PAMIC is a multidisciplinary approach in which professionals from the medical, occupational therapy, social sciences and clinical psychology combine to prevent and manage disability issues in leprosy. The programme is hospital based and is held in the outpatient department. An assessment form based on the WHO ICIDH concept is used to identify impairments, activity limitation and participatory restriction.

The disability issues are prioritized according to patient's perception and possible interventions are identified. About 250 patients were assessed using this tool and the results are presented. 84 % of patients had activity limitation and 82 % participatory restriction. As far as activity limitation is concerned approximately 95% of patients were able to perform Activities of Daily Living, 61 % had to change their vocation with 34 % adapting to their vocation with the disability. 20 % of perceived participatory restriction in their domestic life, 19% had participatory restriction with relatives and about 36 % had participatory restriction in societal roles including vocations.

The main advantage of the assessment tool is that disability issues are seen in the light of patient's perception and interventions are drawn according to his/her priorities. The assessment form brings out finer details of activity limitation and participatory restriction so that specific interventions can be decided upon. Interaction between professionals helps to arrive at the best possible way to implement interventions taking into consideration social and economic issues

SOCIAL ASPECTS

OSA 1

A HEALTH PROMOTING INTEGRATIVE COMMUNITY DEVELOPMENT PROGRAMME

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Social stigma and ostracism affect those with and 'cured' leprosy, and others in a community who have persons with disabilities, inequalities and loss of social capital. Community integration and community involvement using community resources and facilities can enhance social esteem, improve quality of living and help integrate those with physical, mental and social disabilities. Partnerhips between the statutory, voluntary and private organisaitons within a community may be facilitated through the services of a paid community co-ordinator.

Healthy Communites which include Healthy Cities and Healthy Villages are part of the World Health Organisaiotn plans to promote healthy and active communities in developed and developing countries. Health Care systems vary in many countries of the world from a Health Service funded mainly through Taxation as in the UK, to combinations of Tax based insurance and private funding in other countries. Many 'cured' patients of lerpsy or Hansen Disease carry the stigma with their assocviated disabilities with them throughout life independent of any corrective surgery that may have been performed.

In our village in the UK we demonstrated a posotive 72% uptake of resources and 70% improved quality of living.

OSA 2

A IMPORTÂNCIA DA AVALIAÇÃO DA QUALIDADE DE VIDA EM PACIENTES COM HANSENÍASE

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Introdução: A hanseníase, se não tratada, resulta em graves distúrbios psicológicos, físicos e sociais. Devido ao estigma que a doença causa, os índices de qualidade de vida desses pacientes decai consideravelmente.

Casuística: Foi aplicado o questionário de avaliação da qualidade de vida da Organização Mundial da Saúde (OMS), adaptado para as condições dos pacientes com hanseníase. Foram analisados 30 pacientes (16 homens e 14 mulheres), na faixa etária de 18 a 72 anos, que estão em registro ativo e acompanhamento pós- alta, no Centro de Saúde Escola Capuava (ambulatório de hanseníase). O questionário explora os seguintes itens: físicos, psicológicos, nível de independência, relacionamento social, religião e lazer.

Resultados: O nosso estudo revelou que a qualidade de vida diminui com a evolução e progressão da doença, principalmente em relação aos fatores psicológicos, relacionamento social, nível de independência e alteração da imagem corporal. Os pacientes com as formas avançadas da doença relatavam exclusão social, incapacidade ao trabalho e diminuição da atividade sexual.

Discussão: A hanseníase pode ser vista como uma doença que leva à alterações psicológicas, socioeconômicas e espirituais que vão progressivamente afetando as pessoas que não estão preparadas para encararem esses fatos. Apesar de multidroga terapia anti-hansênica ter proporcionado um certo otimismo em relação às perspectivas de eliminação da doença e prevenção das incapacidades, observa-se que os estigmas da doença ainda permanecem e os centros de tratamento não estão preparados para auxiliar estes conflitos. Conseqüentemente, o grau de declínio da qualidade de vida precisa ser revisado e correlacionado com vários fatores ambientais e sócio-demográficos, incluindo-os no protocolo de atendimento aos doentes com hanseníase.

OSA 3

A IMPORTÂNCIA E A NECESSIDADE DO ACOLHIMENTO AO PACIENTE COM HANSENÍASE: UM ENFOQUE BIOÉTICO

Letícia Maria Eidt

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A Hanseníase, doença ainda hoje lembrada como nos tempos bíblicos com todos os seus estigmas e preconceitos, gera vários sentimentos e angústias que contribuem para a diminuição da auto-estima em seus portadores. Os pacientes quando procuram atendimento chegam fragilizados, necessitando, além do tratamento medicamentoso poliquimioterápico, sobretudo, de um tratamento humanizado. O presente trabalho apresenta os resultados de uma pesquisa qualitativa fenomenológica, realizada com hansenianos em acompanhamento no Ambulatório de Dermatologia Sanitária, localizado na cidade de Porto Alegre, centro de referência para tratamento da Hanseníase no Estado do Rio Grande do Sul, Brasil. Os dados foram coletados por meio de entrevista semi-estruturada e dialogada, posteriormente transcrita para aplicação do método fenomenológico. A importância do respeito ao ser humano hanseniano, o acolhimento e o carinho por parte da equipe de saúde, contribuindo para o resgate da auto-estima e para a adesão ao tratamento, são alguns dos aspectos abordados pelos pacientes. A autora reflete, ainda, sobre a necessidade de tratar os doentes na sua integralidade e sobre a preocupação em não se descuidar da dignidade humana como medidas necessárias à humanização do atendimento aos portadores de Hanseníase.

OSA 4

A QUESTION OF JUSTICE: REHABILITATION OF PERSONS AFFECTED BY LEPROSY

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The German Leprosy Relief Association (GLRA) supports leprosy control services in 14 states in the south-east and south-west of Nigeria. About one third of Nigeria's population of 120 million live in this area. As the backlog of leprosy cases requiring treatment declines, the GLRA has increased the profile of social and economic rehabilitation of persons affected by leprosy. In the new spirit of partnership with persons affected by leprosy, the GLRA in Nigeria has adopted the motto: "nothing about you, without you". To operationalise the concept, a series of meetings and consultations was held with field officers and representatives of persons affected by leprosy. The consultation with persons affected by leprosy was the first of its kind in Nigeria. It was a most rewarding and revealing experience. Data on the focus groups and their recommendations are presented and discussed. The paper concludes on the following note: that most persons affected by leprosy are asking for a hand-up, not a hand-out. That main-stream socio-economic field is heavily tilted against persons affected by leprosy that 'affirmative action' is necessary to bridge the gaps and assist persons affected by leprosy in the 'normalisation' process. That ILEP in collaboration with IDEA International is best positioned to play 'advocate-extraordinaire' on behalf of the affected persons and to raise the considerable sums of money needed for effective and sustainable rehabilitation. That a world without 'LEPERS' is attainable in this century, long before a world without leprosy. That the pursuit of this goal is not a favour to persons affected by leprosy but a question of justice for all.

OSA 5

A STUDY ON THE SETTLEMENTS OF THE LEPROSY AFFECTED IN INDIA

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Introduction: As soon as IDEA's activities were established in India, an all embracing study covering more than three hundred self settlements of persons affected by HD was launched in India for the first time, to find out the occupational requirements of the inmates and to assess their living conditions, family setups and all about their lives. It was a massive study covering as many as nine endemic states in India.

Objectives:

1. To study the living conditions of the inmates in the settlements.

2. To study the occupational status of the inmates.

3. To find out the needs and requirements of the inmates.

4. To offer suitable remedial measures.

Operational Modalities: A detailed questionnaire was worked out and the settlements were visited by a team comprising of a health educator, social worker and a physio-technician. Exhaustive interviews were carried out to get the required data.

Conclusion: After the collection of the data, they were analyzed and a comprehensive relief package was worked out and the same was administered among the inmates at the behest of IDEA in the various settlements spread out in different parts of the country which had helped to enhance their integration with the general public, dignity through self reliance and economic advancements through occupational gains.

OSA 6

ASSESSMENT OF DISABILITY, SOCIAL AND ECONOMIC SITUATIONS OF THE PEOPLE AFFECTED BY LEPROSY IN SHANDONG PROVINCE, PEOPLE'S REPUBLIC OF CHINA

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As the decline in prevalence of leprosy, social and economic rehabilitation (SER) has become a major priority in leprosy control programme in Shandong Province. In the preparative phase of a SER programme, a province-wide survey was conducted with a semi-structured questionnaire in order to provide policy makers and programme managers with some basic information on the disability, and social and economic situation of the people affected by leprosy. In this paper the results of the study for the people affected by leprosy living in the communities were presented

OSA 7

CONHECIMENTO CIENTÍFICO E CONTROLE SOCIAL: A INSTITUCIONALIZAÇÃO DO CAMPO DA HANSENÍASE (1897-2000)

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Pesquisa realizada para obtenção de título de doutorado analisa as concepções e práticas de controle social da hanseníase, mediante estudo das fontes documentais de domínio público na perspectiva da Psicologia Social. O processo de institucionalização da hanseníase é enfocado a partir da noção de campo científico de Pierre Bourdieu e dos conceitos e definições cristalizadas em produtos científicos como livros, revistas e índices bibliográficos. A perspectiva diacrônica aponta as transformações ocorridas ao longo dos anos: do paradigma da hereditariedade ao bacteriano e à imunogenética atual. A série histórica analisada (1879-2000) mostra que o discurso hegemônico, excluindo os discursos marginais, tratou a doença, não o doente, ao qual não deu voz. A institucionalização do campo da hanseníase ocorreu por movimento mais amplo da Medicina Social que objetivava a promoção da saúde mediante o controle dos doentes por meio de estratégias de governamentalidade. A especialização progressiva do campo da hanseníase reduziu as possibilidades de reflexão sobre a doença pela hegemonia discursiva.

OSA 8

DELAY IN PRESENTATION: IDENTIFYING CONTRIBUTING FACTORS USING BASIC QUALITATIVE METHODS

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In leprosy, the variety of help-seeking actions in a great diversity of pathways by which individuals finally present and star treatment. Many of these contribute to delay and so increase the risk of disability.

To identify the factors contributing to delay requires an analysis of decision making relating to help-seeking actions. We adopted this approach, using a variety of qualitative methods in seven centres in three continents. We used semi-structured interviews and organised group activies with patients currently receiving MDT. We validated our findings through interviews with field staff, and with project managers, teachers, political leaders, religious leaders and practitioners in alternative medicine.

The presentation will contrast the relative importance of different causes of delay between centres and suggest ways in which these may be addressed. We will comment on the effectiveness of the methods used and their implication for skills and resources. A Handbook describing our field methods and case studies will be available at the Congress.

OSA 9

DELAY IN PRESENTATION -RESULTS F FIELD-WORK IN PARAGUAY

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We used qualitative methods to explore the factors contributing to delay in presentation in Paraguay – semi-structured interviews with patients and others and free listing with staff.

Interviews with patients and focused on help-seeking actions. We asked staff to list the normal responses of patients to (1) the diagnosis of leprosy and (2) the need to inform the family members of the leprosy diagnosis.

Staff identified the most common responses to the leprosy diagnosis as denial, fear of rejection and punishment from God. In our second series of interviews (total 14) two young women had been excluded from school and had returned to treatment after a ten year break. One young woman had twice tried to commit suicide. One man said he had cried much at the diagnosis. An older woman asked several friends to pray for her as she felt suicidal.

Responses from staff to the need to inform family members of the leprosy diagnosis included concealment, giving a different diagnosis and fear of endangering children. In the first series of interviews 18 of 36 patients expressed fears. These included fear of the response of neighbors (9), fear of the response of the family (4) and fear for the impact on the family (3).

In our presentation we will expand these findings and discuss their contribution to delay in presentation.

OSA 10

DEVELOPMENT OF A SCALE TO MEASURE PARTICIPATION

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Improvement in social participation should be an important outcome of interventions in socio-economic rehabilitation. Up to now, no standard, simple, measure of participation has been available for use in the context of Nepal and other leprosy-endemic countries. Different individuals visiting a client/patient see the situation differently, and simple comparison between people or measurement of change within a situation has been difficult. Given the increasing interest in and importance accorded to rehabilitation of people affected by leprosy worldwide, development of an instrument to measure participation has become an urgent need.

Based on observed and spoken indicators of participation from observational studies, a scale is being developed to simplify and standardise measurement of participation (or restrictions in participation), particularly in the context of clients who previously had leprosy. The conceptual framework of the scale is based on the International Classification of Functioning, Disability and Health ((ICF), WHO, 2001). 'Participation restrictions' are defined as "problems an individual may experience in involvement in life situation". The scale is intended primarily for use in assessment of socio-economic rehabilitation and therefore will emphasise domains of participation which reflect this aspect.

The scale is being designed, developed and tested according to standard principles for health measurement scale development. Items were generated and piloted in Nepal; the programme has since been extended to include six centres in India and two in Brazil, in an attempt to produce a culture free scale. The methodology used in design and a draft scale ready for psychometric testing will be presented.

OSA 11

DEVELOPMENT OF SOCIAL WELFARE AND REHABILITATION SYSTEM FOR LEPROSY PATIENTS IN LEPROSY COLONY, CHANTHABURI

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The author has conducted an evaluative research on development of social welfare and rehabilitation system for Leprosy patients in Phrangkayang Leprosy rehabilitating colony at Chanthaburi province.

The study was based on descriptive research and qualitative research using participatory observation, focal group discussion and in-depth interview. Overall findings revealed total 911 members comprising registered in-patients, unregistered in-patients and relatives. Problems of high deformity resulted in limitation and disadvantages for further development. Focus was made on development of social welfare and rehabilitation system which were facilitated by intersectoral collaboration such as establishment of water resources, vocational promoting funds, guidance and support on agricultural promotion, health care, etc.. These result in better mutual cooperation and formation of self-help groups which promote interactive self-reliance and increase community participation. The author has made relating recommendation including better care of disable and old aged patients, protection of land invasion, restructuring of leprosy colony into cooperative colony in order to be more independent and decrease financial burden of the government. These will lead to total elimination of Leprosy as public health and social problems.

OSA 12

DO NEEDS VARY AMONG PEOPLE WITH LEPROSY, PEOPLE WITH DISABILITY AND OTHERS FROM THE SAME RURAL AND URBAN AREAS?

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Aim: To assess and compare observed and felt-needs among people affected by leprosy, people with disability and others living in the same rural and urban localities.

Methods: 14 slums in and around the leprosy control area of 'The Leprosy Mission' in Calcutta, and 20 nearby rural villages were selected for an in-depth survey. 1400 respondents were randomly selected from both rural and urban areas, including 400 with leprosy-related problems, 300 with other disabilities and 700 from the same rural and urban areas, but without leprosy-related problems or disability. The latter group consisted of people with no cultivable land, marginal farmers who own only a small piece of land and other slum-dwellers.

Results: Few significant differences were found between the three groups of respondents regarding some of the key indicators such as employment status and community facilities. They agreed about their fundamental needs, although the priority ranking was slightly different between the groups. Employment and income generating activities were most frequently cited as a first choice, whereas toilet facilities were the most common second choice. Basic amenities remain a major problem for the majority of our respondents in both villages and slums. Health care also ranked among the top five required services. Respondents showed interest in schemes that would require their direct involvement and own contributions.

Conclusion: No remarkable differences were found regarding observed or felt-needs between people affected by leprosy, disability or general poverty. Their needs appear to be determined by their socio-economic conditions rather than the differences in disability and disease status. The results show a desire for self-sufficiency among the respondents. Future programme activities should take this into account and programme staff should adopt a role of facilitator, rather than service provide

OSA 13

EXPERIENCES OF GENERAL PATIENTS ATTENDING GENERAL OPD IN GMLF'S LEPROSY REFERRAL HOSPITAL

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It is necessary to know the reactions of public towards the process of integration, where they need to take treatment along with leprosy patients. As such, 300 persons with general ailments but not afflicted by leprosy, attending General OPD started in GMLF leprosy referral hospital have been interviewed to understand their experiences and attitude towards attending the OPD.

The results show that the reasons for taking treatment from a clinic situated in leprosy hospital include several socio-economic factors. While, majority of the patients come to GOPD because, fee is less, few attended GOPD because it is near by. There are some patients who attended because they don't know that it is a leprosy hospital and some have adequate knowledge about leprosy and attend GOPD with scientific conviction. Patients with different complaints of minor nature only attended the GOPD. Majority came voluntarily and the remaining were motivated through friends and the Social Worker appointed by the GOPD, who visited the field to create awareness. Majority of the patients were satisfied with the medicine and the cost. As a result repeated attendance is observed.

[1] P.M.W.

[2] Project Officer

[3] Director,

OSA 14

GENTE PREVENINDO GENTE

Rosarina de F. Sampaio da Silva

Presidente da Associação das Prostitutas do Ceará

Atualmente a Hanseníase faz parte do conteúdo programático das oficinas da Associação das Prostitutas do Ceará (APROCE). Voluntários do MORHAN junto com nossa equipe de educadoras sociais, estão participando de treinamentos em conjunto. Até o momento, nossas programações incluíam apenas DST e AIDS. Com a hanseníase, discutimos o que é a doença, como identificar a doença e esclarecimentos sobre a importância do tratamento para a cura definitiva. Após 15 oficinas realizadas percebemos que as profissionais do sexo tem demonstrado muito interesse pelo novo tema. Todas as 300 profissionais do sexo que participaram das oficinas pediram que fossem realizadas outras oficinas e mais de 80% demonstraram terem assimilado como suspeitar da doença. Cientes da presença de um significativo número de casos da doença em nossa cidade e com a experiência na prevenção das DST/AIDS há alguns anos, queremos também colaborar a diminuir o preconceito que tanto atrapalha a identificação, tratamento e cura da Hanseníase. Unindo as forças de todos um dia a Hanseníase será coisa do passado. Outros resultados serão apresentados

OSA 15

HOW THE NUMB FEET SYMPTOM IS SEEN BY THE LEPROSY SUFFERERS

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This study explores the relationship between leprosy sufferers and what perception they have of the numb feet symptom and how much they know and do about the resources available in order to prevent and cure plantar ulcers. Three different opinions have resulted from this research. The first group saw their feet as being normal, the second said their feet were kind of dead and the third one thought they were vulnerable. The first two ways of perceiving the problem are cause for concern since they don't raise the appropriate awareness about the risk factor and adequate self- treatment practices. However, the image of vulnerability the third group has can be positive because it can prevent the onset and aggravation of the ulceration process, although the existence of both external and internal factors make it difficult for some to adopt and carry out care practices at home, on a day to day basis. It has been concluded from this research that health orientation, health education and the availability of accurate information about the disease, alongside awareness about how to take care of their own bodies could play an invaluable part on the prevention and cure of plantar ulcer. Furthermore, a good relationship between patients and health workers as well as psico-social help to patients, and to their relatives, are the basic requirements for the quick identification and overcoming of the disease, helping to improve the patient's trust on the treatment and leading to a better understanding of the necessity for the continuity of treatment at home.

[**Key words**] Leprosy, numb feet, self-treatment and plantar ulcer.

OSA 16

IMPACT OF SOCIO-ECONOMIC REHABILITATION INTERVENTIONS FOR 25 YEARS- AN ANALYSIS

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German Leprosy Relief Association Rehabilitation Fund (GLRA-RF) was instituted in 1974 at Chennai, India to promote socio economic rehabilitation of those displaced leprosy affected persons by offering the following services such as financial assistance for self employment and micro enterprises, Housing programmes, Referrals for Training cum career guidance, Placement services, Educational sponsorships, Supply of mobility aids and appliances, Empowerment through 'Resource Link' a quarterly circular and Networking and lobbying.

The services of GLRA-RF were carried out through 52 Non Governmental Organisations situated in 11 States in India. During the period of 25 years an amount of Rs.5,914,274 was advanced by GLRA-RF and an amount of Rs.4,591 714 was mobilised through banks as loans towards self employment scheme to help 7401 leprosy affected persons needing economic assistance. The housing scheme benefited 1055 persons affected by leprosy. Through training and job placements, 6502 persons were benefited. One of the encouraging results of the loan scheme as part of the economic reinstatement is the high rate of repayment. Micro enterprises were started out of the self help groups so that the efficiency of individuals are pooled together.

After analysing the response of the beneficiaries it is revealed that the rehabilitation interventions have enhanced their normalization process of the individuals

OSA 17

IMPORTANCE OF IMPLEMENTING PUBLIC RELATION TECHNIQUES IN RESOURCE MOBILIZATION AND IMAGE BUILDING OF NGO WORKING FOR LEPROSY ELIMINATION

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By every passing year, scene in the field of leprosy is changing quite rapidly, from medical point of view, Leprosy has become a curable disease and it is quite possible that many of the states in India will declare themselves as a leprosy free state in near future.

However reality indicates that although to a great extend, it may be true but lot of ground is yet to be covered to eliminate leprosy in its true sense, and asa result of this it is quite important to have more and more programs for elimination of leprosy by involving people's active participation.

It is well known fact that no program can be effectively implemented without availability of sufficient-funds and other resources which can be made available by pursuing people to contribute for the cause.

It is understood that there are nearly 200 N.G.O.'s engaged in anti-leprosy programs in India but it is also a very alarming fact that only a very few of them are really in a position to carry out their routine functions in a perfect manner while others are facing a very serious financial crisis.

To overcome this serious problems it is absolutely necessary to apply the practices of good public relations in the working of every non-governmental organization to improve its local funding source by doing good work and also projecting it before the society with the help of print and electronic media. While working in the field of leprosy for the last 11 years I have observed that in India many organizations are doing a commandable work, however they are not very serious about image building activity which can help them to solve many of their important problems like resource, human resource, peoples' co-operation and so on.

OSA 18

LEPROSY IN CARIOCA CONTEXT: PATIENTS EXPERIENCES IN RIO DE JANEIRO, BRAZIL

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Leprosy continues to be a problem throughout Brazil. High incidence and prevalence rates of leprosy can be found in neighborhoods of the North Zone (Zona Norte) of Rio de Janeiro and of the Baixada Fluminense, the lowland floodplain outside of Rio. For 11 months in 1998-1999, I interviewed patients at public health posts and hospitals in Rio de Janeiro about their experiences with leprosy and leprosy treatment. I attempted to identify elements of national and local culture that might shape or construct these experiences. I also examined problems that patients experienced within their socioeconomic and cultural milieu. Patient narratives revealed that gender, occupation, religious beliefs, living conditions, concepts of the body, and folk models of leprosy all contributed to how this disease was experienced by patients.

OSA 19

LEPROSY VILLAGE/LEPROSARIA IN SHANDONG PROVINCE — PAST, PRESENT AND IN FUTURE

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In the late phase of the leprosy control programme in Shandong Province, there are a few old and disabled ex-patients affected by leprosy in the 54 leprosy villages/leprosaria. This makes the running of these leprosy villages/leprosaria more costly. In this paper, we reviewed the history and the role of leprosy village/leprosarium in the care of leprosy patients and in the leprosy control programme in Shandong province, the People's Republic of China. And then we analyzed the present situation of leprosy-affected people living in these leprosy villages/leprosaria, using the information collected from a questionnaire-based survey. Finally, we made some suggestions and recommendations for policy makers concerned and leprosy control managers, in order to improve the present situation and better use of exiting resources

OSA 20

O ESTIGMA NA REALIDADE INTRAFAMILIAR DO ADOLESCENTES COM HANSENÍASE

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Objetivou-se como o estigma se expressa na realidade intrafamiliar do adolescente portador de hanseníase, com incapacidade física, manchas visíveis, hiperpigmentação pelos efeitos colaterais da clofazimina e suas reações desde o diagnóstico até a alta. A pesquisa foi realizada no Centro de Saúde D. Libânia - Fortaleza – Ceará. Entrevistaram-se 22 adolescentes de 13 a 21 anos. Os procedimentos envolveram entrevistas, grupos de encontro e consulta aos prontuários. Referencial Teórico usado – Modelo de Kübler-Ross (1920). Percebeu-se a presença do estigma subjetivo e intrafamiliar centrado em alguns familiares; estigma social em parentes/contra-parentes, vizinhança e escola. Cinco dos entrevistados apresentaram idéia de suicídio, abandonaram estudos e emprego. Das falas emergiram 3 eixos temáticos com temas e sub-temas: HANSENÍASE E SEUS SIGNOS (manchas e neurites: abominação do corpo, vergonha, deterioração da auto-imagem, estigma subjetivo), HANSENÍASE: REAÇÔES PÓS-DIAGNÒSTICO (Reação dos adolescentes: estágios de Kübler-Ross negação, raiva, isolamento, depressão, barganha e aceitação, Reação dos conviventes: apoio, proibições, estigma familiar; Reação do Grupo social: estigma social); HANSENÍASE: ESPACIALIDADE E TEMPORALIDADE (processo de diagnóstico – tratamento – expectativa de alta, alta) Conclui-se que os adolescentes necessitam de suporte psico-sócio-sanitário para enfrentar a doença em todas as manifestações e aderir ao tratamento para evitar a emergência e incapacidade físicas, o que pode afastá-lo da convivência social, da escola e do trabalho. Sugere-se formar grupos de auto-ajuda, promoção da auto-estima, combate aos estágio depressivos que possam levar ao abandono do tratamento e depreciação da imagem corporal.

OSA 21

O IMAGINÁRIO RELIGIOSO DE PACIENTES DE HANSENÍASE

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O foco da pesquisa são as relações entre a religiosidade do paciente portador de hanseníase com o processo saúde-doença. Como a hanseníase ainda se vê mesclada dos preconceitos e medos em torno da "lepra", estigmatizada desde os tempos bíblicos, este estudo tem por finalidade compreender as características destas relações a partir do mundo vivenciado pelos hansenianos, tanto pelos que tiveram este mundo limitado pelas instituições asilares da primeira metade do século XX quanto pelos hansenianos que são hoje tratados pela terapêutica vigente. Elaboramos dez entrevistas semi-estruturadas, cinco com ex-internos e cinco com atuais hansenianos, além de cinco questionários com profissionais que atendem portadores de hanseníase sobre as influências da religião no tratamento dos pacientes. Observamos que a religião possui diversos papéis diante da situação de doença de acordo com a história que o indivíduo traça. Os ex-internos freqüentavam a religião institucionalizada imposta pela gerência asilar, ao mesmo tempo em que exerciam sua religiosidade mais particular diante das questões próprias da doença e do mundo em que viviam, mesmo este confinado pela instituição total. Os atuais hansenianos sentem o peso do estigma da hanseníase na impossibilidade de comentar a doença ao grupo religioso ao qual pertencem, salvo os casos onde houve a necessidade de esclarecê-la aos membros do grupo. A religião pode tanto dar respostas ou servir de refúgio, fornecer meios de enfrentamento ou mudar os hábitos. Os profissionais de saúde assinalaram a confiança na reabilitação e ajuda da comunidade religiosa como aspectos positivos da religião e o abandono do tratamento e a culpa como aspectos negativos.

OSA 22

O SIMBOLISMO DA HANSENÍASE NA VIDA DAQUELES QUE A VIVENCIAM

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A Hanseníase é uma doença milenar carregada de estigma e preconceitos desde os mais remotos tempos. O presente trabalho teve como objetivo desvelar quais as repercussões e o simbolismo desta doença na vida daqueles que a vivenciam, utilizando para tal, uma abordagem qualitativa fundamentada na fenomenologia. Participaram do estudo seis pessoas com a doença Hanseníase em idade compreendida entre 57 e 75 anos, de ambos os sexos, moradores no Hospital Colônia Itapoã na cidade de Viamão, antigo centro para internação e tratamento da doença de Hansen, no Estado do Rio Grande do Sul, Brasil. O instrumento utilizado foi a entrevista semi-estruturada com uma questão norteadora central: "Qual o significado da Hanseníase na sua trajetória de vida?". A entrevista gravada foi posteriormente transcrita para a aplicação do método fenomenológico. A análise dos dados revelou os sentimentos e experiências destas pessoas em relação a Hanseníase como sendo um processo de crescimento pessoal muito importante em suas vidas. Dentre os relatos, destacou-se o sofrimento pelo afastamento das pessoas devido ao medo do contágio, porém, muita força e luta marcaram a superação da doença

OSA 23

O SUJEITO E A HANSENÍASE

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Afinal, quem é o sujeito portador do mal de Hansen? Ele é um sujeito, sr. ou sra, fulano de tal, ou é um hanseniano? A questão que pretendo polemizar, se é que isso é possível, é: - qual é o estatuto de sujeito assujeitado ao mal de Hansen? Quando ouço dizer sobre "analisar o perfil" ou fazer um "estudo sobre a personalidade" dos hansenianos percebo aí uma visão comportamentalista e unilateral desse sujeito. A patologia passa então a defini-lo, dando-lhe uma condição única de existência: um SER de hanseníase. E tudo passa a girar em torno desse mal avassalador (avassala-dor).Tenho observado em alguns casos que há um histórico, anterior ao diagnóstico, de alguma dor emocional, decepção ou raiva, que fez apresentar os sintomas que, posteriormente, foram identificados com hanseníase. Os pacientes reagem contra esse mal como se precisassem atacar o inimigo, e na maioria das vezes sentem-se impotentes diante de tanta crueldade que esse mal causa. É como se o mal de Hansen encarnasse uma entidade mobilizadora que sugasse, que ceifasse a existência deles, roubando-lhes até mesmo a dignidade.Raiva, dor e hanseníase passam a ser sinônimos para dizer o quanto a vida é injusta, o quanto são desgraçados (e o são!) e o quanto a vida lhes deve. Sentem dó de si mesmos e se vitimizam do próprio sintoma, acontecendo o que Freud chamou "ganho secundário".

OSA 24

PARTICIPATION RESTRICTION: A QUALITATIVE STUDY OF INTEGRATED AND VERTICAL APPROACHES TO LEPROSY.

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Background: Integration of leprosy into the general health system is very much emphasized by health care planners. One prime reason stated for this is to reduce participation restrictions that are attached to this disease. This study was conducted in India, to compare the level of participation restriction towards leprosy in communities with a vertical and an integrated programme.

Methods: The data were collected in three areas of five villages each. The first two areas were in an integrated programme to test for internal consistency and the third in a vertical programme. All the leprosy patients with visible deformities in these villages were enrolled in the study, and an in-depth participation restriction measurement scale was administered. In addition, focus group discussions (FGD) were conducted among the family members of leprosy patients and participative rural appraisal (PRA) was done in the communities. The data were analysed using qualitative methods.

Results: A total of 24 leprosy patients with visible deformities participated in the in-depth participation restriction measurement exercise from 15 villages. 15 FGDs were conducted with families of leprosy patients and an equal number of PRAs with communities were done. The results show that participation restriction was virtually non-existent among the communities with the integrated approach and minimally experienced by leprosy patients in this model. However, a high level of self-stigmatization among leprosy patients was observed in the vertical approach and equally a high level of participation restriction was found in their communities, which led to reduced interaction between the leprosy patients and their communities. This presentation also discusses the integrated community based - primary health care adopted in the study villages.

OSA 25

PSYCHIATRIC MORBIDITY AMONG LEPROSY PATIENTS IN NEPAL

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Aim: To assess the psychiatric and social problems caused by the stigma associated with leprosy, and to measure the extent of these problems.

Methods: In 1991, more than 400 Nepali leprosy patients were interviewed using a WHO self-reporting questionnaire (SRQ20), designed to detect non-psychotic disorders. The questionnaire was supplemented with questions about the patient's family and social situation. The same questionnaire was used in interviews with 150 leprosy patients in 2000/01. In addition, 166 non-leprosy affected people were interviewed to assess the levels of psychiatric stress in the local population.

Results: Psychiatric morbidity in this assessment is indicated by a score of greater than 11 of 20 in the SRQ20. The 1991 data showed a low but significant level of mental health problems among leprosy patients, and identified significant factors predisposing to psychiatric 'stress'. Our results indicate an increase in the psychiatric morbidity among leprosy patients in the 10-year period between the assessments using the SRQ20, from 16% (67/411) in 1991 to 31% (46/146) in 2001. Interestingly, non-leprosy affected individuals assessed on our study also appeared prone to high levels of psychological stress, as indicated by their scoring highly in the SRQ20.

Conclusions: While the perceived 'curability' of leprosy and the decline in deformity undoubtedly improved individual and social acceptance of the disease, leprosy patients remain vulnerable to psychiatric morbidity and depression

OSA 26

REHABILITATION IN THE EYES OF INSTITUTIONALISED LEPROSY PATIENTS

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There are thousands of leprosy patients staying in colony today and new patients are also coming to the colony for their rehabilitation. This fact is disturbing in connection with the community-based rehabilitation of leprosy patients.

In this direction a study is undertaken to know the opinion of Institutionalized leprosy patients in nine Districts of Vidarbha Maharastra India. A data is collected from 175 Institutionalized leprosy patients and analyzed. In this study, the knowledge of leprosy patients their experiences in the families and with society, the reasons for their rehabilitation from normal social environment, their opinion about their rehabilitation their educational economical and own status in the family and Society etc. such factors are studied in detail

However, it is also found that not only old or deformed patients are settled in colony but the patients with no visible deformities are also coming today in colony for stay and this is disturbing. It is also found that qualified patients have more psychological problems and today on the verge of elimination the patients are facing familial social physical economical psychological and medical problems. These patients have no hope about their acceptance in the family and society as one of them and don't believe that the concept of community-based rehabilitation will be seen in reality in future completely

OSA 27

SELF HELP GROUPS OF PEOPLE WITH DISABILITIES IN NEPAL- AN EVALUATION

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Partnership For Rehabilitation is a socio-economic rehabilitation programme of the International Nepal Fellowship, based in Pokhara, Nepal. The programme has been working with people affected by leprosy for over 20 years. In 1997, PFR started to establish self-help groups of people with disabilities with dual aims of the improvement of the economic status of the members and improvement in social participation. Most group members were affected by leprosy, but people with other disabilities were also included. The format of the self-help groups was based on UN ESCAP guidelines [1991], and included the principles of a comprehensive model of disability and methods of introducing micro credit schemes. However, the functioning of each group has varied in response to priorities set by the group members.

The first three groups set up in three communities of western Nepal have completed four years of operation and the outcome of the initiative has been evaluated.

The evaluation had two parallel aims:

1) To evaluate progress against the objectives set by PFR prior to group establishment.

2) To assess the current ability of disabled people, their families and communities to include people with disabilities into the communities represented by the self-help groups.

The results of the evaluation, which uses qualitative participatory techniques including focus group discussions and individual interviews with group members and community leaders, will be presented.

OSA 28

SOCIETY'S ATTITUDE TOWARDS REHABILITATION OF LEPROSY AFFLICTED AFTER 2000 A.D.

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In connection with leprosy programme, India is trying to achieve the goal of elimination of leprosy in the country. In coming years the case load may be reduced but as long as leprosy is there leprosy afflicted persons may have to face social problems. Therefore, it is the real difficult task to change the attitude of the society in general towards leprosy afflicted. In this direction a study is undertaken and data is collected from various personalities having different qualificational status, age group and occupations. A questionnaire was designed and information about their knowledge, attitude towards acceptance of the patients, their involvement in social and religious programmes, their rehabilitation etc. is collected. The data is tabulated and analysed.

It is observed that there are still 35% people who have shown negative attitude. They have shown their inability to accept the material prepared by leprosy afflicted and 15% have suggested to keep leprosy patients away from normal social environment.

It is most surprising to receive such opinions from general public on the verge of elimination of leprosy, which are indicating to have need of continuous and consistent efforts on health educational programmes especially for many years in future.