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Mini Review Article

Prevention of disability in leprosy: the different levels

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Prevention of disability in people affected by leprosy is primarily seen as prevention and management of impairments secondary to nerve function impairment. This article describes four different levels at which appropriate interventions may lead to the overall prevention of disability. These are - prevention of disease, timely diagnosis and adequate treatment of the disease, early recognition and adequate treatment of nerve function impairment and finally, prevention and treatment of secondary impairments due to nerve function loss.

Key words: Leprosy , Neuropathy, Rehabilitation, Prevention of disability

Introduction

When the phrase 'Prevention of Disability' (POD) is used in relation to leprosy affected people, it usually refers to the prevention and management of secondary impairments (e.g. ulcers, contractures) which may follow the primary impairments of loss of protective sensation and muscle imbalance which are the direct result of nerve damage. In the WHO's International Classification of Functioning Disability and Health (WHO 2001), disability is a generic disablement term which covers three domains of functioning: impairments, activity limitations and participation problems. Subsequent to a disease or disorder, persons may be left with effects of the disease at the body physical level (anatomy, physiology, mental), the personal functioning level (eating, dressing etc.) and at the societal-economical level (e.g. social participation and interaction).

POD activities and publications related to POD, however, are usually concerned with prevention and treatment of primary and secondary impairments. Many studies and booklets have been published and devoted to this more 'narrow' understanding of POD (Watson 1988, Srinivasan 1993, Watson 1994, Cross 2007). The purpose of this article is to present and discuss a wider, more holistic spectrum of POD so that POD managers may expand their approach to include activities at all different levels.

Level 1: Prevention of disease - targeting the endemic areas, north, south, east, west

It is common knowledge that when socio-economic conditions improve, leprosy incidence declines (Irgens 1980, Saikawa 1981, Noordeen 1985, Alfonso et al 2005). Leprosy virtually disappeared from most European countries long

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before effective anti-mycobacterial drugs became available.

In India, most new cases of leprosy today are reported from the north Kerala; in south-west India has never had many patients with leprosy compared to the rest of the country. By socio-economic indicators, these two regions in India differ markedly. In USA, most indigenous leprosy cases have always been reported from the southern states, Louisiana, Texas, Florida (www.gov/hansens/data). The majority of leprosy patients in Turkey have always been from the east of Turkey where socio-economic conditions are generally not as good as in western/central Turkey (Saylan and Aytekin 1986). Most migrant workers to Europe in the 19-sixties and seventies came from the east of Turkey in search of a better income/living. In the 18th and 19th century, leprosy was most prevalent along the west coast of Norway where the 'lower class' fisherman were living under poor hygienic conditions (Irgens 1980). Hence, it could be hypothesised that all (inter) national non-governmental organisations, supported by government policies, whose goals include the improvement of socio-economic conditions in leprosy endemic countries, are in the battle to eliminate and eventually eradicate leprosy.

Those that have a political and/or public voice in leprosy endemic countries and have leprosy care and management as one of their main responsibilities should use all possibilities to promote measures that are known to assist in prevention of the disease: BCG vaccination, improvements in sanitation and hygiene and chemoprophylaxis of contacts of index cases and awareness raising about leprosy.

Level 2: Timely diagnosis of disease

Early diagnosis of leprosy in endemic areas depends on two important groups of people. Knowledge and awareness of the early signs and symptoms of leprosy need to be present in both the health professionals and the general public who should feel free to report without fear/ anxiety regarding the possible diagnosis of leprosy. There are three cardinal signs with variable sensitivity and specificity for the diagnosis of leprosy: hypaesthesia in a skin lesion, enlarged peripheral nerves and a positive skin smear. In most countries in which leprosy is endemic, the diagnosis and treatment of leprosy is now integrated in the general health services and diagnosis is made, often too late, on the basis of (hypaesthesia in) skin lesions only.

The important epidemiological indicator for timely diagnosis of leprosy is the presence of disability (impairment, grade 2) at the time of diagnosis. The WHO target for disability at time of diagnosis is less than 5%. A percentage of less than 5% disability at time of diagnosis would be indicative of timely diagnosis and/or early reporting. There is a vast difference in the reported percentage of disability at time of diagnosis within leprosy endemic countries (WHO 2008).

From a POD point of view at this level, it is important that in leprosy endemic countries knowledge about leprosy especially regarding diagnosis, remains a significant part of the curriculum of health professionals. Within the general public, the leprosy fear factor should be reduced to zero by all possible means of awareness raising. In addition, easy accessibility of health care facilities and un-interrupted free availability of drugs are of paramount importance.

Level 3: Early recognition and adequate treatment of nerve function impairment

Nowadays it is common practice for a nerve function assessment (NFA) to be performed at the time of diagnosis. Both voluntary muscle testing and sensory testing have been well researched in leprosy and their usefulness in clinical trials has been accepted (Brandsma 1981; van Brakel 1996, 2000; Birke et al 2000). The baseline NFA at diagnosis serves as a future reference when patients may report with signs and symptoms of a

leprosy reaction: reversal reaction or erythema nodosum leprosum (ENL). Often reactions will be accompanied by nerve function impairment. Many patients have signs and symptoms of a 'reaction' at their first presentation. Leprosy reactions may also develop after initiation of drug treatment and may even occur following formal cessation of drug treatment (Walker and Lockwood 2008). Unfortunately, many patients can also develop insidious loss of nerve function without an obvious 'reaction'. This may especially be the case on the lepromatous spectrum of the disease.

NFA should be performed at regular intervals following diagnosis and often be continued post RFT (release from treatment), depending on classification and whether nerve function impairment (NFI) was present at time of diagnosis (Croft et al 2003). The sooner NFI is detected and treated, the better the chances for nerve function recovery. Table 1 lists other factors that play a role in the reversibility of nerve function impairment. Unfortunately, many patients present with irreversible nerve damage at time of diagnosis. Others may develop 'reactions' and nerve function loss following diagnosis which may not respond to available medication. The three Ds (drugs, dose and duration) remain an important area for research for better treatment of patients to prevent or reverse nerve function impairment.

Level 4: Prevention and treatment of secondary impairments

Primary impairments are the immediate results of NFI : loss of protective sensation, loss of autonomic function (hydration, sweating) and muscle weakness/paralysis. Secondary impairments are the problems that can be attributed to the primary impairments e.g. skin cracks, ulcers and joint stiffness.

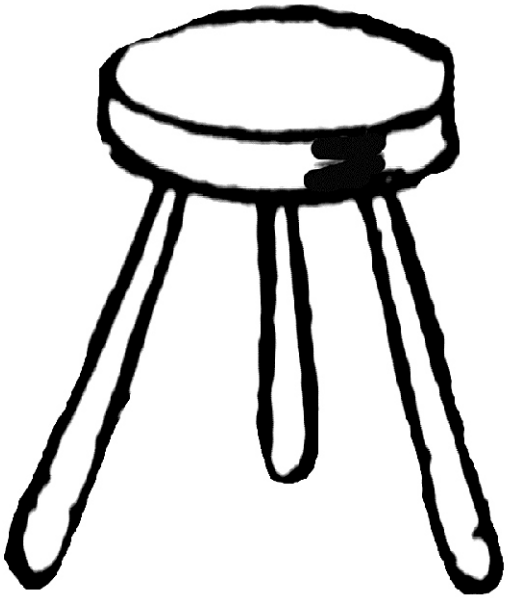
In the last 10-15 years, the focus in disability prevention/ education has been changing from 'lecturing' patients to 'empowering' leprosy affected people, as evidenced in the title and content of the recent WHO publication “I can do it myself” (Cross 2007). Self efficacy is the term that it often used in this context. Self efficacy can be defined as “… the belief in one's capacity to succeed at tasks” (http://wilderdom.com/self). With regard to wounds/ulcers, the major 4th level POD problem this means: “I can prevent and heal my own wounds/ulcers”.

People at risk of harming themselves need to become responsible for their own health, preferably guided and mentored by peers. There should be a paradigm shift from being dependent on, to increased inter/independence. The illustration of a three-legged stool (3P),

Table 1 : Factors influencing nerve function recovery

Duration of NFI (often on history/ not exactly known)
Severity and extent of NFI
Type of reaction (poorer recovery in ENL)
Severity of reaction
Classification (Ridley-Jopling)
Nerve(s) involved (e.g. better recovery in median as compared to ulnar)
Medication: drugs, doses, duration
Adherence
Gender ? Age ? Surgical release?

NFI : Nerve function impairment



Personal factors :
Personality
Religiosity/ spirituality
Values/ beliefs
Locus of health control (Wallston 2005)
Self efficacy (Sherer et al 1982) etc.

Figure 1 : Success of POD (level 4) depends on 3Ps (the three legs of the stool are needed for balance).
Pills : MDT, other drugs, etc.
Procedured : Dressings, soaking, surgery, footwear, exercises, splints etc.

common in Africa and Asia, may help (Figure 1). Two legs of the stool can be seen as pills (medicine) and procedures (other interventions) by health personnel. The stool is balanced by the third leg : personal factors. The persons at risk of further impairments and increasing activity limitations and participation restrictions, becomes his or her own health manager when guided in the right way. Patients with permanent loss of protective sensation are at life-long risk for additional and more extensive impairments.

Activity limitations and participation restrictions

As mentioned, most of the management activities related to POD are limited to prevention and management of primary and secondary impairments. In recent years, as the result of multinational and multidisciplinary meetings, two scales have been developed that are helpful to assess to what extent impairments affects common daily activities and social participation (Cross and Choudhary 2005, van Brakel et al 2006, SALSA Study Group 2007). These scales are helpful to evaluate the effect of interventions targeted at alleviating activity limitations and participation restrictions.

The SALSA-scale (screening for activity limitations and safety awareness) is a scale that assesses difficulties in the area of personal functioning e.g. writing, dressing, eating. As most activities on this scale relate to the hand, this scale would be very useful to assess the extent of impairments on hand function and to evaluate the potential benefits of corrective surgical interventions or splints that aim at enhancement of hand function. The P-scale (participation restriction) is a useful scale to assess to what extent problems exist in the area of socio-economic function e.g. work, social engagement /interactions. This would be a

useful scale to evaluate the effect of interventions that are directed at the larger community and policy makers. Community based rehabilitation (CBR) managers working with leprosy affected people may want to use this scale to assess the effect of their specific interventions that are aimed at improving 'quality of life' for leprosy affected people.

Discussion

This paper discusses four levels at which interventions should take place to prevent and manage disabilities in leprosy affected people. As stated in the introduction, the paper limits itself to the possible consequences of nerve function impairment. The disease specific impairments due to lepromatous leprosy i.e. eye complications, laryngeal involvement are not discussed. They are usually a later manifestation in the disease and can be prevented by early diagnosis (level 2).

Prevention of leprosy can be seen to have three components. First, as indicated above, improvement in socio-economic conditions will lead to a decline in number of new leprosy patients in leprosy endemic countries. Examples of socio-economic development indicators are literacy rate, sanitation/ hygiene, housing and access to health services. Second, BCG offers partial protection for development of leprosy (Setia et al 2006, Velema and Ogbeiwi 2007). Third, rifampicin for close contacts of an index case will afford some protection of leprosy in those contacts (Moet et al 2008). The following questions could then be asked - should a single dose of rifampicin be considered for all persons in areas with high endemicity of leprosy? At regular, which length, intervals? For 'close' contacts of an index case only? But, then an ethical question may follow - can the identity of a primary index case be revealed?

Early diagnosis of leprosy depends on the health infrastructure e.g. health staff's knowledge of leprosy and accessibility of services. Early diagnosis also depends on the awareness of early signs and symptoms of leprosy in the general population and the willingness to report for possible diagnosis of leprosy without fear. The level of health literacy amongst health workers and the general population is an important factor that will determine early diagnosis/reporting (Nutbeam 2008).

The specific expertise which is available in a vertical program is often lacking with the integration of the leprosy program into the general health program. Nowadays leprosy is often diagnosed only on the basis of one of the three cardinal signs : hypaesthesia in a skin lesion. This may contribute to a late diagnosis of patients with diffuse lepromatous leprosy who do not show distinct skin lesions. If this is the sole criteria for diagnosis, people with diffuse lepromatous leprosy, not having distinct skin lesions, may go undiagnosed for a long time while the disease is progressing and *M. leprae* continues to be discharged in the environment.

Most impairments in leprosy are nerve related. They can often be prevented by early diagnosis of the disease and timely recognition and adequate treatment of leprosy reactions. Some impairments are not nerve related e.g. collapse of nose, hoarseness of voice, enlarged or eroded earlobes and loss of eyebrows. They are the result of late diagnosis/reporting or defaulting of lepromatous patients and, unlike nerve function impairment, can always be prevented.

The WHO target of less than 5% disability at time of diagnosis as an overall indicator for early case detection, is based on the WHO grade 2 disability i.e. visible impairment. Grade 1 sensory loss and weakness are excluded in this target. To date, there are no reliable figures on grade 1 impairment at time of diagnosis and how many of those patients might be impairment free at RFT or progress to additional or more severe impairments following diagnosis.

Many patients report with NFI, others develop NFI post diagnosis. In many cases, permanent NFI can be prevented by timely diagnosis of NFI and the

institution of appropriate medication (van Veen et al 2008, Feuth et al 2008). All patients affected by leprosy, especially those with high risk for nerve damage, must be educated about early signs and symptoms of neuritis/reaction so that they will self report for early intervention. Unfortunately, the drugs that will guarantee prevention of nerve function loss or nerve function recovery are not available. Cortico-steroids have only limited effect. More trials with cortico-steroids with different doses and duration and/or trials with alternative/newer drugs are needed. Multiple interacting factors determine nerve function recovery. The role of surgery in prevention of nerve function loss or recovery of nerve function is still debated (van Veen et al 2008, 2009). A recently developed reaction severity scale should be used in future inter-ventional randomised trials to assess possible benefits of medical/surgical interventions (van Brakel et al 2007).

The ICF lists personal and environmental factors that can play a role in the development of coping and management of disability. In ICF terminology, personal and environmental factors can be facilitators for health; they can be an asset and enhance functioning and participation. Several studies have shown that self care/ help groups elicit mechanisms in the individuals and the group that empower people with disabilities to improve their own health and that they may even have positive influences on the community of which they are part (Benbow and Tamiru 2001, Cross and Newcombe 2001, Cross and Choudhary 2005 ab). Interestingly, religious observance (religiosity /spirituality) as a personal factor is not mentioned in the ICF. Only in a recent draft categorization of personal factors is religion mentioned. That religion/spirituality plays an important role in coping with disability has been shown in many studies (Koenig and Cohen 2002, Levin and Steele 2005, Wallston 2005). In a recent ICF meeting in Quebec, it was realised that personal factors need to be further developed and defined. The role of personal factors in adherence to POD principles and practice has not been well researched in the field of leprosy thus far (Figure 1) (Sherer et al 1982, Wallston 2005).

The International Leprosy Associations technical forum meeting recognised that early diagnosis of the disease and early recognition of NFI are important factors in the prevention of impairment. Evidence was summarised and avenues for future research indicated (ILATF Report 2002). A later consensus meeting on POD focussed more on the practical implications of level 3-4 issues and summarised state of the art conclusions with respect to prevention and management of primary and secondary impairments (Consensus 2006). For the time being, these two documents remain the key documents to consult with respect to POD in the field of leprosy.

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