

REVIEW

Organizing and managing a programme for self-care in leprosy

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Introduction

Peripheral neuropathy is a common complication of leprosy that can lead to a wide range of impairments, including chronic skin ulcers and corneal injury. As a result, people with neuropathy need to practise long-term self-care routines to care for their eyes, heal ulcers and prevent further injury. As stated in a previous article in this series, the World Health Organization (WHO) defines self-care as ‘the ability of individuals, families and communities to promote health, prevent disease, maintain health, and cope with illness and disability with or without the support of a health-care provider’.¹ Self-care in leprosy is a set of practices by persons affected by leprosy which equips them with the knowledge and motivation that they need to take care of themselves and to prevent impairments. People practising self-care need access to self-care kits, assistive devices (such as crutches) and protective footwear. They need access to medical services for conditions that will not heal or when surgery or prosthetics are required. They also need support from families and the broader community so that work requirements do not lead to excessive weight-bearing, hence ulcers that do not heal or that recur. Individuals who practise self-care are often supported by peers in self-care groups (Ilozumba and Lilford²), or by family members.³ Here we set the scene by describing the systems level or organisational principles that are necessary, albeit not sufficient, conditions for the promotion of effective and acceptable self-care. In the next article, we will describe the psychological principles that need to be considered in promoting self-care. Then, building on

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organising principles and psychological theory, the processes of self-care will be described by Dr. Joydeepa Darlong.⁴

Self-care does not exist independently of the broader social and political environment. Thus, concerted action is required across a system in order to initiate, enhance and sustain self-care. Building on El-Osta *et al.*⁵ who describe a generic four level model of self-care, we conceptualise this system across three ‘levels’ (Figure 1). The first (macro) level is that of the policy and funding environment—the ‘organising authority’, such as a Non-Government Organisation (NGO) operating within a government leprosy programme. The organising authority must set the stage by mobilising resources in terms of people, facilities, equipment and information systems. The second (meso) level involves mobility of resources to translate upstream policy into downstream action. This bridging task typically falls to ‘facilitators’; people who link the organising authority to the community. The third (micro) level involves peer leaders and individuals who are affected by leprosy who must be enabled to learn and practise self-care as part of their daily lives. We will now describe the three levels in more detail.

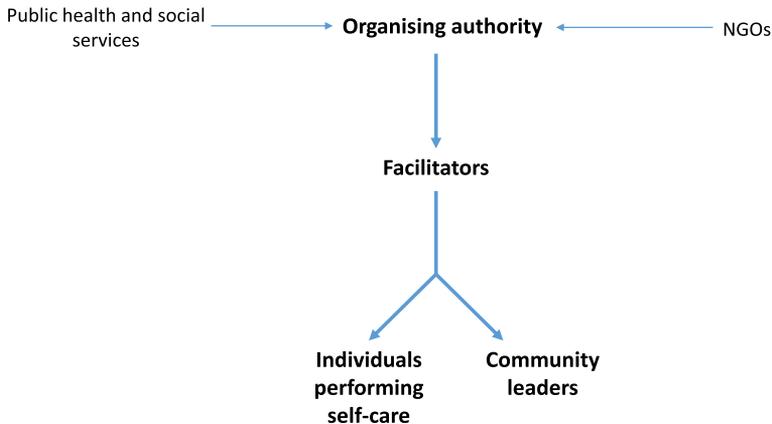


Figure 1. Stylized representation of a typical system to bring about an improvement in self-care.

Self-care in the context of the broader system

LEVEL 1: THE ORGANISING AUTHORITY (MACRO-LEVEL)

While it is persons affected by leprosy who are responsible for their own self-care, a successful self-care programme must set the conditions in which successful and sustainable self-care activities can be implemented. This requires an ‘organising authority’ that can put the building blocks in place, and remove existing barriers to successful implementation of self-care. The organising authority is typically the Ministry of Health and its relevant branch, for example the Leprosy Programme, or an NGO (which will need to collaborate with relevant health authorities).

There are several issues to consider at this macro level. First, existing services and resources should be identified since any programme of improvement must build on existing human and physical infra-structure. Second, the leprosy self-care programme may be implemented independently or it may be integrated with other programmes such as those serving other

Neglected Tropical Diseases (NTDs), or tuberculosis. Third, a programme to promote self-care for people with leprosy may, or may not, be part of a broader programme of early detection and new cases of leprosy, contact tracing and multidrug therapy (like The Leprosy Mission Trust India Replicable Model project to enhance leprosy care within the existing government health system). Fourth, the programme must take into account the availability and quality of rehabilitation and mental health service provision so that people can obtain basic equipment and be referred appropriately when required. Fifth, the organising authority needs to involve persons affected by leprosy and their organisations from the planning stage, to win hearts and minds and to ensure a person-centred approach to self-care. Sixth, the organising authority needs to recruit (or re-deploy) facilitators and then ensure that they are adequately trained, as described below. Seventh, infrastructure should be put in place, including measures to ensure the availability of equipment and establishing workable referral pathways. Eighth, registers of people with or at risk of leprosy disability should be established and maintained (as discussed below). Ninth, policy should include plans to make the intervention sustainable. For example, if funds to support facilitators can be committed only for a fixed period, then un-remunerated peer leaders will need to be identified and trained to take over the facilitation role. Tenth, any intervention takes place in a political context and among competing objectives. It is thus crucial to develop relationships with those who can facilitate, or indeed thwart, successful programmes. This requires 'political work' encompassing influential people in communities and in the broader health and social system. Engagement of this type can also be directed to tackling stigma and dispelling misconceptions about leprosy and disability.

Care is often limited to those affected people who voluntarily attend health clinics or who are actively undergoing treatment. However, self-care needs to be practiced by people who have nerve damage even if they do not have current ulcers or eye-problems. Thus, a functioning patient information and monitoring system/register is vital to ensure that interventions can be properly planned and resourced, and that people can be identified and self-care initiated before problems arise or recur, assuming that issues of privacy and confidentiality are properly covered. Registers can help to ensure that the data collected are sufficiently reliable and sensitive to indicate change in a person's impairment status and ensure that the data can be used to inform policy and action. Registers may include information not just about leprosy disability but also the incidence and severity of new cases. Alternatively, or in addition, people with long standing effects of leprosy may be included in a general disability register, which may be an official resource that provides access to equipment, resources and services. Registers can facilitate reporting of key indicators (including quality of care) from the prevention of disability programmes and medical rehabilitation activities in leprosy at a local, district, state and national level. The standard disability assessment can be completed before entering baseline details, or updating impairment details in the register. Each patient should have a single entry in the register and during subsequent reviews, impairment status would be updated as per the disability assessment. Each patient in the register should be reviewed every 6 months. An electronic register would help to facilitate and streamline reporting. Whether the organising authority should rely on official registers or, in addition, create an independent system for monitoring is a matter for local judgment.

LEVEL 2: FACILITATION (MESO-LEVEL)

Facilitators link the organising authority to the community by engaging with the communities in which persons affected by leprosy live, helping them access available health-care services and devices, as well as providing training, education, psychosocial support and advocacy.

Facilitators also ensure the quality of self-care interventions in the community by regular monitoring and evaluation.

Facilitators are often appointed by an NGO or health authority who pays their salary. Where possible, persons affected by leprosy or their organisations should be meaningfully involved in the recruitment process. In some programmes, facilitators are recruited from community health workers (e.g. Accredited Social Health Actor (ASHAs/Mitanins in India)) where their leprosy work may be combined with other health care tasks. Facilitators may also be recruited from the general public or on the basis of general managerial and relational skills. Alternatively, or in addition, facilitators may be selected from people affected by leprosy. Cross recruited people who already practised self-care, who were empathetic and who had good problem solving skills.⁶ Once recruited, facilitators should be provided with training on self-care. Training should include—but not be limited to—the clinical aspects of leprosy and its treatment, objectives and organisation of self-care (both individually and in groups), barriers to self-care (including disadvantages caused by gender, disability or race), qualities and the role of a good self-care group leader, how to run effective self-care group meetings, indications for referral to a health facility, and assessing the level of self-care at home. The training should ideally be co-designed and co-delivered by persons affected by leprosy. Training should be culturally appropriate and delivered in the local language or dialect.

Facilitators also have an important role in engaging with the broader community, especially community leaders, to create a supportive social environment. Where possible they should influence work conditions such as to reduce pressure on vulnerable limbs. Facilitators should establish a relationship with community leaders and others, such as teachers, who are influential in shaping local attitudes. This type of engagement can facilitate an encouraging social environment, mitigate stigma and promote sustainability of self-care interventions.^{7,8} For those who choose to practise self-care individually, rather than as part of a group, family-based interventions may help make up for the loss of group support.

LEVEL 3: THE COMMUNITY (MICRO-LEVEL)

The self-care programme is played out at the community level. In some places there may be only one person affected by leprosy. In others, it may be possible to form self-care groups, but people who wish to practise individual self-care should not be coerced to join such a group. Where a group exists, it is the facilitator's job to train peer leaders on the basis of 'train the trainers'. Peer leaders should be nominated or elected by members of self-care groups. Facilitators should mentor and monitor the work of peer leaders and refresh their training regularly. Where there is no group, the individual takes responsibility for their own care but the facilitator should engage with the broader family, encourage a supportive home environment and explore the basis for self-care actions.

The content of the peer leader training replicates, for the most part, the content of the facilitator training. However, it should be noted that, while the facilitators could be expected to be literate with some degree of formal education, the same may not be true for peer leaders. Therefore, any training of the peer leaders by the facilitator should take into consideration the literacy level of the peer leaders, and make the appropriate adjustments. This means that, in practice, delivery methods such as story-telling, performance, drama and song should be preferred to classroom type lecturing with visual aids where possible. As stated above, the details of self-care itself are described in a companion article.⁴

Conclusion

Much self-care literature has focussed on the ‘mechanics’ of self-care itself. However, self-care does not just happen—it is influenced by the broader environment. In this short article, we have emphasised two things. First, the quality of self-care will depend on the overall organisation of self-care programmes, from the organising authority through facilitators to people affected by leprosy. Second, at each of these levels, the broader environment must be engaged with the organising authority, as well as health and social services; facilitators must arrange access to devices and services; and the communities must create an enabling, non-stigmatising environment for their members who are affected by leprosy.

Ethics approval

Not required.

Competing interests

The authors have no competing interests.

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Authors’ contributions

BC, SC, RJL: contributed to the development and editing of the manuscript. RJL: Director of the NIHR RIGHT funded project at University of Birmingham and contributed to the conception of this review, and critically evaluated the intellectual content.

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