

## Disabilities in leprosy - The new concepts

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The concept of disabilities has undergone changes in recent years and disability is no longer a mere physical dysfunction. It includes activity limitations, stigma, discrimination, and social participation restrictions. In addition to the presence of an illness or impairment, the understanding of disability now explores the relationship between disease / illness / impairment, the persons functioning within daily activities / social roles, and the social, cultural, and physical environments that enable or limit an individual's ability to participate fully in his or her community and daily lives. International Classification of Functioning Disability and Health (ICF) has recognized several dimensions of disability viz., body structure and function (and impairment thereof), activity (and activity restrictions) and participation (and participation restrictions). It also recognizes the role of physical and social environmental factors in affecting disability outcomes and has shifted the focus from the cause of disability to its effect, thereby emphasizing the role of the environment (physical, cultural, social, political) rather than focusing on disability as a 'medical' or 'biological' dysfunction. There is not much information available about these relationships in leprosy related disabilities. Studies are required in different patient groups having different socio-cultural background to develop a better understanding of these issues. Accordingly the need for services can be worked out for rehabilitation of the patients released from the treatment and "Cure".

### Introduction

Leprosy - related disabilities are challenge in endemic countries. A considerable portion of disability load is the result of failure to incorporate activities relating to prevention of disabilities using simple technologies and patient motivation into leprosy management. With the availability of newer drugs and new treatment regimens, leprosy patients can be completely cured in 6 to 12 months without any disabilities. Since most serious consequences of "cured" leprosy patients are caused by permanent

peripheral nerve function impairments, it is important to minimize nerve damage during its course. Prevention of impairments and disability (POID) is integral to the success of management of leprosy affected persons.

Leprosy program has also undergone several changes. From a well supported, high priority specialized program, it has now been integrated within general health and social services. Radical rethinking is necessary if we want to sustain early case detection, treatment, prevention of disability and reduction in the consequences of

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leprosy including stigma (Smith 2010). The biggest challenge lies ahead for the leprosy program managers to sustain interest and maintain services. They need to have a focused and coordinated approach to leprosy control at the primary health center level. Maintaining expertise for leprosy in health workers is another challenge since the disease is becoming relatively rarer. These issues are to be tackled appropriately.

### **Newer Concepts of Disabilities**

The concept of health and wellness has expanded and new understanding about the disabilities has been promoted in recent years. Now the disability is considered to be much more than a mere physical dysfunction and includes activity limitations, stigma, discrimination, and social participation restrictions. Disability is now conceptualized not as presence of an illness or impairment but rather as the relationship between the disease / illness / impairment, the persons functioning within daily activities / social roles, and the social, cultural, and physical environments that enable or limit an individual's ability to participate fully in his or her community and daily lives.

Several dimensions of disability are now recognized in the International Classification of Functioning, Disability and Health (ICF) viz. body structure and function (and impairment thereof), activity (and activity restrictions) and participation (and participation restrictions). This new classification also recognizes the role of physical and social environmental factors in affecting disability outcomes. The ICF has shifted the focus from the cause of disability to its effect, thereby emphasizing the role of the environment (physical, cultural, social, political) rather than focusing on disability as a 'medical' or 'biological' dysfunction (WHO 2011). The term includes mental and social disabilities as well.

### **Disability Measurement Tools**

In view of the changed and expanded understanding about disabilities newer tools are needed to measure disabilities. Simple measurement of deformity and resultant functional disabilities no longer represent detailed "Cause and effect" relationship as required. Global disability measurement tools have been developed to measure these broad concepts (van Brakel et al 2006, Melchior and Velema 2011, Kelders et al 2012). A number of generic disability tools have been recommended and tried for disability assessment in lymphatic filariasis (Lynne et al 2012). These generic tools are suggested to be necessary and appropriate measures of disability impact for LF as they have been developed and validated internationally allowing for multi-country surveys.

The leprosy - related disabilities need assessment of the extent of disability and its determinants among persons with after release from multi drug treatment. It can be argued that a leprosy specific tool would allow greater sensitivity in the assessment of outcomes, particularly for patients in chronic stages of the disease where the physical impacts are irreversible and quality of life rather than cure becomes the aim of intervention.

Several scales have been developed applied and tested in leprosy. SALSA scale (Screening of Activity Limitation and Safety Awareness) is one such scale (Nicholls et al 2005, Ebenso et al 2007). SALSA stands for Screening of Activity Limitation and Safety Awareness and it is a questionnaire that measures activity limitation in peripheral neuropathy (leprosy and diabetes). It is a cross cultural tool, comprising 20 items of daily activities, related to the three domains of mobility, self care and work. The questionnaire is administered by an interview. It is a subjective tool placing the interviewee at the center presenting how the client himself perceives his

functional level. The SALSA group at Yahoo has been established to give information and facilitate communication between people who use or want to use the SALSA as a clinical tool or in research. The SALSA Scale is available in several Indian languages.

### **The Disability Scenario in Leprosy in the New Context**

As a consequence of impairments, people affected by leprosy may experience limitations in activities of daily living (van Brakel and Anderson 1997, Tonelli et al 2012, Nardi et al 2012). To date, there is little insight into the impact of leprosy impairments on daily activities and social participation. Future projections of the global leprosy burden show that 5 million new cases would arise between 2000 and 2020, and that in 2020 there would be an estimated 1 million people with WHO grade 2 disabilities (Richardus and Habemma 2007).

There is very little data on the types of problems faced by people with leprosy - related disabilities (PLD) and the resulting needs they have for services. To what extent persons affected by leprosy also experience limitations in activities and perceive participation restrictions is not well known, as these specific issues receive only limited attention during treatment (Frederik et al 2010). Most studies have been performed in leprosy endemic countries and have focused only on impairments (Croft et al 2000, Shumin et al 2003, Richardus et al 2004).

An international, multicentre study (in Brazil, China, India, Israel and Nigeria), in which an activity limitation questionnaire was used, showed a consistent increase in activity limitations with age and increased level of impairments (Kelders et al 2012). Participation problems have been reported in leprosy endemic countries by a limited number of studies (van Brakel et al 2006, van Brakel et al 2012, Nicholls et al 2005). Major

deter-minants of participation were severity of impairment and level of education, activity and stigma (van Brakel et al 2012).

In leprosy, being a chronic disease, patients have time to adapt to the increasing impairments and limitations in activities. This adaptation may contribute to the mildness of the perceived restrictions in participation and autonomy. Probably for this reason “Phantom limb” phenomenon is not common in leprosy affected people (Malaviya 2003). The severity of participation problems consistently increases with the severity of impairments (Frederik et al 2010).

The current “Enhanced global strategy to further reduce the disease burden due to leprosy” of WHO describes the necessary elements of prevention of disabilities and rehabilitation of persons affected by leprosy. Though much progress has been made in reducing the number of leprosy patients registered for MDT globally, relatively little is known about disability after release from treatment. Therefore there is an urgent need for data on leprosy-related disability to assess the need for prevention of disabilities (POD) and rehabilitation services. Such data are also needed for program monitoring, evaluation and for advocacy (van Brakel and Officer 2008).

The development of a specific disability assessment tool, relevant to assess leprosy impact in the contexts and cultures of endemic areas, is vital for accurate reporting and measurement. The most commonly reported psychological issues - feelings of shame, humiliation, low self-esteem, and fear are not measured by any tools. Likewise, the most commonly reported environmental issues are not well measured by the tools.

### **A lot needs to be done**

A focus on morbidity management is increasingly required for leprosy related disabilities as we spend more years with elimination levels of disease. Reliable information about patient and

community needs and the measurement of outcomes of the POD and POID activities is required to ensure best management for the prevention and alleviation of leprosy related disability.

Treating and preventing disability should be an integral part of any control program and it is recommended that patient released from MDT programs should be followed up on a long term basis with regard to appearance or worsening of disabilities. Only 10% cases are deformed means only one tenth of the total cases need continued attention. In addition to early detection and provision of MDT, the process of POID has to be addressed at every level of care.

A comprehensive concept of POID needs to be developed involving all areas of leprosy control viz. early detection, MDT, nerve function assessments, identification of high risk patients, prophylaxis, treatment, reconstructive surgery and rehabilitation. POID at the initiation and during MDT call for proper recording of base line data and regular follow-up information about nerve function, detection of high risk cases and management of reactions.

A delay between presentation and diagnosis indicates the need to strengthen the training of medical professionals to facilitate early diagnosis, while a delay between diagnosis and treatment needs to be addressed by improving both patient and physician participation and co-operation (Renita et al 2010). The sensory and autonomic nerve fiber damage occurs almost simultaneously because cross-sectional damage to the nerve trunk occurs at certain levels in leprosy affected nerve trunks. If unattended, it may progress further and motor fibers are also damaged leading to muscle wasting, palsies, postural changes and contractures. The disease may leave

residual effects of nerve damage, in the form of sensory, motor and autonomic nerve paralysis, in the eyes, hands and feet. If a recent onset nerve damage remains untreated for 3 to 6 months it may become permanent.

Diagnosis of clinical borderline leprosy is relatively simple but the value of detailed records should not be undermined by presuming that six or twelve months of MDT is the answer. An initial record of disease, when patient enters the MDT program, is essential to keep track of events. The deformities and condition of the nerves should be carefully recorded so that we know how the patient is progressing. If the patient develops any reactive episodes and or painful tender nerves, he needs management preferably under supervision. Regular testing should include accurate measurement of function in the eyes, hands and feet and recording of other disabling or stigmatizing signs in face. This is more important because activity of disease in nerve persists longer and may continue to exist even after skin is free from disease.

An important indicator for timely diagnosis and treatment of leprosy patient is presence or absence of WHO grade 2 impairment (WHO 1988) at the time of diagnosis. From the POD point of view at this level, it is important that knowledge about diagnosing leprosy remains a significant part of curriculum of health workers (Brandsma 2011). Early signs and symptoms of leprosy should be known well to the community also to promote self reporting in its early stages so that cure is affected without NFI. Within the general public, the leprosy fear factor should be reduced to zero by all possible means of raising awareness. In addition, easy accessibility of health care facilities and un-interrupted free availability of drugs are also important (Brandsma 2011).

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Health education is an important component of the management scheme and key to success and it should start the day patient is put on MDT and continue thereafter even after he is released from treatment. Patient is told about the causation of injuries and ulcers and the role of sensory loss in this context is made clear. The patient should be explained the cause of anesthesia and also the methods to protect their hands and feet if affected. Simple and easy to follow instructions are important to ensure compliance. The patients must understand their physical limitations due to disease and accept that. Once this has been achieved, they can be empowered to adapt to the new situations.

Self-care is the responsibility of individual who has nerve function impairment (NFI). The health workers are expected to educate and guide patients in self-care practices. The hydro-oleo therapy and passive exercises are prescribed to keep the skin supple and mobile. Looking for injuries, redness, blisters and impending ulcers in hands and feet on daily basis is essential. If found

promptly treating them, goes a long way in preventing mutilations. The patients are taught protected use of hands and feet. They are advised to use visual feed back while using their hands for different tasks and use both hands with conscious effort. Use of tools and appliances with protective (molded) handles at home and at place of work can be suggested.

Proper counseling is done in several sittings and options are suggested. It is for the patients to decide and choose the one that suits him best under the circumstances. A constant feedback is obtained as it helps to check whether the patient understands his self-care routine and carrying it out. During visits the patient can be asked to demonstrate his self-care skills. Special checks are to be made for "think-blink" and footwear

The physician must recognize the psychology of the person who has lost sensations in their limbs. Even intelligent patients continue to use their infected finger and continue to walk on wounds destroying their feet. Many patients who feel stigmatized by disease and by their deformity retain an immense desire to perform normally in the society. They want to walk faster, do other activities with their hands rejecting protective appliances that identify them as disabled. They love to do things with their own hands and even succeed at times at the expense of injury and infection. With a low self image it is less likely for them to save their hands and feet. We have to spend some time to explain to them the physiology, pathology, mechanisms and psychology of their deformities and encourage them to believe that their limbs can be saved with some extra care.

The agencies working for leprosy continue to identify and prevent physical disability. However, there is limited motivation and financial support to develop substantial rehabilitation programs that support mental health and well-being,

minimize barriers from stigma, provide adequate intervention for chronic disabilities to prevent their further progression and assist in re-engagement with daily activities which are important for patients both physically, mentally, and socially.

#### **Need for Multidisciplinary Rehabilitation Program**

To improve daily life activities and social participation, leprosy affected persons may benefit from multi disciplinary rehabilitation treatment. Since impairments are important contributors to limitations in activities and participation restrictions, interventions such as footwear and devices to compensate for these impairments can be considered along with psychological counseling. The most important determinant for future impairment appears to be impairment status at diagnosis. This indicates a need for specific activities to prevent worsening of impairments after RFT, especially surveillance of persons at high risk, training in foot and hand care, and provision of assistive devices.

In addition to physical impairment, the stigma of leprosy has a large impact on many people's lives, affecting their physical, psychological, social and economic well-being. People with disability are often burdened with social stigma that promotes a cycle of poverty via unemployment, social discrimination and threats to mental health. Stigma has multiple causes; these should be addressed in partnership with communities and persons affected. Stigma reduction activities and socio-economic rehabilitation are urgently needed in addition to strategies to reduce the development of further disabilities after release from treatment.

To improve social participation, interventions may be needed at different levels. At the personal and physical level this would include measures

such as improving education, income and activity, addressing physical impairments and rehabilitation; and at the societal level, reduction of stigma in the community and addressing other environmental barriers.

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