

## **EDITOR'S COMMENT**

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Over the last few years, there have been significant changes in philosophy and practice in leprosy rehabilitation programmes. With the integration of leprosy services into general health services these programmes are no longer vertical, stand-alone services, and are moving from a medical model where prevention and reversal of deformities were the prime focus of interventions, to a psychosocial model with emphasis on inclusion, economic rehabilitation, and access to other services and human rights. These shifts and changes have thrown up challenges as well as opportunities.

While it is clear that there will continue to be demands for care by persons affected by leprosy, it is not yet clear who will actually benefit from community level rehabilitation to address the economic and other psychosocial impact of the illness. Studies have shown that a significant proportion of persons affected by the disease tend to grow poorer, especially those with deformities. However, not all persons with deformities deteriorate economically. Conversely, some persons without deformities tend to slide down the economic ladder. There are also issues related to motivation and expectations of benefits from some sections of the affected population who have been used to charity.

Leprosy rehabilitation programmes until recently tended to be more institution based and charity-based. The current transition from medical to psychosocial, and from institutional to community based processes, in line with the move towards promoting rights and inclusion, would need much capacity building at all levels to adopt these approaches.

On the side of opportunities, many leprosy hospitals are in an advantageous position to develop services for other groups of persons with disabilities, utilising their existing expertise. They can develop expanded community based rehabilitation programmes to cover persons with different disabilities, playing a referral, training and support role. At the field level, the workers and volunteers can form the first level contact with the larger community. Some hospitals with a CBR programme can grow into centres for training of CBR personnel, with the institutional back up and other resources available with them. Along with training, the potential to develop research projects in CBR is also good, as is being done in some centres.

This volume has many articles on persons affected by leprosy, highlighting issues of concern. Leprosy rehabilitation programmes that are moving towards decentralised and community based strategies need to keep these issues in mind as they shift their focus from a 'client-centred programme' to a 'client and community centred programme'.

**Dr. Maya Thomas**

Editor

J-124 Ushas Apts, 16th Main, 4th Block

Jayanagar, Bangalore - 560 011, India

e-mail: m\_thomas@rediffmail.com

**HELPING CHILDREN WHO ARE DEAF  
FAMILY AND COMMUNITY SUPPORT FOR  
CHILDREN WHO DO NOT HEAR WELL**

Authors: Sandy Niemann, Devorah Greenstein, Darlena David

This book will be of help to parents, caregivers, health and rehabilitation workers, and others, to teach a deaf child how to communicate to the best of his/her ability. The activities in this book were developed by families with children who are deaf or cannot hear well, deaf adults, community based development workers, health workers, educators and other experts in over 17 countries. ISBN 0-942364-44-9

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**GUEST EDITORIAL**

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**LEPROSY AND STIGMA**

David Seddon\*, Janet Seeley\*\*

Leprosy is a chronic mycobacterial disease with primarily skin and nerve manifestations. It is also a socially constructed 'condition' with far-reaching implications for the attitudes, feelings and social behaviour of all concerned – those who have the disease and the condition, those with whom they interact, and those who find it difficult or refuse to interact with them. Indeed, leprosy has become a stereotype of a stigmatised condition; if someone talks of a person being 'like a leper', we know immediately that the person is being shunned and is being excluded in some way from society.

Leprosy is sometimes responsible for physical impairment and disfigurement and in some cases also for mental impairment. But, arguably more significantly, leprosy also gives rise to reactions and responses whose roots lie, not so much in the disease itself, or in its physical or mental manifestations and consequences, but rather in ideas about 'normality', 'difference' and 'acceptability', and in fears of contagion and contamination – in the stigma attached to the condition. The lessons learned from the experience of stigma for people living with leprosy, serve as a stark reminder for those who hope for the removal of stigma from the lives of others living with chronic conditions.

One of the great hopes of anti-retroviral therapy for people living with HIV, for example, is that if HIV and AIDS are seen to be manageable chronic conditions, the stigma so frequently and widely attached to them will subside. Indeed, assertions are being made that this is so (1) but if one turns to look at the experience of people who have been living with leprosy, which, unlike HIV and AIDS is a curable condition, one might doubt such optimism. The collection of papers in this issue tell of the persistent stigmatisation experienced by so many people who have had leprosy, or, who have a family member who has had leprosy.

Repugnance at deformity, revulsion at visible ulcers or wounds, and – above all - the fear of contagion (which also applies in the case of HIV/AIDS), can perhaps be understood if people have little knowledge of the causes of the disease and the condition. Perhaps the

reasons why 'leper' has long been used as a term for people who have been cast out, or rejected, can also be understood where knowledge of transmission is limited and the disease is considered contagious. But, stigma is not only the result of a person's revulsion at deformity or concern about 'catching' the disease and thereby developing the condition. It often also implies a judgement or moral statement – the 'leper' is 'unclean', perhaps because of some misdeed or sin. Perhaps the victims are at least to some extent, themselves to blame. This applies also in the case of HIV/AIDS, where there is not only widespread concern about 'catching it' through touch, or indirect contact, but also a degree of moral condemnation linked in part to the supposed modes of transmission (sexual intercourse, whether homosexual or heterosexual, drug use and shared needles, etc.) and in part to a vaguer notion of blame.

Physical deformity or impairment is not a necessary condition to provoke stigma. It is not only the people suffering from leprosy as a disease, or from the condition (impairments) that may result from it, who are stigmatised. People from the families of those who have suffered with leprosy may have no impairment themselves, but their association with someone with the disease taints their life. 'Courtesy stigma' (2), which affects people related to, or even friendly with, a person who has had leprosy, may seem irrational to those who know how leprosy is contracted; but stigma is seldom rational. The impact of so-called 'courtesy stigma' weighs heavily on many people's lives, affecting even their marriage and employment prospects. As Waxler (3) observes, leprosy provides an example of the social transformation of a disease from a medical condition to a condition, that has significance and meaning in society.

If one looks at the history of leprosy, one finds a disease bound up with fear and strong beliefs. Opala and Boillott (4) in their study of leprosy in Sierra Leone, show the importance of understanding people's world view in order to counter stigma and fear. They categorise three different world views in Sierra Leone of people living with leprosy: 1) as victims of dangerous powers beyond their control; 2) as manipulators of dangerous powers and 3) as morally corrupt people. If one is seen as a victim of misfortune rather than being morally corrupt, the response from people around one will be rather different and the impact of treatment on diminishing stigma also very different. Thus, if leprosy is seen to be a person's own fault or the fault of his or her family, one can comprehend why everyone associated

with the affected person suffers discrimination. Countering such beliefs lie at the heart of rehabilitation for people affected by leprosy.

Effective treatment has done a considerable amount to diminish the threat of leprosy and thus to diminish stigma: 'in the past, leprosy was viewed as a severely stigmatising condition that progressively devalued and marginalised the affected persons; finally to culminate in segregation, away from homes and society, in colonies of similarly deformed people. During this process, not only did society devalue them, but they also rated themselves lower on the value chain. The scenario is different today' (5). But as the papers in this issue clearly illustrate, although undoubtedly things are better than they were, leprosy continues to be a scourge. The disease, and the stigma and social exclusion that so often attach to it, persist in many places, particularly in South Asia.

The papers in this issue of the Asia Pacific Disability Rehabilitation Journal, concerned as they are with leprosy in South Asia, reveal the continuing significance, medical and social, of this disease, condition and social phenomenon within the sub-continent. This is not to underplay the progress that has been achieved - in the treatment of leprosy as a disease, in health policy and programmes more generally (including through 'community based rehabilitation'), and in social attitudes towards the condition on the part of health practitioners, social service workers and the wider community – but simply to draw attention to the fact that the issues associated with leprosy have not entirely gone away and that stigma in particular, remains a major concern.

\*Professor of Development Studies

School of Development Studies, University of East Anglia

Norwich, NR TJ, UK

e-mail: j.d.seddon@uea.ac.uk

\*\*Senior Lecturer in Development Studies

School of Development Studies, University of East Anglia

Norwich, NR TJ, UK

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### **Source Directory of key disability information resources with CD-ROM**

Three hundred of the most practical and useful disability resources are listed in the Source International Information Centre directory and CD-ROM, "Disability, development and inclusion: key information resources". The information, compiled as part of the Disability Knowledge and Research Programme, is aimed at organisations working with disabled people in developing countries. It covers a wide range of themes including human rights, gender, poverty and mainstreaming, as well as planning and management of disability programmes and service delivery relating to children, community-based rehabilitation, mental health and HIV and AIDS.

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**DEVELOPMENTAL ARTICLES**

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**LEPROSY AND DISABILITY IN BANGLADESH**

S.G. Withington\*

**ABSTRACT**

*While the worldwide strategy on leprosy to date has focused on disease control, disability and stigma are the main concerns of people affected by leprosy. A large emphasis on leprosy by NGOs in Bangladesh, has yielded quality longitudinal data regarding physical impairments due to leprosy, and a number of important studies on nerve function impairment due to leprosy, have been published. Some of these data and studies are summarised here, and their potential benefit in understanding and preventing leprosy-related disability is discussed. The rate of visible physical impairment (WHO Grade 2 disability) among people newly affected by leprosy in Bangladesh was nearly 9% in 2003, significantly higher than the target of 5%. There is strong evidence that such impairments can be expected where diagnosis is delayed. New nerve function impairment in patients on treatment, may be expected to occur in over 60% of the highest risk group within two years. New nerve damage is often clinically silent in early stages, but is not routinely checked for in many integrated leprosy control programmes.*

*On this basis, it appears that there is significant under-detection and/or under-reporting of leprosy-related disability at diagnosis and subsequently, especially where leprosy is fully integrated into general health programmes. The measurement of activity and participation limitation due to leprosy in Bangladesh, as elsewhere, has been limited thus far. Progress in development of community-based responses with and by people affected and disabled by leprosy has been modest, though significant efforts are underway.*

## **INTRODUCTION**

Leprosy is a chronic mycobacterial disease with primarily skin and nerve manifestations. Damage to peripheral nerves occurs both as a direct result of invasion of Schwann cells by the causative agent “*Mycobacterium leprae*” and subsequent immunological reaction to the same (1). Damage to the posterior tibial, ulnar, median, facial, lateral popliteal, trigeminal, and radial nerves is the main cause of physical impairment and resulting limitation of physical activities and social participation in people affected by leprosy (2). Sensory function loss is a cause of repeated injury, ulceration and limb shortening. Corneal sensation loss may result in unrecognised corneal injury and significant visual loss. Motor function loss is a cause of finger and toe clawing, failure of eye closure (lagophthalmos), and foot and wrist drop.

Notwithstanding the wide variety of physical impairments and associated disabilities resulting from leprosy, the prevailing strategy in leprosy is focused on disease control through the systematic implementation of treatment of infection by “*Mycobacterium leprae*” with Multi-Drug Therapy (MDT). This is in part because early case detection and treatment reduces the incidence of physical impairment at diagnosis. In addition, it is hoped that through intense control efforts, the overall incidence of leprosy will be reduced by reducing the reservoir of infection. This reservoir is believed to be confined to those untreated affected persons who have little immunological response, though this assumption has been recently questioned (3,4). These ‘lepromatous’ cases of leprosy represent around 15-40% of the total caseload. Good case-holding practices also facilitate the early detection and treatment of nerve function impairment in field programmes (5,6).

While most countries treat leprosy in a fully integrated way within the public health system, caring for leprosy patients by general multi-purpose health staff, Bangladesh retains a specialist arm to leprosy and TB control. The Health authorities continue to encourage a very active role by non-Government Organisations (NGOs) in this regard. The resultant excellent record keeping and long-standing close collaboration with NGOs makes Bangladesh an important case study in regard to leprosy control. NGOs have been primarily responsible for leprosy treatment and care for around 75% of new leprosy cases since 1995, and The Leprosy Mission alone, cares for 50%, over 4000 new cases annually (7).

The focus on leprosy by NGOs in Bangladesh, means that routine and reliable longitudinal statistical data on disability in leprosy are available, which is not the case elsewhere in the world on such a large scale. Several seminal research projects have also been completed. The Bangladesh Acute Nerve Damage Study (BANDS) followed a cohort of over 2500 new patients for 5 years, to describe the history of nerve damage in leprosy and response to treatment (8). The TRIPOD (Trials in Prevention of Disability) studies researched the potential of prophylactic steroid to prevent new nerve damage (9), and to treat both very early (10) and longstanding (>6 months) nerve damage (11).

This paper seeks to collate some of the available data and research on disability related to leprosy, and to examine recent developments in work by NGOs, in particular The Leprosy Mission International, with leprosy affected people living with disabilities in Bangladesh.

#### **DATA COLLECTION**

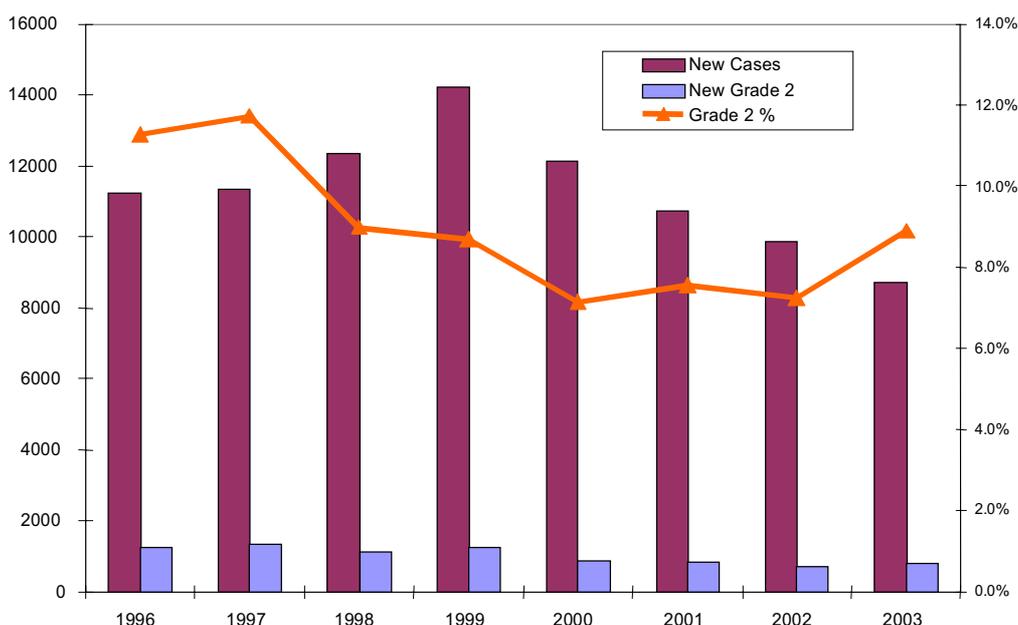
Data on leprosy control progress is routinely collected and returned to the National Leprosy Elimination Programme (NLEP) headquarters in Dhaka for examination quarterly. Data is segregated by sex, and treatment classification. Incidence of WHO 'Disability' Grade 2 status among new cases, equating to a visible impairment due to leprosy, or a significant sight-affecting impairment of the eyes resulting in vision less than 6/60 in either eye, is routinely monitored. Population data is derived from national census data, most recently updated in 2001.

Eight NGOs are involved in leprosy control in Bangladesh. Many are implementing tuberculosis control programmes alongside leprosy work, and work within public health centres in close collaboration with government health colleagues. The longest and largest single project collaborating with the NLEP in systematic leprosy control activities is the Danish Bangladesh Leprosy Mission (DBLM), a project of The Leprosy Mission (TLM) in north-west Bangladesh, close to Nepal. Case detection and trends from DBLM were reported in 1996 (12), and much of the research work has been undertaken and new strategies in the field of leprosy-related disability in Bangladesh trialled in this project. The published Annual Reports of DBLM and other TLM projects in Bangladesh have been used as sources of data presented here.

## OVERALL TRENDS IN INCIDENCE AND PREVALENCE OF LEPROSY

The number of new leprosy cases in Bangladesh with visible physical impairment at diagnosis (characterised by the World Health Organisation as Grade 2 ‘disability’), has gradually declined in the last decade as shown in Figure 1. Nevertheless, the percentage of those with such impairments still stands above 5% at diagnosis (the unofficial target of many countries), and increased in 2003 despite active community awareness programmes in many areas where NGOs are working. Impairment rates at diagnosis are higher in multibacilliary (MB) patients, who have lower immunity to “Mycobacterium leprae” and more advanced disease, and in men.

**Figure 1. Bangladesh total new leprosy cases and those with visible (WHO Grade 2) impairment at diagnosis by year**



In comparison with India, Bangladesh has a relatively high rate of visible physical impairments due to leprosy at diagnosis, despite or perhaps because of the very active approach to leprosy and high quality data recording of NGOs. Many NGOs have documented much higher rates than government services over long periods of time, both within Bangladesh and elsewhere.

Failure to detect or record leprosy-related nerve function impairment in overworked primary health care services, is the most likely explanation for these discrepancies. There are, in addition, large numbers of new cases of leprosy who might be expected to have nerve function impairment at diagnosis, on the basis of the BANDS data on people with neuritis, many of whom had a 'silent' nerve function loss, of which they were unaware, but which was detectable on specific sensory or muscle testing.

These observations call into question lower rates reported elsewhere in Bangladesh, and its neighbouring countries, especially in integrated programmes where staff have little training, time or inclination to test for and record physical impairments in new cases of leprosy. Data from north Bangladesh and elsewhere, have demonstrated a clear relationship between delay to diagnosis with onset of MDT treatment, and the development of physical impairments due to leprosy (13). One study (14), reported most of the delay being due to a 'wait-and-see' approach by the affected person, though a significant number of intermediate treatments were attempted before definitive diagnosis and treatment for leprosy, highlighting the need for enhanced community and health provider awareness.

### **NEW PHYSICAL IMPAIRMENTS**

Many more affected persons develop physical impairments over time. In five years of follow-up of the BANDS cohort from the DBLM project in north Bangladesh, the incidence rate of new Nerve Function Impairment (NFI) amongst MB affected persons was 16.1 per 100 person years at risk (PYAR), with 121/357 (34%) developing NFI during the observation period (7). Of the 121 with a first event of NFI, 77 (64%) had this within a year after registration, 35 (29%) in the second year, and the remaining 9 (7%) after 2 years. The incidence rate of first event of NFI amongst Paucibacilliary (PB) cases, was much lower with only 2.5% developing NFI during the observation period. A simple prediction rule developed based on these observations and published in 2000 (15), assigned new leprosy cases to one of three risk groups (mild, moderate and high risk) on the basis of leprosy treatment group (PB/MB) and the presence or absence of any nerve function loss at registration. Persons with PB leprosy and no nerve function loss had a 1.3% (95% CI 0.8-1.8%) risk of developing NFI within 2 years of registration; persons with PB leprosy and NF loss present, or MB cases with no NF loss present, had a 16% (12-20%) risk; and patients

with MB leprosy and NF loss present at registration had a 65% (56-73%) risk of developing new NFI within 2 years of registration.

Treatment of nerve function impairment, detected within 6 months of occurrence, typically includes a moderate dose (1mg/kg/day) of oral corticosteroids for three to four months. Croft et al have shown the practicality of this in field programmes, largely run by paramedical staff (16). Implementation of field treatment of neuritis is, however, probably only available in a small number of centres world-wide, limiting its access for people on treatment for leprosy. In Bangladesh, many medical officers have little experience of leprosy and are reluctant to prescribe steroids in the event of leprosy reactions or where nerve function loss is occurring, let alone authorise trained field paramedical workers to detect such nerve damage, prescribe steroids urgently, and follow-up treatment. Nevertheless, the TRIPOD study clearly documents the safety of such an approach under field conditions in rural Bangladesh and Nepal. This information needs to be more widely disseminated and discussed, in order to minimise future disability in people affected by leprosy.

Recent studies have demonstrated significant rates of self-healing of neuritis, and long-term follow up of the BANDS cohort has not clearly shown a benefit of standard steroid therapy (8), indicating the need for further research into optimal treatment of leprosy-related neuritis. The TRIPOD 1 study (9) attempted to prevent new nerve function impairment in 600 affected persons in Bangladesh and Nepal, with new MB leprosy through administration of 4 months of low dose prednisolone. At 4 and 6 months a clear protective benefit in the treated group was evident, however, by 12 months this effect was no longer statistically significant, and was not considered sufficient by investigators to warrant the recommendation of routine preventative treatment with steroids. The TRIPOD 2 study used highly sensitive tests to detect and treat very early sensory ulnar and posterior tibial nerve damage due to leprosy, using Semmes Weinstein graded monofilaments at selected standard sites on the feet and hands. No advantage was shown over routine field testing with ball-point pen in terms of neurological outcome (10), when testing is done appropriately under field conditions. The TRIPOD 3 study showed no evidence for the use of steroid in persons with nerve function impairment detected more than 6 months after onset (11), which highlights the need for early diagnosis of leprosy and early detection of new impairments.

## **ACTIVITY AND PARTICIPATION**

There are few data regarding limitation in activity and participation for leprosy affected people, in Bangladesh. Activity limitation scales are not used in any leprosy project of Bangladesh, to the author's knowledge. Croft et al have documented a dramatic change in knowledge, attitude and behaviour of the general community towards leprosy and leprosy affected people in an area heavily saturated with community level health promotion activities regarding leprosy (17). In a one year cohort of 2364 new cases in north Bangladesh, over 15% had detectable physical nerve damage due to leprosy, and 2.1% reported specific social problems and stigmatisation due to the disease within a month of initial diagnosis. Such problems in participation were significantly higher for women than men (4.2% vs 1.1%) (18). Anecdotally, paramedical workers report a dramatic decrease in stigmatisation from two decades earlier, where affected persons (and sometimes leprosy programme staff) were routinely refused entrance to local shops, workplaces, buses, and banks, and were forced to live apart from their relatives and neighbours. Such occurrences have now become rare, though relevant legislation restricting travel and public participation remains unrepealed.

In recent years, TLM has attempted to facilitate the mobilisation of leprosy-affected people into groups for self-help and development purposes. To date, over 200 groups of 5-15 people over a wide area have formed with the objectives of mutual support in keeping healthy and mobile, developing joint savings and credit facilities, increasing self-confidence and self-reliance, and forming a common platform for advocacy. Many of these groups are from rural communities and are a relatively homogenous group of people with physical impairments due to leprosy. Some have joined with people living with other disabilities. In other locations, especially in Dhaka, the groups are more heterogenous still, incorporating people, usually women, both with and without disabilities. They are often more concerned with addressing common issues of poverty and general ill-health than disability per se. As yet, the coalescing of these groups into wider networks is in a formative stage, though specific capacity-building efforts with this in view have been planned in discussion with these groups and communities. There is also no formal link between these groups and other groups or organisations working with persons with disability in Bangladesh, nor with the international advocacy and development umbrella organisation of people affected by leprosy.

## **CONCLUSION**

In Bangladesh, as elsewhere in South Asia and the world, only in the last few years has any kind of decline in new case detection been documented, and this is not true in all centres. Some have expressed concern that declines may be artefactual (19) and related to less emphasis on leprosy following 'elimination', which has largely been achieved through greatly improved case management and shortened treatment regimens. If many leprosy cases remain hidden, this is more so for leprosy-related disability. Most national programmes, including Bangladesh, do not routinely test persons on treatment for new nerve function impairment, or do so only quarterly, and the data is often not recorded, nor collated centrally. It is reasonable to assume that most persons developing nerve function impairment while on treatment are undetected and untreated, though data suggests that a considerable proportion will self-heal, at least to some degree.

The paucity of data on limitations in participation of people affected by leprosy, is regrettable. Attempts to develop standardised scales to measure activity and participation limitations are underway (20), but are not widely known or used by programmes treating leprosy. Moreover, they are likely to require significant training and financial commitment to implement. The emergence of national and international networks of people affected by leprosy is encouraging. In Bangladesh, despite the large numbers of people affected, this movement is still in its infancy, though a large constituency is developing, and through networking will hopefully coalesce into a strong movement for advocacy and change. The scarcity of interaction between these groups and other groups of disabled people, and organisations working in the field of disability limits the transfer of benefits gained for and by people living with disabilities to people affected by leprosy. In future, it is to be hoped that stronger alliances can be formed with others in the health, disability, and development sectors, to ensure the mainstreaming of leprosy, to accelerate its de-stigmatisation, and to enhance quality of life for the many people affected by it in Bangladesh and beyond.

\*C/o. The Leprosy Mission New Zealand  
PO Box 10227, Balmoral  
Auckland, New Zealand.

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## **AN ANNOTATED BIBLIOGRAPHY ON LEPROSY**

Compiled by J.H. Calcraft\*

### ***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.

\*48 Holland Drive, Andover  
Hampshire, SP10 4LY, UK  
e-mail: Calcraftj@aol.com

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**OVERVIEW OF PREVENTING VISUAL IMPAIRMENT  
BY FIGHTING AGAINST AVOIDABLE  
BLINDNESS IN CHINA**

Lin Yan\*

***ABSTRACT***

*From 1999, an unprecedented coalition of many international non-governmental organizations (NGOs) have been providing support to the prevention of blindness in China. Since the launch of this national campaign six years ago the future holds promise of achievement and opportunities. This article gives an overview of preventing visual impairment by fighting against avoidable blindness in China.*

**INTRODUCTION**

In February 1999, the global campaign “Vision 2020: The Right to Sight”, was officially launched in Geneva by Dr. Gro Harlem Brundtland, the Director General of WHO. This represents the Global Initiative for the Elimination of Avoidable Blindness by the year 2020 (1). Seven months later, the International Agency for the Prevention of Blindness (IAPB) General Assembly was held in Beijing. During the IAPB General Assembly, the Chinese Ministry of Health, and China Disabled Person’s Federation together with WHO launched the first national campaign “Vision 2020: The Right to Sight”, in China (2).

**PREVALENCE, INCIDENCE, MAGNITUDE  
AND MAIN CAUSES OF BLINDNESS**

Reliable epidemiological data on overall blindness and visual impairment in the entire country are still difficult to obtain, but based upon the national sampling survey of persons with disability for the disabled in 1987 and the epidemiological surveys in some provinces in 1980s, the rate of bilateral blindness in China is 0.43-0.45% nationwide (2,3). However, China is a country with great difference between provinces and prefectures; showing 0.43% in Shanghai, 0.57% in Yunnan, 0.40% in Sichuan, 0.56% in Shunyi County and 0.12% in Ninghe County

(4). In some areas, the rate of blindness is 2 or 3 times higher than the national average. One of the examples is Tibet; the rate of blindness is over 1.00% (5,6). Based on these prevalence data, China has at least 5 million bilateral blindness. In other words, about 18% of the world's blind population is in China. In absolute terms, China's ever-increasing blind population has already surpassed the total population in countries such as Denmark, Finland or Norway (1). Up to 80% of cases of blindness are avoidable, either resulting from preventable conditions or being treatable (1,2,7). An average 50% of the blindness in China is cataract blindness (1,7). Thus, the cataract backlog in China is 2.50 million. Among Tibetan persons aged 40 years and over, the prevalence of age-related cataract is 11.8% (6). Other common causes of blindness in China are corneal disease, trachoma and glaucoma. Eye injury is becoming a major occupational hazard in some mining areas.

In addition to the bilateral blindness, there is a considerable number of unilateral cataract blindness and low vision cases. According to WHO calculation, an average of 3.4 (2.4-5.5) people have low vision for each blind person (8). Therefore, the total number of people with low vision in China should be at least 17.0 million persons.

According to a WHO estimate, the annual incidence of blindness in China is 450,000, of whom 400,000 are due to cataract (1). This means that in China, one person becomes blind every minute. From 2000 to 2020, the population aged 60 years and above in China will increase by 90% (9,10). This will further increase the incidence of age-related cataract.

#### **AVAILABLE HUMAN RESOURCES AND CATARACT SURGICAL OUTPUT**

The number of ophthalmologists in China was 23,606 in 2004, showing an increase of 7.3% from 1999 (11). The ratio of ophthalmologist to population in China is 1 : 55,000. Over the past 6 years, since launching the global campaign "Vision 2020: The Right to Sight", the annual number of cataract surgeries in China is gradually increasing, but the current number of cataract surgeries is still far below the numbers required to clear the existing backlog. During the past 17 years, 5.50 million cataract operations were performed (12,13). The remaining backlog is calculated as: 2.5 million + (400,000/year x 17 years) – 5.50 million = 3.80 million.

In 2004, the number of cataract surgeries performed in China was 569,408 (14). If the current number remains unchanged, at least 7 years are required to clear the existing backlog.

However, it is only recently that there has been an increase in the annual average. Till 1994, the annual cataract surgeries performed was about 140,000; the Cataract Surgical Rate

(CSR) is only about 136 (15). The CSR increased to 446 nationwide in 2004. The differences between provinces are indicated in Table 1.

**Table 1. Population, number of cataract surgeries and cataract surgical rate (CSR) in 2004**

| Province       | Population<br>(In million) | No. of cataract<br>surgeries | Cataract surgical<br>rate (CSR) |
|----------------|----------------------------|------------------------------|---------------------------------|
| Beijing        | 14.23                      | 17,028                       | 1,197                           |
| Tianjin        | 10.07                      | 5,800                        | 576                             |
| Hebei          | 67.35                      | 25,097                       | 373                             |
| Shanxi         | 32.94                      | 13,623                       | 414                             |
| Inner Mongolia | 23.79                      | 8,136                        | 342                             |
| Liaoning       | 42.03                      | 25,793                       | 614                             |
| Jilin          | 26.99                      | 12,199                       | 452                             |
| Heilongjiang   | 38.13                      | 10,033                       | 263                             |
| Shanghai       | 16.25                      | 25,159                       | 1,548                           |
| Jiangsu        | 73.81                      | 30,689                       | 416                             |
| Zhejiang       | 46.47                      | 25,217                       | 543                             |
| Anhui          | 63.38                      | 25,367                       | 400                             |
| Fujian         | 34.66                      | 16,482                       | 476                             |
| Jiangxi        | 42.22                      | 16,405                       | 389                             |
| Shandong       | 90.82                      | 44,625                       | 491                             |
| Henan          | 96.13                      | 49,763                       | 518                             |
| Hubei          | 59.88                      | 24,302                       | 406                             |
| Hunan          | 66.29                      | 15,970                       | 241                             |
| Guangdong      | 78.59                      | 48,101                       | 612                             |
| Guangxi        | 48.22                      | 20,326                       | 422                             |
| Hainan         | 8.03                       | 35,00                        | 436                             |
| Chongqing      | 31.07                      | 67,18                        | 216                             |
| Sichuan        | 86.73                      | 26,869                       | 310                             |
| Guizhou        | 38.37                      | 7,538                        | 196                             |
| Yunnan         | 43.33                      | 19,710                       | 455                             |
| Tibet          | 2.67                       | 2,500                        | 936                             |
| Shaanxi        | 36.74                      | 13,834                       | 377                             |
| Gansu          | 25.93                      | 9,000                        | 347                             |
| Qinghai        | 5.29                       | 3,217                        | 608                             |
| Ningxia        | 5.72                       | 2,334                        | 408                             |
| Xinjiang       | 19.05                      | 10,199                       | 535                             |
| <b>Total</b>   | <b>1,284.53</b>            | <b>569,408</b>               | <b>446</b>                      |

Given the number of ophthalmologists and the number of cataract surgeries performed, on an average, one ophthalmologist conducts only 24 cataract surgeries during one year.

### CATARACT SURGICAL OUTCOME

In addition to the number of surgeries, the outcome of surgery needs to be considered. There is still lack of nation-wide, reliable epidemiological data on overall quality of the surgeries. Based on the report by China Disabled Person's Federation (CDPF), the immediate outcome of the cataract operations performed during the past 10 years shows 97-98.1% of the operated patients have had a visual acuity equal or better than 0.05 for the best corrected vision (12). Clearly, this figure has not come from an epidemiological survey and may only represent an immediate outcome of the surgical operations.

However, population-based studies have demonstrated poor results, with rates of less than 6/60 acuity in the operated eye of 35.7-53% as documented in Table 2. There were two cross sectional surveys to evaluate the operated clients at Shunyi County of Beijing and Doumen County of Guangdong in 1996 and in 1997 respectively (16,17). In 2000, another cross sectional study was carried out in Tibet at Tibet Eye Care Assessment (TECA), to investigate the cataract clients operated from the past 10 years ago to the last one month (18). The study was jointly conducted by the Seva Foundation, Tibetan Health Bureau and Tibet Development Funds.

**Table 2: Data on cataract surgical outcome from TECA and compared with the findings in Shunyi and Zhongshan**

| Prefectures and counties | Visual acuity (Presenting vision, not best corrected) of the eyes after cataract surgical operation (Aphakic and pseudophakic) |                  |               |                       |                            |
|--------------------------|--|------------------|---------------|-----------------------|----------------------------|
|                          | Vision   |                  |               | Percentage of aphakic | Percentage of pseudophakic |
|                          | Good (>6/18)   | Poor (6/24-6/60) | Blind (<6/60) |                       |                            |
| Lokha                    | 9 (22.5%)  | 7 (17.5%)        | 24 (60.0%)    | 21 (52.0%)            | 19 (48.0%)                 |
| Nakchu                   | 22 (57.9%)   | 6 (15.8%)        | 10 (26.3%)    | 25 (65.8%)            | 13 (34.2%)                 |
| Lingzhi                  | 24 (64.9%)   | 6 (16.2%)        | 7 (18.9%)     | 23 (62.2%)            | 14 (37.8%)                 |
| Total                    | 55 (47.8%)   | 19 (16.5)        | 41 (35.7%)    | 69 (60.0%)            | 46 (40.0%)                 |
| Zhongshan                |  |                  | 53%           | 94%                   | 6%                         |
| Shunyi                   |  |                  | 45%           | 61%                   | 39%                        |

Of course, it is not possible to determine whether the cataract surgeries in Tibet were performed by Chinese ophthalmologists, by Tibetan or by foreign teams. There is lack of information on pre-operative vision or surgical complications. Moreover, these findings are outcomes of surgeries performed a long time ago and therefore may not represent outcomes of current surgeries.

Fifteen or twenty years ago, Intra Ocular Lens (IOL) was not commonly used in China. Lack of appropriate spectacles among the aphakic population is the major reason for the less than acceptable visual acuity outcomes among the cataract-operated population. In addition, inappropriate selection of cases, less than competent surgical technique, and inadequate follow-up may also contribute to the poor outcomes. Along with local production of IOLs and other sophisticated equipment, better results are becoming increasingly possible for cataract surgeries.

### **CATARACT SURGICAL COVERAGE**

Cataract surgical coverage (CSC) is defined as the ratio of people who have had a cataract surgical operation from among the people with cataract vision less than 6/60. CSC reflects the number of treatment services available, access to those services and utilisation of those services by the population. Theoretically, previous CSC should be derived from the cataract surgeries at a certain point of time and the cataract blind people at the same time. Unfortunately, it is very hard to match these components and difficult to determine how many cataract blind people died each year. By using the number of cataract backlog in 1980's, the CSC in China from 2001 to 2004 is shown in Table 3.

**Table 3. The Number of cataract surgeries and cataract surgical coverage in China (12,13,14)**

| Item                           | 2001    | 2002    | 2003    | 2004    |
|--------------------------------|---------|---------|---------|---------|
| No. of cataract surgeries      | 491,000 | 513,000 | 574,000 | 569,408 |
| Percentage of pseudophakic (%) | 78.3    | 83.0    | 88.0    | 88.4    |
| Cataract surgical coverage (%) | 18.9    | 17.1    | 16.9    | 15.0    |

It is increasingly apparent that CSC can be improved by an active blindness prevention programme. This is particularly so in those areas with long-term intervention, where the CSCs are much higher than the national level. For example, CSC in Shunyi is 48%, 40% in Zhongshan and 50% in the sample areas of TECA.

Available data suggest that CSC of women is usually lower than that in men within the same area (18). This may reflect an influence of social rejection of women in those areas and/or higher life expectancy of women.

## **BARRIERS TO IMPROVE CATARACT SURGICAL RATE (CSR)**

There are several factors contributing to the low volume of cataract surgery in China.

### **1. Cost of the surgery**

Most of the farmers in rural China have to pay for their own medical expenses. The cost of a cataract operation in China varies widely, but the average cost is around 2,500-8,000 Yuan per eye. However, the average annual income of the poor farmers in China is less than 2,000 Yuan (9,19). Thus, the surgical cost alone equals 2-4 years of their annual income. Not surprisingly they cannot afford to access the service.

### **2. Distance to the service centre**

Most cataract affected blind people live in rural areas while most ophthalmologists work in urban areas. Within a county, the distance between a village and the county town varies from 15 to 200 kilometers; and transport connectivity is quite poor in some places. There is no official data on what is the percentage of counties that have the capacity to perform cataract surgeries; but the data from a national survey on eye care resources in 1997, showed that only 39-42% of the county hospitals have ophthalmoscopes, 57-63% have a slit lamp, 19-36% have an operational microscope, 59-63% have a tonometer, 54-58% have trial lens sets and 27-40% have a perimeter (20,21). This means that less than 30% of the county hospitals are able to perform modern cataract operations. Patients accompanied by an escort have to travel over hundreds of kilometers to a city for the service. Clearly, this is more than what poor people, with little or no disposable income, can afford.

### **3. Quality of the service**

It is increasingly apparent that poor outcome of surgery is a major barrier to community acceptance (22). The national survey on eye care resources revealed that only 28.74% of the ophthalmologists nationwide, graduated from a recognised university; 53.81% have the expertise to perform cataract surgeries (20,21). In county hospitals, the lack of qualified cataract surgeons is even more pronounced.

#### **4. Community awareness**

11.63% (6.43% for male and 16.92% for female) of the population aged 15 years and over are illiterate (19). The affected persons may not come for services even if surgery is available as they do not know cataract is treatable. Blindness may be accepted as part of the ageing process.

#### **LESSONS LEARNED AND SUGGESTIONS**

During the IAPB General Assembly held in Beijing in 1999, the international society suggested, that in order to reduce the cataract backlog and “operable” cataract, it is necessary to operate each year, on at least as many eyes that develop cataract. In China, the number should be higher than that due to a rapidly ageing population. Based upon the practice during the past two decades, the lessons learned and suggestions for the future are:

- In the past, much attention has been paid to train cataract surgeons. However, increasing the number of cataract surgeons and surgical services is not adequate enough to improve CSC and CSR. Community-based efforts are needed to identify, educate and encourage patients to accept the surgery.
- While successfully operated ex-patients are the best promotion for cataract surgeries, poor outcomes will have a strong negative influence in the community. Fear of a poor outcome may be a legitimate reason for people to refuse the surgery. Therefore, the quality of surgery needs to be improved through better training and quality assurance programmes. Training activities should be carried out with an emphasis on those counties without a cataract surgeon.
- There is no direct linkage between increase of expensive equipment and cataract surgical output, but it has a negative impact for people to access the service due to the far more increased cost. It has been suggested that the major type of cataract surgical operation in rural areas is still ECCE + IOL, and not by phacoemulsifier (23).
- Government attention should be concentrated on increasing efficiency and providing affordable, accessible and appropriate eye care.

\*Deputy Director General

Advisory Center for Social Service in the China Rehabilitation Research Center

China Disabled Person's Federation

e-mail: linzhao@public.bta.net.cn

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## **Signs of Development in Deaf South & South-West Asia: histories, cultural identities, resistance to cultural imperialism**

Author: M.Miles

The revised article offers evidence and hypotheses for a short cultural history of deaf people, culture and sign language in South Asia and South West Asia, using documents from antiquity through 2005. The past five years have seen some remarkable progress of deaf people, sign language and education in this vast region.

A further new bibliography has been added of 110 items on “Deafness and Signing in the Arab Middle East” with some historical material and light annotation.

Available at: <http://www.independentliving.org/docs7/miles200604.html>

## **INCLUSION OF PERSONS WITH DISABILITIES IN CHINA**

Eric Zhang Guozhong\*

*China, as the largest developing country in the world, has 60 million persons with disabilities, an estimated number on the basis of result of 1987 First National Sampling Survey on Disability. According to United Nations, during the past two decades or so, concurrent with the rapid economic growth and social development, China's Human Development Index (HDI) was 0.522 in 1975 and the figure rose up to 0.74 in 2002. In terms of world ranking, China's HDI ranking was 111th (among 174 countries) in 1992 and it rose to 94 (of 177 countries) in 2002 (UNDP website at: <http://hdr.undp.org/reports>). As result of a series of positive legislative and administrative actions and the work of disability organisations, the general living conditions and overall social status of people with disabilities in the country, has improved remarkably. Yet, people with disabilities remain a vulnerable group and many still encounter specific difficulties in a society whose economy is experiencing a tremendous market-oriented transition. Much remains to be done in order to ensure the full realisation of "Equality, Participation and Sharing" for people with disabilities.*

### **INTRODUCTION**

Most laws and policies use the definition of disability in the Law on the Protection of Disabled Persons (promulgated in 1990). According to the Law, a disabled person refers to one who suffers from abnormalities of loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and has lost wholly or in part the ability to perform an activity in the way considered normal. And "the term disabled persons refers to those with visual, hearing, speech or physical disabilities, intellectual disabilities, psychiatric disabilities, multiple disabilities and/or other disabilities" and "the criteria for classification of disabilities shall be established by the State Council", the cabinet of China's central government. This definition

and related policies and standards, were deeply influenced by the medical-social models popular in the 1980s, in particular, the WHO's International Classification of Impairment, Disability and Handicap (IC-IDH). The definition is now under review.

### **LEGISLATIVE FRAMEWORK**

China's Constitution provides a general principle on protection of people with disabilities. Article 45 establishes that "all citizens ... have the right to material assistance from the state and society when they are old, ill or disabled. The state develops the social insurance, social relief and medical and health services that are required to enable citizens to enjoy this right..." and "the state and society help make arrangements for the work, livelihood and education of the blind, deaf-mute and other handicapped citizens. In addition, more than thirty national laws contain specific provisions concerning people with disabilities and the protection of their rights, including the Civil Law, the Criminal Law, the Law of Education, the Law on Higher Education, the Labour Law and so on.

The Law on the Protection of Disabled Persons (enacted in 1991) is of significant importance to the protection of the rights of people with disabilities. It contains fifty four articles and nine chapters that address rehabilitation, education, employment, cultural life, welfare, access, legal liability, etc.

Article 3 of the Law sets a principle of anti-discrimination that stipulates:

"disabled persons are entitled to enjoyment of equal rights as other citizens in political, economic, cultural and social fields, in family life and other aspects. The rights of disabled persons as citizens and their personal dignity are protected by law. Discrimination against, insult of and infringement upon disabled persons is prohibited."

The Law in its Article 49 through 52, also establishes general provisions for enforcement and list some types of rights violations and their repercussions, and make reference to applicable civil or criminal laws and administrative procedures.

By 2003, all thirty provincial congresses issued local disability regulations. Local authorities now take more initiatives in producing supplementary policies.

## **INCLUSION AND PARTICIPATION OF PEOPLE WITH DISABILITIES IN SOCIETY**

### **Education**

By the law on Protection of Disabled Persons, the State “guarantees the right to education for disabled persons... and provide[s] compulsory education for children and youth with disabilities... and the State charges no tuition for those disabled students receiving compulsory education.”

Other laws, such as the Law of Education, the Law of Vocational Education, and the Law of Higher Education, contain special provisions for people with disabilities. For example, the Law of Education stipulates that “the State supports and develops the undertaking of education for persons with disabilities, “ and that “the State, society, schools and other educational institutes shall provide education to persons with disabilities according to their physical and psychological characters and needs and give them assistance and convenience.” Para.3, Article 10 and Article 38, Law of People’s Republic of China on Education [(enacted in 1995)].

In practice, a mixed system of integrated education and special education has increased the educational opportunities of people with disabilities. The China Disabled Persons’ Federation reported that in 2000, the overall enrollment rate of school-aged students who were deaf, blind, or intellectually impaired was about 77% (1), which was lower than the national enrollment average of school-aged children without disabilities (2). In 2003, there were about 323,000 school-aged children with disabilities that did not have any access to education, due to such factors such as families’ poverty (3). Through initiatives such as “Project Hope” and “Spring Drizzle,” efforts are made to help those who have dropped out, including boys and girls with disabilities, to return schooling (4).

Mainstream institutions accept people with disabilities, whilst special education is also available. However, primarily for some learners who are blind, deaf or have severe intellectual disabilities, although some such students may choose to study in a mainstream or special surrounding. A large number of physically disabled and some intellectually disabled students may have not been counted by the authorities as disabled students, as they normally study in mainstream schools.

According to the Ministry of Education, in 2003, there were 1,551 registered special schools that enrolled 365,000 students with disabilities (5). Overall, 66.23% of students with special learning needs were studying in mainstream schools or/and classes affiliated with mainstream schools (6).

According to the Law on Higher Education, no institution shall reject any student on the basis of his or her disability. Yet, some students with disabilities still face barriers such as the physical examination requirements of some universities. Such requirements were recently lifted by the Ministry of Education in order to give effect to equal educational opportunities for students with special needs. In 2003, 3,072 disabled students enrolled in universities and 827 others, in special higher institutions (7). According to another report, 93.93% of eligible disabled students were accepted by and enrolled in universities in the previous years from 1996 to 2000. The lack of accessible conditions and reasonable accommodations on campuses occasionally remains barriers for people with disabilities.

### **Rehabilitation**

China's health care system is currently undergoing critical transition, as the previous system of "medical care at public expense" is being gradually replaced by a fairly market-oriented "social basic medical insurance" system, based on financial responsibility that is shared jointly by individuals, their employers, and the State. With this background, people with disabilities access health services on an equal basis with others, though appropriate services, especially rehabilitation services, might not be available at all for a large number of persons. There are no statistic data on how many disabled persons enjoying health and medical care. Although employed people used to and may still enjoy medical care at public expenses, more tend to buy basic medical insurance nowadays. In 1994, only 374,600 employed workers and 25,700 retirees were covered by basic medical insurance, while in 2002 and 2003, the amounts rocketed up to 94,000,000 and 109,020,000. This is also the case for disabled persons (9, 10).

The Law, however, does attach great importance to rehabilitation, and the Government has included rehabilitation in national economic and social development programmes. The Government has developed and supported urgently needed rehabilitation programmes that aim to mainstream and facilitate the participation of people with disabilities, in society. These

programmes include sight-restoring cataract surgery, low-vision training, speech training for hearing-impaired children, corrective surgery for people with physical disabilities, and provision of assistive devices. From 1996 to 2000, about 4.33 million people with disabilities received rehabilitation services. Services were delivered through key rehabilitation centers as well as Community Based Rehabilitation (CBR) initiatives. CBR aims to improve the physical functioning and independent living skills of people with disabilities, in order to facilitate their participation in social life and their communities, and is an important part of rehabilitation efforts in China. According to the “National Programme on Disability in Tenth Five-Year Plan Period,” some 5.1 million people with disabilities will receive rehabilitation services delivered through the joint efforts of governments and communities from 2001 to 2005 (11).

In response to the needs of many people with disabilities, especially those in poverty-stricken rural regions, who could not afford rehabilitation services, the Government and NGOs collaborated on some programs such as “Rehabilitation for All among Leprosy-disabled Persons” and “Helping the Hearing-Impaired by Donating Hearing-Aids,” which have helped over one million people. With support from commercial banks, the Government also established a project called “Rehabilitation for Poverty Reduction among Persons with Disabilities.” In the 5-year period from 1996 to 2000, the project received 2,210,148,000 RMB yuan of earmarked funds, to help people with disabilities in poverty. For 2003, some 650 million RMB were earmarked for the project.

### **Employment**

Approximately 83.9 % of people with disabilities were reported to have employment in 2003 (12, 13), though it is likely lower than the rate of other groups of population, compared to the figures in year 1987, when only 50.19% of people with disabilities in urban areas and 60.55% in rural areas were employed, the recent situation of disabled persons has improved greatly (14).

In China, the right to work is guaranteed by the Law, which states that, “no discrimination shall be practised against disabled persons in employment, engagement, status regularisation, promotion, determining technical or professional titles, payroll for labour, welfare, labour insurance or in other aspects.” Correspondingly, employers like state-run welfare enterprises should not deny people with disabilities employment.

The Government has established a quota system. By 2003, the quota scheme policy was practised by 1,519 counties and 640 cities of all 31 provinces (See <http://www.cdprf.org.cn/shiye/sj-03.htm>), that requires all public and private employers to reserve no less than 1.5% of job opportunities for persons with disabilities, in accordance with specific regulations established by local provincial governments. Law on the Protection of Disabled Persons establishes that specific quota or ratio may be determined by local provincial governments yet in practice the quota is no less than 1.5%. Those who fail to meet the required quota, must pay a fee to the Disabled Persons' Employment Security Fund, which in turn, supports vocational training and job-placement services for people with disabilities. The taxation authorities and disabled peoples' organisations are involved in the process of monitoring.

Through initiatives such as tax incentives and financial, technical and other resource assistance, the Government supports welfare enterprises that recruit employees with disabilities and encourages people with disabilities to engage in self-employment.

In addition, to enhance the employment prospects and opportunities of people with disabilities, more than 3,000 employment service centers are now in operation (3). These centers were established with financial support from the Government and local communities, and provide services ranging from practical job-oriented vocational training (including IT, sewing, and domestic animal raising skills), to employment matching and consultation for people with disabilities seeking jobs.

### **Communication**

Articles 37, 38 and 45 of the Law on the Protection of Disabled Persons, guarantee access to information and communication for people with disabilities. In accordance with the Law, the Government has included goals for accessible information and communication in the latest national development programme. Progress has been uneven. The situation in coastal regions and major cities is encouraging. For example, in Shanghai, most local TV programmes are broadcast in alternative formats, i.e., with subtitles or in sign language. In contrast, in many other parts of the country, accessible communication is still a new and underdeveloped concept and should be promoted further.

A standardised national sign language has been developed. The China Braille Publishing House and other publishers produce Braille and audio reading materials, including Braille

versions of China's constitution and other major laws. However, due to limited resources, there is still a large gap between supply and demand. Braille and talking materials are often available only in libraries and activity centres in major cities and towns.

In economically developed regions, there are a number of newspapers that are popular and are run by and for people with disabilities, such as the Chinese Times in Beijing. There are also some disability-specific journals and newsletters that enjoy local and national audiences, such as "China Disability", a monthly magazine. Blind People in China, another monthly magazine, is printed in Braille, for persons with visual impairment, and circulated nationwide. By law, reading materials for persons with visual impairment may be shipped free of charge through the public mail system.

The Criminal Procedure Law requires that personal and/or legal assistance, including sign language services, be provided to people with disabilities in cases of emergency, and in legal circumstances, such as court or public hearings. These services are available, but sometimes are not sufficient to meet the demand.

Due to the advocacy and promotional activities of disabled peoples' organisations, efforts have been made, in recent years, to develop high-tech devices that accommodate the needs of people with disabilities. User-friendly pagers, mobiles phones and internet-based communication technologies and services have been developed for people with visual or hearing impairments. There are also websites such as "Deaf Online" that have become popular among hearing impaired youth. However, these new services are rather expensive and have so far benefited only small groups of young people with disabilities, living in cities. Many people with sensory difficulties still face communication barriers.

### **Accessibility**

Both the Government and organisations of people with disabilities recognise the importance of accessibility to the full inclusion and participation of people with disabilities. As required by the Law on Protection of Disabled Persons and other policies, the State and society should take positive actions to promote and build accessible physical, information and communication environments.

Codes for Design on Accessibility of Urban Roads and Buildings (JGJ 50-2001) is the most influential national accessibility policy (15). The Codes were issued by the Ministry of

Construction in June 2001 and were formulated based on a document issued in 1988. The Codes apply to all urban roads, built environments, and relevant facilities for public usage, residence, office space, business, services, cultural activities, education, sports activities and workplaces, both newly built and renovated. Most of the codes are now compulsory.

The Codes are supported by the Law on the Protection of Disabled Persons, which requires that the Government gradually take barrier-free measures to realise the Codes.

There has been progress in improving accessibility, though implementation has not been satisfactory in all regions. Problems include limited awareness of accessibility needs, shortage of technical and financial resources, and the relative lack of local economic and social development in many regions. Although large cities such as Beijing, Shanghai, Tianjin, Guangzhou, Shenzhen, Shenyang, and Qingdao have made the most progress, 133 other cities and provinces have established government task forces to promote accessible construction and 147 cities have adopted local implementation regulations (“Statistic Report of the Development of the Undertakings for Disabled Persons in China in 2003” (canliangfa (2004)10. See <http://www.cdprf.org.cn/shiye/sj-03.htm>). Some regions, including Beijing, have even promulgated local by-laws on accessibility. However, accessible environments and facilities remain unavailable in many localities, prompting the Government to call for more action in small towns and rural areas, to progressively improve accessibility.

The accessibility of inner-city transportation has improved rather quickly in big cities. For example, accessible bus lines began operation in Beijing in November 2004 and city authorities promised more accessible bus and subway lines in coming years. Likewise, in southern China’s Shenzhen city, the newly constructed subway system that began operation in the end of 2004 is completely accessible. Most major airports are now accessible, and the Ministry of Railways is developing new by-laws on accessibility for railway areas.

Access to information and communication for persons with disabilities is guaranteed by law. In 2004 and 2005, the Governmental ministries, civil society, and disabled peoples’ organisations co-sponsored two Information Accessibility Seminars attended by delegates and experts from the Ministry of Information Industry, the Ministry of Sciences and Technology, the China Disabled Persons’ Federation, the China Blind Association, and more than 30 media and about 20 locally and internationally renowned corporations, such as Microsoft, IBM, Nokia, Motorola and Siemens. Participants discussed how to create an accessible information

environment for people with sensory disabilities through legislation and the use of accessible technologies such as programming, web design, and communication format adaptation.

### **Housing**

Although the Constitution establishes that “all citizens ... have the right to material assistance from the state and society when they are old, ill or disabled,” no separate legal instrument specifically addresses the issue of housing for people with disabilities.

In general, people with disabilities have the right to housing on an equal basis with others. Although some own their own homes and some are entitled to equal access to public housing programmes, such as the Affordable Housing Programme and the Comfort Housing Programme, most people with disabilities are believed to live with their families and caregivers, as families usually play an important role in caring for and supporting members with disabilities.

About 10 million, or approximately 17% of people with disabilities remain living in poverty (16), mostly in remote rural areas. Approximately, 140,000 families with members having a disability do not have suitable housing, and another 60,000 families live in housing with poor-conditions that urgently need renovation. In response to this situation, the Government is currently working with local partners on a programme called “Helping Poor Disabled Persons in Renovating Housing.” The project receives funds from the Central Government, local governments, and other sources, while disabled peoples’ organisations and local communities contribute technical assistance and manpower to disabled peoples’ households in need. The programme began in 2003 and has benefited many people with disabilities (16).

### **Culture, Sports and Recreation**

According to the Law on Protection of Disabled Persons, the needs of people with disabilities should be integrated in the mainstream cultural arena, to promote their full participation in society.

Public cultural facilities, such as libraries, museums, art galleries, public parks, and sports venues are open to and expected to make reasonable accommodations for people with disabilities (8). Depending on the policies of local authorities, admittance to such activities

may be available free of charge. In some cities, there are community-based cultural and recreation facilities, although some may be used infrequently by people with disabilities, due to a lack of accessible local transportation.

The China Disabled People's Performing Arts Troupe is one of 131 arts troupes of people with disabilities in the country. In recent years, it has toured through dozens of cities in China and throughout the world, positively portraying and demonstrating the special arts talents of people with disabilities.

Every four years, there is a national sports competition for people with disabilities, which attracts thousands of athletes from every part of the country. In recent years, Chinese athletes with disabilities have also been active in the international arena, particularly in world championships such as the Paralympic Games and other international and regional sports tournaments. China also will host the upcoming 2008 Paralympic Games in Beijing, and the 2007 Special Olympic World Games in Shanghai.

### **Civic and Political Participation**

People with disabilities as a group, are exhibiting increased political awareness and participation. In 2003, more than 3,200 persons with various types of disabilities and their relatives were elected as deputies of the National People's Congress and local people's congresses and as members of the National People's Political Consultative Conference and its local bodies above county levels, hence increasing the voice and influence of people with disabilities in legislative and policy-making processes.

### **Disability Awareness and Actions**

The State Council Coordination Committee on Disability (SCCCD) is the national coordinating body for disability policy within the Government. It was initially set up in the 1980s, as the China Coordination Committee for Celebrating UN Decade of Disabled Persons. The Coordination Committee is currently chaired by a Vice Premier, and has members from 36 governmental departments and ministries in the fields of health, civil affairs, education, labour, and social security, as well as a national organisation of people with disabilities. The main responsibilities of the SCCCD are to formulate and monitor the implementation of key disability policies, strategies and programmes; resolve major issues concerning disability; and coordinate

the actions of different governmental departments. The SCCCD has played a significant role in drafting disability-specific laws and policies, and in particular, the Law on the Protection of Disabled Persons and four consecutive national development programmes on disability. Every five years since the 1980s, these national programmes have set goals and medium-range objectives for the disability-related activities of various governmental departments and local authorities, obliging them to take positive measures and actions, such as providing rehabilitation and education services, promoting accessible conditions, and supporting access to sports, culture and artistic activities for people with disabilities. Each year, the SCCCD and its local bodies in provincial, city and county level governments throughout the country coordinate major events, such as the observance of the National Day of Assisting Disabled Persons, on the third Sunday of May. There are similar coordination mechanisms at provincial, city and county/district level governments as well.

China Disabled Persons' Federation (CDPF) is a national umbrella organisation of, and for people with various types of disabilities. CDPF and its associated local federations are playing an important and unprecedented role in advocating and protecting the rights of people with disabilities, and participating in the policy-making process that affects or concerns people with disabilities. In close collaboration with other departments and civic organisations, the CDPF also provides assistive devices and rehabilitation, education, and employment services to people with disabilities. The CDPF receives resources support from the Government, charitable donations, and fund-raising activities.

With support of the CDPF, there are some 38,000 grassroots associations of people with disabilities, that are active throughout the country, at the community and village levels, and provide various types of practical assistance and services for citizens with disabilities in their communities.

\*International Department  
China Disabled Persons Federation  
No.186, Xizhimen Nanxiaojie  
Xicheng District, Beijing China - 100034  
e-mail: ericzgz@yahoo.com.cn

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**ORIGINAL ARTICLES**

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**GENDERED EXPERIENCES: MARRIAGE AND  
THE STIGMA OF LEPROSY**

Leonie Try\*

**ABSTRACT**

*Stigma is rife in many areas of health and healthcare and it has implicit impacts that are often overlooked. Due to the continued social construction of the stigma of leprosy, it is clear that a greater understanding is needed of how stigma is experienced. This study considers the experiences of marriage of those vulnerable to stigmatisation due to leprosy and more specifically identifies different experiences of leprosy-affected women and men and the possible implications.*

**INTRODUCTION**

The stigmatisation of those suffering from leprosy continues in Nepali societies and is a contributing factor to Nepal's relatively high prevalence rate of 3.04 in 10 000 (1), although it is feared the true rate is much higher than official estimates. In this area, the main ethnic group are the Maithili. There are an estimated 33.4 million Maithili people, of whom about 2.6 million live in Nepal.

There has been recognition of the detrimental effects that stigma may cast over women's prospects of marriage (2,3,4,5), but this will also be dependent upon the cultural context. However, research that specifically focuses on the impact of stigma on gender differentials of marriage is minimal, and the author is unaware of any that directly considers the stigma of leprosy in this context.

Marriage in Hindu culture expresses the value of fertility and reveals the status, caste and kinship structures. Therefore, it is understandable that leprosy would have an effect on experiences of marriage for persons with leprosy and their families.

Marriage is one area that may be affected by 'courtesy stigma' (6), where close family and friends of a stigmatised individual also suffer stigmatised behaviour. Bainson et al. (3) suggested

courtesy stigma of leprosy does occur, while research has found courtesy stigma deriving from a disabled individual can affect the chances of marriage for siblings (2).

The situation of girls and women with leprosy must be placed within the socio-cultural context which affects female status in general (7). Every society perceives health and disease differently and this local context plays a significant role in the construction of stigma. Evidently, the specific culture of a community or society will affect the widespread attitude towards leprosy (8). In many Hindu societies, including Nepal, leprosy is still “conceived as divine retribution for past sins” (9). Accordingly, serious consideration must be given to how religious and cultural beliefs influence the construction of the stigma of leprosy and consequently affect the disclosure of symptoms and the access to healthcare.

## **RESEARCH DESIGN**

The research was undertaken at the Lalgadh Leprosy Services Centre in Janakpur District, South East Nepal. Field workers and hospital staff assisted in the organisation of the research, which used predominantly qualitative methods.

The research illustrates a selection of experiences of leprosy-affected people, rather than representing a wider population with participants being selected both on the recommendation of staff and randomly.

### **Data collection**

A set of nineteen semi-structured interviews, with nine men and ten women were conducted in Nepal over a six-week period. Both Nepali and Maithili are spoken in the area, so a translator was used for the interviews. Following experience gained in pilot interviews and in accordance with Maithili culture, all interviews were gender segregated - male translators and interviewers were used with the men and vice versa. The interviews were recorded for reasons of accuracy following the consent of all participants.

### **Analysis**

Data analysis was undertaken using thematic or ‘content analysis’, which identifies key themes and frequency of themes in the content of the interview transcript texts. The analysis process was closely connected to and supplemented by concepts identified prior to data

collection, and the key themes are linked to the wider context of the aims, objectives and research questions of the study. The analysis was structured by the key themes identified from the data and uses material from the interviews to illustrate and support the discussion.

### **Limitations encountered**

Conducting interviews through translators raised the most concerns for the research process. The main risk was that the information obtained through translators may not be accurate. Inevitably, the direct translation of certain words, phrases or concepts often did not exist, so the translators had to re-phrase the question to obtain the information required. Such limitations highlight the importance of careful preparation for interviewing, as well as the value of recording the interviews, to cross-check the information given by the participant.

### **Ethical statement**

It was essential for those involved in this research, to recognise their ethical obligation to prevent any harm to the participants, especially as the topics of research are of a sensitive nature. Consent to take part was gained from all participants and all participants were assured of their anonymity and were free to withdraw from participation, or withdraw any previously gained data, at any time.

## **FINDINGS**

The key themes to emerge from the data were: Stigma: Perceptions and Behaviour; Marriage; and Attitude and Expectations.

### **STIGMA: PERCEPTIONS AND BEHAVIOUR**

Theoretically and practically, stigma was the core element of the data and research. Two aspects of stigma - the perceptions and beliefs about leprosy and stigmatised behaviour - are inextricably linked, despite being considered here as separate components.

#### **Perceptions**

Perceptions of leprosy include beliefs about what causes the disease, how it is transmitted and the cognitive reactions that encourage the stigmatisation of individuals. Gender differentials of perceptions were detected through cultural behaviour, awareness and

understanding of normal gender relations. Normal can be defined here as conforming to the usual, regular or typical standard.

### **Beliefs**

The interview excerpts are referenced in the following manner: (Male 15) indicates that the quote is taken from interviewee number fifteen who was male. A plethora of beliefs about the causes and transmission of leprosy were revealed. The fear of transmission was evidently the main cause of concern, as previous research also found (10). These fears were based on prevailing inaccurate beliefs.

It is still commonly believed, that touch is the main cause of transmission; yet other beliefs deem that transmission occurs through food, water, air and faeces. As one participant described:

“Usually when they [bathers at the river] saw me, they put their hands on their face [because] they thought that if they didn’t do like that the disease would be transmitted to them. They were thinking leprosy was very infectious disease, it could transmit through contact, through air, or faeces.” (Male 15)

One man was warned against sleeping next to his wife as “even the sweat transmits the disease” (Female 4). Another participant told how his work colleagues believed “...it is transmitted through air, urine and defecation. So, if you work with us we could get this disease” (Male 17).

Along with fears of transmission, beliefs of how leprosy is caused play a significant role in generating stigma against affected individuals. The Hindu belief that leprosy is a punishment for sins committed in a previous lifetime (9), was also common:

“I had been asking with God that what did I do so he gave me this type of punishment” (Male 15).

If it is believed that the individual is responsible for their leprosy, because of sinful behaviour in a past life, then this will influence the way society responds to leprosy-affected individuals. A previous study in the same area around the Lalgadh Leprosy Services Centre found that 77 % believed that individuals were responsible for their leprosy (11). Such perceptions of the causes of leprosy have implications for courtesy stigma and the effects on marriage. Therefore, not only has such a nasty disease affected individuals, but the belief is that they

must also have been sinful people to bring it upon themselves, rendering such individuals unattractive for marriage.

### **Gender Perceptions**

The dominant patriarchal nature of Nepalese society creates an interesting setting for research into gender differentials. In contrast to the distinct gender perceptions identified by Rao et al. (5), there was a range of opinions justified on biological and social grounds, as to whether leprosy-affected men or women suffer more. In addition to opinions that either men or women suffer most, an equal number of participants felt that leprosy places an equal burden on both.

“They both get equal treatment. They force them to live an isolated life on the bank of some river or a solitary place. People don’t discriminate between males and females. If they have leprosy, they get equal treatment” (Male 1).

“Be it a male or a female, the treatment is the same. As far as I can see both sexes are treated the same way. They are ignorant people who treat differently. Wise people don’t have stigma” (Female 16).

One male identified the greater impact of leprosy on women’s than men’s lives, even though it was he who had contracted the disease:

“My wife was faced with so many big problems than me. Nobody wanted to keep her in their house, she did not get anything, she did not manage anything, because still female are dependent on men, if men refused to help her then how could she survive. Man can survive with a small piece of cloth but female can’t. I heard that many of female who had leprosy they isolated from community, they had to stay on side of river in a hut and died there, even they had their sons. No one tried to protect her” (Male 15).

This statement reflects this man’s awareness of gender roles and relations and the cultural boundaries that exist for men and women in society. It also shows that he feels women are treated worse if they have leprosy, as they are already dependent on others for their living. As one woman observed, “women suffer more” [because] “After marriage, husband is everything for a wife” (Female 19). Male dominance in society and the household, over

important decisions, income and other household members, allows men to retain more respect than women if they become stigmatised due to leprosy.

### **Behaviour**

Two key aspects of stigmatised behaviour were identified: those people performing actions in accordance with their perceptions (family, community, work colleagues); and the type of behaviour. Existing gender relations should be recognised when considering behaviour towards leprosy-affected individuals. Negative behaviour towards leprosy-affected males and females was evident from both male and female family and community members. There was no apparent gendered pattern of those targeted by negative behaviour, at least not in this study.

An important distinction must be made between behaviour in the domestic and public arenas. The domestic sphere is the focal point of family interactions and activities. Family members come into close contact with one another through these interactions and activities. Therefore, it is within the household, that stigmatised behaviour is often most acute towards those affected by leprosy. Half of the participants recognised a difference in the behaviour of family members since their diagnosis of leprosy (Male 1, Female 4, Female 5, Female 8).

The everyday activities of cooking, eating, housework and sleeping arrangements were affected to varying degrees for most individuals (also shown by Rao et al. (5), and specific to Nepal (10) de Stigter et al.). Restrictions over usual behaviour associated with the preparation and consumption of food was a widely identified problem. Both men and women were prevented from eating within the vicinity of other family members and eight participants told how a separate set of utensils was put aside for use only by the leprosy-affected individual.

The expected gender roles for men as wage earners and women as carers and home-keepers are strictly upheld in Maithili culture, more so in rural areas, where most participants were from, than in urban settlements. In accordance with socially expected roles, leprosy-affected females experienced more restrictions on their daily activities within the domestic sphere. This is to be expected, as the majority of women's work is centred around the household, whereas men's role as primary income earner increases his value to and within the family, reducing the impact of stigma on their status.

More men than women, complained of being stigmatised by family members. This is probably because women are socialised to conform and accept their culturally assigned subservient role from childhood (5) and therefore, may be more accepting of imposed restrictions than men. Women are accustomed to restrictions on their movements and spend much of their time within the home, undertaking the duties that are expected of them. Furthermore, if a woman is forbidden from doing the very activities that ultimately defines her position in the household, her worth is immediately drawn into question (5).

Within the community, dominant perceptions generate fear among groups, which often escalates leading to collective action to banish affected individuals from the village: (Male 13), (Male 17), (Female 18).

“My villagers told me that I could not stay in village. I had to stay in outside of my village” (Male 13).

The research showed that many of the changes in behaviour by families towards leprosy-affected individuals were reflected in community-based stigma. Again, changes were most apparent through restrictions over usual (usual in this sense is understood as something that occurs on a regular daily, weekly or monthly basis and is expected or accepted of that individual) activities, such as sitting amongst people (Male 15), access to public water sources (Female 11, Male 15) and even access to roads:

“I was not allowed walking through main road. So usually I came to my house from cottage through side road and after taking food I returned through same road” (Male 15).

Such public displays of stigmatised behaviour perpetuate fear, reinforcing false beliefs, which in turn, encourage stigmatised behaviour at the household level. Yet again, the common perceptions and beliefs combined with the shock and fear of leprosy, drive these changes in behaviour.

### **Summary**

The findings show, that perceptions and behaviour act to mutually reinforce each other. Preconceived ideas and beliefs affect cognitive responses and these responses and the primary perceptions about the disease lead to certain types of behaviour. There are cognitive

dimensions, which stimulate varying responses to leprosy and the responses, which affect behaviour towards the stigmatised individual.

Beliefs and perceptions can be identified and therefore differ at the individual, family, community and society level. The stigmatisation process will also be shaped by the cultural, religious and social characteristics of the society within which it develops, “not simply the biological characteristics” of the disease (8).

### **MARRIAGE**

Marriage is a significant aspect of Maithili culture. It was found that the stigma of leprosy does have an impact on marriage for leprosy-affected individuals and also on the marriage prospects of relatives (courtesy stigma). The data revealed mixed experiences of marriage.

#### **Support**

Despite evidence of a number of failed marriages as a result of leprosy, an equal number of cases of support (includes emotional and financial support) were seen. Notably, the support females received was mostly from relatives rather than their husbands. A woman’s father, mother, uncle or siblings were more likely to defend her against criticism (Female 8), take her food when excluded from the family (Female 5, Male 9), or accompany her on hospital visits (Female 18), than her husband. There were two examples of support from husbands; in one case a husband was supportive initially, but eventually left (Female 5). In another case a husband was supportive, but he too was leprosy-affected (Female, 8). Unwavering support from wives to their husbands was much more evident (Male 7, Male 13, Male 17, Female 19). Often, this full support was in spite of pressure from family and community members to leave their leprosy-affected spouse. Conformity and acceptance of gender roles in Maithili culture, is one explanation for why women appear less likely to leave their leprosy-affected husbands, than men are to leave their leprosy-affected wives.

#### **Marriage Failure**

As other studies have indicated or speculated (2,3,4,5), it was found that leprosy is detrimental to marriages, both existing marriages and for the marriage prospects of unmarried individuals. The arranged marriage of one participant was cancelled when his future in-laws found out he had leprosy, despite his completion of treatment:

“All arrangements for my marriage had been done in the village where I used to work. Then...the whole village came to know that I had leprosy. So, the marriage could not take place” (Male 3).

There were four cases of marriage failure, of which three husbands left their leprosy-affected wives and one wife left her leprosy-affected husband. This is lower than the third of leprosy-affected individuals who were deserted by spouses in previous research (12). Still, in each of the cases, the reason for the spouse leaving was the fact that their wife or husband had been diagnosed with leprosy. Again in all four cases, the separation was not immediate, but occurred after a period of a few months, following diagnosis. During this time the wife or husband was pressured to leave their leprosy-affected spouse (Female 4, Female 5, Female 16, Male 15, Female 19, also Waxler, (8) 74).

The only male participant whose wife left him, described in-depth the time when his marriage broke up (Male 15). In this case, much pressure was put upon the wife to leave her husband. His leprosy was used to justify her decision, which was further strengthened by the fact that they did not have any children. It is interesting to note, that it was not only the wife’s family but also members of his own family that were persuading her to leave him. Her parents clearly preferred their daughter to divorce rather than stay married to her leprosy-affected husband, this in a society that regards divorce as a harsh fate for a woman. The uncle of one participant forced her to stay at her husband’s house despite abuse causing her “mental problems” (Female 5). But for the uncle this “...was not so big problem for him as divorce” (Female 5).

In addition to family pressure, wounds were often the cause of marital tensions. One participant believed that her husband left her because of her disease, but more specifically he left at a time when she had more ulcers (Female 5). Ulcers are a common visual signifier of leprosy and generate fear of the disease.

### **Secrecy**

During the time of a marriage, high levels of secrecy about leprosy, were evident. This secrecy was driven by fears of not finding a bride or groom for their children or relatives. Many of the participants said they had hidden leprosy when they married, or when arranging the marriage of a family member (Female 8, Female 4, Male 13, Female 18). One man

talked about his sister's marriage and the precautions taken by his leprosy-affected father to conceal his disease:

“On the day when my sister was married my father stayed on the farm. Came back in the night, ate, slept and when he woke up in the morning, he again went to the field. This is the secret why they didn't know” (Male 6).

In the arrangement of her son's marriage one woman did not disclose her and her husband's leprosy to the bride's family, as she believed that, “if we disclosed the truth we were afraid he would have to stay unmarried” (Female 8). Concerning her granddaughter's marriage prospects, she feels there should not be a problem “...if they [prospective grooms] are ignorant of our having disease” (Female 8), which is possible, as they have no visual signs of leprosy.

Again, the prevalence of visual signs of leprosy is important, this time in affecting the opinion of prospective partners in arranged marriages. One study showed that 85% of women left home to prevent courtesy stigma affecting their daughters' chances of marriage (13).

### **Culture, marriage and gender relations**

It is clear that in Maithili and Nepali culture, it is undesirable to marry someone who has been or is affected by leprosy. The gender implications of these findings are significant, especially in terms of marital relations. The dependence of a wife upon her husband is demonstrated in the case of a woman whose husband left her when he found out she had leprosy. She returned and stayed at her parent's house for the following ten years. She then decided that it was her husband's duty to care for her, so asked him to take her back despite him having remarried. She now lives as a house-worker with her husband, his second wife, their children and in-laws. She wants to stay with him because she wants him to take care of her (Female 18). This woman realises her dependence on her husband and her status within society as a single woman, so would rather endure the verbal and physical abuse (Female 18) of her current situation than return as a disgrace to her parents' house. Other women expressed the difficulties faced by leprosy-affected women in marriage:

“Female will be faced more difficulties than male. Because feeling of male and female is not equal. Male is more selfish than female, they think that if wife will get leprosy

then he could be get another wife easily, but female can not get another husband easily. Yes male can earn and there is much option for them but for female after marriage there is no other choice” (Female 13).

This illustrates the culturally acceptable marriage options for men and women and highlights the cultural restrictions women face in earning income and being dependent. Both these points indicate firstly, that it is unacceptable for a woman to leave her husband (for any reason), and secondly, that even if she does, she is likely to face many restrictions, whereas remarriage is not an issue for men.

Maithili culture permits men to remarry easily, yet as discussed, divorce for a woman is highly undesirable, degrading her status in society. So when leprosy is the reason for divorce, this places her in an even more vulnerable position (14). Remarriage for a female leprosy-affected divorcee is difficult. When asked if she thought she would remarry, one woman thought she would have problems in remarrying because she would not be accepted: “Even if I like someone he will not accept me because I am a leprosy-affected person” (Female 19).

One young girl remarried only months after her first husband left her, as she felt that she might not get a chance to marry again. Her second husband is also leprosy-affected (Female 5). Another young man felt:

“I think I will not be able to find a girl without leprosy, because they will doubt if I could be able to support her, but I am hopeful I will get a girl who had been leprosy affected. And if we have good understanding, we can lead good life” (Male 1).

### **Courtesy stigma and marriage**

The transfer of stigma to those associated with a stigmatised individual, labelled, ‘courtesy stigma’ (6), was most often found to affect the families of leprosy-affected individuals (Male 1, Male 13, Male 15, Female 16). Threats against the safety of a family were used in three cases to force the family to expel the leprosy-affected individual from the village:

“Then my villagers forced to my uncle, they said “Your nephew have leprosy, so what will you do either you kick him out or you have to leave this village. That time my uncle

requested me that I should leave this village otherwise he will be in trouble, so my uncle also afraid about it” (Male 13).

Courtesy stigma was also found (in five cases) to be detrimental for the prospects of marriage of unmarried family members as also suggested by Vlassoff (13). One woman believes as well as causing the end of her own marriage, her leprosy will affect her siblings’ prospects of marriage. She also explains the actions, which are proposed to avoid any problems for the weddings.

“They also said that if I remain with their family no one would come to marry them, if I am around, no body will be ready to offer his son or daughter to my sisters and brother. I had been to my parents’ home a short while ago. During that time negotiation for the marriage of my younger sister was in progress. The family members were discussing over the problem as to what to be done with me, because if I am there, it could create some problem in the marriage. So, I should be kept in Lalgadh during the marriage so that the groom side will not know about me. They will not invite me to attend the marriage. They’d say that I am married somewhere and because of some problem, I couldn’t attend the marriage. My parents think that there will be some problem if they called me.” (Female 19).

Courtesy stigma is also causing secrecy about leprosy to protect the future of family members. No evidence was found of courtesy stigma leading to the break up of a marriage, but it was found to have prevented marriages from being arranged. When one couple was searching for a bride for their son, many proposals were offered, but nothing ever materialised (Female 8), as the community had told the prospective families that she and her husband were leprosy-affected. Another participant was told to leave the village “...because it might cause problem in the marriage of [his] brothers and sisters. It hurt me so I left” (Male 3). Evidently, pressure is placed on both the affected individual and his/her family.

From her experience this non leprosy-affected person believes that in marriage, women face more courtesy stigma than men:

“If boy is from leprosy colony (In this context the boys and girls are not leprosy-affected themselves, but live with their families at the leprosy colony) and he is educated

then he can marry with non leprosy colony girls and girls may not think about his background, she will accept it. If girl is from leprosy colony and wants to marry with non-leprosy colony person he will see her background, whether she is educated, good status, anything. I have seen lots of leprosy colony boys have married with non-leprosy colony girls and having a peaceful life, but I have seen many didi's [older sisters] marry non-leprosy colony guys, and when they found out they are from leprosy colony they left them. And also many girls got hatred from the husband's family" (Female 2).

It was also found that men are more able than women to gain social standing, to challenge the negative perceptions of courtesy stigma due to their leprosy-affected family, through educational and economic progress. This research found evidence that leprosy-affected males are more able to retain some respect, whereas women's status is degraded.

### **Dowry**

Dowry, a gift to the bridegroom's family before the first wedding ceremony, was discussed by two participants; both felt that generally, leprosy-affected males should not expect a dowry. One male said that he did not expect to receive a dowry because he is affected by leprosy (Male 1).

From a female perspective, one participant believed that if a girl is leprosy affected then a larger dowry will be requested for her marriage:

"In Terai if you are from leprosy-affected family marriage won't happen and if they get married then lots of dowry will be asked for" (Female 2).

These examples reflect the lower status of a leprosy-affected individual in marriage. Families that accept a leprosy-affected person into their family expect compensation for doing so, either through larger dowries from leprosy-affected girls, or by not paying dowry to leprosy-affected grooms.

### **Summary**

Cultural attitudes to marriage are central to the findings and that the traditional marital customs for men and women are strongly adhered to. It was evident that leprosy is more detrimental for married women than married men and the chances of remarriage for divorced leprosy-affected women are poorer in comparison with leprosy-affected men.

Leprosy adds another dimension to the marital position of individuals, both male and female. Underlying this, is a strong reflection of women's position in Maithili culture and how their status as an individual in society, a housewife and mother is degraded when she is also leprosy-affected. This in turn increases women's vulnerability to abuse and divorce (also proven for disabled women (14)).

These cultural and stigma based gender perceptions define the standards for males and females in the selection of marriage partners and automatically exclude certain families for consideration of an arranged marriage. The perceptions of the causes of leprosy also have implications for courtesy stigma and marriage. For instance, parents are unlikely to choose a bride or groom from a leprosy-affected family, if they believe that sins or bad spirits cause leprosy. Especially so, if as one family believed when a girl "...bears a child, even that child will have this disease" (Female 19), leprosy-affected brides will clearly be avoided.

Courtesy stigma was seen to cause tension between existing married couples and their families. Furthermore, the high level of secrecy about leprosy during the arrangement of marriages conceals the true extent of courtesy stigma. The existence of secrecy is a clear indicator of people's fears of courtesy stigma affecting their families' prospects of marriage.

## **ATTITUDES AND EXPECTATIONS**

One recurring theme was the attitude and expectations of individuals. Though not directly applicable to the research objectives, through the data it became apparent that the individual's personal attitude towards their own situation and towards other people, influences their well-being and response to their disease. The specific context of an individual's perspective affects how each person processes and deals with knowledge and in this instance, the stigmatised behaviour they encounter. There were two distinct aspects: the ways in which a community stigmatises leprosy-affected individuals; and how stigmatised each individual feels in that situation.

Through recognition of individual attitudes affecting stigma, a distinction can be made between internal and external stigma. External stigma is expressed by society towards leprosy-affected individuals, which has comprised the majority of discussion on stigma in this study. Internal stigma occurs when an individual who is leprosy-affected or associated with a leprosy-

affected person feels stigma about their own disease or disability and therefore effectively stigma towards themselves. Internal stigma may be a result of inaccurate beliefs about the disease, or as a result of degradation by others.

### **Positive Attitude**

A number of participants had positive attitudes, two men specifically, through their commitment to combating stigma and helping others, one through the self-help group he is a part of (Male 13) and the other through self-confidence (Male 9):

It is apparent therefore, that an individual's feelings about the stigmatised behaviour they face and how they deal with it, is as much about their personal attitude towards leprosy and themselves (internal stigma), as how society perceives and acts towards that individual (external stigma). Both members of a young married couple had positive attitudes and high expectations for their future, in finding work and building their own home (Male 3, Female 5). The wife felt they must forget the past (Female 5) and prove to everyone that they can make it, despite all they have been through (Female 5).

### **Internal Stigma**

In four cases, internal stigma was evident and they all claimed they had experienced no external stigma (Female 11, Female 14). Yet still they made a conscious effort not to be around people (Male 7, Female 11, Female 14), because they felt uncomfortable interacting with others in the village who knew about their leprosy.

Understandably, constant experiences of negative behaviour and degradation may lower self-esteem. There were three cases of very low levels of self-esteem. One woman had a very low opinion of herself claiming: "I am not capable of doing anything", "Do you think I am worth doing something?" (Female 8). Another woman felt inferior because her deformed feet prevented her from working and hence removed her independence (Female 18). Again, the culturally defined male and female roles are exacerbated with the added dimension of leprosy. It also illustrates that within such a strict patriarchal society, women are more vulnerable to exclusion, self-stigmatisation and lower self-esteem than men, especially when leprosy is an additional source of internal stigma (16,17).

### **Summary**

Internal stigma affects how individuals cope with external stigma, but it should also be recognised that external stigma can influence internal stigma.

The relationship between internal stigma, external stigma and the attitude of the individual is set in the context of the personal experiences and beliefs of each individual. This relationship lies at the centre of understanding how attitude and self-esteem play a crucial role in addressing stigma. An individual's positive and confident attitude towards their leprosy – as in the previous examples - can defy the actions of others, help to re-educate society about the disease, and reduce the stigma felt by that individual. This is an idealistic perspective and understandably, the poverty, reality and hardships of everyday life that so many people face, apart from leprosy, prevent or inhibit the ability to do this.

### **CONCLUSION**

The stigma of leprosy remains an ingrained element of society, with family and community based stigma excluding individuals from activities and interaction. There are clear gender divisions in these restrictions which conform to traditional gender roles of Maithili culture. Such strict traditions were also influential over marriage and the impact of the stigma of leprosy on individuals and their families. Leprosy has a detrimental effect on some affected married individuals, while equal levels of support were also revealed.

Courtesy stigma was significantly concealed due to the secrecy surrounding leprosy at the time of a marriage. The fear of courtesy stigma, demonstrated through secrecy, indicates the considerable extent of the problem.

The attitudes of individuals, their experiences and current situation were found to be a significant element of how they cope with any stigma they face. This was an unanticipated result that emerged from the data and it would be interesting and valuable for further research to be conducted in this particular area.

A gender-aware approach is essential for the consideration of the problems specifically suffered by leprosy-affected women and men, in understanding how local culture can influence local perceptions and attitudes and therefore an individual's experiences of leprosy. Furthermore, such a gender-aware approach is vital to enable a full understanding of how

leprosy affects marriage for women more frequently and more seriously than for men, in recognition of the cultural context these experiences occur in.

Throughout all areas of analysis visual signs were found to be significant in causing stigma, especially in affecting prospects of marriage. This demonstrates a need for an emphasis on the prevention and reduction of deformity, as a part of a holistic approach to leprosy and stigma elimination.

\*C/o School of Development Studies  
University of East Anglia  
Norwich, NR4 7TJ, UK

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**THE EFFECTS OF THE STIGMA OF LEPROSY ON THE INCOME  
GENERATION OF LEPROSY AFFECTED PEOPLE IN THE  
TERAI AREA OF SOUTH EAST NEPAL**

J. H. Calcraft\*

**ABSTRACT**

*This study explores the effect of stigma on the income generation of people affected by leprosy in the southeast Terai area of Nepal. Semi-structured interviews were conducted to explore experiences of stigma and the impact on income generation. Results showed a negative effect on income generation – with employment being lost as a direct result of stigma in several cases. The negative physical effects of the disease were for many the main reason for lost income, or employment.*

**INTRODUCTION**

Leprosy has affected people for thousands of years. It was, and often still is, seen as a contagious, mutilating disease. Today, leprosy can be clinically cured relatively easily, yet the effects that it has on a patient's life can carry on indefinitely. It is a stigmatising condition, and can lead to the person affected being rejected and excluded from society (1). Other examples of social exclusion are available in literature (2,3,4,5). Stigma itself is a complex issue with the capacity to affect all facets of life of a person affected by leprosy. This study has focused primarily on the impact of stigma on income generation. This is an important issue, as a person's sense of self-worth, and how others perceive them, is interwoven with their income level and employment status. Income generation covers employment type and ability to secure employment. The type of employment that a person has, is linked to their status, and well-being.

**NEPAL**

Nepal is one of the world's poorest and least developed countries, with a Gross Domestic Product per capita of \$1400 (2002 estimate). Most of the population is dependent on agriculture, and 42 per cent are below the poverty line. Life expectancy at birth in 2003, was recorded as

being 59 years (men 59.36 years, women 58.63 years). Nepal is multicultural; the 1991 Census of Nepal recorded 60 caste and ethnic groups and 70 languages and dialects (CIA World Factbook website <http://factbook.wn.com/nepal> World Factbook. Accessed 13th August 2004).

Nepal is the world's only Hindu kingdom. It is a hierarchical society where caste continues to play an important part in dictating a person's position based on Hindu notions of purity and pollution. Furthermore, caste determines an individual's behaviour, obligations, and expectations (6).

The Hindu culture of maintaining purity, and avoiding pollution, is likely to have a bearing on the treatment of people affected by leprosy. This means that such people are thought to be ritually unclean, and contagious.

In a predominantly Hindu country such as Nepal the belief that deformity is a result of divine punishment, is likely to contribute to the stigma experienced by people affected by leprosy. It is perhaps doubtful whether leprosy would be associated with social stigma were it not for the distortions it causes to physical beauty (7).

### **The Maithili people**

One of the ethnic groups of Nepal is the Maithili people, found in the south-eastern Terai region of the country, in Janakpur and the surrounding area. About 10.8 per cent of Nepal's population are Maithili, making them the second largest group in Nepal.

The Maithili are predominantly Hindu, with the remainder made up of Muslims and Christians. The Maithili as a people are known for their religious devotion and are traditional in terms of cultural behaviour. Most Maithili live in isolated rural regions; this isolation has sheltered the majority of the Maithili from the 'modernising' influences of the towns and cities.

Maithili culture is male dominated. Females are restricted in what they can and cannot do. When it comes to income generation, the norm of society is for a woman to remain in the house once married and carry out the housework, paid employment is not common for women. Lower caste women will work in the fields, but this is the exception rather than the rule. This will have a direct influence on the issues involved in this study, because there is no effect on income generation for women who do not have paid work to begin with.

## **Leprosy in Nepal**

Nepal is one of ten remaining countries that have a leprosy prevalence rate greater than 1 per 10 000 population, and at the end of 2003 was ranked fifth in terms of leprosy prevalence rates in the world (8). According to an annual report of the Leprosy Elimination Programme (Nepal) for 2002/2003, the prevalence rate of leprosy was 3.04 per 10 000 population in 2002/2003.

The Maithili as mentioned inhabit the Terai area of South-east Nepal. The Terai is a relatively flat strip of land in southern Nepal which borders India. According to a report of internal leprosy elimination monitoring and evaluation in Nepal, of July-August 2003 (9), more than 80 per cent of leprosy cases in Nepal, and of annual case detection, is contributed to, by 20 endemic districts of the Terai region. This makes the Maithili people an obvious choice for a study of leprosy related matters. This study was undertaken in collaboration with the Nepal Leprosy Trust.

The Nepal Leprosy Trust was founded in 1972, with the purpose of improving the lifestyle of people affected by leprosy and other marginalised people. The Nepal Leprosy Trust is registered as a non-governmental organisation (NGO) in Nepal, and as a Charity in England. The Trust aims to provide medical, social and economic benefits by providing employment and support.

The Trust runs the Lalgadh Leprosy Services Centre (LLSC) in the Southeast Terai near Janakpur. It is here that the data collection took place. The major principle in all of the Trust's activities is to reduce the stigma that wrongfully and unjustly surrounds leprosy. The aim is to promote the full participation in society of all those affected, including family members.

## **Leprosy**

Leprosy (or Hansen's disease) is caused by *Mycobacterium leprae* (*M.leprae*). It is a disease affecting the skin, (where the signs of infection are often first discovered) and other organs, but the involvement of the bacillus in the peripheral nervous system causes the most serious damage to the patient. Leprosy is the only bacterial disease to be characterised by the invasion of peripheral nerves. This invasion and subsequent damage leads to peripheral neuropathy if treatment is delayed (10).

According to Robinson (11), leprosy can be explained in terms of disease (biomedical perception), illness (self-perception) or sickness (social perception). Health workers tell affected persons that they have the disease leprosy according to physical symptoms. The illness leprosy is experienced by the person, and is shaped by cultural and social influences. The sickness leprosy is the problem as perceived and named by society, and it is this that reflects social stigma.

### **STIGMA**

As stated previously, leprosy as a disease has wide reaching impacts beyond the medical impact, most notably stigma. Goffman (12) has provided the most widely accepted definition and description of stigma. According to Goffman, the term 'Stigma' originated with the ancient Greeks. Stigma referred to bodily signs designed to expose something unusual or bad about the moral status of the signifier. The Stigmas were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor – a blemished person, ritually polluted, to be avoided, especially in public places. Today, the term is applied more to the disgrace itself than to the bodily evidence of it.

The term stigma will be used in this study to refer to an attribute that is deeply discrediting. Stigma has a double perspective: does the stigmatised individual assume that his/her differentness is known about already, or is evident on the spot, or does he/she assume it is neither known about by those present, or immediately perceivable by them? In the first case one deals with the 'discredited' and in the latter, the 'discreditable'.

Goffman (12) also describes what he calls 'courtesy stigma' as being the extension of a person's stigma to people who are related through the social structure. The relationship leads the wider society to treat both individuals in some respects as one – there is an obligation to share some of the discredit of the stigmatised person.

Hetherington et al. (13) develop Goffman's ideas and point out that stigmatisation, is personally, interpersonally, and socially costly. It is a social construction that involves at least two fundamental components: firstly, the recognition of difference based on some distinguishing characteristic or 'mark', and secondly, a consequent devaluation of the person. Stigmatised individuals are regarded as flawed, compromised and somehow less than fully human.

Bainson and Van den Bourne (7) describe a set of ‘affective dimensions’ that involve the emotional reactions that individuals, groups or communities develop towards leprosy patients. These emotions include pity, anger and fear. With leprosy, it is the element of fear that is most likely to lead to stigmatisation rather than any other affective dimension.

### **Leprosy, Stigma and Income Generation**

A person’s sense of well-being and the level to which they see themselves as useful, is inextricably linked to their income generation, and ability to secure employment. For the spouse or parent, the ability to provide for dependants is linked to a sense of worth and fulfilment in their role.

There are few studies on leprosy, stigma and income generation. However, some researchers have explored the topic. Deepak et al. (14) state that, “even today, social stigmatisation is frequent so that affected persons with clear signs of chronic manifestations are often unable to work, or to marry, they become dependent for care and financial support, leading to insecurity, shame, isolation and consequent economic loss.” While Scott (15), in his study of the psychosocial needs of leprosy patients in South Africa, discovered that all of the subjects were afraid of losing their work, and 17 out of 30 did not mention the name of their disease to their employers. Kaur and Van Brakel (16), in their study of leprosy affected beggars in India, point out that they have found that the combination of leprosy, physical impairments and social stigma leads to ‘dehabilitation’ of the leprosy affected person, which ends with the person becoming a beggar. Dehabilitation in this context, is defined as loss of former place in society or social role, causing loss of dignity, job and/or position leading to physical displacement. Nicholls and Smith (17) comment on the experience of people affected by leprosy, in their set of operational principles for rehabilitation of people affected by leprosy – pointing out that many such people live in extreme poverty and have few opportunities to earn an income. They may be excluded from their former work place or denied access to their former market. They go on to state that the physical impact of leprosy may make it impossible to continue in their former occupation. This is a point that is extremely relevant, it is not simply a matter of stigma being the sole cause of income loss, there are complicating factors involved.

In a study on community behaviour in eastern Nepal towards leprosy affected people, de Stigter et al. (18) show that persons affected by leprosy tried to hide their disease out of fear

for negative community behaviour (stigma). They state that ‘persons affected by leprosy experience exclusion from social life...they have difficulties in gaining employment or they are refused jobs. In general, persons affected by leprosy experience unsympathetic reactions, insults, hate, abandonment or rejection...’ They go on to indicate that the motive for such negative community behaviour is a “fear of infection by germs”, as well as “fear of a curse of God”.

### **METHODOLOGY**

This research was conducted from May to July 2004, at the Lalgadh Leprosy Services Centre, near Janakpur in the Dhanusha District of the Southeast Terai of Nepal.

Semi-structured interviews were conducted with leprosy affected people in Nepal. Nineteen interviews were conducted, nine with men, and ten with women.

The aim was to be illustrative of leprosy affected people, rather than representative of the wider population. Four of the interviews took place at the hospital and fifteen were held either at the meeting locations of the Lalgadh Leprosy Services Centre self-help groups, or in participants’ homes. Interviewees were selected both on the recommendation of Trust staff as well as randomly. The candidates recommended by staff were purposely selected on the basis of their known experiences, in relation to the research. The randomly selected candidates were members of self-help groups, and were therefore not fully ‘random’. However, no information was known about them in advance by the interviewers, unlike the purposely selected candidates.

Given time and resource constraints and the constant threat of imposed strikes by the Maoists, this combination of purposive and random selection was considered to be the most appropriate for the study.

The basic criteria for selection of purposive and randomly selected candidates were:

- Gender,
- Leprosy affected person, or a family member/close friend of a leprosy-affected person.

The interview location (either the candidate’s home village, or on the hospital compound) was not considered relevant to selection.

Prior to the commencement of interviewing, a general interview framework was created – giving a pattern of question themes and areas, to help guide the interview. This framework was reviewed after a number of interviews had been completed and amended, on the basis of that experience.

Due to the difference in language (both Nepali and Maithili are spoken in the area), translators were used for the interviews. Translators were briefed prior to interviewing on appropriate techniques and styles of questioning that were acceptable (i.e. not asking leading, or closed questions, and allowing the participant to speak – not answering for them etc.).

The author undertook the interviews with men (with a male translator), while a female colleague talked to the women with the support of a female translator. The women especially are very reserved around men; so all interviews were undertaken according to a strict gender division.

To aid the translation process, all of the interviews were recorded, with the participant's permission. The transcription and translation of the interview recordings was undertaken by Trust staff and the research team.

For analysis of the data, a simple indexing system was applied to the text of each interview, to allow for easy referencing. Once a significant number of transcripts had been completed and preliminary analysis had been undertaken, common themes were identified and noted.

It was essential for the researchers to recognise their ethical obligation to prevent any harm to the participants, especially as the topics of research are of a sensitive nature. Consent to take part, was gained from all participants. All participants were assured of their anonymity and were free to withdraw from participation at any time. Data protection was of vital importance whilst in Nepal and all data were kept securely, both at the accommodation and whilst out in the field. All translators were briefed on the importance of confidentiality of the interviews they undertook and the texts they dealt with.

## **FINDINGS AND DISCUSSION**

### **Stigma and income loss**

In a developing world context, as found in Nepal, the loss of income is a very serious matter, given the lack of formal safety nets, and the likelihood that relatives and friends may have limited resources themselves, and therefore, may be unable to provide assistance.

Interviews highlighted several incidences of income loss of leprosy-affected people, due to stigma. This was not clear-cut for all cases, as, frequently there are complicating factors involved, most commonly a physical effect of leprosy diminishes income generating capacity, which then works alongside stigma. The interview excerpts are referenced in the following manner: (Male 1) indicates that the quote is taken from interviewee number one, who was male.

The first interview was conducted with a 35–40 year old male from Dharan in Eastern Nepal. He had worked in a restaurant – preparing food and doing other general work (Male 1). He recalled the following situation when he was diagnosed as having leprosy:

... no one was ready to give me work. They all hated me and the restaurant where I was working sacked me telling that I had leprosy and this could be transmitted to others if he stays here. I was in complete destitution, without food, water and shelter. No body allowed me to stay at their place. I had to beg alms for food in Dharan...  
(Male 1)

Begging is an all too common result of leprosy – as pointed out by Kaur and Van Brakel (19).

When asked if the reason for his leaving the restaurant was solely his leprosy he responded:

Yes, this was the only reason, when the customers saw me with leprosy, they stopped coming to the restaurant and the business was almost a flop. So, I was sacked. (Male 1)

This man had been employed for two years in his position, and claimed to have been enjoying the work. To be fired for having leprosy is sadly not an isolated occurrence.

Another case of stigma related income loss is found in interview 15. This was with a 40 year old man whose employment, in his own words, had been:

every work like labour, farming, ploughing, digging and any other farming or labour work. I was able to do any work. (Male 15)

This man developed visible signs of leprosy – wounds on his hands and feet, and as a result of this he was unable to get work. His income suffered as a result of the stigma of both his potential employers and colleagues.

Interviewer – Before this disease were they offering to work? Participant – Yes, they offered me. Interviewer – And after this disease? Participant – No, nobody asked me. (Male 15)

When after I got serious wound, usually they did not want to give me offer to work. But some times they offered me work when no other labourers were available there. (Male 15)

Because there were wounds in my hand and foot they usually told me that I had to work separately, not with them. Other labourers usually told that if I went to anywhere for work they did not want to go there for work (Male 15)

This man obviously felt that he was still physically able to carry out the work, in fact the interview provided background information that shows his physical fitness levels:

I used to play wrestling in my village on any carnival. Some times I taught many boys of my villagers. Still some are very good wrestlers... (Male 15)

A similar case is found with interviewee 17. He was a 35-year-old male who prior to leprosy had been employed to weigh logs and do other work. His situation changed with the onset of the disease, and the associated stigma:

In the beginning I was not accepted to work with other labourers. So, I couldn't earn at that time. I had to take a loan to meet day-to-day expenditures. [...] It was the disease. Because people wouldn't like to work with me, I had less job opportunity. (Male 17).

The subject again has suffered a decrease in his income generation, through the loss of work due to stigma. He claims to be physically able to work:

I don't feel any difficulty in doing work. I soak and scrub my hands and feet every day to remove dead skin and after that I apply oil, and that keeps me fit (Male 17).

But the man does make reference to some negative effects of the medicine taken:

... My work efficiency has considerably deteriorated after this disease. The medicine creates weakness in the months of summer (Male 17).

Another clear example of stigma affecting income generation is found in interview 13. This was with a 65-year-old male, who is currently acting as a facilitator of a self-help group. The participant was previously employed in agriculture. He was required to work on a farm due to an unpaid loan of his fathers:

My father had died when I was a small boy, I survived in my mother's sister's house and I had to pay some loan which was borrowed by my father, to pay that loan I became a servant of the lender. In that period he did not give me any salary, just food (Male 13).

With the onset of leprosy and the appearance of the visible signs of the disease, this man encountered stigma leading to a loss of income generation:

After I developed the wound my owner refused to give me that work, so I lost my job (Male 13).

Interviewer – Ok in that period you lost your job, after that were you able to do work?

Participant – Yes I was able (Male13).

The interview also revealed that the participant developed physical problems inhibiting his income generation at a later date. However, this was after the original stigma related income loss.

### **Income loss due to physical effects of leprosy**

From the interview process, it is clear that the main source of lost income generation is the debilitating physical effects of leprosy. In the majority of cases, there is a physical problem of some degree, even when there is a clear-cut stigma related income loss, there is often a physical problem which also troubles the person.

For some people, the physical effects of leprosy prevent the continuance of physically based employment, which is the main type of employment found amongst the rural population in which the study was carried out.

My dad is unable to work because he has deformity in one hand and one foot ... (Female 2).

We stopped our business for some time, when we got this disease ... Because we were weak. We didn't have power to work (Female 8).

Although we are labourers, due to our physical problem we are not able to work and are sometimes suffering without food for many days (Female 12).

Before that even before I was married, I used to do all kinds of work, household and working in the field. Then I got a wound and then I stopped working (Female 18).

For other people affected by leprosy, the physical effects are less inhibiting of their work activities, and will simply restrict the amount or type of work that they can carry out. The following examples highlight this point...

At that time I was physically normal and strong, but now the disease has affected my hands. I cannot hold things properly with my hands. I can do only easy work now. People have no sympathy with me. No one offers me any job. The previous life was undoubtedly better (Male 1).

The effect of this disease on me is that it made me weak. I can't do work in my full capacity. I don't get appropriate diet. Since there is ulcer in my feet, I am unable to work in the field (Male 9).

I was making more income when I did not have leprosy, but after this disease I became weak and my income was poor. Now I am doing business, which is not physically hard to me, so now it is easy and more beneficial for me. Because it is not necessary for me to go in sunlight or field, it can be done in a room (Female 14).

The issues surrounding leprosy are grounded in the attitudes and emotional reactions of both, the people affected by leprosy and the people with whom he or she comes into contact. The loss of income generation is one part of the overall leprosy related stigma issue, and is itself governed by the attitude of the employer. In the majority of cases, a lack of knowledge and understanding of the facts about leprosy, leads to the assumption that leprosy will be easily caught by anyone coming into contact with an affected person. In the work place this is obviously going to be a highly unwelcome problem, leading to the stigmatisation of the leprosy affected employee – colleagues refuse to work with the person, customers may refuse to be served, or will stop business altogether. This is all amplified by the appearance of visible deformity.

Fear is the route of stigma – fear of exposure to the disease, fear of being infected, and fear of association with a person affected by leprosy and of courtesy stigma. This was highlighted

in the interviews through the attitudes described by the interviewees - of the person with leprosy, of their family and of the community. For example:

When they found out that I have leprosy, the immediate reaction was, they stopped me from entering into the house and they wanted me to stay away from the family. They thought if I am around, I can transmit the disease to them (Male 1).

They became anxious to see the wound. They said that this disease would infect them. Seeing the wound they started to hate me (Female 5).

His son had told him many times in the past – why are you going to Lalgadh? You’ll be found out. The son made him not go for treatment because of fear of stigma. He thinks that he would be in better condition if he had gone for treatment then (Male 10).

The attitudes and emotions of the person affected by leprosy who experienced stigma at home, in the community and in the work place, show some variation, but to generalise, there is an overriding sense of disappointment, anger and sadness at the actions of their former colleagues/employers, and of family and community members.

Towards the general leprosy stigma experience, there is again a mix of emotions and attitudes coming through in the interviews. Some people seem to accept their condition, and are confident in their ability to convince people of their ‘cured’ status – their personality and character cause them to become indignant at the thought of stigma – they’re cured so why should there be any stigma?

Others are less confident/optimistic and are greatly troubled by the anticipated stigma problems that will be experienced/ have already been encountered. The extreme examples of this condition are seen in the few cases of ‘self-stigma’, identified in the study.

The male biased nature of Nepali and more relevantly of the Maithili people, has a bearing on the situation of leprosy affected individuals. As described previously, it is the norm for women to not have paid employment, but to work in the home. The effects of stigma on the income generation of women with leprosy is minimal, as there is no income generation to begin with, however, stigma may prevent them from doing their unpaid work, and may lead to divorce or mistreatment by the spouse or family.

Age, education level, ethnicity, caste, religion, level of visible deformity (Judged according to WHO grading: Grade 0 = No anaesthesia, no visible deformity or damage; Grade 1 = Anaesthesia but no visible deformity or damage; Grade 2 = Visible deformity or damage present) (20) - these factors all have bearing on the income generation of the person with leprosy. The age of the interview participant may limit the opportunities that they would normally have for employment – the very young and the very old have limited earning ability, therefore, the occurrence of leprosy will have a limited impact on their short-term income generation. The poorly educated have less opportunity in the work environment than they otherwise would have – they are limited in the type of work that they can do, and therefore, the income that they can generate. In Nepal, ethnicity, caste and religion have an influence on the type of life that can be led – opportunities are restricted for certain castes. The level of visible deformity, as mentioned previously, will also play a large role in the life of the person affected by leprosy – the more visible the leprosy, the greater the likelihood of stigma and income loss. It is therefore not just a simple matter of leprosy affected people losing income due to stigma – the background situation needs to be considered, as well as the quality of life that would have been available without leprosy, before the full impact of the disease can be determined.

## **CONCLUSION**

Today, leprosy can be clinically cured relatively easily, yet, the effects that it has on a patient's life can carry on indefinitely. It is a stigmatising condition, and can lead to the person affected being rejected and excluded from society. Stigma itself is a complex issue, with the capacity to affect all facets of a leprosy affected person's life.

The question of whether there is a decreased income due to stigma for the person affected by leprosy was addressed in each interview, and as described previously, there were several cases where stigma did indeed account for a decreased income. Although this was not true in all cases, sufficient evidence was discovered to show that this is a current problem faced by people affected by leprosy in Nepal. Where a stigma related problem was present, the consequences for the person affected by leprosy, were extremely negative.

The greater effect of leprosy on income generation was found to be from the physical effects that often come with the disease. In the majority of cases, there is a definite loss in

income, and in income generating ability of the interviewees, or of their leprosy affected family member.

There was however, no evidence from the study to suggest that courtesy stigma of families causes decreased income. In several cases, the person affected by leprosy was separated from the family, thus eliminating the possibility of courtesy stigma.

In many cases, the person is ostracised by their family (to avoid catching leprosy). This has a profound affect on the well-being of a Maithili person affected by leprosy, as, to be cut-off from one's family is unthinkable for most. For a family to be willing to act in this way towards a close relative, shows the degree to which leprosy is feared in the local culture – it overrides the importance of family ties and duties.

The general pattern of events for a person affected by leprosy in the Terai of Nepal, as determined through this study, is for the diagnosis of leprosy and subsequent disclosure about the disease to family and community, to cause stigma against the person. This is manifested in several ways – verbal abuse, ostracism from social functions, enforced isolation and separation from the family, and also in some cases, the loss of income generation and a decreased standard of living. If this particular aspect of stigma is carried through to its conclusion, then the person may be forced into destitution.

In many cases, going forward for treatment is left too late to avoid deformity. This is due to either a lack of knowledge of the symptoms of leprosy (i.e. the person does not recognise that they could have leprosy), or through fear of stigma. Once leprosy has been diagnosed, then it is only a matter of time before people find out and stigma begins. In either case if treatment is not received soon enough, deformities will develop – most commonly of the hands and feet. The act of avoiding stigma by not going forward for treatment, will eventually cause stigma to occur anyway – this is an unfortunate vicious circle.

Stigma is more evident when obvious physical deformity is present; therefore, a job is more likely to be lost due to stigma of a person with visible leprosy, than if the leprosy is invisible. The deformity that causes the stigma, often also inhibits the physical ability to work. It is therefore difficult to separate these two aspects of the problem.

It should be borne in mind, that the interviewees were expressing their personal opinions on issues, from their specific viewpoint. These opinions are subjective, and another person if

asked about the same incident, may well give a different account of events. However, it was not feasible to corroborate the data gathered, due to the restrictions of time, and paucity of other data.

Further study is required focusing on the issues raised by this research, in order to further understand the relationship between leprosy, stigma and income generation. The initial data gathered in the course of this study provides a basis for a more detailed, longer-term research. It is hoped that this study may add something to the stigma elimination efforts of groups such as the Trust. Such work is vital to the long term goal of leprosy elimination, as, until stigma is dealt with, the disease cannot be fully cured.

“The fight is not over yet. But it is winnable. There are enough men and women of goodwill who can spread the word that leprosy is curable, and that leprosy sufferers need not – must not – be shunned... Unless the message reaches every continent, every country, every village, every patient, the disease will prevail in dangerous pockets.” Kofi Annan (21).

\*48 Holland Drive, Andover  
Hampshire, SP10 4LY, UK  
e-mail: Calcraftj@aol.com

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## DO SELF-REPORTED CHANGES IN LIFE SITUATIONS HAVE A ROLE IN SCREENING FOR INDIVIDUALS AT RISK OF PARTICIPATION RESTRICTIONS?

P.G. Nicholls\*, Z. Bakirtzief\*\*, W.H. van Brakel\*\*\*, R.K. Das-Pattanayak\*\*\*\*,  
G. Norman, M.S. Raju, R.K. Mutatkar\*\*\*\*\*.

### ABSTRACT

*This research focussed on the importance of leprosy affected persons' self-reported changes in life situations as indicators of underlying change in participation status as defined by World Health Organisation's International Classification of Functioning, Disability and Health. The authors designed a one-question questionnaire to be used at the primary level to explore recent changes in participation status reported by people receiving treatment for leprosy and assessed its potential as a means to identify individuals experiencing participation restrictions. Primary level workers explored and reported change in the domains of physical status, psychological status, plus changes in relationships with family members, with friends or with community and changes in the ability to work.*

*Five centres in India participated in the study, collecting data on 197 individuals affected by leprosy. Using the Participation Scale, the authors made baseline and follow-up assessments and recorded self-reported changes at the time of follow-up. Regression analysis demonstrated that self-reported changes in physical and psychological state were predictive of changes in scores on the Participation Scale. So too, were reported changes in the ability to work. Discussion focuses on the potential for a simple screening procedure that would draw attention to individuals experiencing participation restrictions, who may be in need of counselling or rehabilitation interventions.*

### INTRODUCTION

The present paper is the third in a series of publications concerned with the impact of leprosy and resulting restrictions in social participation. The first publication in the series, describes

the development of a scale that measures participation restrictions – the Participation Scale (1). The second describes the development of a screening tool for use at the time of diagnosis to identify individuals at risk of participation restrictions (2). The present paper describes research that assesses self-reported changes as indicators for participation restrictions. The research made extensive use of the Participation Scale and demonstrates its potential as a tool for assessing the status and needs of people experiencing participation restrictions related to leprosy.

The World Health Organisation International Classification of Functioning, Disability and Health defines participation as involvement in a life situation (3). Participation restrictions may occur in any life situation across nine areas of activity and participation. In the context of leprosy, they are recognised as the outworking of the stigmatisation and self-stigmatisation with which the disease has always been associated (4).

The development of the Participation Scale provides field workers with an important tool to assess the impact of leprosy, identifying people experiencing participation restrictions that may be classified as mild, moderate, severe or extreme. It provides information that may guide decisions on the need for interventions, for example, health education, advocacy, rehabilitation or self-care. The present research arose from the suggestion that affected persons' self-reported changes may be important indicators of changes in participation that may signal the need for a more formal assessment using the P Scale, followed by appropriate counselling or rehabilitation interventions. Central to this process would be a one-question questionnaire used by clinic workers at the primary level, to elicit information about recent changes in participation status reported by the affected persons.

This approach parallels the procedures of participatory evaluation, in which the beneficiaries of rural development programmes identify financial, social and personal changes arising from development interventions (5). The approach values the people affected and is responsive to the information they provide.

The objective of the present research, was to field test a one question questionnaire and assess its value in detecting changes in participation restrictions during treatment and follow-up.

## **METHODOLOGY**

The chosen approach for the research, was to conduct baseline and follow-up interviews with persons currently receiving multi-drug therapy for leprosy and to assess the value of self-reported changes as predictors of change, in scores on the Participation Scale. Fieldwork was conducted by the team involved in the development of the Participation Scale (1).

Inclusion criteria required that participants be affected by leprosy and come from the local control area. Excluded were individuals who were newly diagnosed, or not willing to give written informed consent. Also excluded, were people finding it difficult to communicate, for example, due to a language barrier or mental impairment.

The authors made an opportunistic selection of persons attending out-patient clinics. Baseline interviews were conducted at the first visit after diagnosis and start of treatment. Follow-up interviews were conducted after at least one month. Identification and demographic information was recorded on a purpose-written form and a baseline assessment of participation status was made using the Participation Scale. These were completed in the four months up to August 2003. At the follow-up interview, patients' assessments of recent positive or negative changes resulting from leprosy, were recorded and a repeat assessment of participation restrictions was made using the Participation Scale. Follow-up interviews were completed in late 2003.

Data was entered on computer using EPI-INFO software. From the narrative reported by interviewers, data was coded reflecting relevant positive and negative changes. The authors also coded the details of physical and psychological changes and decisions to conceal the leprosy diagnosis.

For the analysis, Student's t test was used to assess changes in Participation Scale scores between baseline and follow-up and logistic regression analyses to quantify the predictive value of changes reported by patients.

To ensure adequate statistical power for significance testing, each centre in India was asked to complete 40 paired baseline and follow-up interviews. The centre in Brazil was asked to complete 100 interviews, making a total of 300 paired baseline and follow-up interviews. In the event, centres in Brazil were unable to complete fieldwork, so the results presented here

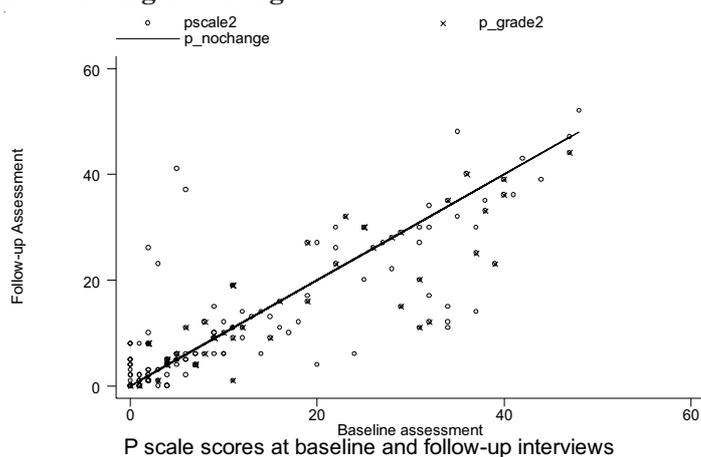
are based only on the data received from centres in India. This does result in some loss of statistical power and limits the applicability of the results.

## RESULTS

Table 1 summarises Participation Scale scores at baseline and follow-up. There were 197 complete paired assessments. At baseline, 17 individuals (8.6%) were classified as experiencing mild restrictions, 20 (10.1%) as experiencing moderate restrictions and 21 (10.7%) as experiencing severe restrictions. The equivalent figures at follow-up were 18 (9.1%), 22(11.2%) and 16 (8.1%). None of the participants experienced extreme restrictions. Figure 1 presents a scatterplot comparing baseline and follow-up scores, including a line demonstrating no change. There was no statistically significant difference between baseline and follow-up scores, though it is apparent that some individuals experienced important changes during the follow-up period.

Among participants, the WHO Grade 2 disability rate was 74%. In Figure 1, individuals with Grade 2 disability are denoted by “x” while individuals with grades 0 or 1 are denoted by “o”. Using Student’s t test, no statistically significant difference was found in P scores between WHO grades, or when comparing individuals with grade 2 disability with combined grades 1 and 0. Neither was there evidence of a statistically significant difference in change between baseline and follow-up scores within WHO grades.

**Figure 1. Comparison of baseline and follow-up scores from the Participation Scale, including a line denoting no change.**



**Table 1. Changes in participation scale scores between baseline and follow-up, including row and column percentages.**

| Baseline Assessment | Follow-up Assessment |                  |                   |                   |               |
|---------------------|----------------------|------------------|-------------------|-------------------|---------------|
|                     | None (0-12)          | Mild (13-22)     | Moderate (23-32)  | Severe (33-52)    | All           |
| None (0-12)         | 130<br>(93.5,92.2)   | 5<br>(3.6,27.8)  | 2<br>(1.4,9.1)    | 2<br>(1.4,12.5)   | 139<br>(70.6) |
| Mild (13-22)        | 6<br>(35.3,4.3)      | 6<br>(35.3,33.3) | 5<br>(29.4,22.7)  | 0<br>(0,0)        | 17<br>(8.6)   |
| Moderate (23-32)    | 3<br>(15.0,2,1)      | 5<br>(25.0,7.8)  | 11<br>(55.0,50.0) | 1<br>(5.0,6.2)    | 20<br>(10.1)  |
| Severe (33-52)      | 2<br>(9.5, 1.4)      | 2<br>(9.5,11.1)  | 4<br>(19.0,18.2)  | 13<br>(61.9,81.2) | 21<br>(10.7)  |
| All                 | 141<br>(71.6)        | 18<br>(9.1)      | 22<br>(11.2)      | 16<br>(8.1)       | 197           |

|         | Participation Scale at baseline | Participation Scale score at follow-up | Difference in scores |
|---------|---------------------------------|--|----------------------|
| Mean    | 11.11                           | 10.76                                  | -0.35                |
| Std Dev | 13.04                           | 12.35                                  | 7.00                 |
| Median  | 6                               | 6                                      | 0                    |
| Maximum | 48                              | 52                                     | 36                   |
| Minimum | 0                               | 0                                      | -23                  |

Figure 2 presents case studies of two individuals with extreme opposite experiences. The first of these, describes a man who made substantial progress in coming to terms with his disease. He gained in confidence and resumed normal work activities. He developed new hope for the future. His experience was in direct contrast to the experience of the individual

in the second case study. This man experienced continuing physical problems and consequent reduction in his ability to write, or to maintain normal economic activities. Early lack of care from the family was no longer a problem, but he retained concerns for his future physical and economic well-being. This led to self-stigmatisation and self-imposed restrictions on social activities. Both these individuals proved able to describe their experiences. The changes they described, are reflected in important changes in scores on the Participation Scale.

**Figure 2. Case studies of individuals experiencing extreme changes in levels of participation restrictions.**

**Person ID 24012 – male aged 35 years - decrease in P score of 23 points**

**Narrative:**

1. Anaesthesia is reduced, patches subsiding.
2. Now feeling happy and hopeful about recovery from the disease.
3. He is now more industrious than earlier.
4. It appeared that he has now got over the fear of the disease.

**Person ID 24022 – male, aged 50 years - increase in P score of 36 points**

**Narrative:**

1. Patches have spread and dryness increased.
2. Weakness in fingers.
3. Fears worsening of ailments.
4. Self-stigmatised.
5. Family members have become more sympathetic and show more concern for his health.
6. Swollen fingers make him unable to hold objects and write.
7. Economic activities reduced.
8. Fear of poverty.
9. Physically and mentally disturbed due to increase of ailments. This restricted the social activities.

Scores on the variables describing self-reported change are presented in Table 2. The most common reports of increased problems relate to the work situation and to the psychological state. These same variables, along with the physical state, were also most commonly reported as improving. The high levels of statistical significance between reported changes and changes

in scores on the participation scale, suggest that self-reported changes do provide valid indicators for changes in social participation as measured by the Participation Scale.

**Table 2. Self-reported change and observed changes in participation score.**

| <b>Domain</b>            | <b>Direction of change</b> | <b>N</b> | <b>Median difference in P score</b> | <b>Statistical significance</b> |
|--------------------------|----------------------------|----------|-------------------------------------|---------------------------------|
| Any psychological change | Worse                      | 27       | 0                                   | p<0.001                         |
|                          | Same                       | 150      | 0                                   |                                 |
|                          | Improved                   | 18       | -12.5                               |                                 |
| Any physical change      | Worse                      | 12       | 1                                   | p<0.001                         |
|                          | Same                       | 162      | 0                                   |                                 |
|                          | Improved                   | 23       | -10                                 |                                 |
| Any family change        | Worse                      | 6        | 7                                   | p<0.01                          |
|                          | Same                       | 186      | 0                                   |                                 |
|                          | Improved                   | 5        | -15                                 |                                 |
| Any friends change       | Worse                      | 6        | 4                                   | p<0.001                         |
|                          | Same                       | 185      | 0                                   |                                 |
|                          | Improved                   | 6        | -15.5                               |                                 |
| Any community change     | Worse                      | 8        | 2                                   | p<0.001                         |
|                          | Same                       | 178      | 0                                   |                                 |
|                          | Improved                   | 11       | -12                                 |                                 |
| Any work change          | Worse                      | 29       | 0                                   | p<0.001                         |
|                          | Same                       | 149      | 0                                   |                                 |
|                          | Improved                   | 19       | -12                                 |                                 |
| Concealed diagnosis      | Worse                      | 181      | 0                                   | n.s.                            |
|                          | Same                       | 16       | -1                                  |                                 |
|                          | Improved                   | -        | -                                   |                                 |

Finally, regression analysis was used to explore the association between responses to the change questions and change in participation score (Table 3). This draws attention to the importance of changes in physical and psychological state, as well as changes in the work situation as the primary indicators of a change in participation status. In each case, self-reported problems are associated with an increase in the participation score – that is, increased participation restriction.

**Table 3. Results of multivariate and stepwise regression procedures to quantify the predictive value of self-reported change as a predictor of change in participation scale score.**

|                      | Univariate analysis    |        |                 | Multivariate analysis  |        |                 |
|----------------------|------------------------|--------|-----------------|------------------------|--------|-----------------|
| <b>Psychological</b> | -3.50                  | p<0.01 | (-6.01 - -0.99) | -3.25                  | p<0.01 | (-5.60 - -0.90) |
| <b>Physical</b>      | -3.99                  | p<0.01 | (-6.72 - -1.27) | -4.43                  | p<0.01 | (-7.10 - -1.76) |
| <b>Family</b>        | 0.05                   | p<0.05 | (-3.88 – 3.99)  |                        |        |                 |
| <b>Friends</b>       | -0.68                  | ns     | (-5.00 – 3.64)  |                        |        |                 |
| <b>Community</b>     | -2.06                  | ns     | (-5.58 – 1.46)  |                        |        |                 |
| <b>Work</b>          | -2.13                  | ns     | (-4.83 – 0.56)  | -2.69                  | p<0.05 | (-5.29 - -0.09) |
| <b>Concealment</b>   | -2.44                  | ns     | (-5.66 – 0.79)  |                        |        |                 |
|                      | Adj R-squared = 0.3370 |        |                 | Adj R-squared = 0.3361 |        |                 |

## DISCUSSION

The intention of this research was to assess the value of self-reported change as a predictor of real changes in participation restriction as assessed, using the Participation Scale. Affected persons' self-reported experience of change do have predictive value. Specifically this is true of one's reported changes relating to one's psychological state, to one's physical state and to changes in the ability to work. This suggests that a basic screening process that recorded self-reported changes in key life areas may have value in identifying individuals at risk, or already experiencing participation restrictions. The design of the proposed tool is presented in Figure 3. Such a tool might be used in the context of health service delivery, or as part of a rehabilitation programme. It would make only limited demands on staff time and

skills. Its adoption in the field situation would require that individuals reporting negative changes receive appropriate assistance in the form of counselling, home visits or rehabilitation interventions.

**Figure 3. Proposed screening tool.**

| <b>Screening for self-reported changes in participation status</b>                 |        |
|--|--------|
| <b>Has leprosy caused any change in your life since your last/recent visit?</b>    | Yes/No |
| If any positive or negative changes, please explain:                               |        |
| <i>All responses should be followed up by the following exploratory questions:</i> |        |
| <b>Any positive or negative changes in your physical state?</b>                    | Yes/No |
| If yes, please explain:  |        |
| <b>Any positive or negative changes or impact in your family?</b>                  | Yes/No |
| If yes, please explain:  |        |
| <b>Any positive or negative change or impact among your friends?</b>               | Yes/No |
| If yes, please explain:  |        |
| <b>Any positive or negative change or impact in your community?</b>                | Yes/No |
| If yes, please explain:  |        |
| <b>Any positive or negative change or impact in your work?</b>                     | Yes/No |
| If yes, please explain:  |        |
| <b>Note changes that have occurred:</b>  |        |
| Positive changes:  |        |
| Negative changes:  |        |
| <b>Note actions to be taken:</b>   |        |
| Referral to social/rehabilitation worker for assessment                            | Yes/No |
| Provided advice  | Yes/No |
| Arranged home visit  | Yes/No |
| No current action but follow-up at next MDT visit                                  | Yes/No |

The basic design of this screening tool may be of wider application, for example, in the context of other chronic stigmatised conditions such as HIV/AIDS.

## **CONCLUSION**

The present research has confirmed the importance of self-reported changes as indicators for real changes in participation among people affected by leprosy. Self-reported psychological and physical changes have predictive value, as do reports of changes in the ability to work.

The research provides evidence that screening self-reported changes may be effective in drawing attention to individuals requiring some form of counselling or rehabilitation intervention. The screening process may be adopted in the context of other stigmatised conditions.

\*Address for correspondence  
School of Nursing and Midwifery  
University of Southampton  
Highfield, Southampton, SO17 1BJ, UK  
e-mail: p.nicholls@soton.ac.uk

\*\*Postbox 1527, SP 18041 – 970, Sorocaba  
Sao Paulo, Brazil

\*\*\*KIT Leprosy Unit, Wibautstraat 137 J  
1097DN Amsterdam, The Netherlands

\*\*\*\*The Leprosy Mission Research Resource Centre  
Shahadara, Nanda Nagari, Delhi 110095, India

\*\*\*\*\*Medical Anthropology, School of Health Sciences  
University of Pune, Pune – 41007, India

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**BRIEF REPORTS**

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**IDENTIFYING CHILDREN AT – RISK FOR SPEECH AND  
HEARING DISORDERS – A PRELIMINARY SURVEY  
REPORT FROM HYDERABAD, INDIA**

Sanjay Kumar, Joan D’Mello\*

***ABSTRACT***

*The objectives of the study were : to identify children at risk for hearing loss and speech and language problems; to train interneers in identifying children at risk in regular schools and to provide awareness to school teachers about the risk factors. The school teachers were given an orientation to use the questionnaire to elicit information on features considered as risk factors, for speech and hearing problems and other disabilities. 6591 children were screened using the questionnaire developed for the study. The results of the study show the percentage of children identified at-risk for hearing loss was 15.96%, for speech and language problems it was 1.89 % and for other disabilities it was 0.76%*

**INTRODUCTION**

The incidence / prevalence of hearing loss in school - age population is about 11.3% (1). Accurate estimates of incidence and prevalence are difficult to establish because of differences among investigators about the definitions applied, the population sampled, test methods used and way in which the data were analysed.

The National Sample Survey Organisation (NSSO), Government of India, 1991 report shows that in rural India 2.7 % are children with hearing impairment in the age group 0 to 14 years. In the same age group, the urban statistics are 3.0 % and for speech disability it is 8.9% and 8.3% of the rural and urban areas respectively (2).

The cause of the hearing loss may be due to impacted wax; ear infections; growths in the ear; noise induced hearing loss; progressive or late onset genetic hearing loss; injury; viral infections such as mumps, measles; bacterial meningitis; ototoxicity; trauma; auto immune disease (3); sudden deafness of unknown etiology.

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The practice of screening school – age children has been in existence for more than 50 years in the west. In India, school screening programmes have been conducted since 1965 as per reports available (4,5,6,7). However, hearing health has not been given due importance by a majority of the school authorities. The importance of hearing screening is to identify the children at- risk, which may hamper their scholastic performance, and to refer them for detailed investigation and intervention.

With a severe financial crunch being faced by several programmes, it is not economical to mass screen all children in the schools. It is desirable that a target population be identified using trained volunteers.

Most school screening programmes concentrate their annual screening efforts on children from nursery school - age through grade 3. Above grade 3, the screening is normally conducted at an interval of about 3 or 4 years.

As reported by Bess and Humes (8) the following groups of children require more attention than what routine screening provides –

1. Children with pre-existing hearing loss.
2. Children enrolled in special education programmes.
3. Children with multiple handicaps.
4. Children with frequent colds or ear infections.
5. Children with delayed language or defective speech.
6. Children returning to school after a serious illness.
7. Children who experience school failure that exhibits a sudden change in academic performance.
8. Children referred by the class room teacher.
9. Children who are new to school.

Screening is usually conducted using audiometry and immittance tests. With advancement in technology, the Oto Acoustic Emission (OAE) has also been a recommended method.

Recognising that hearing loss can occur at any time and can have a consequence on scholastic performance, the present study was carried out.

### **OBJECTIVES**

1. To identify children at risk for hearing loss and speech and language problems.
2. To train interneers in identifying children at risk in regular schools.
3. To provide awareness training programmes to school teachers about the risk factors.

## **METHODOLOGY**

### **Selection of the schools**

Fifty one schools across five mandals of Hyderabad district were selected for the study. These schools are special regular schools, providing opportunity for working children to continue their education. There are about 212 such schools in Hyderabad district. For the present study, the schools in the following Mandals were taken for the study - Amberpet, Khairatabad, Marredpally, Musheerabad, Secunderabad, Tirumalgiri. The total number of children studying in the schools selected for the study from classes' 1<sup>st</sup> to 4<sup>th</sup> standard was 6591.

### **MATERIAL**

A questionnaire was prepared for screening the children in the selected schools. The questionnaire consisted of nine questions, eight of which were 'close-ended' questions. Each question is a statement of a particular symptom, seen amongst children, to be identified by the teacher. The ninth question is an 'open-ended' one which deals with gathering information on any other associated problem (other than those mentioned) seen in the children.

The questionnaire was originally prepared in English and later, it was translated into the local languages. The instructions given in the questionnaire were brief, self-explanatory and unambiguous. The language of the questionnaire was tested for simplicity before its actual application. The first eight questions related to 1) Oro-facial deformity like – Atresia, Microtia, cleft lip and palate, or any abnormality of the head and neck; 2) the most common and prevalent infections of the ear (middle ear); 3) any kind of possible problem in the child's ear due to the persistent behaviour of putting objects into the ear; 4) and 5) symptoms of conductive hearing loss (loss because of the problem in the ear canal or middle ear or both) and sensory-neural hearing loss (loss because of the problem in the inner ear); 6) problems of poor attention or inability to follow instructions; 7) unilateral hearing problems, manifested by directing one ear (the better ear) towards the speaker; 8) speech problems such as misarticulations in speech, stuttering or stammering and delayed speech and language development. The last question was an open-ended question to identify any other kind of problem or disability such as mental retardation, cerebral palsy, visual disability, physical disability and others.

## RESULTS

The data were analysed using descriptive statistics, shown in the following tables.

**Table 1. Showing the type of symptoms (pointing towards hearing loss) identified Mandal-wise**

| <i>Mandals</i> | No. of Children | No. of children identified with various symptoms considered as at risk - through questions 1 - 7 |           |            |           |            |           |           | % of children at risk |
|----------------|-----------------|--|-----------|------------|-----------|------------|-----------|-----------|-----------------------|
|                |                 | No. of With Risk   | Q1        | Q2         | Q3        | Q4 & Q5    | Q6        | Q7        |                       |
| Amberpet       | 296             | 32   | 0         | 8          | 0         | 7          | 5         | 3         | 10.00%                |
| Khairatabad    | 4220            | 406  | 15        | 139        | 16        | 96         | 39        | 23        | 9.62%                 |
| Marredpally    | 500             | 60   | 6         | 9          | 5         | 16         | 7         | 3         | 12.00%                |
| Musheerabad    | 454             | 46   | 3         | 17         | 4         | 5          | 5         | 2         | 10.13%                |
| Secunderabad   | 659             | 25   | 0         | 5          | 0         | 4          | 2         | 6         | 3.79%                 |
| Tirumalgiri    | 462             | 19   | 1         | 5          | 2         | 3          | 2         | 1         | 4.11%                 |
| <b>Total</b>   | <b>6591</b>     | <b>588</b>   | <b>25</b> | <b>183</b> | <b>27</b> | <b>131</b> | <b>60</b> | <b>38</b> |                       |

Key: -

Q1. Number of children identified with oro-facial anomalies

Q2. Number of children identified with ear discharge/aches

Q3. Putting objects in the ear

Q4 & Q5. Number of children speaking with abnormally soft/loud voice

Q6. Inattentive in the class and unable to follow instruction

Q7. Directing ear towards the speaker.

The analysis of question - 8 that was targeted to identify speech and language problems was tabulated and is shown in Table 2.

**Table 2. Percentage-wise distribution of various speech and language problems**

| Type of Speech Problems | No. of Children with Problem | Percentage    |
|-------------------------|------------------------------|---------------|
| Misarticulations        | 27                           | 0.39 %        |
| Stuttering              | 60                           | 0.91 %        |
| DSL                     | 38                           | 0.57 %        |
| <b>Total</b>            | <b>125</b>                   | <b>1.89 %</b> |

**Table 3:** Percentage of children identified with other disabilities

| Types of Problems           | No. of Children with Problems | Percentage |
|-----------------------------|-------------------------------|------------|
| Other Physical Disabilities | 50                            | 0.76 %     |

**Table 4:** Percentage of children reported with ear infection

| Types of Problems      | No. of Children with Problems | Percentage |
|------------------------|-------------------------------|------------|
| Ear Discharge/Ear ache | 183                           | 2.78 %     |

## DISCUSSION

Out of 6591 children screened who were studying from class I to class IV, it was possible to segregate the at-risk children through the questionnaire used for the purpose of the survey. Though it is not possible to give details of age and gender wise distribution, the overall percentage of children with risk indicators for hearing loss was 15.96 %. In addition, 1.89 % had at-risk factors for speech and language problems, 2.78% reported ear infection, and 0.76% had other additional problems.

Literature shows that the problem of ear discharge decreases with age and it is attributed to the cephalo – caudal development of the face. This process changes the shape of the eustachian tube from a horizontal to an inclined position, thereby reducing the direct access of the infection to the middle ear, via the eustachian tube. Thus, a percentage as low as 2.78 % of children with ear infection may be seen in this study.

The school- wise distribution shows that the percentage was highest in Marredpally (12%) followed by Musheerabad, Amberpet and Khairatabad showing 10.13%, 10% and 9.62% respectively. However, it was 4.11% and 3.79% in Tirumalgiri and Secunderabad respectively. The reduction in the percentage of disability in Secunderabad may be attributed to their prompt treatment, as they may be taking advantage of the available services at Ali Yavar Jung National Institute for the Hearing Handicapped (AYJNIHH), Regional Centre which is situated at Secunderabad and the other rehabilitation centers. As cited by Bess et al (1) 11.30% of the school going population has hearing loss. In this study, 9.62% to 12.0 % of the school going children are said to be at - risk for hearing loss and 1.89 % for speech and language problems which supports the usually referred statistics that about 10% of the School going children may have some degree of hearing loss.

The school screening report (7) showed that 14.55% of the children in the age group of 10-13 years had ear problems and 50% of these children who came for a diagnostic follow-up test showed that 66% had confirmed ear problems such as impacted wax, dull tympanic membrane and upper respiratory tract infection. Thus, the present study shows that the identification of hearing problems using the questionnaire method and by training of functionaries has proved worthwhile, as the statistics are fairly comparable with the earlier school screening data.

Mild hearing loss whether conductive or sensorineural, can result in distorted or diminished speech sound perception. According to the American Academy of Audiology (9), unilateral or asymmetrical hearing loss can disrupt critical binaural auditory processing skills.

Behaviour problems have also been found in pre - school and adolescent children with conductive hearing loss. Behaviour problems such as irritability, lack of responsiveness, withdrawn behaviour have been reported (10).

A proper referral can help the hearing to be restored. It is the child's right not to be disabled at birth, or later. Prevention of impairment and disability are of primary importance (11).

As the main objective of this study was to train internees in Educational Audiology, it was possible to provide them with the experience of preparing the questionnaire, translating the material and field-testing the questionnaire for ambiguity. It provided them an opportunity to conduct a pre-survey training programme for the teachers. The training programme oriented

the teachers about hearing impairment, causes, and symptoms in particular and it also touched upon topics such as speech and language problems and additional problems too. The teachers are now aware on the subject of providing appropriate referral for the children identified as at-risk for speech and hearing problems. The survey also provided a platform for the trainees to analyse the questionnaire results and inform the school authorities of the survey results.

In India, provision of services is made difficult due to the distance and lack of adequate number of professionals to provide all the intervention needed. Thus, training of other functionaries such as school teachers may be a worthwhile effort. There is a great need for media to act as partners to disseminate material on prevention and rehabilitation.

\*Ali Yavar Jung National Institute for the Hearing Handicapped  
Southern Regional Centre, M.V. Nagar  
Secunderabad - 500 009, A.P. India  
e-mail: adsr@sisfy.com

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