EDITORIAL

Self-care for people affected by leprosy

Richard J. Lilford^a

^a*Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, Edgbaston, Birmingham B15 2TT, UK
e-mail: r.j.lilford@bham.ac.uk*

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This edition of the journal is dedicated to self-care for people affected by leprosy who have peripheral neuropathy. It is widely accepted that such people should practice self-care. But self-care does not just happen—it takes place within an organisational context. Here we lay out a set of guidelines to inform the organisation and practice of self-care. These guidelines were developed as a package of work carried out as part of a grant funded by the UK National Institute of Health Research (NIHR). This grant—Transforming the Treatment and Prevention of Leprosy and Buruli ulcers in Low and Middle-Income Countries (LMICs) under the Research and Innovation for Global Health Transformation (RIGHT) programme—includes the development and evaluation of self-care or self-help programmes across three participating countries—Nigeria, Nepal and India.

In Nigeria, an incomplete stepped wedge cluster trial (‘staircase design’) on self-care is underway. In Nepal, we are evaluating a self-help intervention, where self-care is accompanied by economic empowerment. This study is taking place in 18 villages participating in a parallel cluster trial described elsewhere.¹ In India, we are evaluating a holistic intervention that includes, in addition to self-care, case finding, and medical and psycho-social support for people affected by leprosy. In all three countries we are also evaluating the sustainability of previous self-help interventions where funding has now come to an end.

Self-care in the above interventions is supported by a set of guidelines that we have developed. The research team initially came together in Manila, Philippines in September 2019 during the 20th International Leprosy Congress. Plans were made to establish the International Scientific Guidelines and Advisory Committee (SGAC). The SGAC reports to the research grant Executive Steering Committee, chaired by Professor Kara Hanson.

The SGAC, involving different stakeholders, public/community and policy representatives, as well as researchers experienced in implementation science, met in June 2020. The aim was to provide a framework that would offer direction to health services and Non-Governmental Organisations (NGOs) who wish to promote effective self-care. The guidelines would be intended as a resource for organisations implementing self-care programmes rather than as a manual for individual communities. The guidelines aimed to set out general principles and frameworks and to provide examples. We hope that these generic guidelines will be useful

for those seeking to develop or enhance self-care programmes for leprosy and maybe even for other conditions.

The guidelines thus aim to produce a ‘state-of-the-art’ summary of best evidence and opinion currently available to implement self-care in the field of leprosy. The SGAC met two more times (November 2020 and May 2021) where further reviews and discussions took place between the committee members. This whole process was informed by frameworks encompassing psychological, organisational and societal factors affecting implementation of interventions.^{2–5} An iterative process was followed, in line with international standards for guideline development.^{6,7}

These guidelines include three specific features. First, they are explicitly informed by modern psychological theory. Second, they are co-produced with people who have experienced leprosy and those responsible for implementing guidelines. Third, they cover not just the self-care procedures themselves, but also the organisational changes that must be put in place to support self-care in the community. Thus, we conceptualise a self-care (or self-help) programme as having three organisational levels. The upstream, macro level is that of the organising authority that initiates and funds the programme, typically an NGO (such as The Leprosy Mission) or a Public Health Authority. The downstream, micro level is the level of the community where the actual self-care programme is played out. Sandwiched between these levels is the meso level that links the organising authority to the community. Typically this level involves ‘facilitators’ who have to be hired, trained and deployed. It is the job of the ‘facilitators’ to engage with communities and people affected by leprosy, helping them to access devices and services, and providing education, psychosocial support and advocacy.

Based on these principles we include the following articles:

- (1) A scoping review of the literature for evidence on self-care and how it should be organised for maximum effect.⁸
- (2) The overall organisation of self-care programmes covering the organising authority and the link to communities.⁹
- (3) A summary of the psychological theory that should inform the implementation of self-care.¹⁰
- (4) Details of how self-care should happen at the community level, covering people affected by leprosy and the broader community in which they live.¹¹
- (5) An overview of assistive devices (especially orthoses) as a useful support service to self-care programs.¹²
- (6) An account of real-world experience in training for and implementing self-care.¹³
- (7) Perspectives of persons affected by leprosy.¹⁴

These guidelines do not include economic empowerment, which is the hallmark of self-help (as opposed to self-care) programmes.¹⁵ The RIGHT programme will provide the evidence that will enable us to extend self-care guidelines to incorporate economic empowerment (and hence become self-help guidelines). In this way, we intend to provide the social and medical framework to finally extinguish the biblical connotations that the word ‘leprosy’ still invokes.

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