dairy rehabilitation.
41. Irregular work is the main problem in the tailoring rehabilitation for majority (38%) of the patients.
42. Providing loan in installments is the demerits in the housing rehabilitation for 60% of the patients.
43. Majority of the patients in domiciliary, housing, bank loan rehabilitation suggested to increase the amount of loan .
44. In the dairy rehabilitation majority (50%) of the patents suggested the fodder and veterinary facilities for the cattle may be made available.
45. In the housing loan rehabilitation majority(80%) of the patients suggested that the amount of loan should be given at once.

CONCLUSION:

In Dindigul District, there are 3 organisations (NGOs) working for the rehabilitation of leprosy patients. Of which the selected NGO (DLCC) has been working for a long time than the other two NGOs in their District. The DLCC provides treatment for leprosy and rehabilitation measures for leprosy cured patients. As far as treatment is concerned, the NGO is doing commendable work. Most of the patients are satisfied with it. But regarding the rehabilitation, patients are not fully satisfied with the rehabilitation programs presently available in this NGO. The nature of the rehabilitation programme is individual based, and only economic assistance is given to the cured patients. Integration of the patients in the community / Society can only be achieved by the collective efforts of the patients, the medical, paramedical, and social worker and society as a whole.

The various types of rehabilitation programmes offered by the NGO, end with helping the patients economically. As a matter of fact that, leprosy affects not only the body of a patient but also oppresses the minds of the patients, they feel, fear, shame and insecurity some times than themselves desire to isolate, and hide themselves. Thus they become depressed and lose their interest in themselves and their surroundings. So besides economic rehabilitation social and psychological rehabilitation should also be provided, community - based rehabilitation could be implemented.

Since the leprosy disease, which was ridden with wrong notion for many centuries, society the in study area still has its own inhibitions to fully accept the patients normally, so the health education to both, family members and the society is would go a long way to educate and demonstrate the correct ideas about leprosy in society and the acceptance of the leprosy patients. The problem of leprosy therefore needs to be approached from various angles.. But because of paucity of funds, the NGO selected (DLCC, Nilakkottai) is unable to live upto to expectation of the leprosy cured patients in the rehabilitation with the view to experience self reliance and economic development through self employment. Patients expect some more concrete measures in their direction for which the Government must come forward to fulfill the expectation in to larger interest of not only rehabilitate the patients but to promote the integration of the patients and thereby preservation of social health in the society at large.

SUGGESTIONS

The study based upon the findings has come out with certain suggestions for improving the socio-economic conditions of the patients and their integration in the larger society in the form of undertaking certain concrete measures in this direction.

- All types of rehabilitation offered by this hospital are individual based and so, community based rehabilitation, covering Socio-psychological aspects of rehabilitation could be introduced.
- The rehabilitation programmes must yield benefits to all patients irrespective of their personal background.
- More funds should be sanctioned for different types of Rehabilitation especially for domiciliary and housing.
- Adjustment in repayment of loan in all types of rehabilitation is needed.
- Since the patients have expressed in domiciliary rehabilitation the amount at present is too meager to make investment for gaining a reasonable flow of income, the amount is to be raised to atleast Rs. 2,000/- each.
- The repayment of loan must commence once the patients start reaping the benefits from the investment they made.

- Assistance to get contract work like school uniform, or regular order for tailoring should be arranged and marketing facilities may be arranged.
- In the dairy rehabilitation, Fodder and Veterinary facilities for cow should be made available.
- The amount of loan given to the patients under housing rehabilitation needs to be increased. The Government can also assist these patients by building houses under its programme of IRDP.
- The Government should reserve some jobs for the educated/skilled patients with view to create self-employment.
- The total integration of the patient after rehabilitation should be developed through economic activities and self-reliance.
- In housing rehabilitation apart from loan, materials related to house building, may also be provided or help them to get them.
- Second time loan should be sanctioned to all who are badly in need of in all types of rehabilitation.
- Periodical follow-up is necessary to see whether the money is being used properly.
- Periodical visit of the staff of DLCC must be sometime which does not affect the regular work.

- Alternative programmes can be implemented.
- Stipends to all trainees undergoing training in voluntary agencies should be provided.
- An integrated approach involving inter sectoral co-operation should be adopted in rehabilitation of leprosy patients and to eliminate stigma.
- The rehabilitation worker must keep in close touch with each industrial co-operative, mutual support grouping should be encouraged.
- Teaching facility should be established to teach the medical student on leprosy recent advantages and strategies.
- In addition to free medical care and drugs social assistance should include, assistance for travel to and from the clinics, help for families in which, the bread winner is unable to work and job placement for discharged patients.
- People should express sympathy towards the patients instead of abuse and hatred.
- Health education, and awareness programme should be given much important to erase the social stigma attached with leprosy. To the community around the leprosy patients.
- Patient / Family members must be informed through mass media that leprosy is curable.

- Health and Extension Education on prevention, cure of leprosy in the study area must be undertaken in a machinery zeal.
- Social worker should be appointed for educating the public.
- Mass media, News Paper, Film show exhibition should be made available to enlighten the people about the scientific knowledge about leprosy.

APPENDICES

- I. HISTORICAL BACKGROUND OF LEPROSY
- II. LEPROSY INFRA-STRUCTURE FACILITIES IN TAMIL NADU
- III. DINDIGUL DISTRICT PROFILE
- IV. LIST OF NGOs WORKING FOR REHABILITATION OF LEPROSY
PATIENTS IN TAMIL NADU
- V. ACTIVITIES OF THE SELECTED NGO (DLCC NILAKKOTTAI)

BIBLIOGRAPHY

INTERVIEW SCHEDULE

APPENDIX NO.:I

HISTORICAL BACKGROUND OF LEPROSY

Leprosy, one of the oldest scourges of mankind, is not a disease of modern civilization and Industrialization as AIDS. Most probably Leprosy originated in India and the first authentic description of different types of leprosy comes from India. Leprosy was described as "Kushtha" in Sushruta Samhita written in India in 600 BC. According to Vagbhata (600 AD), the name "Kushta" was derived from "Kushnati", which means eating away in Sanskrit.

In China leprosy was first recorded in the Nei Jing. One of the earliest Chinese medical classics (400 BC), in which its clinical features were described under the name "Da Feng". The earliest Japanese references to leprosy are also from the 4th century BC. The first indisputable evidence of bone involvement due to leprosy was found in an Egyptian mummy of the 2nd Century BC. Pompey's soldiers returning from Egypt (62BC) are said to have brought leprosy to Italy.

It has been described in Skeletons of Egyptian mummies from the 5th Century AD. Moller-Christensen has demonstrated the occurrence of the leprosy in Skeletons unearthed from Church burying-grounds associated with leprosy hospitals in Denmark, from as early as 12th Century.

The disease was probably brought to the mediterranean region by the soldiers of Alexander the Great returning from their Indian Campaign in 327-326 BC. At the beginning of the 13th Century, leprosy was common in Europe, from Iceland to Italy and at that time there were about 19,000 leprosy hospital in Europe. Leprosy started decreasing in Europe from the 15th Century, probably due to better hygiene and housing as living standards improved.

Leprosy was first introduced into America in the middle of the 16th century by immigrants from Europe. Later, slaves from America took this disease to the Americas, especially Brazil.

Leprosy is thought to have reached its peak in Europe during the 16th Century. Endemic leprosy disappeared from Northern Europe at the end of the 19th Century.

There is some evidence, for example, that an epidemic of leprosy occurred in the Eastern provinces Nigeria from the 1920 onwards.

Today this disease is still found in Portugal, Spain, Italy, Greece, Turkey, Cyprus and Southern Russia.

Americas<--Rest of Europe<--Greece<--India-->China-->Korea-->Japan
 \Africa/

Possible routes of spread of leprosy.

APPENDIX NO.:II

LEPROSY INFRA-STRUCTURE IN TAMIL NADU:

(According to 1992 report)

Govt. Leprosy Control Unit	- 102
Survey Education & Treatment Unit	- 20
Urban Leprosy Centre	- 80
District Leprosy Officer's office	- 23
Voluntary Organisation	- 33
Temporary hospitalization wards	- 52
Leprosy Training Centre	- 14
Leprosy Rehabilitation & promotion Unit	- 1
Sample Survey and Assessment Unit	- 7
Reconstructive Survey Unit	- 9

APPENDIX NO.: IV

IMPORTANT VOLUNTARY ORGANISATION WORKING FOR REHABILITATION

IN TAMIL NADU (DISTRICT WISE)

MADRAS:

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1. Gramaltes Referral Hospital & Leprosy Centre, Shenoy Nagar, Madras.
2. German Leprosy Relief Association, Shenoy Nagar, Madras.
3. Leprosy Relief Work, Emmaus, Switzerland, Shenoy Nagar, Madras.
4. The Voluntary Health Services, Adayar.
5. Hindu Mission Hospital, 36, G.S.T. Road, Tambaram.

NORTH ARCOT:

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1. I.E.L.C. Leprosy Control Project, Mission Compound, Ambur.
2. Rawttak puram Hemarjick, Rural Centre, Aurovilli.
3. St. Thomas Hospital & Leprosy Centre, Chettupattu.
4. Shieffelin Leprosy Research & Training Centre, Karigiri.
5. Worth Trust, 41, Thirukkalam Road, Katpadi, North Arcot.
6. CHAD Hospital, Leprosy Control Programme, Christian Medical College & Hospital, Vellore.

SOUTH ARCOT:
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1. The Leprosy SET Centre,  
The Leprosy Mission,  
Vada Thora Salur Tiyaga drug.
2. Sethi Nilayam, Rural Hospital and Leprosy  
Control Centre, GST  
Vellore, Muttathu.

PERIYAR:  
~~~~~

1. Assisi Leprosy Hospital Centre
Talavadai.
2. Christian Hospital,
Medarappakkam.

CHENGALPATTU:
~~~~~

1. Dinapandu Medical Mission,  
R.K.Pet, Chengalpattu.

KANCHEEPURAM:  
~~~~~

1. Kastarba Kusht Nivaran Nilayam,
Malavandangal, Kancheepuram.

SALEM:
~~~~~

1. Leprosy Relief Rural Centre,  
Settipatti, Rawlta Kuppam.

TRICHY:  
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1. Holy Family Hansenorium,
Fathima Nagar, Trichy.
2. C.S.I. Medical Leprosy Centre.
Vandavasi.

TANJORE:
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1. The Society of Sacred Heart,  
Leprosy Centre, Salakkattai,  
Kumbakonam.
2. The Kumbakonam Hind Mission Hospital,  
13, Mutt Street, Kumbakonam.

MANAMADURAI:  
~~~~~

1. The Leprosy Mission Hospital,
Dayapuram, Manamadurai.

TUTICORIN:
~~~~~

1. St. Joseph's Leprosy Hospital,  
Arokyapuram, Tuticorin.

MADURAI:  
~~~~~

1. Arokyapuram, Andipatti, Peryakulam.

DINDIGUL:
~~~~~

1. Christian Fellowship Community Health Centre,  
Ambiligai. Dindigul District.
2. Poorna Suga Leprosy Project,  
St. Joseph's Hospital, Dindigul.
3. Damien Leprosy Control Centre,  
Drowiya Nagar, Nilakkottai.  
Dindigul District.

## APPENDICES-V

### ACTIVITIES OF DLCC-NILAKKOTTAI

#### HISTORISITY LEPROSY CONTROL CENTRE AT NILAKKOTTAI:

Damien leprosy Control centre was started July 2nd in 1969, that time Rev. Justin Diraviam was the Arch Bishop of Madurai Diosis. He decided to minimise the leprosy in that diasise. Congregation of inoculate conception was founded, in this Sr. Ernestin Mary was the mother superior thought about the leprosy. Due to their decision (solutions) Sr. Ernestin sent two sisters from her congregation for the training in the leprosy. After the training period the two sisters had started their service in few villages in the initial stage it was found in Silukuvarpatti, then it shifted into Batlagundu. In Batlagundu, these two sisters were seated strong and covered the nearby villages like Pattiveeranpatti, Kallupatti, Vengadastrikottai. In that villages they have covered and continued/identified about 20,000 population during that the prevalence rate was 23/1000 persons.

This devoted/dedicated service was ran smoothly and find successful, so the mother superior decided to sent another two sisters in their congregation for further training on leprosy, after the training in 1972, they covered Ammapatti about 20,000 population and also covered Kanompatti and Viruveedu about 20,000 population, and this service was running smoothly.

In the year 1974, German Leprosy Relief Association in Germany, they came forward to help in the financial aspect (fund) upto 1980 the four sisters were the field staff and they also did all the activities and in the year 1981 nearly 1.6 lakhs population covered by these sisters.

GENERAL INFORMATION ABOUT DAMIEN LEPROSY CONTROL CENTRE:

Panchayat union covered: NILAKKOTTAI, BATLAGUNDU, USILAMPATTI AND CHELLAMPATTI

|                       |   |                                                           |
|-----------------------|---|-----------------------------------------------------------|
| Panchayat covered     | : | 47                                                        |
| Hamlets covered       | : | 288                                                       |
| Pop. Project area     | : | 1,66,970                                                  |
| Maximum area covered  | : | 450 sq. Kms.                                              |
| Clinic centre         | : | 16                                                        |
| Government hospital   | : | 1                                                         |
| Primary Health Centre | : | 8                                                         |
| Maternity Centre      | : | 15                                                        |
| Number of Schools     | : | Anganwadi 106<br>Primary 161<br>Middle 21<br>High. Sec. 9 |
| Main occupation       | : | Agriculture coolies, Business                             |
| Leprosy conscience    | : | Good                                                      |
| Leprosy prevalence    | : | 1.4                                                       |
| Open case rate        | : | 3.7                                                       |
| Deformity case ratio  | : | 6.9                                                       |
| Incidence             | : | 10.2                                                      |

OBJECTIVES OF THE CENTRE:

This hospital has been functioning under the three major objectives.

- i) Preventing Leprosy not to spread more and more.
- ii) Giving treatment through MDT.
- iii) Rehabilitating the disabled persons.

Area coverage of the hospital are Nilakkottai and Usilampatti. This area are divided into 8 divisions and patients affected by leprosy are identified and found out the reasons for the incidence of leprosy and expand the measures to prevent the leprosy through which economic standard of leprosy patients is increased.

|                                      |   |       |
|--------------------------------------|---|-------|
| Total population of the covered area | : | 82908 |
| Total number of examined person      | : | 73152 |
| Newly detected cases                 | : | 259   |
| Patients came voluntarily            | : | 22    |
| Other members of patient's home      | : | 15730 |
| Examined patients among the above    | : | 14486 |
| Detected cases among the above       | : | 16    |

### I)HOSPITAL FACILITIES:

There is a medical team headed by Medical Officer which goes to the area/village to detect the persons affected by leprosy once in 28 days. They are instructed to come to the hospital the admission time for the outpatient in between 8.00 A.M and 1.00 P.M. on Saturday and 3.00 P.M. to 5.00 P.M on weekly days. Rupees ten will be charged for admission per head. There are separate wards for male and female. In the Damien leprosy control centre there are enough facilities for controlling leprosy like X - ray units, physiotherophy, Dressing room, Lab facilities, operation theatre, special channels and shoes units, recreation ball which include T.V. Radio etc.

### II)MEDICAL FACILITIES:

Leprosy patients are divided into two groups according to the nature of diseases. They are Multi bacillary and Pauci bacillary of which former is infections and the later is in non-infections, the treatment also differs from one to other.

---

Treatment for  
infection diseases  
(MBC)

Treatment for non-  
infection diseases  
(PB)

---

I. Intensive therapy will be  
given for 14 days regularly  
and Refampsine (600 mg)  
capsule will be given for 14  
days.

Lambrine, Cloforsemine,  
Hamseptron (100 mg)

Treatment will be given  
for 6 months, the dose  
may depend upon the  
age of patients.

Refampsine capsule two  
per month, BCT as a  
usual.

II. Monthly dose for three  
years.

Hamseptron 50 mg.

Depson 100 mg (daily)

B complex tablets regularly

Refampsine 600 mg. two  
capsules. It is monthly  
twice.

---

There is injection also by name Dicalcium Diamine Disphosphane. It is not practical because it should be given to the patient in six months, identifying the improvement and progress of this injection is very difficult and time taking.

Leprosy patients are given treatment not only leper's but all other hands of disease like headache, wounds fever etc.

The ultimate aim of this hospital is now changed from leprosy Control Centre programme into leprosy eradication centre programme due to the introduction of Rifampine. The reason for the conversion of control into eradicated is that dapsona acted to make bacteria it static, but Rifampine eradication the whole bacteria.

### III) IMPARTING HEALTH EDUCATION:

A medical team goes to a village and they give health education (processing of finding) to the villages door by door at the team of conducting the survey. They give more knowledge/information about leprosy to the patients for finding.

### IV) INSPECTION OF SCHOOL GOING CHILDREN:

|                        |   |       |
|------------------------|---|-------|
| Total number of school | : | 299   |
| Students               | : | 45925 |
| Examined students      | : | 40122 |
| Newly detected         | : | 30    |
| Treatment              | : | 30    |

### V) ACTIVITIES WITHIN THE CENTRE:

|                                        |   |       |
|----------------------------------------|---|-------|
| No. of outpatients treated             | : | 12170 |
| Prevented from infections Environment: |   | 27    |
| Skin smear test                        | : | 1573  |
| Number of patients                     | : | 81    |
| Produced special chapels               | : | 256   |



#### VI) ACTIVITIES IN THE COVERED AREA:

A team under the Chairmanship of Chief Medical Officer with seven members goes to the field as 'a mobile clinic' for four days per week and giving treatment.

|                                                       |   |      |
|-------------------------------------------------------|---|------|
| Number of registered cases                            | : | 7122 |
| Under the inspection of the centre                    | : | 1891 |
| After getting treatment                               | : | 2915 |
| Complete treatment                                    | : | 246  |
| Average cases getting treatment through public clinic | : | 213  |

#### i) MULTI DRUG TREATMENT:

It was started in 1983 in small scale now it has developed to larger extend in 1987. 240 out of 246 are being given MDT treatment to get cure.

This centre has received fund in memory of Arch Bishop Justin Dhiraviam from Dr. Maria Louis Arokiaswamy and this centre has decided to help the poor women at the time of their marriage by giving money through the interest of the above fund. On the basic of this Rs. 4000/- is given for three women each.

#### VII) ACHIEVEMENTS OF THIS CENTRE:

1. It was 23.1 cases per 1000 at the beginning it come down to 3.6 cases per 1000 in the last year and now it has again come down 1.4 cases per 1000. Total number of cases getting treatment 246, getting treatment by MDT - 240.

2. This has examined the physically handicapped children hoping that this case be cured by surgery.

|                                             |   |    |
|---------------------------------------------|---|----|
| cases underwent surgery                     | - | 21 |
| Children getting caliper                    | - | 15 |
| Children getting treatment through exercise | - | 6  |

3. With the help of Aravind Bye Hospital, Theni, Damien Leprosy Control Centre and Sophia Hospital conducted a free eye camp and identified 32 persons (Cat act patients) and gave treatment through surgery.

#### VIII) HEALTH EDUCATION ABOUT LEPROSY:

It generates awareness among the poor people leprosy affected patients, children, students, women and age old people through film shows, exhibition, dramas, street play and other mass media, mail post, notice, adult education and other education institutes like Arulanandhar College, Karumathur, Gandhigram Rural Institute, Gandhigram.

#### IX) REHABILITATION OF LEPROSY PATIENTS:

It is not only the medicine which cure the disease but also the minds of the patient which should get satisfaction to rejoin the society from which one come to the hospital. In order to make the patients to rejoin the main stream the centre has established Rehabilitation programme for the leprosy patient from 1981.

The different types of rehabilitation programme are:

1)Domiciliary 2)Dairy 3)Tailoring 4)Housing and 5)Bank assistance.

Besides the above, guidance are also given for the disabled patients for vocational training & placement, small saving and guidance for old age people.

NUMBER OF BENEFICIARIES IN EACH TYPE OF REHABILITATION:

This centre flourish the life of the poor by giving rehabilitation to the affected leprosy patients and non affected patients, poor students and youth both men and women.

|                                          |        |
|------------------------------------------|--------|
| Patients who got loan without interest   | : 630  |
| Total patients repayed                   | : 525  |
| Patients borrowed loan from the bank     |        |
| with low interest                        | : 39   |
| Patients built houses without interest   | : 26   |
| Free sewing machine after training       | : 71   |
| Present tailoring trainees: Men & Women: | 3 & 10 |
| Employees from ITI                       | : 8    |
| Students getting scholarship             | : 31   |
| Milch cow without interest               | : 41   |

CENTRE AND FINANCE:

It functions with the help of German, Canada, Australia and other Leprosy Relief Funding Agencies.

FUTURE PLAN OF ACTION:

This centre has planned to establish a sub centre for controlling and preventing T.B. 20,000 persons are examined so far as a first phase.

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IV EMPLOYMENT AND INCOME:

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OCCUPATION:

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- a) Unemployed
- b) Agricultural - Farmer
- c) Agricultural - Cooly
- d) Sugar cane cutter
- e) Carpentry
- f) Petti business
- g) Money lending
- h) Priest / Religious leader
- i) Government Job
- j) Beggary and other

INCOME:

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Monthly (in Rs.)

SOURCE OF INCOME:

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- a) Agriucultural - Cooly
- b) Money lending
- c) Business
- d) Land
- e) Jewel
- f) Livestock
- g) Government Job
- h) Other.(specify)

V FAMILY PARTICULARS:

- a) No. of family members - Male - Female (including Children)
- b) Type of residence - Roof / Tile / Pucca
- c) Type of family - Joint / Nuclear

VI FACILITIES IN RESIDENCE:

- a) Toilet
- b) Water

Food habits - Vegetarian - Non-vegetarian

VII PARTICULARS ON DISEASE AND TREATMENT:

- 1) Status of deformity
- 2) Are you a migrant? Yes / No
if yes, Reason.
- 3) Was there precedence of leprosy in your family? Yes / No
- 4) Who did recognise your disease?

- 5) What was the symptoms of your disease?
- 6) What was your feeling immediately after the recognition of your disease?
- 7) What was your first step you took to cure the disease?
- 8) What were the reactions of your family members towards disease?
- 9) Problems during treatment?
- 10) Liking aspects in the hospital during treatment?
- 11) Opinion about the treatment?
- 12) Suggestions, if any.

VIII KNOWLEDGE ABOUT THE DISEASE:

- 1) Do you know leprosy is a contagious disease? Yes / No
- 2) Do you know children are more vulnerable to the disease than adults? Yes / No
- 3) Do you know there are two types of leprosy? Yes / No
- 4) What according to you is the cause for leprosy?
- 5) What is the common name for leprosy in this area?
- 6) What is the mode of transmission of the disease?
- 7) What is the problem in going back to your previous Job?
- 8) What are the problems faced by the deformed patients in this area?
- 9) What are the problems faced by the sons and daughters of the patients? if any
- 10) What are the factors that influence the patients to be accepted in the family / community?
- 11) What are the problems in social acceptance even after rehabilitation?
- 12) Do you want to be separated? Yes / No
if yes, Reasons -
- 13) Are you mainly depending upon this rehabilitation programme?

- 14) Opinion about this rehabilitation programme.
- 15) What are the steps to be taken by the Government and NGOs to erase the stigma attached with leprosy?

IX REHABILITATION:

A. DOMICILIARY:

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- 1) What type of article for which loan was sanctioned?  
Goat / Sheep / Petishop / Others
  
- 2) No. of Goat available at present?  
  
Not at all  
0 - 2  
3 - 5  
6 - and above
  
- 3) What is the source of repayment?  
a) What is the problem in repayment?
  
- 4) Have you completed the loan? Yes / No
- 5) Have you got second time loan? Yes / No
  
- 6) If no, what was the reason, you did not get second loan?
  
- 7) What are the problems in Domiciliary rehabilitation?
  
- 8) What suggestion do you like to offer to the rehabilitation Programme?
  
- 9) What according to you will be a suitable alternative measure for the leprosy cured persons?

##### B. DAIRY:

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- 1) What is the source of repayment?

- 2) Have you completed the loan? Yes / No

- 3) What are the advantages of Dairy rehabilitation?

- 4) What are the problems in Dairy rehabilitation?

- 5) What are the suggestions do you like to offer?

C. TAILORING:

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- 1) What is the source of repayment?
- 2) Have you completed the loan - Yes / No
- 3) What are the advantages of Tailoring rehabilitation?
- 4) What are the problems in Tailoring rehabilitation?
- 5) What suggestion do you like to offer?

D. HOUSING:

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- 1) What is the source of repayment?
- 2) Have you completed the repayment? Yes / No
- 3) What are the advantages of housing loan?
- 4) What are the problems in this rehabilitation?
- 5) What suggestion do you like to offer?

E. BANK LOAN:

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- 1) What type of loan through which you have got benefited?
- 2) What is the source of repayment?
- 3) Have you completed the loan? Yes / No
- 4) What are the advantages of this loan?
- 5) What are the problems in this rehabilitation?
- 6) What suggestion do you like to offer?