

REVIEW

## Self-care in leprosy at the front line

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*Summary* This paper presents current practice regarding self-care in many parts of the world but especially in the context of The Leprosy Mission Trust India.

*Keywords:* Leprosy, disability, self-care

### Introduction

Self-care guidelines support and promote a comprehensive, people-centred and occupation-oriented approach to self-awareness and mental well-being, leading to the prevention of further disability.<sup>1</sup> Self-care interventions can help to create a viable, safe, and enabling environment; they are essential to facilitate access, and provide opportunities to help increase people's active participation in their own health needs, including family engagement.<sup>2</sup> The use of digital health interventions to support the use of self-care interventions<sup>3</sup> must also be considered.

This paper focuses on self-assessment and regular practice of appropriate interventions, which will have a sustainable impact on the prevention of impairment and disability. In addition to a narrow focus on disability, self-care interventions may also lead to empowering individuals, families, and communities to optimize their health and health seeking behaviour by systematically addressing the broader determinants of disability due to leprosy, including social, economic, and environmental factors. Self-care encompasses activities related to health promotion, disease prevention, illness and injury treatment, chronic disease management and rehabilitation.<sup>4</sup> There is a paucity of evidence for the effectiveness of self-care in reducing the prevalence and size of leprosy ulcers<sup>4,5</sup> and no randomised trials have been conducted to examine the efficacy of self-care interventions on leprosy related outcomes.

To successfully engage in self-care practices and adhere to self-care guidelines, leprosy programmes globally use a range of behaviour change techniques to promote compliance, commonly with instructions on how to perform a behaviour, either through training or practical demonstration. Other important factors that influences the practice of self-care are safe working practices during occupational and domestic work.<sup>5</sup> Customised guidance on tool adaptations and work practices will ensure that people are able to conduct their normal activities of daily living (ADL) and occupation while still adhering to self-care principles.<sup>6,7</sup> A cascade

method of training and ‘training the trainers’, whilst also monitoring participants’ compliance with self-care practices, is another component of disability (POD) campaigns.<sup>8</sup> The underlying principle behind all modes of self-care delivery is imparting knowledge, facilitating behaviour change and provision of adaptations, and aids and appliances.

Patients with chronic conditions like nerve function impairments due to leprosy must take an active role in the management of their illness. Each day the patient decides to inspect their limbs, care for the anaesthetic feet and hands, exercise the affected parts, and decide which activity to avoid or modify. Some studies of self-management of chronic conditions, emphasize the fact that no matter what health professionals do or say, patients are in control of important decisions.<sup>9</sup> The question is not whether patients with chronic conditions manage their illness but how they manage them.

Another aspect of successful self-care is self-efficacy, which has been linked to self-care adherence and its influence on the adoption, initiation, and maintenance of health behaviours.<sup>10</sup> Cross suggested that self-efficacy is critical in adherence to self-care and low compliance in self-care is due to low self-efficacy and self-esteem.<sup>11,12</sup> People with greater levels of self-efficacy are more likely to develop positive self-care practices and cope with criticism or stigma. Thus, empowerment through a community-based rehabilitation approach, as a strategy to empower and sustain self-care, resulted in positive psychological and social outcomes as noted in the ALERT programme.<sup>13</sup>

The role of social support is key in the success and sustainability of self-care interventions for leprosy. Studies have shown that support can come from a range of stakeholders, including health care professionals, social care professionals, family and friends, and the wider community. Self-care facilitators and social support during the crucial early stages of behaviour change are very important.<sup>14</sup>

Family influences self-care behaviour by communicating positive messages around treatment and repudiating stigma. Families have been reported as motivating people to treatment,<sup>15,16</sup> ensuring adherence to self-care practices<sup>17</sup> and reinforcing self-belief and positive outcome expectancy.<sup>15</sup>

### **Disability in leprosy**

Disability caused by leprosy is preventable and reversible if detected early. It occurs secondary to nerve damage resulting from inflammation stimulated by the presence of *Mycobacterium leprae* and affects sensory, motor, and autonomic nerves in various degrees. Such disabilities are chronic, with a lifelong risk of worsening, hence self-care practices need to be practiced throughout life and modified progressively.

Sensory nerve involvement results in anaesthesia of the affected part, motor involvement causes muscle weakness and paralysis and autonomic involvement results in loss of sweating thereby causing the development of pre-ulcerating conditions like cracks and fissures.

The physical impairments give rise to disabilities, resulting in limitations of any activity that requires the use of hands, feet, or eyes, and causes restrictions in social participation. Leprosy-related impairment is classified by WHO into three grades: Grade 0—no impairment, Grade 1—loss of sensation in the hand or foot, and Grade 2—visible impairment. Eye impairments are loss of corneal sensation and weakness or paralysis of eyelids. This results in inadequate closure of the eyes causing ocular injuries, ulcers and blindness. Hands and feet have loss of sensation on the palms and soles and weakness or paralysis of muscles causing inadvertent injuries, ulcerations, and loss of function in affected limbs. If multi-drug treatment (MDT) is instituted in a timely manner, and nerve function assessment is monitored regularly,

disability can be prevented. Even after completion of treatment, some people suffer from nerve damage, requiring self-care to protect and prevent further damage. Disability leads to unsightly deformity thus perpetuating poor self-esteem, stigma, exclusion, and discrimination of people affected, by the society where they belong.

People with impaired nerve function are required to substitute for sensory, motor, and autonomic functions by using other senses more acutely: sight substitutes for sensation as a warning of risks of injury or presence of pre-ulcerative conditions like blisters, burns, friction etc; soaking in water and applying oil to substitute for loss of sweating; and exercise for joint movement to prevent contracture and deformity. These essential actions that substitute for the loss of normal function fall in the domain of self-care. Thus, self-care is the key to prevention of disability (POD) activities, and good compliance goes a long way to protect limbs.

The Care for Chronic Conditions model developed by WHO in collaboration with MacColl Institute for Health Care emphasizes that self-care must become central to the development of health provision for people affected by chronic conditions. They also emphasize the need to help people create plans that will help them achieve their own goals.<sup>18</sup>

People with chronic conditions become their own principal caregivers with health care professionals as consultants supporting them in this new role. Although training of the entire leprosy work force in implementing self care is an integral part of health education in all hospitals and disability prevention activities, many people have unfortunately not adhered to such education and thus have struggled to cope with worsening disabilities and loss of limbs.

Prevention and treatment of primary impairment (such as loss of nerve function) falls within the responsibility of health professionals, although affected people can contribute by monitoring themselves. The 2 arms of prevention of disability by self care are:

- (1) Risk reduction methods to prevent new secondary impairments.
- (2) Care of existing impairments to prevent worsening of disabilities.

### **Risk reduction methods**

Adoption of some risk reduction measures are recommended to prevent new impairments from developing. Keeping feet from weight-bearing on the affected part, by resting and use of crutches and appropriate footwear. Certain behavioural modifications need to be learned and practised while engaging in certain activities like avoidance of heat, pressure and rough surfaces. Tool adaptations must be encouraged by using cloth or protective layers when handling hot objects or farming tools. In all risk reduction measures, 'Think, Modify and Act' should be the dictum for all.

Details of daily self-care activities based on work by JM Watson<sup>19</sup> are presented in Annex A.

### **Mental health**

A healthy mind enables a feeling of well-being and allows the ability to cope with negative feelings or circumstances. Mental health diminishes as negative feelings overwhelm, interfering with daily life. Mental health is enhanced when persons have control over their lives, and experience healthy relationships. The usual mental problems are depression and anxiety disorders, which are more prevalent in people affected by leprosy.<sup>20</sup> This is because of disease impairments as well as societal influences, resulting in stigma and discrimination.

Symptoms of depression in people affected by leprosy are mostly associated with people isolated from the community; are living alone; have difficulty with self-care and performing daily activities; having visible and visual impairments.<sup>20</sup>

This needs a multi-faceted approach at different levels, starting from the individual, family, and community. An intrapersonal focus, using cognitive behavioural approaches focus on improving self-esteem, coping skills and level of felt stigma; building psychological and social confidence; and empowerment of help seeking behaviour, involving families and communities of people affected. It is observed that emphasis on knowledge sharing with persons affected using group dynamics enhances understanding and identification of solutions.

## **Training resources**

### **Participatory, problem-based self-care training**

The criteria for which patients are eligible for self-care training will vary. The most general criterion is that any patient with any leprosy-related impairment is eligible for self-care education.

#### METHODS AND CONTENT OF SELF-CARE TRAINING

The training should be a two-way conversation and the trainer should try to give information relevant to the problems the client experiences. He should verify that the client has understood the information. There should be demonstration of self-care techniques. As far as possible, clients should offer the solutions (self-care) themselves (for better compliance) adapting to their local conditions so that self-care is customized rather than standardized. The client should practise what has been agreed under supervision. As far as possible clients should be helped to see self-care as part of daily living and not a specialized activity.

### **Self-care at home**

The client's details of self-care activities should include:

- Frequency of self-care practice? Where?
- Ask what the client is doing about self-care when s/he is very busy.
- Who is assisting with these activities? e.g., family, government health worker etc.
- Observe where bowls, water, oil, scraping stones for skin care are kept and how easily they can be accessed, by asking for demonstration of skin care.
- Check if client has a mirror to inspect the eyes.
- Inspect and see if status of hands and feet correspond with the reported frequency of self-care activities. Ideally, this should be done during home-visits, but interviews in the OPD are also possible; make sure that report information was collected.
- Set reasonable, achievable, short-term targets and celebrate their accomplishment. Repeat.

### **Self-care groups in leprosy**

A group of people affected by leprosy (also can include family members) who share a common purpose of self-care, meet regularly, help one another, interact, communicate, and react. The aims and objectives of such a group are intimate and personal contact, to widen interest in self-care by solving problems, changing attitudes, providing feedback thereby supporting each other and learning from each other regarding prevention of any recurrence of ulcers and worsening of disabilities.

Suggestions regarding group membership and functioning are presented in Annex B.

## Conclusion

Self-care is the most vital sort of self-management, through which people affected by leprosy can change their behaviour to adapt to the irreversible impairment due to the disease. Limited information is available on the effectiveness of self-care management. Self-care practice helps clients reduce the deterioration of impairment leading to permanent disability, improve their physical condition and increase self-confidence. Self-care practice can be compromised by poor knowledge and perceptions about the disease, and its effectiveness is associated with age, sex, livelihood, occupational commitments, educational status, income etc. Enhancing self-esteem and empowering people to take control of their lives with preventive adaptations, may reduce consequent disabling features and internalized stigma. Special focus on improved well-being will go a long way in improving compliance to self-care, thus preventing development of new and worsening impairments.

## Ethics approval

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## Competing interests

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## Authors' contributions

The content and writing of the manuscript was the sole responsibility of the author.

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## Annex A. Methods of self-care<sup>19</sup>

The practice of self-care consists of procedures, techniques, and exercises all of which can be performed at home or at work. To enable oneself to benefit from this, patients need to develop attitudes and abilities that favour the protection of their physical, mental, and social functions.

The main principles guiding practice of self-care would best be described as inspect, prevent, intervene and maintain. Inspection of the affected parts for any unknown injuries, prevent worsening, care for those body parts already injured and maintain the status quo of the impairment and do not allow further damage.

### EYE

**Examine the eyes** routinely once or twice daily.

Use a mirror and inspect for any redness of the eye, corneal injury, foreign body, eyelashes touching, conjunctiva/cornea, injury to the eye.

Ask friends/relative to check. If there is any redness see the doctor immediately.

Test the vision, look at any fixed object from the same distance every day, cover each eye one at a time with the palm and look at the same object daily from the fixed distance.

Report any change in vision to the nearest health worker immediately.

### *Care for the eyes*

If the eyes cannot be closed fully, it is important to keep eyes moist and clean. To clean your eyes daily, rinse your eyes gently with clean water using the cupped palms; do not splash water on eyes; do not rub eyes with any cloth or towel.

Instil prescribed drops to keep eyes moistened; don't rub the eye if it is sore or red.

To protect eyes against dryness and dust, wear sunglasses with large lenses and side-pieces. Wear a hat/ use a head cloth to shield and avoid injury to the eye. Use a cloth around the head to keep the eyes closed at night.

### *Exercise for weak eyelids*

Close the eyes tightly for 1 min, open and close again repeat 30 times doing this 3 times a day; pull eye lids from sideways to close eyelids. to maintain and improve strength of eyelids.

## HAND

### *Examine the hands*

Set aside a definite time each day for this hand-care routine.

Inspect the hand for redness, swelling, hot-spots, blisters, cracks, or wounds.

To soften the hard skin of hands, soak your hands in water for about 20 min.

Scrape off hard skin around cracks and old wound sites with the help of a hard cloth, coconut coir or loofa. Rub in oil on the wet hands immediately after soaking and scraping.

### *Care for the hands*

Always cover wounds with a clean cloth or bandage to protect them against injury, dirt, and infection. Rest the hand as much as possible.

Protect the hands, while cooking food, always hold hot items/utensils from the sides with the help of a thick cloth to protect against heat and fire.

Always use a pair of tongs to poke the fire or for touching hot cooking dishes.

For drinking tea or coffee, put the hot glass inside a cup or simply use a protective padding of cloth, to hold the hot glass, as hot food can burn your hands. Allow the food to cool and eat with a spoon.

Cover the handles of a cycle/rickshaw that is used regularly with a soft cloth to prevent wounds and blisters on your hands. Pad or cushion with cloth all hard and rough objects of daily use like spade, axe etc.

### *Exercise for fingers*

For stiff fingers, apply oil. Rest the back of hand on the thigh. Use other hand by gently pushing forward, to straighten the fingers as much as they will go. Hold and count to ten before you relax your hand. Do this at least 10 times.

For weakness of fingers. Cup the bent knuckle joints of the affected hand into another palm. Then straighten the end two joints as firmly as you can. Do this at least 10 times.

Use the other hand to straighten the end thumb-joint gently but firmly as much as it will go. Do this at least 10 times.

While resting the little finger side of the hand on the thigh, use other hand to firmly support the back of the thumb. Straighten the end joint of thumb as strongly as it can. Do this at least 10 times.

#### FOOT

##### *Examine the Feet*

Set aside a definite time each day for this foot-care routine. Inspect the feet for redness, swelling, hot-spots, blisters, cracks, or wounds.

To soften the hard skin of feet, soak your feet in water for about 20 min.

Scrape-off hard skin around cracks and old wound sites with the help of a soft stone, loofa, or coconut coir. Rub in oil on the wet feet immediately after soaking and scraping.

##### *Care for the Feet*

Always cover wounds with a clean cloth or bandage, to protect them against injury, dirt, and infection. Always check wounds every day. If the wounds are getting bigger, or if the skin around the wound is red and swollen, or if there is any pus or bad smell, then report immediately to the nearest health care centre. If the wounds are smaller and clean, and if there is no pus, then continue with self-care activities.

Give enough rest to your affected foot. Keep the affected foot raised up on a pillow.

Avoid walking. If you need to walk, use crutches, or stick for support.

Protect the feet; always sit away from heat and fire.

Correct way of sitting—either sit on a stool or sit down with the legs extended, to avoid injury to the feet, do not squat, do not sit cross-legged.

Check footwear daily to look for any damage, and to see if there are any stones or sharp things sticking to the soles. Do not wear tight strapped footwear or shoes.

Never walk barefoot. Always wear shoes with protective padding.

To cover long distances, always use a bicycle or other means of transport, instead of walking.

##### *Exercise for the feet*

Hold the two ends of a long cloth with the hands. Place the middle of the cloth under the forefoot and pull the cloth upwards firmly 10 times. Repeat this process about 3 times daily.

Consult the doctor and wear a foot drop—splint or spring attached to the footwear.

##### *Footwear and assistive devices*

Wearing footwear can reduce the risk of infections and injuries. Footwear should fit comfortably and adjust to accommodate the shape of the feet. The micro cellular rubber (MCR) has physical properties to suit the requirements of the anaesthetic feet in leprosy. The MCR forms a protective cushion under the anaesthetic foot that is capable of effectively reducing peak pressure along the gait cycle.

The general principles of MCR footwear are a hard under-sole for protection, soft insole for distribution of weight bearing; should be well-fitting with a heel strap and a heel counter. If necessary, an orthotic modification is used. Moulded footwear for deformed feet are recommended. The footwear should be affordable and acceptable to the patient. No nails or hard objects like metal wire should be used for repair.

Assistive devices are recommended for use to prevent disabilities by protecting the affected person from developing new impairments and by facilitating activities and participation.<sup>21</sup> The

use of such devices improves the functionality of a person, thereby increasing their level of independence in daily living.

## **Annex B. Suggestions regarding group membership and functioning**

### CRITERIA FOR BECOMING A GROUP MEMBER

A self-care group member is usually a leprosy affected person with impairment, a person with a recent history of ulcers and /or family members of leprosy affected people.

**Each group should be conducted by a leader who** understands and practises self-care. Intelligent enough to judge a person's ability to understand, ask questions and solve problems, a good listener and ambitious to see the members of the group engage successfully with self-care practices.

The preferable size of a Group is from 5–7, but certainly less than 10.

### **Several points to be kept in mind for an effective meeting:**

#### (1) Background in common

- Gender
- Age
- Language
- Vocation

#### (2) Environment

- Suitable room/open air
- Rooms—well lighted, ventilated

#### (3) Seating

- Sit in a circle.
- Group facilitator sits on equal terms with participants.
- Eye contact.
- Accommodation and safe Seating is the responsibility of the facilitator.

**Meeting essentials:** The self-care group must meet every week or fortnightly with the facilitator in attendance. The facilitator needs to have a rich knowledge and experience of self-care to facilitate and run the group. He/she needs to have adequate knowledge and experience of self-care, listens to others, and puts people at ease, breaks the silence and is patient. Helps members to identify their own problems and then develop solutions to solve their own problems. He/she must ensure that the participants understand what a self-care group is, check if everyone is present, choose one discussion topic, inspect each other's feet, hands, or eyes, Use probing questions. No advice given unless it is requested by the members emphasizing problem solving by the members themselves; summarizes the main problem areas.

The discussion time should be between 1.5 h to 2 h. The meetings should preferably be participatory. If anyone has an injury/ulcer first let the group discuss how it might have occurred and the steps to be taken to prevent it occurring again and to prevent it worsening. Then the group can monitor any occurrence of the same type of injury among them and mark their progress.

**Topics of discussion could include** footwear, wound care, hand care, foot care, eye care, reactions, neuritis, drugs used in leprosy and importance of regularity.

**Monitoring and Recording** is done quantitatively based on attendance and regularity and qualitatively based on attitude change towards self-care and wound healing, with expected outcome of increased understanding of self-care of hands, feet, and eyes; reduction of injuries/ulcers in individuals; no new ulcers; increased use of protective footwear; attitude changed towards wound healing; stimulated to follow up individually.

Challenges in running a self-care group are stimulating equal contributions from the participants, getting a discussion going, shutting up the moral vocal ones and encouraging the meek to speak.

**Evaluation includes** outcomes achieved, participation of members, appropriateness of the meeting place and length of meeting, challenges, ways to mitigate barriers and action changed for next meeting.