and half a year, most lesions disappeared, but that in scrotur with deep infirtation very slowly. Histopatholoical observation revealed the scattered, degenerative foamy cells and the residual leprosy bacilli In smooth muscle cells in addition to the foamy cell infiltrates in subcutis of the lesions. On transmission electron microscopy, vacuoles with various sises, grouped or scattered leprosy bacilli of granular and solid type were seen. The latter had electronic dennity with peripheral transparent halo, indicating that they still had vital activity.

with peripheral transparent halo, indicating that they still had vital activity. The authors emphasize that the treatment of this kind of leproxy patients had to be strengthened and it is important to pay further attention to the residual bacilli in leproxy control.

PSYCHO-SOCIAL

PS01

EPIDEMIOLOGICAL AND SOCIO-CULTURAL IMPACT OF THE SOCIAL MARKETING PROGRAMME FOR LEPROSY IN SRI LANKA

<u>Penny Grewal</u>¹, Nimal Kasturiaratchi², Padmini Gunawardene³, Dayamal Dewapura¹, Sunil Settinayake³, Lakshmi Somatunga³, Mitchell Weiss⁴, Vinya Ariyaratne³

¹Novartis Foundation for Sustainable Development, Switzerland, ²University of Peredeniya, Sri Lanka, ³Swiss Tropical Institute, Switzerland, ⁴Anti-Leprosy Campaign, Sri Lanka, ³University Sri Jaywardenepura, Sri Lanka

In 1990 a social marketing programme for leprosy was launched in Sri Lanka to detect and treat hidden cases. Social marketing aims to influence the voluntary behaviour of target audiences (e.g. encourage persons affected by leprosy to seek treatment) in order to improve their personal welfare (e.g. cure of leprosy without deformities) and that of their society (e.g. reduce the pool of infection). This involved creating awareness of the signs of leprosy, dispelling prevides, improving access to treatment and strengthening the ability of the health services to deal with the new case load.

A study was carried out among 1,800 non-affected persons including school teachers and midwives in 1997, three years after discontinuation of the social advertising campaign in order to assess its residual impact on knowledge, socio-cultural attitudes and practice. Using the Explanatory Model Interview Catalogue framework, respondents were shown photographs of representative signs of leprosy and given information about symptoms to provide a focus for questions about possible diagnosis, cause, prognosis with treatment, social attitudes and sources of information. Narrative data was collected for a third of the sample.

The findings reveal the long term impact of an intensive campaign and the sustainability of changes in societal attitudes which have been extremely positive, particularly among midwives and school teachers. Minority ethnic groups, such as Muslims, however appear to have been relatively untouched by the campaign. This paper will focus on areas with significant improvements in knowledge, attitude and behaviour (e.g. recognition and medical recourse, prognosis) as well as findings indicating effects that fell short of expectations.

Leprosy has been eliminated from Sri Lanka and this paper will also discuss the epidemiological impact of the campaign.

PS02

LINGERING PROBLEMS OF POOR COMMUNITY PERCEPTION, DISCRIM-INATION AND SOCIAL STIGMA AGAINST LEPROSY-A STUDY OF YOUTHS IN SOUTH-EASTERN NIGERIA.

M.M.Meremikwu, C.O.Odigwe, E.N.U. Ezedinachi, D.G.Nkanga and A.N.Meremikwu University of Calabar, Calabar, Nigeria.

It has been suggested that increasing demonstration of the curability of leprosy would lead to a positive change in social attitude to leprosy patients and a gradual reduction in the age-long social stigma against the disease. To assess the level of community perception and social stigmatization of leprosy against the background of the successful implementation of the WHO MDT Programme in Nigeria, using a semi-structured, validated questionnaire, we studied 657 youth (10-25 yrs; mean = 17.1 \pm 6.6) who were students of five secondary schools in South-Eastern Nigeria. There were 344 (52.42) male and 313 (47.63) female. Most ascribed the cause of leprosy to worms (15.03), virus (28.63), evil spirits (15.83) and a curse (6.03), while a few (26.33) suggested a bacterial agent. Frequency of responses on the modes of transmission were 33.83, 18.13, 15.83, 13.53 and 9.83 for sharing food, breathing, act of witches, sharing a seat, and hand-shake respectively. The hospital (37.63) Church (36.83) and traditional healers (6.87) were suggested as preferred treatment places; while 18.1% said there was no cure. Most would not share classroom seat (85.6%), bus seat (75.0%) or toilet seat (82.0%) with a person affected by leprosy; 82.0% would not even shake hands with them. The reasons for discrimination were fear of being affected by (67.6%), social stigma (40.0%), traditional belief (32.2%) and religious belief (18.3%). There is a great need for health education in this community to improve the epidemiologic knowledge of the disease, its curability and to reduce the level of social stigma against it.

PS03

COMMUNITY ACTIONS TOWARDS PATIENTS WITH LEPROSY IN EASTERN NEPAL.

L. de Geus, H. de Stigter and M.L. Heynders.

Netherlands Leprosy Relief Association, Biratnagar, Nepal.

Many leprosy patients tell about the fear they have for actions taken by the community towards them. Different studies show that due to this patients try to hide their disease and subsequently stop taking their treatment. To see if this fear for community actions is based on real events, 300 community members were interviewed about actions taken by the community towards leprosy patient during the past 20 years. This resulted in 192 patient-stories in total. The majority (94.8%) of the patients described had visible signs like patches (10%)or wounds and/or deformities (84.8%). Of these patients 2.6% experienced only eating restrictions, 43.8% had to sit separately, were not allowed to enter people's homes or to touch other people, 29.2% was not allowed to enter a teashop, not allowed to use a public well, not allowed in social functions, problems to get medical care or had problems in heir work and 12.5 % of the patients were send out of their village. These negative community actions have not changed during the past 20 years. Even last year 13% of the patients was exiled from the village. Also it was found that once the community started taking actions towards a patient, this action continues forever. What however has changed is that nowadays 34.3% of the patients receive positive support compared to only 16% of the patients 20 years ago. Main reason for community actions are: fear of infection by germs and transmission of the curse of God. It can be concluded that the social stigma on leprosy is still present and that the statement "Once seen as a leper, always a leper" is still and that the statement. Once seen as a refer, aways a refer is still true. As actions by the community are taken towards patients with visible signs, it can be concluded that the prevention of wounds and deformities is of high priority in patient education. Patients should be counselled on how to deal with community actions A community programme should be developed in which cause and treatment of leprosy is explained. As knowledge alone is not enough to change the negative behavior towards leprosy patients, a more participatory approach should be developed.

PS04

THE SOCIOECONOMIC ASPECTS OF THE POPULATION AFFECTED BY LEPROSY IN SOROCABA, BRAZIL

Bakirtzief, Zoica

Pontificia Universidade Católica de São Paulo, Brazil

The population studied comprised 1288 patients of one Health Unit, including cured ones. Their profile was: mostly males (56%) economically

active age from 15-59 years old (59%), and 39% above 60 years old. Some coming from neighboring towns (21%) where treatment is available. The number of patients treated in 1996 was 629 whereas the epidemiological registry of active cases was about 450 which means that cured patients still come for medical assistance.

A sample was drawn to be studied in relation to non-leprosy affected households. The results indicated that patients were poorer than the general population as a whole being concentrated in classes C. D and E. Also, the characteristics of the head-of-household were similar as far as age, sex and home ownership (the majority owned ti).

However, the households were different as far as work situation and schooling. That is, more retired persons in the leprosy affected households than their neighbors, and less than 4 years of school in leprosy affected households, whereas the neighbors had up to 8 years of formal education.

The results are discussed in relation to other publications about socioeconomic situation of leprosy patients in Brazil and suggestions for economic rehabilitation are proposed.

PS05

A HEALTHY VILLAGE PROJECT IN THE UK

Dr Derek Browne FRCGP, FRIPHH, MRCP, DTM&H Brockenhurst, Hampshire SO42 7SW UK

Healthy villages can support patients with disabilities with or without infective disease. In our rural community of Hampshire New Forest, we have a practice population of 3500 patients, some have chronic disabilities. We appointed a 'healthy village coordinator' who received referrals from the primary health care team. The co-ordinator identified and collated community resources including facilities in the local schools, village and church halls and linked the individual needs with the community resource. Research data showed that the referred individuals had improved well being, with reduced prescribing of medication and reduced.

A healthy village concept supports WHO Health for All, and Healthy City projects. The model is based on the rural health work formerly carried out by Dr Stanley Browne in the former Belgian Congo, and in China by the late Ma Haida. A world without leprosy needs to integrate people with chronic disabilities in their communities. A 'healthy village project' can provide the structure to support health and social care needs for our patients in the next millennium.

PS06

ACTIVITIES FOR ENLIGHTENMENT ON HANSEN DISEASE IN JAPAN

Akitoshi Murakami and Masao Yuhu, National Hansen Institution

Kikuchi-Keihuen, Kumamoto, Japan

The day April 1, 1996 was the greatest breakthrough in Japan for all ex-Hansen patients who had been segregated in Hansen institutions. On this day, Leprosy Protection Law was abolished, and we staff of the institution shared pleasure with the ex-patients. They have lost many significant things by segregation for more than 40 years after the treatment was established, including bonds of hometown, family and community of their own. There were two reasons for happening of such a sad affair in Japan. One is that Leprosy Protection Law was not abolished; instead it was revised to enact in 1953 under strong suggestion by a couple of Hansen specialist physicians at that time. The other is that Japanese leprosy association ignored Roman Declaration by the 6th international leprosy congress in 1957 that isolation against Hansen disease should be abandoned.

In kikuchi-Keihuen, we started activities for enlightenment in 1992 to the general public that had misunderstood that Hansen disease was an awful disease. As a result, many people had right understanding of the disease, which in turn made it possible for ex-patients to regain bonds of local communities and hometown and family. In addition, abolishment of Leprosy Protection Law in 1996 has promoted this event. In Japan, many of married exe-patients do not have their own children because of duty of a contraceptive operation. Therefore, they particularly enjoy heartwarming exchanges with school children.

Our recent experiences show that activities for enlightenment on Hansen disease is very effective to eliminate prejudice and discrimination. We also appeal that we should never repeat historical fault in other diseases such as AIDS.

PS07

ASSESSMENT OF THE FACTORS BEHIND HIGH DEFAULT RATES AMONG LEPROSY PATIENTS IN NEPAL. (analysis ongoing)

M. L. Heynders

Netherlands Leprosy Relief Association, Biratnagar, Nepal.

In the six districts of the Eastern leprosy Control Project in Nepal approx. 40 % of the registered leprosy patients are non compliant to their treatment. This study was conducted to find the main reasons why some of the registered patients do not finish their treatment. Plattients were called 'defaulters' when they had missed 12 consecutive months of treatment. Platents were released from treatment, 'RFT's', when they had finished 24 does of MDT within 36 months 36 defaulters and 47 RFT's could be traced and interviewed. From all patients in depth interviews were taken at their homes. Topics for discussion were disease related issues, helpseeking behavior, treatment experience, social impact of the disease, and family support. Reasons for defaulting found were: severe side effects. Lack of knowledge about the disease, denaid of the disease, feeling of being cured, no hope for cure, quality of care at Hp's, long duration of treatment Reasons for organizate and of the disease, feeling of being cured, no hope for cure, quality of care at Hp's, long duration of treatment Reasons for compliance and becoming RFT were fear of the disease and the impact of treatment. Most of the patients were hiding their disease for the communities, RFT's were more successful in this Most patients live isolated within the family. The term compliance appeared to be quite narrow, since it was defined as confirmity with "Western" medicine People's decision to continue or not with the prescribed treatment is subject to many different forces, e.g. spiritually, cultural concepts of disease, community pressure, experienced quality of care. To improve the compliance to "Western" medicine the patients do not have to understand the theory underlying biomedicine, but they have to accept in 1 this case other motivational factors must be present, like trust in the received care, receiving enough caring and concerne. Patient education should hertions must be present, like trust in the received care, receiving enough caring and concerne. Patient ed

PS08

FOCUS GROUP WORKSHOPS ON LEPROSY AND ITS IMPACT AMONG RURAL COMMUNITIES IN NORTHERN INDIA - A PRELIMINARY STUDY

Jay Palla, P Ramachandra Rao and Daniel Masih

The Leprosy Mission Hospital, Barabanki, Uttar Pradesh, North India.

Persons affected by leprosy (PALs) often suffer from many social disadvantages and even severe degree of social disruption. It is often seen that even with a medical cure and economic assistance, PALs were not easily accepted back in to their communities. This project aims to bring back community and PALS closer in their social network through a scheme of Focus Group Workshops.

Leprosy workers trained as facilitators conducted Focus Group Workshops in leprosy endemic areas among several community groups. A 6 monthly follow up data were collected, analysed and compared with documented baseline data.

Preliminary results indicated that focus group workshops give ample opportunity for interaction among villagers and has significantly raised their awareness, Knowledge and their ability to communicate with PALs . A significant number of participants shared with their families, friends and neighbours and disseminated the new information they had received. About one third of the participants wish to become facilitators.

It is suggested that community based focus group equipping communities to take care of PALs through elimination to eradication.

PS09

DETERMINANTS OF MDT TREATMENT ABANDONMENT BY LEPROSY PATIENTS IN CITROLÂNDIA

Authors: <u>Maria Beatriz P. Orsini</u>, Gilmar S. Figueiredo, Ilma N. Porto, Maria Aparecida Alves Ferreira, Mônica N.V. Apipe, Ronise C. Lima.

Citrolândia Health Centre, Betim, Brazil

The study presents the analysis of the determinants of MDT treatment abandonment by leproxy patients at the Citrolandia Health Centre, located in a region which developed itself close to a sanatorium. Treatment abandonment has been one of the main obstacles to the elimination of leprosy as a public health problem

It is a qualitative research carried out through semi-structured interviews with patients who have abandoned treatment and others who are being treated regularly. Its main objective is to know the reasons for compliance or non-compliance to treatment.

After a reviewing the records it was observed that 30% of the 179 pacients in the active registry had abandoned treatment

These patients were contacted through mail or visits to their households and then interviewed

Patients claim they have abandoned treatment due specially to their disbelief in a cure, the occurence of reactions and neuritis during treatment and the side effects of the drugs. The authors have come to the conclusion that the social

representations of the disease and its evolution is greatly influenced by leprosy historic and cultural determinants in the region as well as by the difficulty of the service in carrying out educational measures of impact and actions of vigilance to health

PS10

LESSONS FOR LEPROSY PROGRAMMES FROM SOCIAL MARKETING AND SOCIAL ADVERTISING ; USING THEORETICAL FRAMEWORKS TO IMPROVE THE EFFECTIVENESS OF CAMPAIGNS

Penny Grewal¹, Dayamal Dewapura¹, Padmini Gunawardene², Sunil Settinavake

¹Novartis Foundation for Sustainable Development, Switzerland, ²Anti-Leprosy Campaign, Ministry of Health, Sri Lanka

In view of the inevitable scaling back of resources for leprosy in the post elimination era, it is crucial that the community understands more about leprosy, its signs, symptoms and treatment prospects. This will help create a supportive social environment which encourages persons with suspicious lesions to seek diagnosis and timely treatment. Health care providers will also have to be motivated to learn more about leprosy in order to detect and treat or refer new cases.

The behaviour change required with regard to leprosy is a "high involvement" decision. Such decisions are typically made through a series of stages namely precontemplation, contemplation, action and maintenance (Transtheoretical model; Prochaska and DiClemente, 1983). Stage specific strategies are required to move the target audience to action and maintenance. At the precontemplation stage, for example, the target group does not see the proposed behaviour as relevant to their own needs often due to a lack of awareness or different values. This stage requires strategies based on cognitive models to create an interest in and awareness of leproya as well as change of values. After precontemplation, behaviour is driven primarily by perceived benefits, perceived costs, perceived social influences and perceived behavioural control. Once the initial action has been taken, behavioural models become more important than cognitive models.

This paper shows how the transtheoretical model has been adapted for leprosy in Sri Lanka and the stage specific methods used (e.g. highly visible mass media campaign at precontemplation / contemplation; entertainment educational methods like TV and radio dramas at entertrainment educational methods like TV and radio dramas at contemplation, interactive sessions to trigger action, ensuring quality care to motivate compliance). The paper also discusses the experience acquired from its practical application (e.g. difficulties in ensuring that improved recognition is accompanied by stigma reduction) and the advantages and limitations of the theoretical framework.

PS11

A STUDY OF KNOWLEDGE, ATTITUDE AND PRACTICES (KAP) AMONG LEPROSY PATIENTS IN A LEPROSY CONTROL UNIT.

Manas Kumar Kundu, The Leprosy Mission, Purulia.

Manas Kumar Kundu, The Leprosy Mission, Purulia. This study is aimed to assess the existing level of knowledge about leprosy, attitude towards society and day to day practices needed among the leprosy patients. One Leprosy Control Unit is selected for the study. A pretested questionnaire was administered to 336 leprosy patients in random method. Overall level of knowledge about leprosy is found to be low. However, there are significant differences in knowledge, attitude and practice (KAP) among rural-urban, male-female, educated-uneducated, lower-higher socio economic status group of patients. There attitude and practice (KAP) among rural-urban, male-female, educated-uneducated, lower-higher socio economic status group of patients. There are lot of misconceptions in knowledge regarding cause, transmission, treatment and infectivity. Negative attitude of society which reflects negative attitude of society towards leprosy patients is mainly found among those who are deformed. So far as practices are concerned - 62% of patients are attending the clinic regularly, 35% of the patients with anaesthetic hands & feet are practising self care at home and 25% are using MCR shoes. Level of knowledge about leprosy among the deformed is much lower than those without deformity. Since overall KAP levels were low I conclude that regular Health Education to the patients and community awareness programme should be stressed. Health Education has been incorporated as an integral component of leprosy control programme since long time but unfortunately it has been almost totally neglected so far.

PS12

Almenara project, What Freedom Theology can do for leprosy control?

Luciula Guedes, João Climaco, Frei José Mauro, Eduardo_R._de_Abreu

In Brazil, Like others counties in latin America catholic church since the 70' years has been involved in social transformation as we can see in the work of "Pastoral da saude".

The authors relate a experience held in vale do Jequitinhonha-MG, Brazil in the last seven years in which health's profissionais share experience with people born the Jequitinhonhas valley and volunteer of health's pastoral.

The authors discuss the importance of aspectes like religious aind cultuial dimensions of life in rural areas with 180.00 citizens in 16 towns in mortheast of Minas Gerais state

PS13

Leprosy Stigma:

The Phenomenon and its relation with " exclusion locus" and heighbourhood.

Eduardo R. de Abreu

Fundação Hospitalar de Estado de Minas Gerais

In a Field Study established since 1984 and repeated in 1989 and 1998 the author pretend to describe the cultural changes and transformation of the valves relative

to leprosy patients in two towns not for from Sanatório Santa Izabel, a colory Hospital with aproximately 850 mattempt

This paper describe relation ship between citizen from these theree communityes in the last fifteen years.

PS14

THE LEPROSY PATIENTS ATTITUDE TOWARDS THEIR Chronic and recurring ulcers? - A study report

V. Kathe and <u>S.S. Naik</u> Acworth Lepromy Hospital Society for Remearch, Rehabilitation and Education in Lepromy, Wadala, Humbai-400 031, India.

A study was launched to understand what the leprosy patients think about reasons behind their chronic and recurring ulcers and their attitude towards these deformities. Ninety such leprosy patients attending leprosy centre and residing in leprosy colonies were interviewed. Out of them 41 were males and 49 were females in age group of 30 to 45 years. The most of them llitrate (26%) or having primary education (65%) and the profession as begging (23%) and unemployed (40%). 95% of them were suffering from plantar ulcers.

of them were suffering from planter ulcers. The reasons for recurring ulcers were given by them as due to loss of sensation (40%), injuries from stomes, nails and glasses. (31%), blister formation due to "chappies" or corns (21%), the bitser of rats (7%). 37% of them agreed that because of ulcers, their life was disturbed and they are asheed to move freely in the Society (69%). All of them know the medical treatment of ulcers and care of hands and feet. But becuase of severe apthy and frustration they neglected that part and managing only with bandages and oinments. They accepted these vounds are going to be their life component. It is suggested that 50% of them who are earning their livehood can be persuaded through their immediate family members and relatives to take care of their ulcers with successful results. Studies on those lines are needed.

PS15

LEPROSY: A GRASSROOTS PERSPECTIVE

Jose Ramirez, Jr., MSW and Magdalena S. Ramirez, MSW

R & S Social Work Consultants, 3810 Drummond, Houston, Texas, 77025 USA

Persons with leprosy are routinely perceived by many as communicable, unhealthy, unworthy, sinful and unable to be contributing members of society. These erroneous stereotypes can easily become a selffulfilling prophecy, denying those of us impacted by this rare illness the simple opportunity to succeed.

Historically, as ignorance about leprosy escalated, so did funds allocated to isolate and label millions of persons affected by this bacillus. This can best be illustrated on a bell shaped curve.

Conversely, as more and more individuals were placed in segregated settings, the less they were involved in exercising basic civil rights and the more likely they were to be denied opportunities to make choices on how and where to live. This can be illustrated by an inverted bell shaped curve.

As funding now decreases in response to the prospect of "elimination", the Culture of Leprosy is in dire need of a supportive emotional environment. Opportunities for choice, dignity and respect continue to remain flat. Unless this support becomes international policy, persons diagnosed with leprosy in the future will likely live in fear of being "discovered". The pendulum will swing back to the side of exclusion, decapitating all efforts to live like other persons, without disabilities.

PS16

TRANSFORMING THE IMAGE OF LEPROSY: SOCIETY NEEDS A NEW METAPHOR

Anwei Skinsnes Law, MPH

International Association for Integration, Dignity and Economic Advancement (IDEA), P. O. Box 133 Oak Hill, WV 25901 USA

Despite tremendous medical advances, "leprosy" remains the metaphor for the worst that can befall a human being, What are the reasons for this and what are the steps that must be taken to transform the traditional image of despair into a positive image of hope and triumph?

In looking for answers to these questions, it is important to look at the image of leprosy which is presented to the community. When we show the miraculous effects of NDT, do we only show cleared skin lesions or do we show someone who has been given back their future? Do we send a dual message to the public when we say people are cured but then continue to call them "patients".

Positive images of complete human beings are not just for people interested in social issues. They are essential to the effective treatment and control of leprosy and to the elimination of the disease, which includes the elimination of social exclusion, prejudice and discrimination. If society is to change its image of leprosy, it must see individuals with names and personalities who are living full and productive lives, and happened to once have a curable disease called leprosy.

PS17

LEPROSY IN THE UNITED STATES: A CASE STUDY OF A LOW ENDEMIC COUNTRY

Judith Justice

Institute for Health Policy Studies, School of Medicine, University of California at San Francisco, USA

University of California at San Francisco, USA This first comprehensive study of leprosy in the United States provides a case example of a low endemic country. The research assesses the situation of patients who are primarily from immigrant, ethnic and minority groups, and identifies factors influencing recognition of symptoms, availability and access to care, compliance to treatment, and long-term follow-up care. The research also focuses on the vanation in services available to these patients, including the Public Health Service Hospital, Government funded regional out-patients centers, and private clinics and physicians, in addition to how training, knowledge and experience of health care providers in a low endemic country influences diagnosis, referral, treatment and rehabilitation. Changes currently taking place in U.S. health care and the impact of health, welfare and immigration reform upon this vulnerable patients population are documented. One objective of the study is to assess culturally sensitive research methods to determine those most appropriate for conducting research on theory patients in situations similar to the United States. This study therefore provides a model for studying leprosy in low endemic countries. The research findings and recommendations with be useful for other countries with declining patient populations.

PS18

THOSE DISABLED BY LEPROSY DEMAND DIGNITY AND FULL PARTICIPATION

<u>Arega Kassa Zelelew</u> Ethiopian National Leprosy Disabled Association P.O.Box 24530, Addis Ababa, Ethiopia

According to WHO, the term "Disabled Person" means any person unable to ensure by himself, wholly or partly, the necessities of a normal individual and/or social life, as a result of a deficiency, either congenital or not, in his/her physical or mental capabilities.

Disability may be the result of biological factors affecting the individual before birth or the result of natural or manmade causes of damage. Among these factors leprosy is one of the leading cause of disability in the world. The disability caused by leprosy affects the individual's social life more than his physical capacity, because of stigma. I will consider the following points in order to understand the facts.

1. The concept of the causes of disability in our society.

- 2. The problems faced by those disabled by leprosy as compared to those disabled by other causes.
- 3. The need for special consideration of persons disabled by leprosy.

In conclusion, The Ethiopian National Leprosy Disabled Association (ENLDA), which was established with the objective of solving the complicated problems facing its members as stated above, has used all available opportunities to spread such knowledge in order to change attitudes in society towards leprosy disabled persons.

The education of the public by leprosy workers is challenging and must be kept up. Lastly I want to stress again that the leprosy disabled person wishes to enjoy dignity and recognition in society.

PS19

IDEA AFRICA: THE CENSUS & THE TAKE OFF

Ekekezie, Uche 'M

IDEA, Regional Office for Africa, #48, Toyin Street Opp. Water Parks, Ikeja, Lagos, Nigeria

This paper is about people, about an urgent human situation, and about human response to that situation. In the next two years, WHO will declare HD "eliminated". In the meantime, as IDEA slowly but surely becomes established all over the world, IDEA Africa, though still in the process of setting up her Regional Office, has already gotten down to serious business, building up a veritable network across the continent, sponsoring and encouraging direct PAL participation in important international events, creating some pilot projects and making their enabling presence felt here and there. Nigeria leads in this effort and the pioneer members of IDEA Africa are pursuing the programs and targets they had set for themselves with a sense of commitment and with all seriousness.

The main objectives of this paper are to: 1) take a cursory look at the HD situation presently in Africa, from the point of view of African PALs and other IDEA Africa Members, and put the finding side by side with the implications of the imminent WHO elimination target; 2) express the opinion of PALs on elimination by the year 2000; 3) estimate how many people need IDEA intervention in Africa: 4) examine effect of some rehabilitation strategies and methods used by some older organizations who have been in the business of rehabilitating PALs long before IDEA was born.

(This investigation was sponsored by members of IDEA Africa, with logistial support from the TLMI, GLRA and the Federal Government of Nigeria.)

PS20

SOCIAL ACCEPTANCE OF CHILDREN OF PEOPLE AFFECTED WITH LEPROSY.

Mary J. Paul

The Leprosy Mission , P.O. Box 9, Purulia 723 101, West Bengal, India.

A Psycho-social study was conducted on 150 Leprosy affected families and their children and 200 members of the

general public to assess the social acceptance of children of leprosy affected people. Special focus was given on education, occupation, and marriages. The results show that the children of leprosy affected families are well accepted into schools/colleges, also they do not face much discrimination by the general public in getting employment or at the place of work.

However, in the marriage context social stigmatisation of leprosy affected families is still significant. In addition many leprosy affected families expressed rejection without being able to cite specific experiences. The study shows that there is lack of awareness of leprosy among the general public especially among socio-economic disadvantaged people. Designated schools for families of leprosy patients tend to demotivate the leprosy affected families. This calls for counselling of leprosy affected families. This calls for counselling of leprosy affected families. This calls for counselling of leprosy affected families. There is also a need for intensive health education to members of the general public with special focus on those of low socio-economic status and those who hold to orthodox or conservative traditions which tend to potentiate the rejection of leprosy affected people.

PS21

SOCIAL STIGMA STATUS OF PALS IN THE PROJECT AREA COMMUNITY- PRELIMINARY FINDINGS-

T.J. Baskaran Richard, Dilip Christian, Eben Baskaran and Rupert Samuel.

Dayapuram Leprosy Control Project, Manamadurai, Tamil Nadu, South India.

The present scenario of Leprosy with decline of prevalence and deformity among new patients and higher percentage of MDT Coverage with priority for Community awareness, the social changes that has taken place in the community towards the leprosy patients has taken an important preposition.

So a study has been conducted at The Leprosy Mission Hospital, Dayapuram, Manamadurai to find out the General Stigma attached to Leprosy patients especially with deformity together with their knowledge on disease and control programme benefits.

The study population includes patients currently under treatment and OPD Programme, their households, immediate neighbourhood and a community sample, a Community Leader and a Village functionary. Structured questionnaire was designed separately for each category of respondents and was conversed by trained Leprosy workers.

Preliminary analysis suggests that there is a decrease in the level of social stigma. It also reveals the need for continued awareness Programme. The full analysis of the data is being done.

There are measures to eliminate Leprosy and other economic upliftment measures like providing sarees/ dhoties, bed sheets, Bank loans and other financial assistance. This study is designed to measure the status of Social Stigma.

PS22

PSYCHOLOGICAL IMPACT OF STIGMA IN THE ABSENCE OF SOCIAL STIGMATIZATION

<u>Nimal Kasturiaratchi</u>¹, Mitchell Weiss², Penny Grewal³, Padmini Gunawardene⁴, Dayamal Dewapura⁴, Sunil Settinayake⁴, Lakshmi Somatunga⁴, Vinya Ariyaratne⁴

¹University of Peredeniya, Sri Lanka, ²Swiss Tropical Institute, Switzerland, ¹Novartis Foundation for Sustainable Development, Switzerland, ⁴Anti-Leprosy Campaign, Sri Lanka, ¹University Sri Jaywardenepura, Sri Lanka

Leprosy is a stigmatised disease in many societies with serious implications for the management of leprosy programmes. With the wide scale use of MDT in leprosy endemic countries, people have seen positive prognostic features which have led to a significant reduction in fear of the disease and stigma. This collective illness experience is lacking in low endemic countries where stigma may operate differently.

To ascertain how stigma affects help seeking behaviour and the overall illness experience in Sri Lanka, 160 patients were selected at random from three categories of patients on treatment: those detected without deformities, with numbness and with grade 2 deformities. Semi-structured interviews were carried out to obtain narrative accounts of illness experience including patterns of distress, personal experience with stigma, names for the disease, help seeking behaviour and experience with treatment.

The study revealed how patients suffered from their own stigmatising ideas about this illness, rather than social castigation. Their suffering arose from concern about their diagnoses characterised by their internalisation of the cultural syndrome, stress of having their diagnoses known to others resulting in possible social isolation. The distress due to the local term used to denote leprosy is very significant. In addition, financial concerns due to the physical effects of leprosy such numbness or deformities were mentioned as well as symptoms pointing to transient psychological conditions.

The findings indicate that these individually internalised experiences need more attention than the social attitudes towards this disease. To assure quality of care, health care providers who treat these patients must be trained in counselling techniques, psychiatric referral and disability care so that they are aware of the psychological impact of culturally internalised stigma, even in the absence of overt social stigmatization.

PS23

PERSONS AFFECTED BY HANSEN'S DISEASE: WITH A CHALLENGE . . . WITH A MISSION

Ernesto G. Cabanos, Jr.

Department of Health, Eversley Childs Sanitarium Mandaue City, Philippines

Elimination will remain a dream in the hearts and minds of persons affected by HD if integration is not realized, respect and dignity are not restored, and equal rights and privileges are not enjoyed. It is time to consider ourselves equal partners in the delivery of basic information and knowledge.

Our testimonies and success stories are the best educational tools. We can encourage others to seek early treatment, teach prevention of disabilities, assit in early diagnosis and referral, and be a support group. Our physical disabilities can be memories of the past. HD can be just one chapter in our lives.

In the Philippines, we have developed a program whereby facts about HD, testimonies, experiences and success stories are presented in musical and narrative form. Values, culture and lifestyle are portrayed, dramatized and spoken in local dialects. Target audiences are college and university students; areas/ cummunities with high HD prevalence rates; areas/ cummunities with strong social rejection; and companies/ institutions which don't accepted persons affected by HD in the workforce.

We can make a big difference in the hearts and minds of the public. This is a challenge . . . a mission . . . that needs the involvement of each individual affected by HD.

PS24

WHETHER RFT STRATEGY IN MDT LEADS TO MORE AMPUTATIONS IN LEPROSY PATIENTS -A 20 YEAR STUDY

Dr. V. Durai, & Dr. P.K. Oommen Central Leprosy Teaching & Research Institute, Chengalpattu

The introduction of fixed duration of treatment envisages RFT after 6 doses in 9 months and 24 doses in 36 months for PB cases and MB cases respectively. This strategy has resulted in loss of regular contacts between medical team and the residual cases with insensitive hands and feet. This was in contrast to the mono drug treatment period, where patients had regular contacts with medical team. The residual problems such as management of ulcer, care of anesthetic feet & hand requires the attention of medical team even after completion of MDT for prevention of deformity.

In this study, patients admitted in Central Leprosy Teaching and Research Institute from 1976 to 1995 was used for analysis. A total number of 293 amputations, below-knee level, symes and midfoot amputations were done. The amputations performed before 1986 considered as mono era patients and after that considered as MDT era. The criterion for selection of patients for amputations and the surgical team philosophy on management over the last two decades has remained unchanged.

Various factors that lead to amputations were discussed in detail. This study reveals that RFT strategy in MDT has not resulted in decreasing the risk of mutilating surgeries. It is suggested that a working system of POD and also to have follow up of all the high risk patients with insensitive hands & feet, atleast once in a month.

PS25

PROGRESS OR ABANDONMENT?

Les Parker

St. Giles Home, Moor Hall Lane, East Hanningfield, Essex, CM3 8AR England

With so much uncertainy about the future of Hansen's Disease centers throughout the world, the experience of St. Giles, the last HD Hospital in England, and its five remaining residents is an important example of how progress can lead to a feeling of abandonment.

In the mid-eighties, St. Giles ceased to be a hospital and was taken over by a housing association. Over time, we were joined by 25 individuals, most of whom have mental disabilities. I sympathize with them, as they have to be housed somewhere due to similar closure of their own centers, but I question whether this population was the best suited to join us at St. Giles. In addition, our care has decreased from 24-hour, 7-day-a-week specialized medical care to one part-time nurse. The atmosphere is nothing like it was when we all had the same problems and understood each other. In many ways, I feel more isolated and alone than ever.

Hansen's Disease centers have been homes to thousands. As our numbers decrease, decisions about mixed-use for these centers cannot be made simply on financial grounds. <u>Psychological</u>, medical and social factors must be taken into consideration and discussed with those whose lives will be impacted by the decisions. It is essential that abandoned buildings don't result in abandoned lives, no matter how small our numbers may be.

PS26

STEPPING OUT OF THE DARKNESS: A NARRATIVE AND SLIDE PRESENTATION

Bernard K. Punikai'a

President for International Advocacy, International Association for Integration, Dignity & Economic Advancement (IDEA), 1541 Kalakaua Ave., #802 Honolulu, Hawaii, 96826 USA

Twenty years ago I was denied service in a restaurant because I had Hansen's Disease. Fifteen years ago I was arrested for attempting to have a voice in decisions concerning my future. Ten years ago I was appointed to the Hawaii Board of Health. Two years ago I spoke at the dedication of a housing complex for senior citizens and persons with disabilities. Last year I spoke at the United Nations.

The process that led to these changes provides practical solutions for eliminating society's fear and resulting prejudice against people with HD.

When injustices accumulate over a long period of time, the human spirit can no longer accept such conditions, and three things occur: 1) Individuals realize that they have to assert themselves and speak out publicly in order to be seen as people, not a disease; 2) They realize that one cannot fight

discrimination alone so network with others who have had HD; and 3) Reach out to caring people in the community to become partners in overcoming restrictive policies, archaic attitudes and discriminatory actions.

Ultimately, this process shows the community that those of us with HD are many things, but there is one thing we are not - we are not "lepers".

PS27

HOW WILL WE REMEMBER PEOPLE WHO LIVED WITH LEPROSY?

Valerie Monson

The Maui News, Wailuku, Hawaii USA

While documenting the history of leprosy around the world, many dramatic and inspiring accounts have been written or told. Too often, however, the stories come from religious leaders, doctors or social workers and forget to include the words of the people who actually were affected by the disease and had to overcome an ignorant society to live productive lives.

If you visit the original (and now abandoned) Kalawao settlement on the Kalaupapa peninsula, you wil hear detailed descriptions about Father Damien, Mother w111 Near detailed descriptions about Father Damien, Mother Marianne, Robert Louis Stevenson, even the wife of a pharmacist who kept a diary, but you won't hear a single memory of the thousands of people from Hawaii who were taken from their families and sent there with the disease. We will never know who these people were. Even their gravestones, most of them washed away or crumbled to bits are even to bits, are gone.

their gravestones, most of them washed away of triumled to bits, are gone. Fortunately, such an incomplete history will not be repeated at modern-day Kalaupapa where people who had the disease have been encouraged to share their stories in books, newspaper articles and video interviews. As a result, these remarkable individuals will be remembered not simply as "patients," but as human beings with full lives. With these stories, a much more accurate account of life in Kalaupapa -- its tribulations and its triumphs -- has emerged. These first-hand memories are not only necessary to tell the true history of leprosy and how it affected people, but to hearten others who have been recently diagnosed and fear their lives are over. As a reporter for The Maui News, I have written more than 50 articles about Kalaupapa's people, focusing on life after the disease. I would like to share this message so others around the world will do the same.

PS28

MANY FACES OF STIGMA: COMPARISON OF METHODOLOGIES.

Nimal Kasturiaratchi¹, Mitchell Weiss², Penny Grewal¹, <u>Padmini</u> <u>Gunawardene</u>⁴, Dayamal Dewapura¹, Sunil Settinayake⁴, Lakshmi Somatunga⁴, Vinya Ariyaratne⁴

¹University of Peredeniya, Sri Lanka, ²Swiss Tropical Institute, Switzerland, ¹Novartis Foundation for Sustainable Development, Switzerland, ⁴Anti-Leprosy Campaign, Sri Lanka, ¹University Sri Jaywardenepura, Sri Lanka

Although, Leprosy is considered a stigmatising disease the exact nature of stigma is difficult to be studied. Leprosy workers consider stigma as given and attempts to repeal it by educating patients and general public to view it as an "ordinary" illness. This exercise becomes futile when the complex nature of stigma is not understood fully and when its subtle ways of manifesting are not recognised.

This paper presents how stigma manifests itself when three methodologies were adopted to determine it. The methods referred to are: ethnography, empirical questionnaire and analyses of qualitative narrative statements made by respondents made as answers to quanitative questions

These studies, conducted in Sri Lanka, suggests that ethnograhic studies reveal the overall cultural themes of stigma which can be best utilised in health education programmes. The quantitative (empirical) studies on the other hand enabled the understanding of the comparative perspectives of stigma among different types of respondents including the sufferers themselves. The analyses of narratives indicated the subtle mechanisms of internalisation of stigma indicating how psychiatric, social and cultural manifestations could occur.

Social marketing, patients care, and involvement of health care providers within the antileprosy programmes warrant different types of information. The Sri Lankan experience may assist leprosy workers in other countries to select an appropriate methodology to study stigma depending on the needs.

PS29

REHABILITATION THROUGH PARTNERSHIPS

Siegfried Beecken

Partnership for Rehabilitation, P.O. Box 28, Pokhara, Nepal

Usually people affected by leprosy spend most of their lifetime with their family and in their communities. However, there has been a tendency especially in areas where there is a lot of stigma attached to leprosy - to 'draw out' leprosy sufferers from their communities into leprosy institutions. Initially, this assistance provides great benefit. However, on a longer term basis, such institutions can result in both the loss of the natural community support and the creation of high expectations on the side of the leprosy-affected clients, for social and economic security. Thus the clients can become very dependent. In the past help has often been provided from a specialist to a 'leprosy patient' - rather top down. Now is the time to recognise people affected by leprosy as equal partners. It is time to discover communities as partners in our efforts to facilitate help for our clients. As we move towards the eradication of leprosy, it is time to develop sound strategies for rehabilitation, based on such partnerships.

We have to start to go to the homes of our clients, to meet their families and communities in order to be able to understand their situation and to help them to live an independent life with dignity. In addition, it is our responsibility to motivate, equip and enable communities to assist their people affected by leprosy. Treatment of leprosy has been integrated into the general health system. We must now work through an integrated approach in facilitating rehabilitation. Community-based rehabilitation roaches have the great potential to work in real partnership with people with disabilities, including those affected by leprosy and their communities.

PS30

LEPROSY VILLAGES IN THE CENTRAL HIGHLAND, VIETNAM

Vo Tri Toan, Kirsten Løydal Biune and Gunnar Biune Centre for International Health, University of Bergen, N-5021 Bergen, Norway

The Central Highland has Vietnam's highest prevalence of leprosy. The

The Central Highland has Vietnam's highest prevalence of leprosy. The health infra structure is weak, population scattered and consists of more than 50% minority populations with more than ten different languages and cultures. The National Leprosy Eradication Programme is implementing the Special Area Programme for Elimination of Leprosy (SAPEL) and Leprosy Elimination Gia Rai and Banah are the two largest ethnic minorities in Gia La Province. Remoteness of the villages makes health and educational services practically non-accessible. Traditionally they practised slash and burn agriculture and supplement their meager resources by hunting and gathering in the surrounding forest hills. The villages have to move every three to four years when the soil is exhausted. A fixed pattern of movement brings the village back to its first location at fifty years cycles. However, environmental deterioration during the war, immigration of farmers from the lowlands and increase in the indigenous population have made this life style non-sustainable. Socio-econditions in leprosy villages are appaling. The Government of Vietnam attempts to improve the conditions through a special programme for Elimination of Starvation and Alleviation of Poverty Programme (ESAP). For at least 100 years Gia Rai and Banh have segregated leprosy families in special villages where most of the adults have major leprosy deformities and disabilities and have to rely upon their children and neighbouring villages for food supplies. The segregation pattern is unique in the sense that the patterns

disabilities and have to rely upon their children and neighbouring villages for food supplies. The segregation pattern is unique in the sense that the patients have usually lived for a long time well integrated in their village of birth until all families with leprosy in the village split off and establish a new village much the same way as villages which have grown too large split into two. There are no obvious psychological hostility towards the leprosy village, and communication between this and the mother village seems to be free. The traditional organisation of the leprosy village is the same as in the culture as such (matriarchal extended families) with one significant difference; their settlement is permanent and thus more fit for sustainable development. We will present an explorative medical anthropological study done with the aim of developing the 37 leprosy villages widely dispersed in the province to nuclei for improved living conditions and sustainable development for the ethnic minorities as a whole. Data were provided by the local health services and provincial authorities and supplemented with participatory observations in a few representative leprosy villages.

PS31

AN UNUSUAL EXPERIENCE

Shene-tu Chen

ing County Station for Skin Diseases Control, Yihuang County, Jiangxi Province, China

This is a special report given by a doctor having a good and perfect family

One year after being enrolled at the Jiangsi Medical College in 1972, he unfortunately was diagnosed as leprosy. Because of the long established stigma in the society towards leprose, he discontinued his study and was accepted in a leprose village for isolated treatment.

Since then, he did not give himself up as hopeless but put up a tenacious fight against the illness, and served patients warmheartedly inside and outside the village with his knowledge. His selfless service has benefited the health of a great number of people including awang an youth's lite from freezing river. His untiring efforts and contributions to leptonsy control and general health care for more than 20 years made hun trusted by related authorities. He has succeeded in physical and social rehabilitation both.

PS32

COMMUNITY ACTION PROGRAMME FOR SOCIAL CURE OF LEPROSY (CAPSULE)

<u>C.S. Cheriyan, T. Jayaraj Devadas, Dr. Thomas Abraham</u> GLRA/ALES-INDIA, #4,Gajapathy Street, Shenoy Nagar, Chennai 600030.

Leprosy is a unique social disease. A social disease needs a social cure. Any patient affected by any disease other than leprosy ceases to be a patient once he is cured of the disease. But in the case of leprosy it is not to be so. Even after cure one has to carry the tag of Social stigma. This situation warrants the need for ushering in a Social Cure for leprosy patients.

Social cure of leprosy is acceptance of a person cured of leprosy by the contemporary society and allowing him to function as a normal individual socially, without discrimination, let or hindrance, on all walks of life. Capsule is a set of community action programme envisaged to prepare a congenial atmosphere to bring about a Social Cure for leprosy patients.

No programme, however good that be, can bring lasting changes in the beliefs and antitudes of the people unless that doesn't become the peoples programme. The following Special groups are formed and sustained in the community.

- Community Action Groups
- Advocacy Groups
- · Friends of Leprosy affected Groups
- · Participating the patients directly in disability limiting exercises

The above given special programmes initiated will help accelerate the reintegration of the leprosy cured persons into the society which ultimately is the Social Cure for leprosy.

PS33

KNOWLEDGE, ATTITUDE AND PRACTICE ABOUT LEPROSY AND TB IN NORTHERN BANGLADESH

Richard Croft, Rosemary Croft

Danish Bangladesh Leprosy Misson, Nilphamari, Bangladesh

A small survey was carried out in northern Bangladesh to assess and compare the level of knowledge, attitudes and practice towards leprosy and TB among two areas that differed widely in the amount of health education received about these diseases.

The results indicate that without a health education programme, levels of knowledge about the cause and treatability of the diseases are poor. Only 16% of respondents in the 'uninformed' area mentioned 'skin patch' in a question about what they knew about leprosy, and 44% mentioned 'cough' as a symptom of TB. In the area that had received health education, 90% mentioned respectively 'skin patch' and 'cough' 78% of the respondents would not buy goods from a shopkeeper known to have leprosy, 76% if he had TB in the unreached area, but in the community who had received health education the proportions were reversed with three quarters agreeing to purchase from a diseased shopkeeper.

There are low levels of knowledge about leprosy and TB, and unfavourable attitudes in a community that has not received health education. However, knowledge levels were much higher and attitudes more positive in an area that had received a health education programme.

PS34

Bacurau and his Fellows on Their Way: Fighting Against Leprosy Prejudice

Eni caraja, Eduardo R. de Abreu, Helio Dutra Morhan - Nucleo de Berim-MG The authors present fhotos, interviews, friends and relatives testimony of a brave man who fhought since childhood until his death against prejudice in favour of people affected by leprosy, promoting dignity for all.

PS35

ECONOMIC SELF SUFFICIENCY AND SOCIAL INTEGRATION OF DISPLACED LEPROSY AFFECTED PERSONS THROUGH MICRO ENTERPRISES.

T. Jayaraj Devadas, G.R. Srinivasan GLRA/ALES-INDIA, #4, Gajapathy Street, Shenoy Nagar, Chennai 600030.

Persons affected by leprosy in addition to the need to adjust to physical disability may find themselves segregated and displaced in the community. Thus it is important to emphasise the process of normalisation by providing them the opportunutes to enhance their economic and social status.

A Domicillary Rehabilitation Scheme launched by the German Leprosy Relief Association Fund in 1974 has experimented the promotion of micro enterprises by providing the persons, interest free loans.

A study covering 50 beneficiaries revealed that 83% of them have attained enhanced income and self sufficiency through the different enterprises which they could start out of the loans extended by the scheme. The study also revealed that 66% of the respondents have found that their purchasing power has increased by 30% and they can lead an independent life.

 This study revealed that by developing a sound strategy of loans to promote micro enterprises for self employment and monitor the scheme through counselling and followup by trained and comitted staff the social integration of displaced leprosy affected persons can be done on a wide scale

PS36

FACTORS THAT AFFECT LEPROSY PATIENT'S DECISION TO DISCLOSE HIS ILLNESS TO OTHERS

Edgardo M. Gonzaga, M.D., Troy Aguedo Gepte IV, M.D., Socorro P. Lupisan, M.D., Felicita M. Medalla, M.D.

Department of Epidemiology and Biostatistics, Research Institute For Tropical Medicine, Alabang, Muntinhupa City, Philippines

A study was conducted among leprosy patients seen at the Leprosy Section of the Research Institute For Tropical Medicine to determine the factors that affect leprosy patient's decision to disclose his illness to others (based on Triandi's Theory).

Canaditative methods such as Key Informant Interview and Focus Group Discumiton (FGD) were utilized in the construction of the questionnaires. One of the anthors served as the key informant based on his experience with leprosy. The interview was informal. Based on the outcome of the interview, a field guide consisting of open eded questions was prepared for the intended FGD. The FGD was done to elicit opinions and mawers to questions regarding the topic. A group of eight (3) leprosy patients were gathered together in one rooms at the mit. Questionnaires were designed and scaled based on the outcome of the FGD and were pre- tested. Scaling utilized adjectival responses with corresponding discrete number from one to five, of which 1 would indicate a response closest to the selection on the left side, 5 would indicate a response closest to that on the right side. A selection of 3 indicate a neutral response. Data were centered using the EPI-INFO software, STATA software was used in the analytic. To maximize realbility and validity of income hear charterial in the nucleic line in the nucleic in the nucleic intervence intervel.

Data were entered using the EPI-INPO software. STATA software was used in the analysis. To maximize realibility and validity of items in each subscale, item sandysis was performed for all items in the questionnaire using the following methods: 1) descriptive analysis; 2) inter- item analysis; 3) item total analysis; 4) internal consistency coefficient (Cronback's alpha); and factor analysis. Method 5 us were essential in deleting or retaining items in each subscale. Method 5 was utilized to confirm decision.

Eighteen (18) items were found to be valid for scaling, of which two each pertains to social factors, affect, values, motivating factors and habit, while 8 items belong to facilitating factors. More items would have to be developed and pre-tested for scaling to satify the requirement of at least 5 items per factor using the Triandi's Model. Questionsairs construction, as shown in some modules would involve a series of activities and pre-testing before a final draft is assessed as suitable for data collection. 66, 4 **PS37**

HANDICAP AND QUALITY OF LIFE OF LEPROSY PATIENTS

Ruth Leekassa, Elisabeth Bizuneh, Paul Saunderson CHERT, P.O.Box 165, Addis Ababa, Ethiopia

Objective: To assess the quality of life (QOL) of leprosy patients, in relation to their impairment grade (EHF score) and to compare them with other dermatology patients.

Subjects: 60 leprosy patients with varying degrees of impairment, who attended ALERT Hospital, were included. 24 patients attending the acne clinic were included for comparison.

Instrument: The WHOQOL-BREF questionnaire was developed by WHO to assess quality of life. It has been validated in many different cultural settings, and for different disease states. The 26 questions are divided into four domains (physical health, psychological health, social relationships and environment). This instrument therefore addresses the measurement of "handicap" according to the International classification of Impairments, Disabilities and Handicare (WHO 1980) Handicaps (WHO, 1980).

Results: There was a highly significant decrease in QOL in Results: There was a highly significant decrease in QOL in all domains for leprosy patients, compared with acne patients. There was a strong inverse correlation between EHF score and QOL in leprosy patients, for each domain. Female leprosy patients had significantly lower scores than made patients in two domains, psychological health and social relationships.

Conclusion: Leprosy patients have a low QOL when compared with acne patients and this is directly related to their EHF score. The poster describes the use of the WHOQOL-BREF questionnaire.

PS38

THE DEGREES OF DEPRESSION IN LEPROSY

Turkan Saylan, Reyhan Mulayim, Mucella Soydan

Istanbul Leprosy Hospital, Bakirkoy, 34747, Istanbul, Turkey

The aim of this study is to investigate the degree of depression in leprosy patients.

This study was done with the leprosy patients (25 male, 25 female) and non leprosy persons (25 male, 25 female). Both groups had equal social characteristics.

Porteus or Alexander IQ test annd Beck and Hamilton depression scale was used for analysis

In 38 leprosy patients (76.0%) have depression in moderate and severe degree. This ratio was 34.0% (n=17) in control group; 80.0% (n=20) in female leprosy cases; and 36.0% (n=9) in control females.

These results indicate that depression may create more problems for leprosy patients.

Depression may result of the medical and social problems of leprosy patients and worsen to solve of their problems.

PS39

LEPROSY PATIENTS AS CHILD OR ADULT WOMAN-THEIR INTERRELATIONSHIP WITH FAMILY COUNTER PART

S. Joshi, P. Kathe and <u>S.S. Naik</u> Acworth Leprosy Hospital Society for Research, Rehabilitation and Education in Leprosy, Wadala, Mumbai-400 031, India.

Seventy five children and 96 adult leprosy patients attending leprosy clinic in Humbai were interviewed with their family members es-pecially children of leprosy patients and income generating parents of child leprosy patients. It was observed that after initial disturbance at the time of diagnosis, the healthy family

members had shown acceptance and positive beha-viour towards leprosy patients in due course of time (75%), probably due to rapid clinical regra-ssion due to MDT and proper health education in Society. However the healthy parents showed some reservation (40%) but children at large showed positive attitude in acceptance of disease. Seventy women leprosy patients registered during last five years were interviewed for their status and acceptance in families and com-pared with old leprosy women patients residing in leprosy colonies. It was observed that there was a dist ict change in positive acceptance of family members towards women leprosy patients in recent period due to early detection and effective MDT treatment.

PS40

A STUDY ON BEGGING BY EX - LEPROSY PATIENTS ATTITUDE & WILLINGNESS TO REFRAIN

K.D.V. Prasad, B.P.Ravikumar, V.Paul Jeyaraj and K. Durga Raju

Vocational Training Centre, Vizianagaram, Andhra Pradesh, South India

A study was undertaken on ex-leprosy patients living in three colonies in and around Vizianagaram town, to explore their attitude to begging and willingness to be rehabilitated.

This was cross sectional study on 160 inmates. A Pre-tested Open Ended Interview Schedule was administered by our professionally trained social worker.

THE RESULTS

- 1.
- 77.8% of the beggars operate in Urban area.
 82.2% of the beggars are married.
 The average daily income per day is Rs 20/- per person.
 64.3% of the beggars are provided with Rehab Units and all failed; so they continue begging.
 94% of the beggars are not willing to give-up begging.
 The colonies studied are well organised and have registered societies.
 70% of these beggars receive Rs. 75/- per month from provergement lewards pencific.
- 5 6
- 7. government towards pension.

PS41

STUDY OF PSYCHO SOCIAL ASPECTS OF DEFORMED AND NON DEFORMED HANSENS PATIENTS - CROSS SECTIONAL COMPARATIVE STUDY

Ratna Philip

Philadelphia leprosy Hospital : Salur - 535 591, South India

Available 30 deformed Hansens patients were taken from hospital and 30, Grade I deformed Hansens patients matched for the age & sex were chosen randomly from the list of the control area patients of Philadelphia Leprosy Hospital, Salur. A pre tested structured interview schedule was administered by the investigator . Results have been analysed using statistical methods for significance.

Analysis of the results demonstrated a significant difference among deformed and non deformed Hansens patients in the following area.

- 1. Decision making power : (X² n 8.17)
- 2. Eating together with family members: (X² of 7.2)
- 3. Sleeping along with the family members: (X^2 ₀₅ 4.34)
- 4. Change in the job after developing disease in both groups of patients: (X^2_{-05} = 4.59)
- 33.34% among deformed felt like committing suicide after developing deformity and 23.34% are worried about their 5. future

This study demonstrates how deformity effects the psycho social aspects of Hansens patients.

PS42

PSYCHOSOCIAL ASSESSMENT AND COUNSELLING

Maryann Richard, Samjhana Gurung, and Ruth Pariyar

Counselling Department, Green Pastures Hospital, Pokhara, Nepal

Counselling Services at Green Pastures Hospital (GPH), Pokhara, Nepal began in October 1993. A Nepali nurse and I, an Expatriate Counselling Psychologist, have worked together to understand and respond to the counselling needs of the GPH inpatients. Our goal was to help reduce the negative effects of leprosy stigmatization through assessment of those in need and then follow up individual counselling. We began to see referrals from the doctors and our own selection focusing on those who were somewhat confused, not interacting much with others, anxious, depressed and on rare occasions psychotic. A Psychosocial Assessment form was designed to address the person's Psychological and Socio-Economic needs. Using this form as a starting point we assessed each in-patient at GPH (and some selected out-patients) and then chose which persons needed individual counselling. Typically, we met with each person needing counselling for 30 - 45 minutes weekly. Those with depression or psychosis would be met almost daily, but little real counselling is done until they are stabilized on medication. Assessments and counselling follow-up have helped us to focus our efforts on those needing psychosocial help. We then in conjunction with other departments at GPH meet in a rehabilitation team to discuss with the person their concerns and needs looking at strategies for meeting the person's needs. Patients feel listened to and understood. They also feel more able to meet the difficulties they face in their home environments after counselling. As there are no basic listening courses available in Nepal, we began to teach Psychosocial Listenia Courses to nurses in N.G.O.s so that they would be better equipped to wholistically care for persons affected with leprosy.

PS43

GROUP COUNSELLING FOR STIGMA REDUCTION

Maryann Richard and Samjhana Gurung

Counselling Department, Green Pastures Hospital, Pokhara, Nepal

Counselling services at Green Pastures Hospital (GPH), Pokhara, Nepal began in October 1993. A young Nepali nurse took up the half-time post and I, a Counselling Psychologist, joined her as her teacher and supervisor in January 1994. Our goal was to help reduce the negative effects of leprosy stigmatization on persons affected with leprosy through a psychosocial assessment of those in need and then follow-up individual counselling. We began to see referrals from GPH doctors and our own selection focusing on those who were somewhat confused, not interacting much with others, anxious, depressed and on rare occasions psychotic. From the above assessments it seemed to be clear that for some people stigmatization. whether initiated by self-rejection or rejection by others, was a common theme. We felt that the best way to talk about these feelings of rejection was through small support groups. Our groups run 5 x 2 hour sessions over 5 weeks. They composed of 5-6 individuals and divided into men's, women's and children's groups. In these groups people are encouraged to remember things from three phases in their lives: before contracting leprosy, after contracting leprosy up to the present, and life after leaving GPH. Themes which arise are stigmatization, depression, reconciliation, and dependency. Our discussions are supplemented by pictures used to further explain these themes. Using a Group Therapy method more people can be dealt with at one time, they learn from one another's successes and failures, and experience reduced levels of anxiety about their life after leaving GPH.

PS44

A POSITIVE OUTCOME IN COMMUNITY EYE HEALTH CARE SERVICE OF THE LEPROSY SUPPERES IN EASTERN INDIA IN THE LAST TWO DECADES :

Swapan K. Samanta, I.S. Roy

B.S. Medical College, Bankura, West Bengal, India

For many years, social stigma has kept the Leprosy sufferers away from all the social opportunities including the existing health care facilities for the general mass. In Pre Dapsone and Dapsone Era (i.e. upto 1988) Eye Health Care Services and comprehensive Eye health care camps were organised only in the leprosorium for these patients. The materialisation of the concept of 'Release from treatment' following successful Multi Drug Therapy has revolutionised the community eye health care delivery outlook in Eastern India. In post MDT Era the Leprosy affected persons are enjoying all the services rendered for the general healthy people whether in the general hospital or in the mass Eye Operation camps. Even the general healthy cataract blind people of the neighbouring villages, staying side by side of the Leprosy sufferer & accepting the comprehensive Eye Camps being held within the After Care Leprosy colony campus by active organisation and participation of the after care leprosy sufferers organisation. This is a great positive turn to our community Eye Health effort 'From darkness to light'

PS45

THE SCHOLARSHIP PROJECT FOR CHILDREN OF LEPROSY PATIENTS

<u>Türkan Saylan,</u> Ayşe Karadeniz, Nermin Ersoy, Neşe İyier, Dilek Pamuk

Istanbul Leprosy Hospital, Bakirkoy, 34747, Istanbul, Turkey

In this study, we have planned to give results of our scholarship projects, 53% of 545 students were male and 47% [emale. 72% of them were primary school students, 9 were university students.

We will give more information in the poster.

PS46

SOCIAL INTEGRATION THROUGH ECONOMIC REHABILITATION

Neela Shah, Atul Shah, Penny Grewal

Comprehensive Leprosy Care Projects, Ciba Compound, Tardeo, Mumbai, India

Community based rehabilitation services has one important component of economic upliftment and social integration. Economic rehabilitation of PAL's who are physically, mentally or socially handicapped forms an integral part of any disability management program. A unique approach of identification of beneficiary from social history, status verification and need analysis has been adopted. The economic assistance was then made available, preferably in kind (for occupation) to the 188 PAL's. Their social status was closely monitored with follow-up of more than 5 years. The excellent results demonstrate that majority of the PAL's have been well settled and support their family. In some instances the family members have also benefited by the aid. It is a sustainable development from human angle. There is no stigma associated with PAL's can be judged by sheer participation of community in such function and involvement of community leaders and opinion makers. Various other plans have shown their eagerness to spare the funds and be partners in making social integration through economic rehabilitation possible for large number of deserving cases. In fact, the integration of this aspect in other plans is necessary and will become the cornerstone of integration of leprosy disabled with other disabled. The concept, management and benefits will be presented.

PS47

THE SOCIAL REHABILITATION PROJECTS IN LEPROSY

Mücella Soydan, Türkan Saylan, Seval Koçaslan. Dilek Cakir

Istanbul Leprosy Hospital, Bakirkoy, 34747, Turkey

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.

For this reason we planned social projects for our patients. In this study we planned to give 106 projects. 60% of them were from rural area. 47% of the projects were animal projects. We helped them for house reconstruction also (n:23). We could find sponsor for 22% projects.

Their previous and present situation will discuss in the poster.

PS48

A SOCIAL INVESTIGATION OF CURED PERSONS AFFECTED BY LEPROSY IN COUNTES ATTACHED TO SHANGHAI MUNICIPALITY

> Zai-ming Wang et al. Shanghai Zunyi Hospital, Shanghai , China

The goal of basic eradication of leprosy was reached in Shanghai in 1990 and there are 1.411 cured persons affected by leprosy in its county area at present A. specially designed questionnaire was administered to 477 randomly selected subjects (male 344, female 133) with an average age of 6.18, years (355, of them >60 years) among the metinoad cures. Following points were observed in this study: 1) disability rate (WHO II. & III grade) was as high as 59.75%, 2) 135 (28%) were illiterates, 277 (58%) primary level, 57 (12%) primary include school level, 1) 43(9%) hat marred, 434 (154) married, 4 (155) divorsed, 91 (19%) heneft of spouse; 468 (98%) have a harmonious family; 4) there was still discrimination against cures (100, 21%) and cures' family (9), 19%5, 5) less than 2 000 yuan, and as many as 112 (23.5%) cures are still in need of financial support from others; 6) 467 (98%) wish to get help from rehabilitation programme and 415 (87%) like than 2 have home wish to be mediation programme and 415 (78%) with a spray as 112 (23.5%) cures are still in need of financial support from others; 6) 467 (98%) wish to get help from rehabilitation programme and 415 (87%) like thave home visit by medical workers; 7) 458(96%) are basically familiar with the symptoms of relapse and 472 (99%) will consult a doctor actively if relapse occurs.

The above findings indicated a big success achieved in leprosy control and a remarkable

reduction of discrimination against persons atfected by leprosy in Shanghai. But financial straits, daily life care and medical rehabilitation are sensus problems to be solved for the remaining cures. A combined programme of leprosy rehabilitation and community based rehabilitation should be worked out and could be implemented smoothly.

PS49

DEFENSE STYLE ASSOCIATED WITH LEPROSY

Shang-wen Yi

Dong'an County Health and Epidemic Prevention Station, Dong'an, Hunan Province, China

The revised defense style questionnaire was administered to 8 outputients with leprosy (male 7, female 1; average age 33 years) and to control subjects from the general population. The difference of mean score on immature defense style factors (1 ± 5 JII, p=0.01) and on rationalization factor (1 ± 4 J94, p=0.01) in patient's group was significantly higher than those in normal individuals. The patients had a greater tendency towards immature defense style with poor self-control consciousness and serious rationalization psychology. The author recognized that projection (1 ± 7.563 , p=0.01), passive aggression (1 ± 9.790 , p=0.01) and dependence (1 ± 6.250 , p=0.01) were main symptoms of immature defense style, and that in order to reduce the pressure from the community and to ease their psychological suffering they dealed with events they faced with concealment of disease and tried to cover their nervousness and uneasness due to suffering from l-prosy. The author also indicated that passive phycological defense style was more frequently observed in new patients without previous analterpost berapy.

PS50

KNOWLEDGE AND ATTITUDE OF PHC WORKERS IN IBADAN METROPOLIS TOWARDS LEPROSY AND ITS INTEGRATION INTO PHC SERVICES

Raymond O. Olaseinde

Department of Physiotherapy, University College Hospital, Ibadan, Nigeria

Integration of leprosy services into Primary Health Care is a goal of the Nigerian Leprosy Control Programme that aims at making services cost-effective and accessible. Previous studies have shown that health workers do not differ from the general public in their aversive attitudes towards leprosy patients. This study was undertaken to document the knowledge and attitude of Local Government Area (LGA) health staff towards leprosy and integration into PHC in 5 LGAs that comprise Ibadan metropolis and to serve as a basis for planning training programmes. All available PHC staff working in the LGA clinics were interviewed using a self-administered questionnaire. Twenty questions, containing 135 knowledge items were used to produce a score about the cause, treatment, complications and management of leprosy. Sanitarians scored significantly higher (90 points) than Nurse/Midwives (87) and Communty Health Extension Workers (82) (p < 0.0004). Though few had previous inservice training in leprosy (14%), those who had training scored higher (90) than those who did not (84) (p < 0.006). Two attitude scales measured attitudes towards patients and towards integration of services. Both were significantly higher for persons who had attended inservice training. The results point to the value of and need for more training.