

residual mycobacterial antigen (as seen by anti-BCG Ab) is less in the vaccine group at the end of 2 years. A higher degree of lepromin conversion is seen in the vaccine group with the lepromin site biopsies showing well developed DTH reactions. The histopathological observations correlate well with the clinical and

bacteriological data. Nerve biopsies from 8 skin BI negative LL cases done for persisting organisms showed granular AFB in 2 control group cases only. The results indicate a significant additive effect of chemo-immunotherapy as compared to chemotherapy alone.

PSYCHO-SOCIAL

PS1

A STUDY TO ASSESS SOCIAL DISABILITY AND ECONOMIC LOSS TO LEPROSY PATIENTS ON MDT IN NORTH INDIA -- PRELIMINARY STUDY

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Leprosy with its sequelae gives rise to two major consequences for the patients: 1. Social disruption and 2. Economic loss. This study aims at measuring and relating the magnitude of socioeconomic consequences.

Data were analysed taking into consideration, loss of respect and position in the family; loss of social stature; separation from spouse and displacement from home and community as the major social consequences. Cost analysis was done for change or loss of occupation. Loss of man-hours at work in order for the patient to take outpatient and inpatient treatment was also analysed.

Preliminary results indicated that the social consequences contributed significantly to economic losses. The loss of man-hours due to treatment was also significant. Affluent and upper caste patients appear to be less affected while young adult male manual workers with disabilities seem to incur greater losses.

It is suggested that well integrated socioeconomic measures within the MDT Programme will have maximum beneficial effect for the patients.

PS2

A STUDY ON THE NON-DEHABILITATED AND DEHABILITATED LEPROSY PATIENTS

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ABSTRACT: Community Based Rehabilitation is replacing the costly model of institution-based long term care of leprosy patients. It mostly refers to the social and economic rehabilitation of the individual.

The objectives of the study are: (1) To identify the various factors involved in the process of debilitation of persons afflicted with leprosy. (2) To find out the causes why certain patients were not debilitated inspite of their deformities (3) To bring out the social and economic elements in the life of leprosy afflicted persons. (4) To find out the ways and means to enable the leprosy patients to continue their normal life without any interruption. (5) To help to reduce the number of patients who would require rehabilitation through prevention of debilitation.

Fifty non-dehabilitated patients and 50 debilitated patients were taken as samples for the study. The findings of the study is very useful for programme implementing agencies in social and economic rehabilitation of leprosy patients.

PS3

COMMUNITY PERCEPTION OF LEPROSY IN KERALA (SOUTH INDIA)

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Kerala is known for its better health status as compared with other States in India, as indicated by a low infant mortality, a low birth rate and higher literacy rate.

The study is aimed to document the baseline data on knowledge and attitudes of the community towards leprosy, with a view to modify the strategy of leprosy control. It will also help evaluation of the programmes after few years.

Both qualitative methods such as focussed group discussions and quantitative methods such as interview schedules were used for data collection. The study has been conducted at Manjeri sub-district and Kollam Urban pockets in Kerala.

The preliminary findings indicate that there is fear about the deformity and high infectivity associated with leprosy. The community prefers to retain the confidentiality of the disease. Knowledge about the signs and symptoms, about the causation, transmission and cure has also been studied. Higher literacy has shown direct co-relation with high stigma and prejudices about leprosy. Intervention is planned to see whether appropriate Health Education will result in a change in knowledge, attitude and practice.

PS4

COMMUNICATION FOR LEPROSY AWARENESS IN A COUNTRY OF TRANSITION

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In a country of transition, like India, where a relentless war against leprosy is fought with limited and scarce resources, the role of communication for creating awareness about the disease is a pivotal one. Technological advancements have brought about tremendous changes in the methods and means of communication through innovations.

With the objective to study the effectiveness of cartoon strips as a medium for the dissemination of scientific facts on leprosy to the literate and younger sections of the society, within the age group of 10-20 yrs, a study was conducted in two urban and two rural areas covered by GLRA/ALES projects in two states, in South India. 1000 persons each from the urban and rural areas were interviewed.

The medium used to achieve this objective was the print medium. After due consultation with leprologists, educationalists, social scientists and development psychologists, appropriate story lines with the basic themes of positive and scientific facts about leprosy were developed, pretested and printed in the form of compact cartoon strips in two Indian languages. While developing the story lines, the socio-cultural and linguistic backgrounds of the client population were also taken into consideration.

The study tool employed was a pretested questionnaire. The cartoon strips were distributed to the respondents randomly selected, one week before the administration of the questionnaire through a network of volunteers and a post distribution evaluation was conducted.

The strategy was well responded to and the medium was acclaimed and accepted as effective by more than 98% of the respondents. 92% in urban and 87% in rural areas reproduced the cardinal message 'Leprosy is Curable'.

PS5

LEPROSY AND AIDS: BEYOND THE STIGMA

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References to AIDS as the "Leprosy of the 1990's" or to persons with AIDS as the "New Lepers" are frequent. Although it is the stigma that is usually compared, persons with leprosy and persons with AIDS share many experiences that go beyond the bonds of stigma. However, this is primarily true for persons who developed leprosy prior to the advent of sulfone therapy. Many of these individuals were in the prime of life when a diagnosis of leprosy robbed them of their plans and dreams for the future. They saw their friends die at an early age and faced the possibility of their own death daily. They learned to adapt to increasing disability at a young age and had to focus their energies on their illness rather than on work and a family.

In this era of outpatient therapy, it is easy to forget what those persons who contracted leprosy in the pre-sulfone era went through to get to where they are today. In many ways, people with AIDS can help us to understand the difficulties faced by these individuals. It is interesting to see that the insights of a 76-year-old woman with leprosy can help us better understand the feelings of a 32-year-old man with AIDS and, similarly, the experiences of a 32-year-old man with AIDS can help us to better understand the situation faced by a 76-year-old woman with leprosy when she was first diagnosed many years ago.

Through their experiences with disability, chronic illness, death, and the struggle to retain dignity and control in the face of increasing disability, persons with leprosy and persons with AIDS can also shed light on issues related to senior citizens and other persons with physical and social disabilities.

PS6

THE FUTURE OF LEPROSY STIGMA IN VIEW OF ITS PRESENT METAPHORS: A COMPARATIVE ANALYSIS

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Drawing on two anthropological studies conducted in Israel and Thailand, this paper focuses on a comparative analysis of the ways in which metaphorical uses of the word "leprosy" mold its image and reactions to it.

In Israel, with only 200 patients, leprosy exists in the public mind mainly as a metaphor for ostracism. Factual knowledge absent, erroneous perceptions of the disease derive from characteristics of other stigmatized phenomena with which it is habitually compared. Consequently, while individuals claim to be unafraid of

leprosy, they paradoxically maintain that all others do indeed fear it.

In Thailand, successful MDT implementation led to a dramatic decline in leprosy prevalence, followed by changes in social reactions to it, which increasingly resemble those in Israel. Currently, public's knowledge of leprosy derives less and less from actual encounters with patients, whereas more and more from figurative uses of the name of the disease. This turns the study of leprosy metaphorization processes in countries like Israel into an enterprise relevant to understanding and predicting future developments in social trends presently occurring in countries like Thailand.

The analysis of leprosy stigma's future vis-à-vis its present-day references in common parlance raises doubts as to the effectiveness of prevailing destigmatization tactics. The discussion of those doubts aims both at the reevaluation of a wide spectrum of conventional views concerning leprosy stigma and at the synchronization of social remedies with current medical developments.

PS7

SOCIO-CULTURAL DIMENSIONS OF LEPROSY IN BOTSWANA

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A study to determine some socio-cultural factors influencing knowledge and attitudes of the community toward leprosy was done in northern Botswana, where cases of leprosy have been known to exist over the years. The study was largely qualitative, using ethnographic approaches. The research was tailored to capture the ethnic diversity of the region, in particular two ethnic groups, Bayei and Bambukushu.

The name or symptom complex associated with leprosy was "ngara" or "lepero" and this was associated with bad blood. Knowledge on disease causation was lacking which in turn influenced health seeking behaviour of patients. Patients were well integrated and accepted into the social structure of communities. The degree of rejection correlated with seriousness of disease and extent of disabilities and dysfunction. Women caring for these patients experienced some additional burden and identified time as their major constraint.

The present pattern of health seeking behaviour needs to be altered, so that an early diagnosis can be made at health facilities. This will aid appropriate management and prevent occurrence of deformities and disabilities, which in turn will reduce rejection and isolation of patients. Education of community, patients, traditional and religious healers on various aspects of the disease is essential to achieve a change in health seeking behaviour.

PS8

SOCIO-ECONOMIC REHABILITATION OF LEPROSY PATIENTS RELEASED FROM CONTROL THE KARIGIRI EXPERIENCE

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RFC patients are not reviewed routinely, in existing leprosy control activities. However, they continue to have various needs. From the time of inception of the control programme in 1962, about 20,000 patients have been Released From Control by the Leprosy Control Programme of SLRTC Karigiri.

In 1987, in Karigiri, a project entitled "CARE AFTER CURE" was initiated, with the objectives of screening all RFC individuals and identifying their socio-economic needs. Detailed information could be obtained only for 16,601 patients, and out of these, 55.69% of patients were still living, who were then assessed in order to try and provide them their various requirements wherever feasible.

This study details our experiences in the area of socio-economic rehabilitation of patients from this group. It brings out a wide range of the various needs of leprosy patients. It highlights practical problems in identifying needy patients, and suggests ways and means of dealing with problems encountered. It also brings out the stages of social acceptance and other problems encountered by leprosy patients during the course of social rehabilitation. The significance of Cure after Cure, and its usefulness and limitations are discussed.

PS9

SOCIAL INTERACTION AND THE DEVELOPMENT OF INTERPERSONAL RELATIONSHIPS OF THE HANDICAPPED IN INTEGRATED EDUCATIONAL ENVIRONMENT

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Taking the handicap as a socially constructed phenomenon and interpersonal relationships as the context where this construction occurs, this study was developed having as objectives: to identify whether the handicapped child, when living in an integrated context, develops stable interpersonal relationships; if so, what are their characteristics and what kinds of hints are detected about their development's process; if not, what are the characteristics of the handicapped's contacts in the group.

Two integrated groups of pre-school children were video-taped during one academic year, in their free time at the school play-ground, through scanning and focal taking techniques.

Data collected by scannings were treated by Cluster Analysis and by the construction of Minimal Generating Trees.

Data collected by focals originated a categories system, whose components were described by duration and frequency.

It was also developed a qualitative analysis of the interactional sequences of identified stable partnerships.

There were no qualitative differences in the process of development of stable relationships by the handicapped, when compared to the process of the non-handicapped. The observed differences relate to the **rythm** of the development and the **intensity** of relationships. The data also indicated that asymmetrical relationships seem to maintain the dependency and passivity of the handicapped.

PS10

THE IMPACT OF SOCIAL MARKETING ON THE PERCEPTION OF LEPROSY IN SRI LANKA

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In low endemic countries, like Sri Lanka, the fact that leprosy can now be cured without deformities goes unnoticed by the general public. Consequently deep rooted prejudices still prevail, also among health care providers, and complicate case finding efforts.

This was revealed in a knowledge attitude and practice (KAP) survey conducted on a sample of 1,000 people by a market research agency in two districts in Sri Lanka in 1989. These prejudices were directly addressed in a highly attractive national social advertising campaign launched in 1990.

There campaign led to a 150% increase in new patients and every second patient seeks treatment on his/own accord. There is also a perceptible difference in the attitude of new patients.

In order to measure if changes could also be observed in the general public, the KAP was repeated in 1993 on a similar sample of

1,000 respondents. A deeper KAP study of 2,000 people on the entire island is being administered by the public health inspectors.

The paper will present changes in the knowledge, attitude and practice of the general public based on the pre and post intervention surveys. Areas where no/little progress has been made will also be highlighted and explained, if possible. Divergences in the results of the two post KAP studies will also be explored.

PS11

GENESIS AND PROFILE OF LEPROSY BEGGARS IN MADRAS CITY AND ITS LESSONS FOR REHABILITATION PROGRAMMES

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There a total of approximately 1000 leprosy beggars in Madras.

A Study through an interview with 200 leprosy beggars is presented, using among others the following information:

1. Interval between date of diagnosis and date of Social Displacement.
2. Response to the disease diagnosis - by the immediate family/by the village community or urban neighbourhood/by the Employer
3. Reasons for Social Displacement
4. Reasons for choosing Beggary as a Profession
5. Contact with original family/village
6. Attitude towards disease/treatment/cure
7. Attitude towards leprosy staff/services
8. Functional abilities versus individual disabilities
9. Income and Economics of Begging
10. Requirements to stop Begging

The information is utilised to suggest a MODEL Rehabilitation Programme for Leprosy Beggars.

PS12

SOCIAL MARKETING APPROACH TO LEPROSY

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Despite 100% coverage of all registered cases with MDT since 1982 in Sri Lanka, the transmission of leprosy was not interrupted. Active case finding efforts of the hidden cases were expensive and hampered due to a high rate of rejection of the diagnosis.

A social marketing campaign (i.e. the application of commercial marketing techniques to a social cause) was launched in 1990 in order to address these problems.

A national social advertising campaign was developed by a professional advertising agency in order to destigmatize leprosy, create an awareness of its early signs, and motivate patients to seek treatment. The entire primary health care staff, curative medical officers in hospital outpatient departments and other staff were trained in leprosy to enable them to make an initial diagnosis and to reduce their fear of the disease. Monthly meetings of the specialised leprosy staff are held to evaluate progress. More clinics were opened up to accommodate the increased demand for leprosy services. MDT blister packs are distributed for better patient compliance.

The impact has been dramatic. Every year around 2,500 new cases are detected compared to 1,000 in previous years. Moreover every second patient is self reporting (10% in 1989). This indicates

the increased awareness of the early signs of leprosy and reduced fear. If patients continue to seek treatment when they first suspect leprosy, Sri Lanka is well on the road to eliminating the disease.

PS13

PSYCHO SOCIAL PROBLEMS OF CURED LEPROSY PATIENTS AN INTERCONTINENTAL COMPARITIVE STUDY

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The traumas inflicted on victims by leprosy are irreparable, that even the hardest of humans too will undergo abnormal physical, psychological and social changes. This study attempts to compare the lives of two groups of cured leprosy patients inhabited in a village in Morogoro, in Tanzania, East Africa, with that in Anbunagar at Villivakkam, near Madras, in Tamil Nadu, India. All the inhabitants were interviewed for the purpose of this study.

Though situated in two continents, the colonies are identical in origin. In Morogoro the disabled are 50% of the inhabitants in contrast to 80% in Anbunagar. While the former depend on the nearby hospital for food, the latter earn their food through begging, illicit trading of arrack and ganja. The inhabitants of Morogoro are confined to their village, whereas the inhabitants of Anbunagar are wanderers, in pursuit of their occupations. As against 39% in Morogoro, 40% of the inhabitants in Anbunagar are economically better of than the remaining.

It was evident from the responses that the inhabitants in Morogoro and Anbunagar are not upset about their predicaments and ways of life.

As a striking contrast to their counterparts in Anbunagar, in Morogoro, the inhabitants are polygamous. Though socio cultural and moral standards of these two communities were found to be divergent, the impact of leprosy on the attitudes and life styles of them are similar. Human qualities, instincts and passions were found to be similar and universal, no matter colour, creed and geographical boundaries separate them.

PS14

SOCIAL ACTION FOR LEPROSY CONTROL

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Social Action helps to empower the community or groups to identify, understand, analyse and solve its own problem. Social Action in leprosy control is possible if the community is taken into confidence through interactive communication and by addressing control activities to the concerns of the community such as disability and ulcer prevention and cure.

Different culture and area specific models are available and can evolve. Non-skilled roles of health workers are shared by the community groups and individual volunteers owning the responsibility for their actions. Blue print models cannot be designed for social action.

Sustained social action ensures internalisation of norms about leprosy control ultimately becoming a culture pattern. Social Scientists have a role to play in social action as facilitators in the beginning. Social Action refers to developing the partnership between health worker, patient and community for leprosy control. New role sets will have to be developed. Empirical examples are provided from India.

PS15

SOCIAL PROBLEMS OF WOMEN LEPROSY PATIENTS - A STUDY CONDUCTED AT DELHI URBAN LEPROSY CENTRES

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Leprosy is said to afflict women less commonly than men. Unfortunately, the effects are equally devastating if not more on the women than the men. This study carried out at the Urban Leprosy Centres of Safdarjung Hospital and Dr. Ram Manohar Lohia Hospital, New Delhi, showed that the impact of social stigma attached to leprosy was more on educated women belonging to higher socio-economic status. Despite many of the afflicted women getting support from their family, the disease had definite psychological effects. Fear of social ostracism prevented the women to disclose their disease to the community. Deformities and disabilities both deteriorated the functional capabilities and psychological state of mind. Pregnancy did not affect the patients treatment regularity.

PS16

SOCIAL ASPECTS OF DISABILITY AND REHABILITATION IN LEPROSY

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Leprosy is feared mainly because of the deformities and disabilities that it leads to in some patients. Hence this study intends to find out how some obviously deformed/disabled leprosy patients have managed to stay in the society and rehabilitate themselves in the society. The profile of these patients who are staying in the normal community was studied to bring out the factors responsible for absence of stigma and steps taken to overcome it.

A sample of 100 patients was drawn by stratified random sampling method from each of the following three groups: 1. Leprosy patients staying in Sivananda Rehabilitation Home. 2. Leprosy patients staying with their families. 3. Heads/responsible members of households of patients selected for study.

Three different types of schedules were devised corresponding to the three groups. Direct personal interview method using structured schedule complemented with observations was employed for data collection.

The study reveals the needs and requirements of different categories of leprosy patients in the background of the existing resources and facilities. The conclusions of the study would help to formulate rehabilitation programme basing on magnitude of the rehabilitation problem and will be discussed in detail at the time of presentation of this paper.

PS17

LEPROSY: A SOCIOLOGICAL OR MEDICAL PROBLEM ?

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Through time, due to the leading role of medical professionals in healthcare delivery, Health has become erroneously regarded as synonymous with Medicine. But in its real sense, Health is definitely a Social Science. This is evident in the various definitions of Health. The most universally acceptable and the most holistic definition of Health credited to the World Health Organisation describes Health as: "a state of complete mental, physical, social and economic well being, not merely the absence of illhealth." This means that Health is primarily a condition of "complete ... social, economic well being."

What is more sociological than "health behaviour" (the activity undertaken by a person who is healthy for the purpose of preventing disease), and illness behaviour (activity undertaken by a sick person for the purpose of defining his condition and seeking relief from it); (Kasl & Cobb, 1966). In the case of leprosy we are faced with a chronic disease condition with multiple, complex, long-term sociological implications:

Why is leprosy so strongly stigmatised? Why do people who find themselves with leprosy shy away from taking medical treatment even though it is provided free of charge? What explains the multiplicity of complications that are so common among people with leprosy? Why has efficacious medicare failed to solve these problems? How did leprosy which used to be widespread in Europe up till the Middle Ages disappear from the region, long before the discovery of the first effective anti-leprotic drug?

These and other questions unarguably concern the field of Sociology, rather than Medicine. The objectives of this thesis are therefore to:

- stimulate the interest of Social Scientists, especially Sociologists in the field of Leprosy Control;
- show the close relationship between Medicine/Health and Sociology;
- examine the causes of the strong, widespread stigma on leprosy and to suggest ways and means of combating it;
- explore the phenomenon of non-compliance among registered leprosy patients and propose solutions;
- identify the cause of the multiplicity of complications that are so common among leprosy patients and suggest possible solutions to these;
- seek an explanation for the failure of efficacious medicare and 'well-organised' drug delivery services as a solution to these problems.

PS18

ANALYSIS OF MENTAL HEALTH STATE OF LEPROSY PATIENTS

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The present study used SCL-90 to measure and analyse the psychological reaction on 71 leprosy patients of different sex, age, educational background, disease duration, disability and with or without relatives' care. The leprosy patients showed a higher total distress level, total mean score in psychological reactions (105.549 ± 57.214) and a higher mean scores of 10 factors in SCL-90 as compared with those of the normal individuals. The SCL-90 factor scores in patients with disability grade II or III were significantly higher than in those with disability grade I. Mean scores of compulsion depression, phobic anxiety, paranoid idea and psychosis in patients without relatives' care and in hospitalized patients were higher than those of the outpatients. Disease duration was highly associated with total score of SCL-90. The longer the disease duration, the severier were the feeling of hopelessness, phobia and hostility. Among the illiterate patients, depression and phobic anxiety were more serious than those of the patients with educational background of primary level. There was no significant difference of SCL-90 scores among patients of different sexes and age groups. SCL-90 factors were analysed and significant difference among 10 factor scores was observed. Social relationship, depression and phobic anxiety were identified as the most sensitive factors, the next were compulsion, anxiety and hostility. The authors suggest that the solutions of the psychological problems in leprosy patients are: 1) to strive for support from people of all social strata, so as to improve treatment conditions; 2) to strengthen propaganda, so as to reduce the fear of leprosy; 3) to encourage patients with more positive suggestions frequently, so as to make patients relieved from the psychological disturbance; 4) to treat patients as early as possible, preventing disability and ensuring psychosomatic health.

PS19

PSYCHOLOGICAL ASPECTS OF LEPROSY PATIENTS IN ALTO AMAZONAS PROVINCE, LORITO REGION, PERU. OCTOBER 1987-SEPTEMBER 1990

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Thirty eight patients with leprosy were studied in Alto Amazonas. The personality dimensions, introversion-extroversion and stability-neuroticism, were studied with Eysenck's Personality Inventory. Depression and anxiety were studied using Zung's scale. These aspects were also analysed in the normal population. The following variables

were considered: age, sex, place of residence (rural, urban) occupation, type of leprosy and duration of the disease.

Results do not show significant differences between patients and the normal population. However, among the patients studied it was found that:

- Introversion was directly proportional to age.
- Female patients had a greater tendency towards introversion, and an inclination towards depression.
- Urban residents had a greater tendency towards neuroticism.
- Laborers had a greater tendency towards anxiety.
- There were no significant differences among the other variables.

It was interesting to find that leprosy patients were integrated in the society, and segregation was almost nil.

(These paper was financially supported by Red Barnet - Denmark).

PS20

A STUDY OF DEHABILITATION PROCESS OF LEPROSY PATIENTS: INDIA

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The introduction of multidrug therapy is fast bringing down the leprosy prevalence rate. This has necessitated shift toward rehabilitation of patients declared as RFT (released from treatment). It is argued that to avert the problem of rehabilitation, it is better to arrest dehabilitation itself. Therefore, present study focuses on documenting the actual process of dehabilitation.

Data has been gathered using semi structured interview schedule, technique of observation and case study method for indepth understanding. The sample is composed of hundred leprosy afflicted patients around Pune City.

The study reveals that lack of education (43%), non-scientific notions regarding causation and spread of disease (81%) lead to the depression (93%). Further lack of support on part of family and community (64%) and feeling of helplessness by patients her/himself contribute to the process of dehabilitation.

The study further suggests that the role of health education will help ensuring self reporting, taking regular treatment and reduction in stigma, to arrest dehabilitation.

The entire process has been presented diagrammatically.

PS21

MEASUREMENT OF DEHABILITATION IN PATIENTS OF LEPROSY - A SCALE

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Leprosy interferes with the psychological and social life of the patient thus bringing about debilitation or 'dehabilitation'. Therefore it becomes essential to assess the extent and direction of dehabilitation in order to make the treatment plan holistic and effective. The objective of this work was to: a. construct a scale for measuring dehabilitation and b. to standardize it. The methodology included preparation of 52 statements (in English) spread over four sub areas of life viz, family relations, vocational condition, social interaction and self esteem. It was administered to 122 randomly selected respondents. Scores were given to them by summing up the weights of each statement. A high score indicated low dehabilitation. Statistical tests were applied for standardizing the scale. To establish reliability, split-half reliability test and item discriminant analysis were used. Factor analysis

was used to test the validity. The results show that the split half reliability coefficient ranged high (from 0.64 to 0.83) in all four sub areas. The item discriminant analysis had a level of significance of 0.001 for 42 statements while the factor analysis explains variance covered over 70 percent. Hence the scale can be an useful instrument in pointing to specific directions while planning intervention strategy for the total person by way of counselling, case work or rehabilitation.

PS22

REHABILITATION: RESTORING TO USEFULNESS

Makia Malo

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This paper addresses the psychodynamics of transition, by an adult male patient, from twenty-five years at the leprosy settlement of Kalaupapa to his re-assimilation in the city of Honolulu.

In the absence of a mentor, an established support system, and with no analogs on which to build, the presenter will speak of his process; from initial motivation, to fear, shame, trust, despair and crisis, involvement and triumph. Psychosocial developmental milestones are achieved as this ex-patient's journey takes him first to a rehabilitation center for the blind, then to dormitory life on the campus of a major university (at age 37, alone, blind, with hands reshaped by Hansen's disease leaving him unable to use braille, where he would earn two degrees), to marriage and a successful career in the performing arts.

PS23

INTEGRATED APPROACH IN HEALTH EDUCATION OF LEPROSY TO CREATE MASS AWARENESS

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Health Education is very important to prevent and eradicate any disease, so also leprosy, especially in the field. To achieve this, we have tried our best to make the message as simple, specific and clear as possible. Two way communication and interaction was encouraged.

This paper deals with the Health Education given to the School Children, Teachers, and others during the period 1986 to 1992. Film shows and Essay writing competitions on Health Education in Leprosy were held simultaneously during the School Survey every year. MEDEX-91, a Medical and Health Exhibition was organized for the general public in Dec.'91, involving a medical college, various departments of medicine, UNICEF, National Society for Prevention of Blindness, Indian Health Organisation & Others, wherein the cause of leprosy was highlighted. Orientation courses in Health Education for School Teachers were held in 1992. The study was conducted with the help of 'HELP US', a Society involving an Eye Specialist, a Psychiatrist, a Dermatologist, a School Teacher, a Bank Employee & others.

Further details will be discussed at the time of presentation of this paper.

PS24

HEALTH EDUCATION HAS CHANGED THE ATTITUDE OF SOCIETY TOWARDS LEPROSY

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Effective Health Education Programme is playing an important role in breaking the long established stigma in the society towards leprosy. This stigma against leprosy will be completely wiped out during this century.

Before the Dapsone Era, patients were uprooted from their homes and the various ways of helping these patients changed as per the attitude of the community.

The outcome of a study conducted in the control area allotted to the Leprosy Mission Hospital, Naini proved that effective Health Education had changed the tide and it seems we have come to the end of the road of stigma. The result shows that out of 1504 cases, only 20 cases are not coming in open for treatment due to STIGMA. This number is only 1.32% which is very negligible. The number of deformed cases are as follows - Grade I = 175 (11.6%), Grade II = 127 (8.4%), Grade III = 36 (2.39%).

Rehabilitation will not be relevant in the field of leprosy any more since patients are not being uprooted. That does not mean these patients will not require any help they will definitely need assistance for Socio/Economic Development.

PS25

ASSESSMENT OF SOCIAL ACTIONS AND HEALTH EDUCATION IN THE CARE DELIVERY TO LEPROSY PATIENTS

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The aim of the paper is to discuss the procedures of evaluation of the social actions in the care delivery to leprosy patients.

It is noteworthy the hardness to ascertain the quantity of the social actions, the reason why it was chosen to adopt the methodology of qualitative research.

The main tool used was a "questionnaire" to be adopted by the Health Care network. This structured document includes all significant data concerning the leprosy patient life: -maintenance of day life activities, taking into account all psycho-social aspects.

The assessment will be fulfilled in a continuous and cumulative frame.

The expected results could help to implement the integral care to the patient and so to lessen the prejudice against the disease.

PS26

TOWARDS AN UNDERSTANDING OF THE STIGMATIZATION OF LEPROSY

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Brazil is one of the few countries where leprosy is increasing and yet adherence to treatment is under 50%. Interviews with health professionals

corroborated by a survey of the media and scientific publications indicate a total lack of concern with this illness.

Many factors contribute to turn leprosy into a forgotten disease: the decline of leprosy cases worldwide; the changes in local health policy with emphasis on primary care and the lack of emotional impact due to lack of information and the adoption of a new terminology obscuring the understanding among the general public.

The analysis suggest that the strategies employed to overcome leprosy stigma, such as the substitution of the word leprosy by Hansen's Disease, ended up by masking the disease. The results lend support to the relevance of using social representation theory for a better understanding of this masking phenomena and its implications for health care.

PS27

SOCIAL AND CULTURAL ASPECTS OF THE STIGMA OF LEPROSY IN NORTHEAST RURAL THAILAND

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A nine-month anthropological study was performed in a village in northeast Thailand, which was reported to have the nation's highest leprosy case rate. The main purpose was to investigate how the stigma of leprosy was created and maintained, and its effects on patients' adaptation to the disease. The study shows that stigma ideology of leprosy is culturally and socially constructed with its association to states of uncleanness, impurity, pollution, immorality, and sin. Although community members views patients with bodily disfigurement as persons who should be shunned, they tolerate these patients without any attempt to expel patients from the village, and even maintain some social contacts. I discuss factors responsible for the production of the stigma of leprosy (e.g. religion, everyday use of the language, health worker activities). I also show how the stigma of leprosy is understood in relation to a person's position in the Thai social structure (such as class, age, and gender). A diagnosis of leprosy brought severe psychological suffering. Patients have feeling of shame, as well as fear of ostracism, debilitation and the possibility they may spread the disease to family members. Ex-patients, especially those with bodily disfigurement, live with the fear of being ostracized and diseased all their lives

PS28

INFORMACION, CONOCIMIENTO Y ESTIGMA EN LA ENFERMEDAD DE HANSEN.

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Se presentan los resultados de las encuestas realizadas a población escolar de distinto estatus social y diferentes edades, antes y des

pues de recibir información sobre la Enfermedad de Hansen.

El desconocimiento sobre la misma condiciona el rechazo y el estigma sobre la misma.

PS29

PROYECTO DE EDUCACION EN SALUD PARA EL COMBATE AL ESTIGMA DE LA LEPROSIA

Dora Martins Cypreste

Este proyecto tiene su objetivo nel combate del estigma de la lepra aun muy presente en nuestro pais.

A falta de investimentos científicos en tiempos pasados posibilito el tratamiento inadecuado y como consecuencia las incapacidades físicas, el mayor temor de la sociedad.

Por lo tanto se hace necesario un trabajo social que alcance todos los seguimientos sociales nel sentido de dismistificar la lepra y posibilitar la reincorporacion social de los pacientes y ex-pacientes ahora alijados de la sociedad.

Areas de actuacion: Servicios de salud, educacion, grupos familiares, movimientos populares organizados, organiciones en general, utilizandose todos los medios de comunicacion de masa.

Alcanzandose a poblacion en general estaremos contribuyendo para minimizar el estigma asociado al portador de lepra haciendo con que los resultados sociales acompanen lado a lado los tan eficientes resultados clinicos que tenemos alcanzado.

PS30

PROYECTO PARA EL ATENDIMIENTO A LOS PACIENTES IDOZOS DEL SANATORIO DR. PEDRO FONTES

Dora Martins Cypreste

El presente proyecto tiene como objetivo prestar atendimento clinico y psico-social a los pacientes idozos del Hospital Dr. Pedro Fontes. Estos pacientes cuando acometidos de la lepra fueron abandonados por sus familias y hospitalizados compulsoriamente.

Sin oportunidad para un tratamiento eficaz tuvieron como consecuencia las secuelas tales como ceguera, perturbaciones psico-sociales y otros.

Este trabajo viene presentando notables resultados en la recuperacion de los pacientes idozos portadores de la enfermedad, siendo nel momento el unico implantado en Brasil.

Aunque abandonados por la familia hoy estos pacientes se sienten como seres humanos recuperando sus derechos de ciudadanía.

PS31

INTEGRACION SOCIAL Y ECONOMICA DE UN GRUPO DE PACIENTES DE LEPROSIA EN LA ZONA RURAL DE DOMINICANA CON GRAN PARTICIPACION DE LA COMUNIDAD

Rafael Isa Isa, Huberto Bogaert, Sócrates Canario.

Instituto Dermatologico Dominicano, Santo Domingo, Rep. Dom.

Se presenta la información básica sobre un Programa de Asistencia Directa para la Integración Social y Econó-

nica en pacientes de lepra en la Región Sur y Sur-Oeste de la República Dominicana, regiones consideradas por Organismos Nacionales e Internacionales con los niveles más bajos de pobreza en el país.

Se trata de un proyecto de Infraestructura Física y Social que involucre a los pacientes en la Educación, Organización y Participación Comunitaria en colaboración con instituciones de apoyo no gubernamentales y Asociaciones de Desarrollo Locales y Regionales.

PS32

EVOLUCION DE LA ENDEMIAS LEPROSA EN REPUBLICA DOMINICANA 1966-1992

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Se hace una revisión del comportamiento de la endemia examinando la incidencia (tasa anual de detección de casos) y prevalencia desde el inicio de la aplicación de las medidas de control hasta el 31 de diciembre de 1992. Se observa una caída continua de la incidencia desde el año 1976 acompañada de un descenso de la prevalencia a partir del año 1980. Se hace una distribución de los casos por forma clínica, sexo y edad además de su localización en medio urbano o rural.

Los datos revelan una razón prevalente del sexo femenino sobre el total de enfermos con mayoría de varones en las formas multibacilares. El porcentaje de menores de 15 años se mantiene elevado a pesar del esfuerzo realizado, año tras año, para disminuir la endemia.

La situación así encontrada, se atribuye a la existencia de condiciones socio-económicas-culturales que se mantienen en un nivel muy crítico.

PS33

SOCIAL ADVERTISING FOR LEPROSY

Sandya Salgado¹, Upali Herath¹, Rohan Piyadasa¹, Dayamal Dewapura², Penny Grewal³, Padmini Gunawardena², Sunil Settinaiyake²

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Leprosy continues to be one of the most maligned diseases in the world. In order to change its perception a social advertising campaign was developed by a professional advertising agency in Sri Lanka. The campaign stimulates spontaneous demand for diagnosis and treatment by making people aware of the early signs of leprosy, able to spot them in themselves and others, fearless of the consequences.

The emphasis throughout is on physical beauty and how early, regular treatment would leave it unimpaired. It combines nation-wide advertising with popular radio and TV serials in which the hero or heroine suffers from leprosy, but always has a happy ending. All the available mass media are used: TV, radio, bill boards, posters, stickers, direct mailings, newspaper advertisements, etc. The campaign logo, a flower held sensitively by fingers, is a poignant reference to a point where the disease often strikes.

A poster exhibition will display samples of the advertising material used in the campaign as well as summarise the main experience made with social advertising.

PS34

SOCIAL MARKETING: A NEW STRATEGY TO ELIMINATE LEPROSY

Penny Grewal¹, Dayamal Dewapura², Padmini Gunawardena², Sunil Settinaiyake², Francisco Castellanos³, Alberto Barocio⁴

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Poor awareness of the early signs of leprosy and/or fear of social rejection have led to a high hidden case load in all countries. Unless these problems are effectively addressed on a national scale leprosy cannot be eliminated.

Social marketing is being successfully applied in Sri Lanka and Mexico to dispel the fear of leprosy, encourage patients to seek treatment and to provide easy access to treatment.

Social marketing involves the application of the philosophy, concepts, and techniques of commercial marketing to socially beneficial practices. It is built around the knowledge gained from business practices and involves organising the services to suit the convenience of patients. Social marketing also requires the careful co-ordination of the marketing mix of promotion (social advertising), place (treatment points), price (costs for seeking treatment), and product/ packaging to achieve the desired impact.

The paper will elaborate on the concept of social marketing, the key factors for its success and how it differs from traditional approaches of health education. It will also explore the advantages and limitations of the approach as well as the lessons learnt through its application in Sri Lanka and Mexico.

PS35

THE SOCIAL IDENTITY OF THE PHYSICALLY HANDICAPPED

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This study had as its goals: 1. to identify personal aspects of the handicapped's identity, as well as its value attribution 2. to identify the handicapped's perception of the existing stereotypes in the *in* and in the *outgroup*, with its correspondent value 3. to identify signs of collective action for social change. 12 physically disabled, 12 to 36 years old, were submitted to an adaptation of Zavalloni's (1973) Psycho - Social Identity Inventory. Data analysis indicated that most of the attributes designated by the handicapped to itself is positive. Now, when characterizing the other handicapped, the attributes are mostly negative. In relation to what the handicapped think about how he is perceived by the non-handicapped (*outgroup*), the representation is characterized mainly by negative attributes. Such results are consistent with the ones obtained by Zavalloni-positive attributes seem to be, more frequently, related to "WE", while the negative ones to "THEY". The answers obtained to the SELF were exclusively of personal nature, differing from the ones obtained by Kuhn & McPortland (1954) who verified that initial answers reproduced social characteristics and only later ones had a personal connotation. The data indicates, yet, that most of the subjects are in search of social mobility and not of collective action for social change.

PS36

PSYCHO-SOCIAL TREATMENT FOR LEPROSY PATIENTS: METHODOLOGY FOR INDIVIDUALIZED APPROACH IN ROUTINE TREATMENT.

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Though there has been an awareness among the program scientists about the effectiveness of the psycho-social interventions in leprosy control work, the application of such techniques has not yet been achieved, due to lack of standardized methods with in the reach of the Paramedical Workers' comprehension.

To evolve a standardized methodology for the use of paramedical staff out-patients of the referral hospital of Gandhi Memorial Leprosy Foundation have been systematically diagnosed and treated by a group of counselors comprising of a Trained Social Worker, a Paramedical worker and a Psychologist, from psycho-social point of view.

The inferences drawn based on the exercise, presented in the paper, show that psycho-social treatment in leprosy involves a systematic procedure comprising of 3 steps a) psycho-social diagnosis, b) prescription of needs and c) treatment. The paper also presents a tentatively standardized methodology of treatment, which could be easily modified as per the local needs, in the above mentioned 3 steps and the achieved results of application of the evolved methodology in terms of reducing the non-compliance of the patients and preventing debilitation of the patients.

PS37

IMPORTANCE OF SOCIAL REHABILITATION OF THE PATIENTS IN LEPROSY CONTROL

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In the recent years it has been understood that to reach the goal "to control leprosy" or "to eradicate leprosy" one has to take leprosy patient "as a whole" and take in to consideration all the different aspects of disease and conditions related to disease.

Because of leprosy people with deformities can not earn their living and go on begging or living in very bad conditions as outcasts will continue giving the image that "leprosy is a dangerous disease" which cripples and although they say that it is treatable they end up in very bad conditions.

We realized that if we were able to rehabilitate leprosy patient socially in other words if we can create a new way of living and earning money for the treated patient we could prove the society and ourselves that leprosy could be really controlled in the near future.

With this judgement and reason we put on emphasis on the social rehabilitation of the patient together with the medical, physical and protective treatment.

In this study we planned to give 22 case reports about the social rehabilitation of 34 patients. Their previous and present situation and efforts made to realize each project are given in short with the aim of being an example of managing the patient "as a whole" and by this way serving for the real "eradication of leprosy".

PS38

FOLLOWING THE REHABILITATION OF Hansen's Disease Patients UNDER SOCIAL ASPECTS

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In the metropolitan areas and in the middle size cities of Brazil the health system network usually has social workers in its staff not only to assist doctors in difficult situations but also to devise some solutions for those patients whose difficulties are not always been identified by other staff members. Although health service does not take full advantage of all this professional's skills their initiatives regarding leprosy patients have been increasing as the MDT schemes allow a better relationship between patients and health professionals. These experiences have shown some difficulty to make patients come for group discussion specially in urban areas where the treatment is through health centres located in the patient's residential area. One of the patient's reason for not coming is the fear of meet friends or neighbours.

Taking into account that the society prejudice as well as cultural factors is responsible for such attitude the social service of the UCCF has been developing an "action-research" project focusing the level of participation of 2 kinds of patients:

"Those from a slum area, treated in Primary Health Care Centre through community-based program and those referred from different areas of Rio de Janeiro city, treated in the University Hospital.

Considering the illness stages from a social point of view, this video documentary shows through the cases studies problematic situations demanding a social diagnosis. It also shows that the "role of the patients from both institutions in urban area are quite different".

PS39

COPING STYLE IN LEPROSY

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Leprosy is more a social problem rather than simple medical problem. Therefore there is need to know the impact of coping style in leprosy. Here coping is defined any response to leprosy that serves to prevent or control the emotional distress.

100 cases of Hansen's disease were selected randomly. Questionnaire was distributed. On analysis, it was found that coping response depends upon severity of the disease and various coping resources. 22% cases where severity of disease was less, accept the situation but re-define it and find something favourable like hypopigmented patch. They were regular in treatment but they do not want to know about leprosy. 9% feel that the leprosy is curse from God, doing nothing to maintain the situational demand. They were irregular in treatment. 60% were using problem and emotion focused coping together. Emotion focused coping maintain hope and optimism while problem focused coping is responsible for collection of information and action. Positive belief, problem solving skills, social and material resources are important coping resources, which are helpful for early detection regular treatment, and prevention of deformities.

Study of coping gives better insight of each leprosy patient, which can be a great help to select appropriate and effective medical interventions.

PS40

RESPONSE OF NEWLY DIAGNOSED PATIENTS TO LEPROSY IN KERALA (S. INDIA).

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Kerala is known for its better health status as compared with other States in India, as indicated by a low infant mortality, a low birth rate and higher literacy rate.

The Leprosy Mission has recently instituted Leprosy Control Programmes in the Manjeri Sub-district and Kollam Urban Area in Kerala.

The study among newly diagnosed patients is aimed at understanding the acceptance or otherwise of the label of a leprosy patient and the resultant behaviour in terms of patient's perception about the disease causation, treatment and cure. This will help to design appropriate leprosy control strategies to ensure voluntary reporting and regularity of treatment and decreased stigma. Both quantitative survey method of interview schedule and qualitative case studies have been used for data collection.

Preliminary observations indicate a spectrum of total ignorance of leprosy, fear of social rejection and stigma about diagnosis and treatment.

The results of this study are being used to design intervention measures to combat this problem.

PS41

SUMMARY AND RESEARCH OF LEPROSY ACCOUNTS IN THE BIBLE

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This paper systematically and briefly quoted the accounts about leprosy in all chapters of the Bible, providing important reference materials for research of the history of leprosy and social medicine.

In the discussion the author suggested,

1) The term "tsaraath" used in the OLD TESTAMENT did not refer to leprosy alone nor to diseases other than leprosy, but to all kinds of skin diseases including leprosy.

2) Citing some references of the Bible scholars, historians and archaeologists, the author believed that there might have been leprosy patients in the Palestine area at the 12th century B.C., and by the 7th century B.C., leprosy was definitely endemic.

3) From the 7th century B.C. to the 1st century B.C., there were strong fear of and prejudice against leprosy patients in the society of the Palestine area. But Jesus, (whose actual existence is still being debated among scholars, the author mentions him according to the Bible story) unlike the others, showed sympathy and love for the leprosy patients; he dared to contact them and was willing to help them. Such an attitude and behavior were noble and praiseworthy both at that time and at the present.

PS42

THE ACTION OF THE SOCIAL ASSISTANT AND THE IMPROVEMENT OF THE LEPROSY PATIENTS TREATMENT REGULARITY - DUQUE DE CAXIAS PROJECT - RIO DE JANEIRO - BRAZIL

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The study assesses the patients regularity regarding the MDT/WHO leprosy treatment regimen.

The patients clinical records were compared in two different periods: one in the years 1989-1990 when no social assistant was assigned to the program, and other in the years 1991-1992 after the appointment of these personnel.

The results point out to the hypothesis that the treatment regularity is directly proportional to the action of the social assistant working in the health team. The same results can be reached with other kind of personnel (Sociologists, Psychologist, graduate Nurses).

PS43

A SURVEY OF JOB SATISFACTION AMONG LEPROSY PERSONNEL *

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A survey was conducted among the health personnel working in leprosy in two Multidrug therapy (MDT) districts in India to study their levels of job satisfaction. The following four variables were taken into consideration for determining job satisfaction.

- 1) Self-image of the staff.
- 2) Promotional satisfaction.
- 3) Satisfaction towards the introduction of MDT
- 4) The role of pay as a satisfier.

There were 356 respondents in the study, an overall response rate of 96%. The results show that the overall self image of the health staff working in leprosy has improved in the MDT era as compared to what it was in the monotherapy era of the 60's. The dissatisfaction with chemotherapy which was a significant observation before the introduction of MDT has virtually disappeared and it has been replaced by a moderate level of satisfaction. In comparing satisfaction due to Promotion with that due to Pay, the latter was found to rank higher.

In a few instances, physicians, paramedics and personnel from different geographical and administrative structure had significant differences in their levels of job satisfaction. This study analyses these findings in the light of existing psycho-social theories.

* A part of the thesis for a privately undertaken PhD by the First author

PS44

DETERMINANT ABOUT IRREGULARITY ON AMBULATORIAL TREATMENT OF LEPROSY IN AN UNIVERSITY HOSPITAL

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We studied 305 patients with leprosy on ADS-HUPE-UERJ between 1985 and 1990. The socio-epidemiological characteristics were identified with 35,5% of patients on irregular treatment. We also concluded that clinical form presentation, accessibility and principal occupation seems not to be an influence in therapeutic non-adhesion rate, while ethnical group and instruction level suggest important association with the subject.

PS45

IN-FACTORY MDT

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Many leprosy patients find it very difficult to do regular multidrug therapy whilst working in the factories of Manaus's industrial district. The social work department of the "Alfredo da Matta" Institute of Tropical Dermatology sought alternative ways around this problem.

From 1988 onwards, the team started educational work with the factory managers, the staff medical services in the industrial district and with the patients themselves. The result can be seen in the fact that working patients are doing MDT at work in 94 of Manaus's 217 factories.

PS46

HOW THE MEDIA AFFECTS LEPROSY PATIENTS

Bill Malo, Valerie Monson

Kalaupapa settlement, Hawaii, USA

Bill Malo, who was a Hansen's disease patient at Kalaupapa for 25 years before leaving as a healthy man in 1965, still cringes when he sees fund-raising materials distributed by some leprosy organizations. The close-ups of deformed faces and partial limbs make Malo think that leprosy patients are being "exploited in order to raise money" for their care.

Valerie Monson, a reporter for The Maui News, remembers her first visit to Kalaupapa when many patients refused to talk to her because they worried about being exploited to sell newspapers.

Throughout history, leprosy patients have not only suffered physically, but they have been forced to endure mental anguish due, in part, to an insensitive media.

From popular television shows such as "M*A*S*H" and "The Simpsons" to the rock music of "Was (Not Was)" to Vanity Fair magazine, the word "leper" has been used to conjure up images of fear, shame, pity or disgust.

What can we do?

Malo believes that leprosy organizations can help by showing healthy patients -- those who have been treated with sulfone drugs -- along with sick ones to raise money. By presenting "the other side of Hansen's disease," the public would realize there is hope and that patients can have full and happy lives.

Monson, who has managed to gain the trust of the patients at Kalaupapa and has been writing about the community for four years, believes a serious effort must be made to inform the professional media that the word "leper" is considered repugnant and that Hansen's disease is no longer a death sentence.

The media can make an enormous difference not only in how the public views people with leprosy, but how people with leprosy feel about themselves.

PS47

PUBLIC PRECONCEPTIONS OF LEPROSY. A LINGUISTIC APPROACH.

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Preconceptions of stigma and segregation have played a dominant role in the discussion of public education on leprosy. All too often health workers, representing the values of educated middle class, have taken it for granted that segregation was practiced among ordinary people.

We have found as a common pattern is the co-existence in society of two parallel sets of terms for the disease, one with cultic associations, where the disease connotes "uncleanness" or "pollution", leading to ostracism; the other, secular set of terms has no such connotations or implications.

In the Bible, the cultic concept in Hebrew is *tsara'at*, initially was not compatible with leprosy. In the Septuagint Greek translation of the Old Testament, *lepra* was used, and this became also the term in the New Testament. Only during Renaissance did it become the medical term for leprosy. Local equivalents like *spettlik* existed in northern Europe, and this became the root of the word hospital (house, spetal). Independent secular terms, such as *spillsjuka* in Norway, did not connote uncleanness and caused no segregation among lay people. Segregation was introduced on "scientific" basis, and the medical establishment used the term *spettlik*. In Ethiopia the biblical term *tsara'at* was translated into the ancient church language Ge'ez by *lym* in both testaments, a word is used also in contemporary Amharic, connoting a skin disease. Other words (*amminna/daw* *siha/ha*, *ha/ha*) are used in daily speech to depict the progressive symptomatology of leprosy. None of these terms connotes "uncleanness" or carry association to stigma or segregation.

In the Koran, *jazam* is conceptually the same as *tsara'at* in biblical Hebrew. Again a number of symptom-related terms replace *jazam* in daily reference to leprosy, and these do not imply segregation.

In an ancient Sanskrit text, Charaka Samhita, sexual excesses are given as one possible cause of *kushtha*, leprosy. This association has certainly caused some stigmatization among educated Indians. Still, a leprosy patient retain his caste, and does not become an "untouchable". In most contemporary Indian languages, the term for leprosy is not related to *kushtha*. The idea of segregation is correlated to higher classes and urban life.

Leprosy workers should carefully study the linguistics of leprosy in the society to make sure that public education does not contribute to stigmatization of leprosy where no stigma in relation to the disease is observed in the society.

PS48LA LEPRE VUE PAR LE LEPREUX AFRICAINKongawi Kinda
Zaire/Africa

L'idée que le lepreux africain a sur l'origine de sa maladie est tout à fait différente de celle des scientifiques.

Malgré l'explication scientifique, le lepreux africain croit que sa maladie provient d'une malédiction, d'un mauvais esprit, d'une sorcellerie ou des ancêtres mécontents. Le traitement médicamenteux ne suffit pas à convaincre ce lepreux africain.

La prise en charge d'un lepreux africain doit tenir compte de deux aspects importants:

1. L'aspect technique qui consiste à soigner et à suivre le malade mais aussi
2. L'aspect psychologique qui consiste à préparer spirituellement le malade en lui expliquant que même si sa maladie est envoyée par un mauvais esprit, il existe un Etre suprême capable de neutraliser tous ces esprits. Si l'on suit bien ses traitements et l'on croit en ce Etre qui est DIEU, on sera guéri et aucun mauvais esprit ne pourra s'approcher de celui qui croit en Dieu

PS49

SOCIOECONOMIC AND PSYCHOSOCIAL DIMENSIONS OF LEPROSY: A CASE STUDY ON TREATMENT TYPES AND PATIENTS COMPLIANCE

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Leprosy is a social disease and the social stigma attached to leprosy is universal in all directions in all societies. The lower socioeconomic groups are more prone to experience in view of the lower socioeconomic status. One of the social factors favour the spread of the disease is low standard of living. Tamilnadu is one of the leading states in India to witness a high prevalence rate of leprosy. The status of deformities caused a great concern in view of the disfigurement of the patient due to the disease which leads to serious psychological, economic and social difficulties. The study is based on the analysis of socioeconomic and psychosocial dimensions of leprosy patients in relation to their preference towards the treatment types and their compliance to express their satisfaction and willingness to continue to follow the regular treatment. The present study also made an attempt to identify the major socioeconomic and psychosocial dimensions with reference to monotherapy and multidrug therapies (MDT). The study was based on questionnaire survey by direct observation methods conducted among 300 respondents chosen in various endemic areas of the districts of Tamilnadu. The data were analysed with the help of Factor analysis, a multivariate statistical technique to decipher the major dimensions. Twenty major dimensions were emerged with an eigen value ranging from 15.54 to 1.00 with a total variance of 69.64%. The dimensions worth mentioning are: Infrastructure facilities, Treatment considerations, Family Response in view of Deformity, Status of Patients, Environmental Effect, Social effects of disease, Regularity of Treatment, Accessibility and Treatment efficiency, Efficiency of Treatment, Treatment Adoption and Treatment Efficiency

PS50

STUDY OF PSYCHIATRIC MORBIDITY IN HANSEN'S DISEASE AT A REHABILITATION CENTER

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The number of Hansen's patients in India is about 3.2 millions out of 11 millions of patients throughout the world. The present study is on psychiatric morbidity in Hansen's patients at a rehabilitation center, among out-patients and in-patients. Fifty out-patients and fifty in-patients were administered General Health Ques-

tionnaire and screening questions from Indian Psychiatric Survey Schedule. Sociodemographic data was also collected. Analysis of results shows that out-patients outnumber in-patients in having psychiatric illness with a 19:5 ratio which is statistically significant. The predominant diagnosis is Dysthymia, of Secondary type, according to DSM III R. There are no observed differences in different types of Hansen's disease, different durations and presence or absence of Leprosy reactions. The results are discussed:

PS51

PROBLEMS AND COPING STRATEGY OF FAMILIES WITH DEFORMED AND NORMAL LEPROSY PATIENTS

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Disease status in leprosy is an important determinant of the kind of non-medical problems the patient and his family have to face in the society. Though several epidemiological studies were conducted to understand deformities and disabilities, sociological understanding about them is meagre. This paper attempts to understand the magnitude of the problems and the coping strategy adopted by the affected families of both deformed and non-deformed (normal) leprosy patients.

This investigation, as part of a larger study "Acceptance level of leprosy patients in the family" conducted by the CSSRL, GMLF, Wardha covered a sample of 500 leprosy patients and their families spread over in four leprosy control units in Tamil Nadu.

A large number of medical, demographic and other variables had differential impact on families facing problems with deformed and non-deformed leprosy patients. The extent of the problems faced by these families and the coping strategy adopted were analysed. Implications of the results for the control programme are discussed.

PS52

HUMAN RELATIONS RESEARCH AMONG LEPROSY PERSONNEL AND STRATEGIES FOR BEHAVIOUR MODIFICATION *

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This study was conceived to understand the behaviour of health personnel working in leprosy in India, towards patients and fellow health-workers. The latter was studied in three areas:

- 1) Interaction with supervisors.
- 2) Inter-group behaviour, between paramedics and doctors.
- 3) Inter-departmental relationships.

The data was collected using a perception-attitude-behaviour (PAB) scale developed specifically for this purpose. The scale consisted of four independent test instruments, each of which measured five factors, reflecting five aspects of behaviour towards the group concerned.

The results indicated that a significant number of health personnel did not possess the minimum desirable behavioural standards towards their patients. The quality of relationships was unsatisfactory with supervisory figures and also between paramedics and doctors. However, inter-departmental relationships in the existing infrastructure of leprosy control programmes were found to be satisfactory.

* A part of the thesis for a privately undertaken PhD by the First author

Behaviour modification methods tried at Karigiri, to improve working relationships in both of these areas, are presented.

PS53

LIFE AFTER MDT

Emanuel Faria

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Hansen's Disease is not like any other illness in the sense that effective treatment is all that matters to the sufferer. For those who have it, Hansen's Disease is a life-long problem. Effective therapy is not the end of the story. People with HD worry, and rightly so, about the possibility of becoming disabled and thus being unable to support themselves and their families. Even after being "cured", this anxiety remains.

There is also the possibility of ocular and other medical complications. Completing MDT and being considered "cured" does not guarantee the absence of eye problems and other medical problems later on. Regular eye examination is necessary even for the "cured" in order to detect possible incipient sight-threatening conditions.

In addition, being considered clinically "cured" does not necessarily mean that one is automatically accepted in the community or the work place.

Here in the U.S., we have state-of-the-art treatment, but I anguish at the plight of those who live in regions where care is distant if non-existent. We at Carville have so much, yet it can still be a very lonely place. Rejection experienced in earlier times can result in a permanent inferiority complex if one isn't careful. MDT alone cannot restore one's dignity. The restoration of dignity and a sense of pride in being able to provide for one's family are an imperative part of any cure.

PS54

THE COMPREHENSIVE CARE OF CAMBODIANS WITH HANSEN'S DISEASE IN A LARGE AMERICAN CITY.

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This paper will describe a constellation of physical, psychological and social problems in 39 Cambodian patients with Hansen's disease treated at the USPHS Hansen's Disease Center in Boston. Many of these patients have major hand and foot deformities, caused by lepromatous leprosy. Before coming to the United States as refugees nearly all of these patients suffered major psychological and physical traumas in Cambodia and/or refugee camps. Many contracted infectious diseases such as tuberculosis and hepatitis B. After arriving in the United States they had problems adjusting to their new country, because of cultural and language barriers. These problems continue as their children become Americanized and lose many traditional values. These patients have a high incidence of depression and post-traumatic stress disorder because of their previous suffering. In addition, they face the stigma of Hansen's disease within the Cambodian community. These case histories will show that Hansen's disease cannot be treated effectively without addressing other major medical and social problems. These and similar patients are best served by a medical system that provides comprehensive primary medical care and by providers who are sensitive to their history and culture. A Hansen's disease program should either offer this level of care or work closely with health providers who can.

PS55

THE PARTICIPATION OF HANSEN'S DISEASE PATIENTS IN THE GOVERNMENTAL HANSEN'S DISEASE CONTROL POLICY-"HANSEN'S DISEASE AND THE CONSTITUTIONAL ASSEMBLY" - A BRAZILIAN MINISTRY OF HEALTH'S EXPERIENCE

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The national movement "Hansen's Disease and the Constitutional Assembly" started and coordinated by the Brazilian Ministry of Health's Sanitary Dermatology Division, in 1988, with decentralized seminars from the local and regional levels, had the participation of the government and sectors of the society at large (Movement for the Reintegration of Hansen's Disease Patients - MORHAN), popular health movements, the scientific community.

This paper discuss the methodology used, which allowed the majoritary participation of patients in the decentralized seminars, covering 22 federated units and five macroregions and leading to the reformulation of guidelines and strategies for the endemy's control activities in the country and a background document of subsidies for the 1988 Constitutional Assembly, regarding the chapter on the universal rights of man.

It also discusses the results of the deepening debate about ensuring the exercise of citizenship in relation to the discrimination and restrictions to patients with Hansen's Disease; the right to a job; the restructuring of the colony hospitals; the patients integral and integrated assistance in the service network and the revoking of discriminatory Legislation.

MORHAN'S present participation in the Brazilian Ministry of Health's Chamber of the National Health Council is analysed under the focus of the unfolding of this movement.

PS56

RESTRUCTURING THE COLONY-ASYLUM HOSPITAL, A SHARED ACTIVITY OF THE GOVERNMENT, PATIENTS AND SOCIETY AT LARGE

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The process of restructuring the colony-asyllum hospitals in Brazil is an ongoing reality.

Between 1987 and 1989, the Brazilian Ministry of Health began restructuring the 333 colony-asyllum hospitals housing Hansen's Disease patients and thoses that, though cured, had difficulties in their social integration and restrictions to exercise their citizenship rights.

The specially formed Technical Social Committee, made up by technical and legal MoH staff and by participants from the representative organization of HD patients (Movimento de Reintegração do Hanseniano - MORHAN) created local restructuring groups, supported by the state administration level, moving towards changing the colony hospitals into general or sanitary dermatology hospitals, integrated into the health services network for the entire population and hospital network open to the local community.

The initial survey carried out by a questionnaire filled by the 33 hospital allowed to identify the living situation of HD patients and to define strategies for in loco action.

The participation of HD patients, local groups and the federal administration ensured the effectiveness of this change, and in some places made possible the right to land, jobs, housing, and whole and integrated care of the patient and his family.

PS57

THE MEDIEVAL LEPROSARIUM: ITS PLACE IN MEDICAL HISTORY

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This study is based on the examination charters and operational documents of medieval leprosy hospitals. Such hospitals began to proliferate in Europe in the eleventh century and reached peak numbers of beds in the thirteenth century. These hospitals represented part of an increase in building in general and hospitals in particular. As institutions, however, they differed significantly from modern hospitals. First, their primary intent was not medical. As the name hospital suggests, hospitality was their function and most medieval hospitals housed pilgrims, widows, and orphans. Leprosaria filled this function for those who held the legal status of those diagnosed with leprosy. Therapy and intent to cure did not exist. Leprosy patients were legally dead in medieval Europe and had no access to ordinary necessities. The leprosy hospital offered hospitality to this group, but, in nearly all cases, imposed a semi-monastic lifestyle on the patients, requiring special clothing and diet. The ideal of their custodians was based on hagiography and behavior such as kissing the patients' sores and sleeping in their beds, actions considered likely to infect the person so acting, were highly applauded. A curious feature of many charters of leprosy hospitals was the stipulation that the hospital serve as the retirement home for the persons founding it. Thus, in intent, function, ideal, and even the medieval leprosarium bears essentially no relation to the modern hospital. The medieval leprosy hospital was profoundly different from its modern equivalent, only the name suggesting a continuity, which crumbles under scrutiny.

PS58

THE PARTICIPATION OF THE "MOVIMENTO DE REINTEGRAÇÃO DE HANSENIANOS" - MORHAN - IN THE LEPROSY CONTROL PROGRAM IN BRAZIL

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The paper is an analysis of the contribution of a lay association of patients and professionals engaged in their care - the MORHAN -. This entity start its activities in the eighties and have as aim to contribute to the control/elimination of the leprosy endemy.

The "MORHAN" believes that the fight against the disease is not only to treat the cases but, also, the real and organized participation of the patients and professionals to achieve the betterment of life conditions.

The "MORHAN", while a popular movement, tries to cope with the prejudices associated with the disease and the attitude of charity. The main objective of the "MORHAN" is to favor a position of defense of the citizenship like others popular movements.

It was used the method of qualitative research reporting the history of the Association, its political importance and posing a question to the those concerned with the social aspects of leprosy and/or he health problems in general.

PS59

BEHAVIOR HEALTH CHANGE INTERVENTION ON LEPROSY CONTROL IN SOUTH SULAWESI, INDONESIA

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Leprosy control has been done for years in South Sulawesi. Using MDT system in the last 5 years has a great effects to decrease the leprosy prevalence. Unfortunately the decrease of prevalence can help the occurrence of new cases. In 1992, there was about 2,000 new cases was found and 10% has a serious disability.

Having a traditional health concept on leprosy and practicing leprophobia to hate to the victims is a real obstacles on leprosy control in this area. Back to the leprosy transmitted is "man to man", the intervention of behavioral health change on health promotion, early diagnosis and prompt treatment and rehabilitation can be chosen as an alternative. Supported by a couple of experiences based on two researches by using health behavior change in qualitative and quantitative researches in South Sulawesi, Ngatimin offers a model to support leprosy control include to take care to subclinic patients which were caught by serologic or microbiologic detection.

PS60

NUTRITION, GROWTH AND MENTAL DEVELOPMENT OF CHILDREN OF URBAN LEPROSY PATIENTS

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This paper describes a cross-sectional study of physical and mental development of a high-risk group of 182 socially deprived healthy children of leprosy patients in their pre-school age to early teens. They were rescued at the age of 4 years from the distress of leprosy colony where they were born, and brought up in government after-care homes, under better environmental and messing facilities. Of them, 135 children could be followed clinically for the development of childhood leprosy. Another 84 children of leprosy patients, but living with their parents in the colony were included for comparison. A group of 159 normal children of similar economic status and age group were included as another control group. It was observed that although better environment, food and training were provided in the after-care-homes, so that the children could be brought into the national mainstream, nevertheless 5 children developed indeterminate type of leprosy during the course of 10 years. This is the first report describing the growth and mental development of children of leprosy patients from the Indian subcontinent.

REHABILITATION

RE1

INTEGRATION OF LEPROSY INTO GENERAL REHABILITATION SCHEMES - AN EXPERIMENT IN BOMBAY.

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In Bombay city, there are 6 institutes which are working for rehabilitation of persons disabled due to causes other than leprosy and 8 institutes in voluntary and Government sectors doing antileprosy work through their 153 leprosy clinics. In 1985, a combined workshop was organised for representatives of these organizations to acquaint them with leprosy and discuss possibilities for including leprosy patients in general rehabilitation programmes. Periodic follow up meetings were organised to review progress and resolve difficulties in implementation. Visits of the staff of leprosy institutes to vocational centres and workshops of non leprosy agencies were organised which acquainted them about facilities available at these centres. A booklet giving these details was printed and made available at 153 leprosy clinics in Bombay for ready reference. Since 1987, 206 referrals have been made by leprosy agencies of which 97 were accepted by non-leprosy agencies for the training programme and 95 patients got job placement and loan facilities.

Such an integrated rehabilitation programme for leprosy patients can be practised in cities and district towns where non-leprosy rehabilitation organisations exist.

RE2

A MODEL FOR THE HEALING OF LEPROSY IN KOREA

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Leprosy patients in Korea, regardless of their socioeconomic status, had been roaming around near villages to beg the food for their survival, and they were the symbol of fear, rejection, prejudice, hatred, and segregation, until 30 years ago. Since, drastic changes have been noted. For example, a. According to the WHO definition, leprosy as a public problem has already been eliminated since 1983 (before MDT), but the prevalence of tuberculosis is still one of the highest among southeast Asian countries. b. the living standard of the

HEALED, once beggars on the street, is now better than that of the ordinary population. These are the results of the unique Korean way of approach. Of course, the chemotherapy, physiotherapy, and corrective surgery played one of the major roles -- Physical Rehabilitation. But, the focus should be on the unique Korean way to implement spiritual & socioeconomic rehabilitation. It was not emphasized to the patients that they were the ones to get help from others, instead, it was emphasized that they themselves should do their own best to support themselves with whatever ability they had and furthermore they should seek the opportunities of helping others -- Spiritual Rehabilitation.

The patients themselves gathered together and settled at resettlement villages. They started with the scratches donated from various resources, raising pigs or chicken. The business at the resettlement villages was not run by the government or charitable organizations, but by themselves. The poultry product from the resettlement villages, now, occupies about 1/4 of that in Korea. And, furthermore, they are now the managers of the industry and the general public provides the labor -- Resettlement Village Movement -- Socioeconomic Rehabilitation. It is roughly estimated that this Resettlement Village Project in Korea has conferred a benefit of about 12 billion US Dollars. Over 70-80% of the residents at Resettlement Villages are not patients. And all of the patients have left, in some Resettlement Villages, which have become ordinary villages.

The victims of Hansen's disease in Korea are now happy, prosperous and are no longer the symbol of fear. They are healed and have become a man with all rights and dignity. Even an active case of this disease is considered as a patient with a disease called leprosy. They restored their MANSHIP fully.

I propose that my experience in Korea, Resettlement Village Project run by the patients themselves not by others, be extended to other parts of the World, and my colleagues here be my partners of this campaign.

RE3

COMMUNITY BASED REHABILITATION PROGRAMME OF THE LEPROSY MISSION, INDIA.

Dr. P. D. Samson, Dr. Paul Jayaraj,
Mr. P. K. Roy, Mr. Shirish Shegaokar.

The community based rehabilitation programme was launched in 1990 at 27 different leprosy hospitals of The Leprosy Mission, India. This programme was planned in a systematic way with in build training programmes for the P. M. W. with emphases on proper selection of leprosy patients, trades and market research.