LEPROSY DISABILITIES REQUIRES INTERVENTION: PHYSIOTHERAPY & REHABILITATION

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ABSTRACT

Leprosy is an infectious disease caused by the Mycobacterium leprae and is one of the important causes of preventable disability. Early diagnosis and prompt treatment of all new cases of leprosy with World Health Organization (WHO) recommended multidrug therapy (MDT) remain the key strategies for leprosy control as it would prevent nerve damage and disability. Leprosy is a notifiable disease, endemic in Brazil and still considered a public health problem, with a correlation between the disease population and social condition. The later diagnosis and treatment, the more serious the physical and social disabilities of patients. Stigma and preconceptions resulting from this disease remain in the popular imagination and are linked to the image of the body, because patients may have skin spots, lesions on the mucosa and physical deformities. Physical therapy in leprosy strengthens muscles, decreases and prevents contractures, recovers and maintains joint mobility, maintains tone, integrity and elasticity of skin and prevents deformities. In ulcers, physiotherapy stimulates the healing process, and in cases of surgeries for neural decompression and tendon transfer, it acts in the pre- and postoperative period, controls inflammation, pain, oedema and muscle spasms, maintains functional independence in the activities of daily life and guides the patient toward new patterns of movement post-transfer. Leprosy may affect an individual’s performance of the activities of daily living (ADL) as well as of work- and leisure-related activities. In the multidisciplinary team, after diagnosis, the physiotherapist classifies disability degree and monitors neural function, basing the therapeutic behaviours on information obtained in the neurological evaluation. Institutionally based rehabilitation is an integral, key component in providing the holistic rehabilitation of a patient. However, health workers need to make a conscious effort to focus on the aspects of rehabilitation that will effectively integrate a leprosy-affected patient back into the community. Rehabilitation of a leprosy-affected individual should start at diagnosis and continue until the patient is able to return to an active normal life. Though technology has aided in the rehabilitation of people with impairments across the globe, leprosy-affected patients have not received a great deal of benefit from the technological boom. The translation of technological advances to rehabilitation in leprosy-affected persons has faced several challenges over the years. In a rapidly growing economy, leprosy-affected patients also should be provided with rehabilitation plans customized to their needs within a shorter span of time.

Key words: Leprosy, Social Stigma, Disabilities, Physiotherapy and Rehabilitation.

I. INTRODUCTION

Leprosy, also known as Hansen’s disease, is a chronic infectious disease caused by Mycobacterium leprae, a microorganism that has a predilection for the skin and nerves. Though nonfatal, leprosy is one of the most common causes of non-traumatic peripheral neuropathy worldwide. Early diagnosis and prompt treatment of all new cases of leprosy with World Health Organization (WHO) recommended multidrug therapy (MDT) remain the key strategies for leprosy control as it would prevent nerve damage and disability. An early diagnosis also provides opportunities for reducing or halting further transmission. Despite that, there are many current reports across the world, showing that people are still diagnosed late for leprosy. India is one of the countries with the highest leprosy burden with more than 135,000 new leprosy patients being detected every year, including 5,245 (3.9%) new leprosy patients with a visible disability: grade 2 disability (G2D).

New cases of leprosy occur due to a set of factors associated with the lack of knowledge about the disease, both by health professionals and patients, favouring late diagnosis, the development of physical and social disabilities, stigma and prejudice. A high proportion of grade 2 disability (visible deformity) is indicative of delay in
In the multidisciplinary team, after diagnosis, the physiotherapist classifies disability degree and monitors neural function, basing the therapeutic behaviours on information obtained in the neurological evaluation. New leprosy cases occur due to a set of factors connected to a lack of knowledge of the disease, both by health professionals and patients. Several physicians have no knowledge of the transmission mechanisms of leprosy, and encourage patient behaviours that increase the negative stigma of the disease. Leprosy study participants (42% of them) reported that physicians had not diagnosed them primarily with the disease, confusing it with rheumatism and skin allergies. Physiotherapist intervention is essential for a physical and functional evaluation and for the prevention or minimisation of physical disabilities, considering that many patients have disabilities during the diagnosis phase or develop them during leprosy treatment. These disabilities have a major impact on the patient's social and work life, largely because of the emotional distress associated with the illness.  

**Leprosy - conception of the disease, contact and reasons for preconception**

The later diagnosis and treatment, the more serious the physical and social disabilities of patients. Stigma and preconceptions resulting from this disease remain in the popular imagination and are linked to the image of the body, because patients may have skin spots, lesions on the mucosa and physical deformities. The patient can also manifest feelings of sadness, worry, fear and isolation due to the possibility of suffering preconceptions and rejection in their social environment. Some studies have concluded that stigma affects many aspects of the lives of people affected by leprosy including “mobility, interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious functions”. Despite health campaigns and government actions, society is unaware of the disease and carries erroneous beliefs, fear and preconception. The existence of free and efficient treatment, with easy administration and a high cure rate, is not enough to eliminate stigma regarding this disease. The absence of clarification is commonly observed among those who should guide the population. Professionals who have not had adequate education in their training feel insecure in terms of attending to or touching leprosy patients, favouring behaviours that reinforce the stigma and preconception. It is imperative to discuss all aspects of the disease and to demystify leprosy among health professionals and students. This will allow them to feel safe and prepared to identify and diagnose the disease early, clarify doubts and reassure the patient about treatment and cure. Therefore, it is essential to contact the patient and the professional practice during the course, to develop skills and competencies and to undo erroneous ideas existing among health professionals. The design of new health practices requires an assessment of the training of professionals, who must be able to perceive the multi-causality of morbid processes and to visualise the individual in their environment. It is essential to perform a Disability Grade Assessment and Simplified Neurological Assessment at diagnosis and then every three months during treatment, whenever there are complaints (pain, paraesthesia and muscular weakness), in cases of leprosy reactions, at the end treatment and after post-neural decompression surgery. The disability degree indicates a loss of protective sensitivity and/or visible deformities as a result of neural damage and/or blindness, and is an epidemiological indicator used to evaluate programs, to provide an early diagnosis (the presence of a deformity indicates a late diagnosis), and to compare disability grades at the beginning of treatment and after treatment cessation. The Simplified Neurological Assessment checks the integrity of neural function, identifies neurites early, monitors responses to indicated treatment and determines the need for surgery. This involves a physical examination, with an inspection of the eyes, nose, neck, hands and feet, palpation of the peripheral nerves (ulnar, medial, radial, common fibular and posterior tibial), performing a sensitive sensory threshold test on hands and feet and a manual test of muscle strength assessing movement and the capacity to oppose gravity and manual resistance, in each muscular group referring to a specific nerve. Physical evaluation and monitoring a patient's clinical condition are essential for the preservation of nerve structure and function, identifying deficiencies and preventing future changes. The participation physiotherapy professionals in the clinical/functional diagnosis, treatment and discharge of the patient contributes to disability reduction, recovery of motor skills and avoids the progression of neural complications, all of which are essential for participation in a leprosy control program and in the professional team of a public health unit. The physiotherapist has general professional training, directed to integral care of the patient, and is able to act at all levels of health care. Their work regarding leprosy consists of patient and general population orientation and communication, the prevention of new cases, providing a functional diagnosis, evaluation, treatment and rehabilitation of physical disabilities and social reintegration. In the multidisciplinary team, after diagnosis, the physiotherapist classifies disability degree and monitors neural function, basing the therapeutic behaviours on information obtained in the neurological evaluation. The main approaches include conventional treatment with muscle strengthening and stretching exercises, passive or active
mobilization (assisted or not), proprioceptive neuromuscular facilitation (PNF); the neural mobilization technique, electrothermophototherapeutic resources, hydration, lubrication and superficial massage of the skin, the development and adaptation of orthoses, splints and insoles as well as guidelines for self-care. Physical therapy in leprosy strengthens muscles, decreases and prevents contractures, recovers and maintains joint mobility, maintains tone, integrity and elasticity of skin and prevents deformities. In ulcers, physiotherapy stimulates the healing process, and in cases of surgeries for neural decompression and tendon transfer, it acts in the pre- and postoperative period, controls inflammation, pain, oedema and muscle spasms, maintains functional independence in the activities of daily life and guides the patient toward new patterns of movement post-transfer. Leprosy may affect an individual’s performance of the activities of daily living (ADL) as well as of work- and leisure-related activities. For example, an affected person may have trouble carrying out essential ADL tasks required for self-care and self-maintenance, such as personal hygiene, brushing, bathing, feeding, and dressing. The limitations experienced when performing these activities lead the person to depend on others and restrict his or her social participation. The goal of occupational therapy is to enhance or enable meaningful participation in the ADL and work- and leisure-related activities that are important to the clients served. In the process of rehabilitation, an occupational therapist uses assistive technology/devices to compensate for the leprosy-affected person’s impairments, with the goal of increasing, maintaining, or improving functional skills. Adaptive devices have been found to increase the affected person’s sense of satisfaction and independence in carrying out routine activities and participating in social activities.

**Assistive technology/devices.** Assistive devices should be adapted to a client’s daily routine and context. For example, mittens can be provided (gloves made of soft cloth) to protect anesthetic hands from heat-related injuries during cooking. Often, the tools used or suggested by clients are padded with soft materials to protect hands from pressure injuries, such as utensils, sickles, spades, hammers, screw drivers, and so on. For ADL, padding spoons, forks, toothbrushes, shaving razors, combs, etc., enhances the self-maintenance activity. Padding not only protects hands from pressure injuries but also enables better grip while using tools. Clients need to be trained on the use of adaptive devices in their daily routines to ensure that they use the tools. Loss of digits on hands due to repeated injuries and absorption is a common complication in leprosy-affected people with long-term impairments. As a result, their functional abilities to perform their daily activities are compromised. Grip aids are a kind of adaptive device that is customized to enhance the ability of the hands to hold objects such as pens, spoons, shaving razors, etc. Modulan® material is commonly used to make custom grip aids. Aids such as cosmetic prostheses that use latex rubber for absorbed digits are simple and cost effective. However the effects of cosmetic prostheses need to be scientifically studied to understand their role in reducing stigma due to leprosy.

**Special training.** Along with the adaptive devices, special training can be offered to leprosy-affected individuals. For example, they can be taught compensation techniques for using anesthetic hands in their daily routines. This training can be provided effectively in a group session. For cooking activities, clients can be taught how to cook while protecting their affected limbs. Initially, the occupational therapist demonstrates the technique and then supervises as the client practices an actual cooking activity over multiple sessions. Special training can also be provided for different occupational groups, such as farmers, carpenters, mechanics, tailors, and so on.

**Tendon transfer surgery.** Motor impairments may lead to paralysis and compromise hand functions such as grasp, pinch, and apprehension. The lost movements can be restored to some extent with tendon transfer surgeries. Unfortunately, not all paralyzed hands will benefit from tendon transfer procedures due to contractures, absorption of digits, availability of tendons to transfer, the client’s ability to undergo a re-education process, and various other reasons. In these circumstances, the use of adaptive devices can facilitate the functional ability of the hand. As described above, padding tools used by the clients will enhance the grasp and, thereby, the functional ability of the hand.

**Vocational and diversional activities.** The occupational therapist uses vocational activities to divert as well as to enhance the skill level of clients. Individuals affected by leprosy often stay in hospitals for long periods of time to care for complications such as wounds, deformity corrections, and reactions. Activities such as greeting card making, candle making, carpentry, and tailoring can be used as diversional activities. These activities not only keep patients engaged during their hospital stays but also enhance the skills needed for their livelihoods.

**Community-Based Rehabilitation**
Institutionally based rehabilitation is an integral, key component in providing the holistic rehabilitation of a patient. However, health workers need to make a conscious effort to focus on the aspects of rehabilitation that will effectively integrate a leprosy-affected patient back into the community.

**Preventing Further Deterioration of Impairments** Some of the impairments in leprosy are irreversible because of late diagnosis, late treatment, and the severity of causative factors, as in reactions. Such impairments will persist and cannot be completely reversed. The goal of the rehabilitation team should be to prevent any new impairment or the worsening of a primary impairment to a secondary impairment. 

- *Exercises* Muscle weakness of lesser duration will recover with appropriate exercise and a course of steroids. For paralysis of a longer duration, exercises might only help in maintaining the muscle tone and bulk. Table 6 gives a guideline on the exercises recommended for various grades of muscle strength.

- *Splints* Splints are supportive devices that are primarily used to immobilize a part of the body. Splints are classified into dynamic splints and static splints. Static splints immobilize a joint so as to prevent movement in the area that is immobilized. Dynamic splints allow specific movements that help in maintaining some functions, while other areas are immobilized. Most of the materials used to make splints are low cost, but comfortable, materials. Metal, bamboo, and coconut shells were commonly used in the past. Thermoplastics and plaster of Paris are now commonly used to make different kinds of splints.

- **Splints for neuritis.**
  - **Ulnar neuritis slab** The purpose of the splint is to relieve pain and to provide rest and warmth to the affected nerve. The splint also helps support the weak and paralyzed muscles supplied by the nerve. It can also help to prevent contractures. **Posterior slab / Functional foot slab.** This splint is indicated for patients with posterior tibial neuritis or lateral popliteal neuritis, as well as for those with a swollen foot or leg caused by a reaction. Other indications include an infected or neuropathic foot. The splint maintains the foot in the functional position, which allows damaged tissues to heal. **Palmar slab / Anterior slab / Median neuritis slab.** The purpose of the splint is to provide rest and warmth to the median nerve, allowing it to heal and regenerate. The splint also supports the weak muscles and helps prevent thumb web contracture (if the thumb is included).

**Pre- and post-operative rehabilitation**

The rehabilitation team should involve the patient in the surgical planning sessions, which will have a positive effect on the post-operative results. Group therapy sessions for patients waiting to undergo reconstructive surgery can help motivate the patient and facilitate a positive outcome. Overviews pre- and post-operative physical rehabilitation protocols for patients undergoing tendon transfer surgeries. An emphasis on a customized functional reorientation protocol in accordance with the patient’s profession would be an ideal and effective approach to post-operative rehabilitation. However, due to a paucity of time and funds, many functional rehabilitation protocols are limited to those given in the appendix. An improvement in the SALSA scale score would help determine an improvement in functions after the surgery. Patient delay is the major reason for risk of disability (G2D/G1D) among adult leprosy patients. A patient delay of more than 3 months from the notice of first symptom is a significant indicator for the disabilities among adult leprosy patients. Early case detection campaigns like active surveys in endemic spots should be done periodically as this can reduce delays and promote early diagnosis. Additionally, the program should lay greater emphasis on raising community awareness regarding the disease. Also, health care provider delay of more than 1 month have been significant risk factors for disability among adult leprosy cases. Hence, periodical capacitacion of all HCPs including private practitioners would significantly contribute to reduce diagnostic delay and promote timely referral and early detection. Delays were quantified based on patient recall across a timeline. Patient delay defined as the time period between first noticed symptom by the patient and the first visit to any health care provider (HCP); HCP delay defined as the time period between patient’s first visit to any HCP and the confirmation of diagnosis of leprosy; and total delay defined as the sum of both patient and HCP delays. The primary goal of physical rehabilitation is to restore an individual to maximal physical well-being. However, rehabilitation is not limited to the physical but rather extends to the whole individual. To achieve such holistic rehabilitation, the primary goal should be reversing the physical impairments caused by leprosy, while the secondary goal should be customizing lifestyle modifications for the individual patients, their families, and their communities. Rehabilitation of a leprosy-affected individual should start at diagnosis and continue until the patient is able to return to an active normal life. The physical rehabilitation of the leprosy-affected can be classified into the following categories: (1) Identifying nerve function impairment (NFI), (2) Monitoring impairments, and (3) Preventing further deterioration of impairments. Some of the impairments in leprosy are irreversible because of late diagnosis, late treatment, and the severity of causative factors, as in reactions. Such impairments will persist and cannot be completely reversed. The goal of
the rehabilitation team should be to prevent any new impairment or the worsening of a primary impairment.\textsuperscript{18}

**Changing scenario and challenges in leprosy rehabilitation**

Though technology has aided in the rehabilitation of people with impairments across the globe, leprosy-affected patients have not received a great deal of benefit from the technological boom. The translation of technological advances to rehabilitation in leprosy-affected persons has faced several challenges over the years. A lack of funding and a surfeit of complacency in adapting the technology to benefit leprosy-affected patients are two of the challenges that leprosy programs face in implementing these technologies. Given the technological advancements and the availability of low-cost technology, leprosy health workers need to adapt these advancements and adopt them in their health programs. In a rapidly growing economy, leprosy-affected patients also should be provided with rehabilitation plans customized to their needs within a shorter span of time.

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