

AN ANNOTATED BIBLIOGRAPHY ON LEPROSY

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ABSTRACT

This annotated bibliography, based on a review of the available literature, is divided into two parts. First, a commentary on the key issues raised in the literature reviewed, with a specific focus on psycho-social-economic issues. The commentary begins with the general literature, before moving to a discussion of leprosy issues in Asia, and finishing with a commentary on a selection of relevant papers from other areas of the world. The contributions gathered under each heading are arranged chronologically.

INTRODUCTION

Walter (1) presents a report on the International Leprosy Congress, held in Beijing, 7-12 September 1998. Leprosy and its consequences are described as a complex human problem, which leads to discrimination, stigma and prejudice. It is determined that equal rights for people affected by leprosy to develop their full potentials, is a matter of human rights. The report also discusses rehabilitation needs, pointing out that although previous focus on medical care of leprosy-affected people has been beneficial, it has led to the neglect of holistic psycho-socio-economic rehabilitation. This has led to poor quality of life for many leprosy-affected people. Walter moves on to argue that the leprosy-affected have not been empowered by community and health providers who lack the right attitude and sensitivity. Greater coordination is required at international/NGO/government levels to utilise resources and allow the full development of people affected with leprosy.

Deepak et al (2) present an overview of leprosy, its consequences, and the major surrounding issues. The authors recognise the need to strengthen action to combat the social, economic and psychological consequences of the disease, not only for the individual but also for their families and communities. Strategies for this action are discussed – pointing to the need for greater integration of care programmes. Progress is discussed where it has been made, including: prevention of disabilities, physical, psychological and socio-economic rehabilitation activities in leprosy control programmes; the populations left in old Leprosaria and Leprosy

Colonies; Community-Based Rehabilitation (CBR) programmes, and the mainstreaming and networking of rehabilitation services. The work concludes by describing areas for future action. These include reviewing prevention of disability strategies and socio-economic rehabilitation, as well as strategies of information building and the increasing levels of integration and community based rehabilitation.

LEPROSY AND REHABILITATION

Nicholls (3) presents a set of guidelines for Social and Economic Rehabilitation (SER) of leprosy-affected people. The aim of the guidelines is to provide information and advice to managers and field staff at all levels and in a wide variety of projects (including community based rehabilitation). The earlier sections, intended for senior managers concerned with definitions and strategic issues, include: understanding the need for SER, operational principles and practice, the holistic principle, the participatory principle, sustainability, integration, and general management issues. The later sections are of interest to field staff, with specific attention paid to impact assessment of project activities on the client. The guidelines describe how to select and understand indicators for impact assessment, as well as background theory of the topic. Nicholls also provides case-study material, and suggestions for group work and training sessions – with the intention of making the guidelines accessible to the widest possible range of staff.

Cairns and Smith (4) discuss guidelines for Socio-economic rehabilitation (SER), as presented by Nicholls (3). SER is recognised as being a major priority for people affected by leprosy. The guidelines are said to offer sensible help and ideas for those starting a new project as well as for those already involved in SER activities. The authors point out that whilst the development and publication of these guidelines is important, there are subsequent steps that need to be made. These are dissemination and implementation of the guidelines. Dissemination is a logistical challenge, as those who would benefit from the guidelines are spread around the world, and past efforts are said to show that field workers often do not access such things, for a variety of reasons. Implementation requires that the guidelines are read, and result in changed practices. Co-operation of different organisations and personnel is called for, to enable efficient implementation. A final evaluation stage is recommended, to judge the effectiveness of the guidelines.

Thomas and Thomas (5) present a discussion of the changing face of leprosy rehabilitation in recent years, following the advent of Multi Drug Therapy (MDT). Leprosy services are seen to be becoming increasingly integrated into general health services, moving away from 'vertical', stand-alone leprosy focused services. It is speculated that CBR could become an important method for the vast majority of leprosy affected persons. The main focus of the paper is the authors' concerns regarding the suitability of CBR for leprosy rehabilitation. CBR is said to have been adopted by general health services in many countries as a viable alternative to reach disabled persons from rural areas. The authors point out amongst other CBR problems: hidden costs to the consumer, potential neglect of those with severe disabilities whilst CBR focuses on community participation and equal rights, gender issues, volunteer shortages and funding shortages (for wages). It is concluded that for many people CBR is seen as the only hope for people with disabilities in developing countries, whilst others see it as a process of development with poorly defined boundaries. It is pointed out that despite its problems and limitations, it is difficult to ignore the role of CBR in leprosy rehabilitation.

LEPROSY AND STIGMA

Bainson and Van den Borne (6) present a model of the stigmatisation process in leprosy. The process of stigmatization is said to be divided into two stages. The first stage describes how the cognitive dimensions of leprosy lead to a variety of affective responses towards the disease. The second stage involves how these affective responses can lead to the social devaluation of the leprosy affected persons and consequently, the adoption of negative behaviour towards them. The disease is said to develop in a local context. The process of dehabilitation is described in detail, through the model of stigmatisation.

Frist (7) aims to fill a gap in literature on the psycho-social problems caused by leprosy, to match the vast amount of available text on the medical aspects of the disease. He is concerned to engage with three audiences: people already involved in leprosy work, people with little or no experience of leprosy work, and those who are interested in helping other stigmatised groups. He covers a range of issues through the text, but keeps a focus on the social issues, namely stigma of leprosy-affected people. First, a background to leprosy as a disease is provided. This is followed by an account of progress made in tackling it. Frist then moves on to the issues of social integration - how best to counter the segregation of many leprosy-

affected people - and its implications. Stigma and how leprosy leads to it is covered in some detail. The conclusion is that integration is the key to combating stigma - integration of communities, and of leprosy programmes back into communities. A move from segregated support systems to integrated ones, and from 'vertical' to 'horizontal' support systems is recommended.

LEPROSY IN INDIA

Kushwah et al (8) present the findings of a longitudinal study, undertaken from November 1977 to January 1979, of 344 leprosy affected persons attending a leprosy clinic in Gwalior, India. The results of the study showed that social stigma was present in a variety of forms, and was more prevalent among persons who were illiterate and from low socio-economic groups. The need for social rehabilitation is made clear by the authors.

Kumar and Anbalagan (9) discuss the findings of interviews with 225 adult leprosy persons, the aim of which was to study socio-economic experiences. The results show a high level of social stigma experienced by leprosy affected persons. This is highlighted in various categories, including: marriage difficulties, homelessness, and negative effects on employment. The authors state that the social prejudice and deformities due to leprosy have played key roles in socio-economic deterioration of affected persons. It is recommended that the leprosy control programme be implemented more efficiently and effectively, with active community involvement. It is also suggested that socio-economic debilitation needs to be prevented, and attention is required to focus on the issue of abnormal psychological behaviour amongst leprosy affected persons.

Koticha et al (10) discuss the problem of leprosy in Greater Bombay, India, describing anti-leprosy measures and the role of survey work in case detection. Two retrospective studies are discussed (one showing proportion of industrial workers among new leprosy cases, and the other, the various attributes of workers and their significance to leprosy cases). The result is the undertaking of a cross-sectional prospective survey of over 18,000 industrial workers, where leprosy detection is over 17 per 1,000. The authors conclude that a study of socio-economic and cultural attributes of workers and their relatives in maintaining endemicity is distinctly feasible.

Pal et al (11) present the findings of a study of 195 affected persons attending an outpatient department in Agra. The study investigates regularity of attendance, and reasons for absence.

Causes of irregular attendance were found to be predominantly socio-economic factors. Pal et al (11) point out that as irregular attendance to treatment has a negative effect on recovery, socio-economic factors require attention.

Krishnan and Gokarn (12) discuss their study of leprosy undertaken in an urban slum in Pune, India. Forty five cases of leprosy were found in the population of 4,915, and disability was found to be higher with higher age groups, males, Hindus, widower/widows, unemployed and lower socio-economic classes.

Kopparty (13) investigates the impact of social inequality, prevalent in the form of the caste system in India, on leprosy affected persons with deformities and on their families in Tamil Nadu, India. A sample of 150 persons with deformities and their families, drawn from two districts in Tamil Nadu, was selected for the study. The impact of social inequality was examined through the problems faced by the leprosy patients. About 57% of the sample experienced their deformity as a handicap, which caused social and economic problems, while the rest did not. Kopparty shows through the study, the differing experience of leprosy for different caste groups, in the following: economic problems versus social problems, family acceptance, and family care. It is concluded that the gradual marginalisation, rejection and debilitation of the affected is evident. Caste status is said to be a broad indicator of the nature and the extent of handicaps and acceptance in the family. Kopparty recommends that this factor be appropriately taken care of in rehabilitation and disability management in leprosy control programmes to work.

Kopparty et al (13) examine the nature and extent of social and economic problems of leprosy-affected families having persons with and without deformities and their strategy to cope with those problems. This was carried out through data collection from 500 sample families in two districts in Tamil Nadu, in South India, from 1989-1990. The results of the study showed that about 20% of the families reported that they faced socio-economic problems. The proportion of families, with patients with deformities, facing socio-economic problems was ten times higher than those with no deformities. The two groups coped with social problems differently. Families with persons with deformity adopted 'acceptance' strategies, and non-deformity families adopted 'avoidance' strategies. The authors recommend that appropriate rehabilitation programmes should be developed to restore economic security for affected persons and their families. Community education on leprosy issues is also required to dispel myths and fears surrounding the disease.

Vlassoff et al (14) present evidence from two states of India, Bihar and Maharashtra, on the process of 'dehabilitation' among male and female leprosy affected persons. The study gathered data from 2495 inhabitants of Bihar and Maharashtra, including 934 who were receiving treatment and living relatively normal lives (59% male), 300 members of their families, 1071 who had to leave home or a job (63% male), 100 who were rehabilitated (55% male), and 90 health workers. Additional data were gathered from in-depth interviews and 25 case studies. Important gender differences were apparent in the impact of the disease. While both men and women were negatively affected in terms of their family and marital lives, women suffered more isolation and rejection. The authors conclude that the evidence presented demonstrates the importance of analysing leprosy from a gender perspective, not only because this approach helps to inform one's understanding of the determinants and consequences of the disease, but also because it provides new insights for improved disease control.

Ramesh et al (15), describe the results of a study on low clinic attendance of leprosy affected persons in India. The effect of Health Education (HE) on a sample of 325 absentee leprosy affected persons was assessed in a leprosy endemic area. The results show that 46% of absentees returned to the clinic following HE, which is said to be more effective in the later part of the treatment process. Reasons given for not attending for treatment include: personal reasons, socio-economic reasons, health-care related reasons, and disease/ill-health. The authors conclude that Health Education has proved to be a worthwhile solution to the absentee problem.

Diffey et al (16) present the results of a cross-sectional study in rural South India, the aim of which was to determine whether the socio-economic and nutritional status of cured persons with residual deformity, and their household members, was lower than that of cured persons without deformity. The study involved 155 index cases with deformity, 100 without deformity, and 616 household members. Nutritional status was evaluated using anthropometry. A questionnaire was used to determine disease characteristics, socio-economic parameters, and household information. The authors conclude from their results that cured persons with physical deformity are more undernourished than those without deformity. The authors associate this with a decreased expenditure on food, due to increased unemployment, and a loss of income. Undernutrition in the affected person is said to increase the risk of undernutrition in family members.

Rao and Palande (17) discuss socio-economic rehabilitation programmes run by LEPR-India. The approach used is described as holistic, evolutionary, developmental and participatory. The authors also point out the need for an emphasis on active participation of leprosy affected persons in the rehabilitation process, as well as in evaluating the impact of interventions in restoring normal social and economic life, as seen in the programmes described.

Zodpey et al (18) describe a study carried out in Nagpur, India, of 486 leprosy affected persons. The study describes gender differentials in the social and family life of leprosy affected persons in Central India. Data was collected through a structured interview schedule that included questions on demographics and disease impact on daily life. Socio-economic status was recorded by using the modified Kuppaswamy's scale for socio-economic classification. The authors conclude that, important gender differences have been demonstrated in the family and social impact of leprosy. Women are said to suffer more isolation and rejection from society, mainly due to social stigma. It is recommended that social stigma reduction needs to be emphasised, through the strengthening of community education components of leprosy control programmes.

Jayadevan and Balakrishnan (20) discuss socio-economic rehabilitation in leprosy. It is claimed that leprosy is more a medico-social problem than a disease, and that the social aspects in terms of stigma, discrimination, poverty, deformity and loss of self-confidence are still to be overcome. The authors are critical of leprosy elimination programmes for failing to provide adequate emphasis on the social aspects, especially rehabilitation. A Community Based Rehabilitation (CBR) programme implemented in Kerala State, South India, is given as an example of how the focus can be moved to social issues and rehabilitation. Here, people discuss and plan their needs and requirements and execute them with the help of the local administrations.

One particular project implemented for poor, disabled leprosy-affected people is presented here. The project involves the supplying of goats, cows and residential houses to affected persons – who were given instructions on how to protect and preserve the livestock and to use them as a means for their livelihood. Jayadevan and Balakrishnan conclude that although this is a small project, it has created self-confidence among the affected persons, and strengthened them financially. Family attitudes have also been seen to change positively towards them. It is recommended that increasing efforts should be put into the fulfillment of CBR activities, with local level resources being mobilised at relatively little cost.

Arole et al (20) carried out a study in the state of Maharashtra, India, to compare the level of social stigma towards leprosy in communities with a vertical and an integrated care programme. It was believed previously that the integration of health and rehabilitation services will lead to a reduction in stigma, but a practical demonstration was lacking – justifying this study. Data collection was in three areas, the first two being in an integrated primary health care area, and the third in a vertical care approach. Three methods of data collection were used: 1. In-depth stigma measurement with open-ended questions. 2. Focus group discussions amongst family members. 3. Participatory Rural Appraisal in the study villages, to measure reintegration into the community. Data was analysed with qualitative methods.

The authors cover the following in their results: demography, internal consistency of the integrated approach, self-esteem of subjects, attitude of family members, economic interaction, social interaction, awareness of activities of service providers, knowledge of leprosy facts among family and community and stigma level in communities. The study concludes that with the integrated community-based primary health care approach, social stigma was minimal for people affected by leprosy. Whereas, a high level of both self-stigmatisation and social stigma in the community among the leprosy affected persons was observed in the vertical approach villages. The integrated community-based approach is seen to be effective in reducing leprosy stigma in society. It is recommended for consideration by others, for implementation in their programmes.

Kaur and Van Brakel (21) report on a study carried out in a leprosy colony ('Pashupti Kusht Ashram') in Ambala City, Haryana (north-west state of India). There are 25 families in the colony, and all the adult males are beggars. The men go in a group to beg, whilst the women and children remain in the colony. The study is largely descriptive. The participants were purposefully selected and semi-structured interviews were used to study the socio-economic background, the process of the disease and deformity, and attitudes to beggary. The report covers: socio-demographics, educational profiles, psycho-social and economic problems resulting from leprosy, social participation in the city, previous occupations, social organisation (in and of the colony), attitudes towards beggary, the impact of beggary on the children of the colony, and future aspirations. It concludes that beggary is the social consequence of a failure to deal effectively with leprosy. If given the opportunity and the required support, 80% of the colonies' population said that they were ready to stop begging. Concern was evident for the education and well-being of the children in the colony. Kaur and Van Brakel

point out the need to develop alternate avenues of income generation utilising the existing desires and potential of the inhabitants.

Kaur and Van Brakel (22) also present a study based on case studies of leprosy-affected beggars in Delhi, India. The focus is on the long-term consequences of leprosy, which according to Kaur and Van Brakel means gradual debilitation, through lack of social support and self-confidence, and for some leprosy affected people beggary. Twenty-five leprosy affected persons, begging on the roads of Delhi, were studied by the authors, between September and December 1999. In each case the process of debilitation was studied using the structure of ICIDH-2 (International Classification of functioning Disability and Health), through semi-structured interviews. The report presents four of the resulting case studies to illustrate the process of debilitation. Kaur and Van Brakel conclude that the debilitation of the leprosy affected persons is caused by physical impairments (which cause limitation of activities), and social stigma (which causes participation restriction). Leprosy is seen to cause psychosocial impediments amongst infected individuals. Kaur and Van Brakel recommend that the prevention of debilitation should go hand-in-hand with the rehabilitation of the already debilitated, because: 1. Leprosy affected beggars deserve proper social status in society, 2. Leprosy affected beggars are found here to promote beggary amongst other leprosy-affected people, 3. Leprosy affected beggars perpetuate the prevalent social stigma.

Kaur and Gandhi (23) discuss the social problems caused by leprosy, which the authors consider more severe than the medical problems encountered. A study based on 104 people in Delhi, India was carried out to focus on the level of awareness among people about leprosy issues, and also to investigate attitudes towards the disease and leprosy affected persons. The results of the study show an inadequate level of knowledge of leprosy amongst the interview subjects. A range of attitudes and beliefs are recorded, and social stigma is evident. The authors call for an intensification of public awareness regarding the aetiology of leprosy to minimise the social prejudices associated with the disease.

LEPROSY IN NEPAL

A study by de Stigter et al (24) was carried out to address a lack of current data and understanding on community behaviour towards leprosy affected people in eastern Nepal. Previous data telling of negative community behaviour, often extreme, was not relevant to

the current situation, and was all learned of from leprosy affected persons and not from the community members. This study investigated social stigma towards the leprosy affected, and the reasons for this treatment. Three hundred community members were randomly selected in five communities in Eastern Nepal, and then interviewed. The interviewees were asked to talk about community behaviour towards a person they knew to be affected by leprosy. The interviewee was not asked directly about their own behaviour to avoid them giving “socially acceptable” answers. 192 narratives were generated and gave a picture of the situation in the past and at present.

Negative community behaviour shown up through the narratives is broken down into groups on a scale of negative behaviour, ranging from eating limitations through to segregation. Motives for this behaviour are mostly found in the fact that leprosy is thought to be highly contagious. A curse of God is mentioned as another reason for negative behaviour. de Stigter et al conclude that fear of negative community behaviour of persons affected by leprosy, is based on actual events. Many limitations and restrictions on social life and segregation are still experienced. A main point made is that leprosy is more than just a disease, it can be medically cured, but the social perception still remains. Recommendations made are for a priority of prevention of impairment and disability, as the community recognise leprosy through deformities. Leprosy control programmes should focus on the acceptance of the ‘sickness’ rather than just the disease.

Kumar et al (25) present the findings of a study investigating gender differences in epidemiological factors associated with treatment status of leprosy affected persons. The study was cross-sectional and carried out in the Dhanusha district of Nepal. A total of 273 leprosy affected persons (183 male and 90 female) aged >15 years were included in the study, to collect data on clinical type of leprosy, patterns of physical deformity/disability, site of skin lesions, and socio-demographic information. Statistical analysis of the data collected was carried out using multiple logistic regression. Chi-square/Fisher’s exact test was also used to assess significant differences in values between males and females. The authors (25) conclude that significant gender differences, among leprosy affected persons, were found in the distribution of disability grades and treatment completion status. There was no significant gender difference in the distribution of leprosy types and skin lesion sites. Significant associations were found between treatment

completion status and: gender, educational status, disability grade I and 0, after adjustment for all other leprosy factors.

Heijnders' (26) paper is focused on the different interpretations and meanings of disease and treatment, that are held by different leprosy affected people and different cultures. These are said to have an impact on the way that disease and treatment are dealt with. The article describes the findings of a qualitative study carried out in the Eastern Leprosy Control Project area of Nepal. Twenty-nine people who discontinued treatment and forty-seven people who were released from treatment were interviewed in depth. The interview process explored the way people interpreted leprosy and its treatment, and resulted in the identification of different categories of meaning – which are discussed in depth by Heijnders. Topics covered include: people's recognition of leprosy symptoms (or lack of), different names used for leprosy and associated stigma coping strategies, perceived multiple causation of the disease, motivation for continuing or defaulting with treatment.

Heijnders discusses the dynamics of stigma in leprosy. The different coping strategies employed by people affected by leprosy are explored through a study conducted in the eastern part of Nepal. The study shows that there is a difference between experienced stigma and the anticipation of stigma. It is determined that these two types of stigma result in different coping strategies. The paper shows that stigma is a dynamic process and a concealment cycle is elaborated on, to produce a more detailed understanding of the stigmatisation process in Nepal. It is highlighted that even within the same culture, social differentiation makes a significant difference on the impact of stigma and the coping strategies employed in its management. Stigma is seen to enforce pre-existing inequalities in social class, gender, and age.

Heijnders concludes from the study that there is a difference in 'meaning' between the interviewees and health workers. To improve leprosy services, health education must increase (to include major signs and symptoms of leprosy, means of transmission, side-effects, definition of cure, needlessness of segregation, and the cause of wounds), whilst also listening more to those who are affected by the disease – to give greater insight into people's understanding of their condition and situation, and enable prevention of treatment discontinuation.

In a separate article, Heijnders (27) explores the quality of services received by people with leprosy and the impact of this on adherence behaviour. This exploration is based on a qualitative

interview study conducted in eastern Nepal. Heijnders finds that a person's status within the family and community influences the quality of care received, and in turn, affected the adherence to treatment. Deficiencies in the quality of care experienced, especially amongst women and poor people, are recorded as being: attitude and behaviour of the health worker, the practitioner-centeredness of the care and lack of information sharing, the organisation of the health services, barriers in accessibility of the leprosy services, and lack of, or carelessness in, patient referral. The paper explores these deficiencies and coping mechanisms for them.

LEPROSY IN BANGLADESH

Withington et al (28) present the results of a one-year cohort study of new leprosy cases in Bangladesh, designed to assess socio-economic factors in relation to stigma, impairment status and selection for socio-economic rehabilitation. The study involved a cohort of 2364 newly diagnosed people with leprosy in rural Bangladesh in 1996, with an overall mean age of 31.4 years. Three hundred and sixty people had WHO grade 1 or 2 disability identified at diagnosis, and 50 had stigma identified on interview at a home visit conducted within one month of diagnosis. One hundred and eighty-eight people were selected for specific assistance for rehabilitation. The authors recommend an increased focus by leprosy services on the socio-economic factors associated with poorer physical and social outcomes. It is also suggested that where adequate finances and trained staff are available, efforts could be made to identify those at higher risk of poor outcomes, and to provide or to mobilise appropriately targeted socio-economic interventions.

Plagerson (29) presents a comparison of two methods of leprosy related social exclusion intervention, namely those focused on 'excluded individuals' or, on 'the excluding society as a whole'. The article compares the two through a focus on socio-economic rehabilitation and health education. The findings are based on primary research undertaken in two projects in Bangladesh, involving individual interviews, focus-group discussions, and key-informant interviews. A social exclusion framework is applied to present and analyse findings.

Plagerson concludes that different groups are affected in different ways, experiencing different processes of exclusion. Primary research confirms, that people affected by leprosy in

Bangladesh suffer from economic and social disadvantages as a result of the disease. Health education and socio-economic rehabilitation programmes are both said to be necessary, and to draw on each other to achieve their aims. It is suggested that the lessons learned by leprosy researchers, on exclusion, can be applied to other groups such as people with HIV/AIDS.

LEPROSY IN CHINA

Shumin et al (30) present the results of a study on the people affected by leprosy living in communities in Shandong Province, China. The study was carried out in the preparative phase of a social and economic rehabilitation programme, and involved a province-wide survey that was conducted with a semi-structured questionnaire. The aim was to provide policy makers and programme managers with some basic information on the disability, and social and economic situation of people affected by leprosy. The authors point out, that with the decline in leprosy prevalence, social and economic rehabilitation have become a priority in Shandong Province.

LEPROSY IN AFRICA

Scott (31) provides details of a study based in South Africa. The study aimed to gauge the emotional responses of leprosy affected persons, to a variety of issues. Semi-structured interviews were used, with the subject asked to grade their emotional response to issues including the following: family life, marriage, traditional healers, work, and satisfaction with medical treatment. Scott concludes, that leprosy has a strong influence on behaviour. Grief is said to be the first and most general reaction of the leprosy affected on discovery of the disease. Support is therefore needed as soon as possible. It is advised that counselling skills are necessary for those that inform of the disease. Information on the disease should be made more readily available. Incorrect perceptions of leprosy within marriage, or families, lead to problems. The study also identifies religion as having an influence on negative attitudes, particularly a mis-interpretation of scripture is said to lead to problems.

The psycho-social needs of persons with leprosy, in South Africa, are said to be similar to the rest of the world in three ways: 1. The need for self-acceptance. 2. The need for social

acceptance, especially in family and security (psychosocial, social and economic) is increasingly important. 3. The need for community acceptance. Scott recommends: the design, implementation and evaluation of training programmes for field workers, regarding effective counselling; the development of strategies to de-institutionalise leprosy affected persons and integrate them into the community; and marriage enrichment programmes for leprosy affected persons and their spouses.

El Hassan et al (32) describe a study in eastern Sudan of two communities to determine social and cultural factors influencing knowledge, attitudes and practices towards leprosy – and their effects on treatment seeking and compliance. The study was qualitative and used focus group discussions, personal interviews and direct observation. The two main tribes in the study area were the subjects of the studies. The results of the study cover several key areas: beliefs about cause of leprosy (believed to be due to eating certain meats, amongst other ideas), knowledge of physical symptoms of leprosy, and attitudes and practices. The authors conclude, that the communities in the study area are well aware of the clinical manifestations of leprosy, but were unaware of its cause. Stigma is not strong here, and re-integration into society for those cured by MDT occurs.

LEPROSY IN LATIN AMERICA

White (33) carried out research on cultural aspects of leprosy in Rio de Janeiro, Brazil, for 11 months in 1998-1999. The primary goals of the research are described as being able to understand perspectives of affected persons, on the experience of leprosy in every stage of the illness and to determine how this can be used to improve quality of life of those affected. The study involved the collection of narratives of leprosy and leprosy treatment from 43 affected persons, with questions asked about every aspect of the disease process, as well as patient background. In addition to this, interaction between healthcare workers and affected persons were observed.

White describes, through the study results, a series of cultural models of thought surrounding leprosy issues. These include: leprosy contagion, symptoms, treatment, side effects, and perceptions of being ‘cured’. Other topics covered are: stigma, daily life issues, and leprosy terminology. It is concluded, that an increase in public education on leprosy issues is required to achieve a reduction in cases and an improvement in quality

of life, through media presentations. Health worker training is also required in leprosy diagnosis and treatment. Rehabilitation and psycho-social support facility is also recommended.

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