

REVIEW

## Self-care programmes for people living with leprosy: a scoping review

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### Summary

**Objective** Effective self-care is a key approach for the management and prevention of ulcers for people living with leprosy. Understanding the complexities related to the design and implementation of self-care interventions is key to improving future interventions. The aim of this scoping review is to synthesize the existing evidence on self-care for the prevention and management of ulcers amongst people living with leprosy.

**Methods** We conducted a scoping review using PubMed, Web of Science and Infolep. Studies were included in the review if they reported on a self-care intervention and if they: (i) included individuals living with leprosy (ii) reported on leprosy specific self-care activities (iii) reported on the development, implementation and evaluation of self-care programs.

**Results** The initial search identified 476 articles from the three databases and 15 articles fulfilled our eligibility criteria. The self-care programs and interventions were conducted in eight low and middle-income countries. All interventions included were developed by ‘organizing authorities’ external to the community including governmental and non-governmental organizations. Interventions included education and training either directly with people living with leprosy or with health workers who implemented the intervention. Seven studies reported on clinical outcomes defined as reductions or healing of cracks, wounds or ulcers on hands and feet. A control group was only included in one study and the quality of intervention data varied greatly.

**Conclusion** While this review suggests that self-care interventions for leprosy contribute to improved prevention and management of wounds, they must be interpreted with caution and additional research is needed.

**Keywords:** Ulcer care, ulcer management, self-care, leprosy

## Introduction

Self-care can be defined as the range of behaviours undertaken by individuals to promote and restore health.<sup>1,2</sup> 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 healthcare provider’.<sup>3</sup> Notwithstanding this definition, there are difficulties associated in any review of self-care. First, there are many other definitions apart from the above.<sup>2,4,5</sup> Second, there is overlap between self-care and other concepts such as self-management, self-monitoring, self-treatment, self-efficacy, peer-support that tap into the same or similar underlying constructs.

The predominant terms used to identify the above construct vary by field. While reviews on heart failure<sup>6–8</sup> relate to *self-care*, those in HIV,<sup>9–12</sup> diabetes,<sup>13–16</sup> chronic illnesses<sup>17,18</sup> and stroke<sup>19,20</sup> refer to *self-management*. However, there has been no systematic review on self-care interventions specifically for leprosy. A related review was performed by Casado *et al.*<sup>21</sup> but they specifically focused on community-based programs for people with leprosy. Given that self-care interventions can occur in settings other than the community, we argue that a review specific to self-care is needed. The aim of this review therefore, is to synthesize the existing evidence on self-care for the prevention and management of ulcers amongst people living with leprosy. Casado’s review also included self-help by which we mean interventions based on or including some type of economic empowerment, such as micro-finance. In this review we concentrate on interventions where self-care was the main aim of the intervention.

## Methods

We used the framework derived by Levac *et al.*<sup>22</sup> to determine the stages of our review.

### FRAMEWORK STAGE ONE: IDENTIFYING THE RESEARCH QUESTION

For this scoping review, we adopted a broad research question: what is the existing evidence on self-care for the prevention and management of ulcers amongst people living with leprosy?

### FRAMEWORK STAGE TWO: IDENTIFYING RELEVANT STUDIES

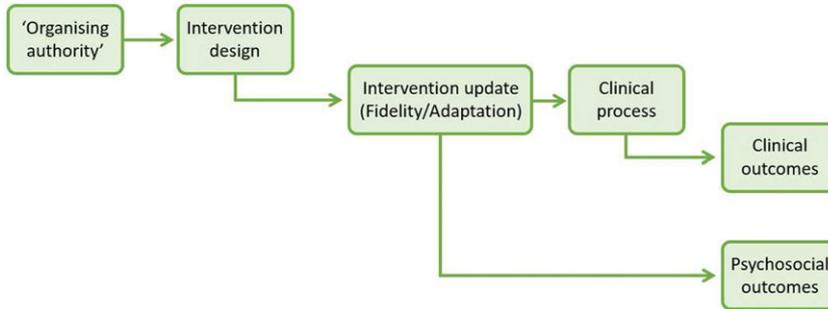
PubMed, Web of Science and Infolup were searched for all relevant literature published before 27th July 2021. Search terms were *self-care* and *leprosy* (Table 1). Reference lists of included articles were also hand-searched for additional references.

### FRAMEWORK STAGE THREE: STUDY SELECTION

Studies were included in the review if they:

- (i) Included individuals living with leprosy who had participated in a self-care program
- (ii) Reported on leprosy specific self-care activities (e.g. visual inspection of the skin and limbs) and or the clinical outcomes (e.g. site and number of wounds)
- (iii) Reported on the development, implementation or evaluation of self-care programs.

The first author (OI) conducted title and abstract screening of all included papers and another researcher (see acknowledgements) performed a duplicate review of 20% of all titles and abstracts.



**Figure 1.** Framework for evaluating self-care in leprosy interventions.

**Table 1.** Search strategy for papers on self-care in leprosy

(‘self care’[MeSH Terms] OR (‘self’[All Fields] AND ‘care’[All Fields]) OR ‘self care’[All Fields] OR ((‘self care’[MeSH Terms] OR (‘self’[All Fields] AND ‘care’[All Fields]) OR ‘self care’[All Fields]) AND (‘groups’[All Fields] OR ‘grouped’[All Fields] OR ‘grouping’[All Fields] OR ‘groupings’[All Fields] OR ‘groups’[All Fields] OR ‘groups s’[All Fields] OR ‘population groups’[MeSH Terms] OR (‘population’[All Fields] AND ‘groups’[All Fields]) OR ‘population groups’[All Fields] OR ‘group’[All Fields])) OR ‘self-help’[All Fields] AND (‘leprosy’[All Fields] OR ‘leprosy’[MeSH Terms] OR ‘leprosy’[All Fields] OR ((‘leprosy’[All Fields] OR ‘leprosy’[MeSH Terms] OR ‘leprosy’[All Fields]) AND (‘ulcer’[MeSH Terms] OR ‘ulcer’[All Fields] OR ‘ulcerate’[All Fields] OR ‘ulcerated’[All Fields] OR ‘ulcerates’[All Fields] OR ‘ulcerating’[All Fields] OR ‘ulceration’[All Fields] OR ‘ulcerations’[All Fields] OR ‘ulcerative’[All Fields] OR ‘ulcers’[All Fields] OR ‘ulcers’[All Fields] OR ‘ulcerous’[All Fields])) OR (‘foot ulcer’[MeSH Terms] OR (‘foot’[All Fields] AND ‘ulcer’[All Fields]) OR ‘foot ulcer’[All Fields] OR (‘foot’[All Fields] AND ‘ulcers’[All Fields]) OR ‘foot ulcers’[All Fields]))

#### FRAMEWORK STAGE FOUR: CHARTING THE DATA

During full-text reading, data were extracted using a piloted data extraction form that included information such as author, date, study aim/objective/research question, setting, intervention design, sample description, general and clinical outcomes.

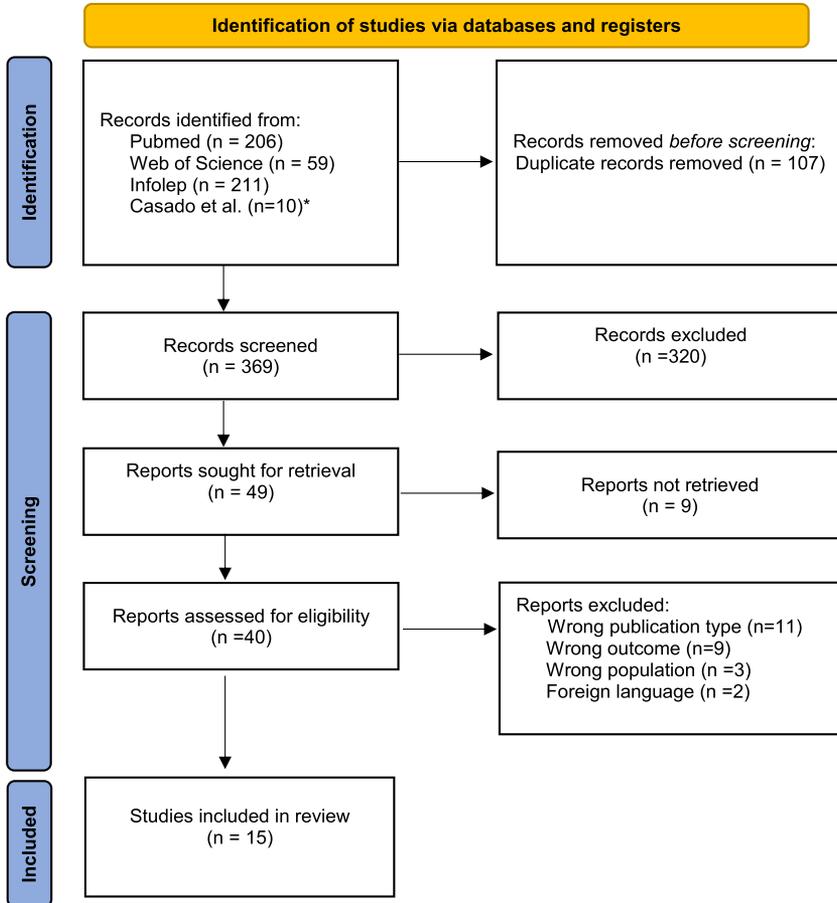
#### FRAMEWORK STAGE FIVE: COLLATING, SUMMARIZING, AND REPORTING THE RESULTS

We adopted a modified version of Lilford *et al.*<sup>23</sup> causal chain for evaluating policy and service interventions. The constructs of the chain provide us with a framework for summarizing and reporting the review results (Figure 1). As stated, the self-care interventions were designed and implemented by an ‘organising authority’. Interventions can be implemented as designed and described with high fidelity or low fidelity and they may undergo adaptations. Intervention implementation results in psychosocial outcomes, such as participation or reduction in stigma and process outcomes, which are related to implementation activities. Additionally, the self-care intervention can include clinical processes such as foot inspection or the use of protective footwear, which result in clinical outcomes including number and site of ulcers.

## Results

### ARTICLE SELECTION (SEE PRISMA DIAGRAM, FIGURE 2)

The initial search identified 476 articles from the three databases and after the removal of 107 duplicates, 369 articles were screened. After screening, we retrieved 40 full-text articles,



**Figure 2.** PRISMA flow diagram. \*All articles in Casado *et al.*<sup>21</sup> were captured by our Pubmed, Web of Science or Infolep searches.

of which 15 articles fulfilled our eligibility criteria. The bibliography of included articles was hand searched for additional references but none was identified, leaving a final list of 15 articles for analysis. Two of these articles<sup>24,25</sup> reported on the same intervention but over different time scales. We therefore report on a total of 15 articles covering 14 interventions. We compared our yields with the study by Casado *et al.*<sup>21</sup> Our search identified all 10 articles which were classified as self-care by Casado *et al.*<sup>21</sup> Five of these articles met our inclusion criteria and they had all been included in our review. We identified an additional 10 articles not included in Casado *et al.*<sup>21</sup> The 15 articles were conducted in the following eight countries— China,<sup>24–26</sup> Ethiopia,<sup>27–29</sup> Brazil,<sup>30</sup> Nepal,<sup>31,32</sup> Nigeria,<sup>33,34</sup> Indonesia,<sup>35,36</sup> India<sup>37</sup> and Mozambique.<sup>38</sup> All articles but one<sup>26</sup> were published between 2001 and 2021.

Reviewing the 15 articles, nine studies obtained quantitative data<sup>24–26,28,29,32–34,37</sup> and the remaining six utilized exclusively qualitative designs.<sup>27,30,35,36,38,39</sup> Only one of the 9 studies that included quantitative data used a contemporaneous control group and this was not obtained by a process of randomization.<sup>32</sup> The other eight articles utilized cohort studies in which

they followed the same group of participants over varying periods of time.<sup>24–26,28,29,33,34,37</sup> Additional details of the included studies are presented in Table 2.

#### INTERVENTION DESCRIPTION

As stated, in all 14 interventions (covering 15 studies), the organizing authorities that initiated and developed the interventions were external organizations rather than the communities themselves. Two interventions were developed by non-governmental organizations,<sup>27,32</sup> two by governmental bodies,<sup>30,34</sup> five of the interventions resulted from collaborations between non-governmental organizations and ministries of health<sup>24,26,27,37,38</sup> and the remaining five interventions were developed by research teams.<sup>28–31,36</sup>

#### DESCRIPTION OF SELF-CARE INTERVENTIONS

All 14 interventions involved implementing self-care programs in communities or healthcare centers and training health care workers and people living with leprosy. Nine of the interventions included the formation of self-care groups in which people living with leprosy learned about wound care and management among other topics such as general hygiene.<sup>27,30,31,33–38</sup> In two further interventions, self-care programs were only delivered to individuals who were formed into self-care groups.<sup>25,26</sup> The final three interventions described interventions that were delivered in specific contexts. The first of these, by Cross and Newcombe,<sup>32</sup> provided self-care training to people living in a purpose built center but did not explicitly create self-care groups. The second study<sup>29</sup> focused on the family unit and included economic empowerment (via micro-finance loans). The final intervention by Hounsoms *et al.*<sup>28</sup> was integrated across lymphatic filariasis, podoconiosis and leprosy and was targeted at individuals. Additional details on all 14 included interventions are provided in Table 3.

#### FIDELITY AND ADAPTATION OF INTERVENTIONS

Five of the 15 studies described an adaptation that was made over the intervention phase.<sup>24,26,27,29,36</sup> We noted that the training<sup>27,29</sup> and footwear provision<sup>26,36</sup> components of the intervention packages were most likely to be adapted. Benbow *et al.*<sup>27</sup> made significant changes in their intervention by including training for facilitators during intervention implementation; initially, there was no formal training, but as the programme expanded a four-day ‘introduction to self-care’ workshop was run, which was later developed further into a four-day training course that focused on facilitation, setting-up and running self-care groups. van’t Noordende<sup>29</sup> faced difficulties in distributing printed training materials which were only distributed after the follow-up assessment had been completed. In regards to footwear adaptations, Smith *et al.*<sup>26</sup> could not meet targets related to the provision of moulded footwear or surgical interventions. Additionally, they also had to provide footwear advice to participants who sought to purchase footwear independently of the program. By creating adapted sandals with families and workers from the health office, Syahputri *et al.*<sup>36</sup> were able to provide footwear as part of their deformity care package. There were two adaptations noted to the recruitment or delivery of the intervention.<sup>26,29</sup> van’t Noordende,<sup>29</sup> due to differences in distribution of diseases per district, had to organise different sessions for people living with the three different conditions (lymphatic filariasis, podoconiosis and leprosy) and their families. In two of the articles, there were difficulties with the delivery of care packages in the intervention. Smith *et al.*<sup>26</sup> experienced delays in starting MDT treatment in one area due to lack of clarity on who had permission to authorize treatment. While in Li *et al.*<sup>24</sup> health care workers faced two key challenges. First, they found it difficult to detect early nerve function impairment

Table 2. Overview of included studies

Authors	Year	Study aim	Sample	Study setting	Outcome measure(s)
<b>China</b>					
Smith WCS, Zhang G, Zheng T, Watson JM, Lehman LF and Lever P	1995	To evaluate programs aimed at preventing and treating impairments due to leprosy	Participant numbers varied in the different intervention programs. Self-care of eyes (313 patients), hands (1010 patients), feet (1094 patients), and footwear (4698 patients)	The study was conducted in eight project areas in six districts including rural and urban settings.	Improvement in measures of disability
Study 1: Li J, Mu H, Ke W, Bao X, Wang Y, Shen Li Mei and Cross H Study 2: Li J, Mu H, Ke W, Bao X, Wang Y, Wang Z, Zeng B and Cross H	2008	Study 1: To assess the effectiveness of government health workers as agents for the prevention of disability. Study 2: To establish the level of adherence to self-care and evidence of self-care associated with sustained impairment control one year after formal supervision ceased	Study 1: 1130 cases (747 males) completed the 3-year prevention of disability project and were available for final assessment. 864 subjected aged less than 60. 866 people from leprosy villages and 349 people living in general communities. Study 2: 81 people (of 218) all had participated in the 3-year prevention of disability. 31 people lived in two leprosy villages (23 males). Mean age 53.7. SD 8.6). 50 people lived in the general community (37 males). Mean age 56.4. SD 8.3.	Guizhou Province	Study 1: Effects of early detection and treatment on neuritis. Study 2: Self-care continuation

Table 2. (Continued)

Authors	Year	Study aim	Sample	Study setting	Outcome measure(s)
<b>Ethiopia</b> Benbow C and Tamiru T	2001	To outline the development of in Ethiopia by ALERT and the successes and failures experiences in the process	Group inclusion criteria: diagnosed with leprosy, beggars could be included if they demonstrated positive behaviour. Group members could be asked to leave groups when not actively participating, dominant or aggressive	Leprosy villages in urban and rural areas	Group development, wound management materials, wound management results, facilitators
Hounsone N, Kinfe M, Senrau M, Ali O, Tesfaye A, Mengiste A, Bremne S, Ahmed A, Fekadu A and Davey G	2020	An economic assessment of introducing a community-based care package for people with lower limb disorder caused by leprosy, LF or podoconiosis	Participants were aged 18–89 years old, 50.2% were males and 71 % had no formal education. Median number of children per household was five. Only 28% of households had electricity, 10% had a radio, 87% were landowners and 66% kept livestock.	Gusha Health Center-Gusha cluster; Guagusa Shikudad district, north West Ethiopia	Health-related quality of life and disability
van 't Noordende AT, Wubie Ayecheh M, Tadesse T, Hagens T, Haverkort E, Schippers AP	2021	To develop and pilot family-based approach to support prevention and self-management of leprosy, lymphatic filariasis and podoconiosis related disabilities in the Ethiopian context	275 people (11.5 affected by leprosy and 160 affected by LF or podoconiosis). 151 females. Mean age was 51 ( $\pm 15$ SD)	Awji zone	Physical impairment, family quality of life, activity limitations of persons affected and stigma

Table 2. (Continued)

Authors	Year	Study aim	Sample	Study setting	Outcome measure(s)
<b>Nepal</b> Cross H and Sah AK	2014	To explore leprosy affected individuals continued participation in leprosy services after participation in RECLAIM project	22 people (21 males). 10 members reported ability to read a newspaper and 11 could read simple messages. All participants had received facilitator training	Community project	Participation in self-care/self-help activities including group meetings, self-care, examination and referral of suspected leprosy cases and conducting home visits
Cross H and Newcombe I	2001	To reduce dependency and improve individual control by empower individuals by shifting the management and from health workers to individuals	254 trainees (66 females and 188 males) with a mean age of 35 years. A control group of 254 (75 females and 179 males) was selected from hospital files. Mean age was 39 years	Self-Care Training Center (SCTC) at the Lalgadh Leprosy Services Center	Admission in hospital for treatment of complicated ulcers
<b>Nigeria</b> Ebenso J, Muyiwa L and Ebenso B	2009	An evaluation to assess the impact of the three self-care groups on ulcer prevalence and readmission rates	22 participants who had been members of 3 self-care groups since 2004 (18 females). The mean age of participants was 62.5 and 9 participants were beggars	Okegbala Hospital	The trend of ulcer prevalence since establishment of self-care groups. The impact on SC on ulcer re-admission and perception of group members on SC
Gidado M, Obasanya JO, Adesigbe C, Huji J and Tahir D	2010	To describe the possible roles of positive deviants among Leprosy	26 ex-Leprosy patients (15 females)	Saye Leprosy settlement in Zaria	WHO disability grading (Eyes, Hands and Feet)

Table 2. (Continued)

Authors	Year	Study aim	Sample	Study setting	Outcome measure(s)
<b>Brazil</b> Souza, NMN, Belmonte ML, Alves MGT, Nascimento RD, Gomes MF and Santos DCM	2021	To analyse a self-care support group for people affected by leprosy from the perspective of Pichon-Rivier's operative groups	Inclusion criteria: oldest participants in the group with the most regularity in the meetings	Self-care group in the municipality of Pernambuco	Evidence of Pichon's theory: affiliation and belonging, cooperation, pertinence, communication, leaning and tele
<b>Indonesia</b> Syahputri, VN	2017	To determine the strategy in decreasing the effect of leprosy deformity through self-care group	15 people living with leprosy disabilities	Self-care group in Tripa Makmur sud-District, Nagan Raya Regency	Family support, personal hygiene, group support, stigma, leprosy disabilities care
Tantut Susanto, Erti Ikhtiarini Dewi, Iis Rahmawati;	2017	To understand the experiences of those participating in self-care groups with the aim of improving the functions of self-care groups to resolve self-care problems in the community	17 Participants. Mean age 49.9 years, 10 males. Two unmarried, 12 married. Education varied no education (1), elementary school (13), and junior high school (3). Unemployed (6), housewives (4) and farmers (7)	Jember, East Java, Indonesia	Perceptions of self-care and treatments. Changes to daily behaviour, health-seeking behaviours and expectations of care givers
Madhavan K, Vijayakumaran P, Ramachandran L, Manickam C, Rajmohan R, Mathew J and Krishnamurthy P	2007	To establish if services can be implemented in a district through the integrated set-up with facilitation by an NGO.	1,232 people were cured but with a disability of leprosy after verification through field visits. Including 631 people whose name were not on the leprosy register but identified by health workers. Additionally, 1,643 general health staff received training	Salem city in Tamil Nadu	Knowledge and practice of self-care and supervision by the health workers

Table 2. (Continued)

Authors	Year	Study aim	Sample	Study setting	Outcome measure(s)
<b>Mozambique</b> Deepak S, Hansine P and Braccini C	2013	To present an overview of national SCG strategy to understand the perceptions of people with leprosy regarding the benefits and challenges of participating in the self-care groups in Mozambique	Average number of members in the self-care groups Nampula was 15.5 and 12.6 in Manica. Nampula ages 20 to 72 years, median 42. Manica 13 to 93, median 47. Nampula 73.5% married, 1.8% divorced. Manica, 51.5% married, 33.1% divorced	Self-care groups in Nampula and Manica provinces	Viewpoints of persons affected by self-care group members affected by leprosy

Table 3. Description of intervention design and outcomes

Authors (Year)	Design	Fidelity/Adaptation	Outcomes
Smith WCS, Zhang G, Zheng T, Watson JM, Lehman LF and Lever P	<ul style="list-style-type: none"> <li>Jointly designed and implemented by the Ministry of Public Health and The Leprosy Mission International.</li> <li>Intervention involved 10 distinct parts, each with different participants</li> <li>Common to all 10 parts: detection and treatment of neuritis, self-care, provision of footwear, training, publicity and health education</li> </ul>	<ul style="list-style-type: none"> <li>Targets related to the provision of moulded footwear, surgery and amputations were not fulfilled</li> <li>Delays in starting MDT treatment in one area due to lack of clarity on who had permission to authorize treatment</li> <li>Some participants did not have baseline and follow-up data</li> <li>Patients in some areas wanted to buy their own shoes, as opposed to receiving program provided shoes. They needed advice on appropriate footwear</li> <li>Seventy-two public health workers from nine pilot counties attended prevention of disability training before the start of the project</li> <li>Public health workers had difficulties detecting to early nerve function impairment in the patients with neuritis.</li> <li>They were also not able to determining the appropriate dosage of prednisolone in complex situations.</li> <li>Additionally, health workers reported low confidence and limited professional skills in dealing with difficult disabilities, particularly difficult disabilities</li> <li>Most local governments provided matched funds for the POD project, funds were used to improve standards of living</li> </ul>	<ul style="list-style-type: none"> <li>Participants in the self-care component reported reductions in wounds on hands (80%), cracks on feet (83%) and reduction in wounds on feet (35%).</li> <li>Locally acceptable and available footwear was provided and among participants 61% reduction in cracks and 21% reduction in wounds</li> <li>Participants followed for 2 years reported a greater reduction in wounds (44%) compared to 1 year (16%)</li> <li>Regularity in self-care for eyes, hands, and feet increased in the first year and plateaued after 1 year</li> <li>An increase in regular performance only occurred after three monthly reinforcements, one meeting was not sufficient</li> </ul> <p>Study 1</p> <ul style="list-style-type: none"> <li>88.5% of all red eyes, 83% of hand ulcers and 62.8% of foot simple ulcers healed completely.</li> <li>There was no significant change in number of people with vision impairment</li> <li>95% reduction in hand and foot crack cases, normally reported at 3rd to 6th month</li> <li>The first year of the POD project was important, as it was during this time that people adopted self-care behaviour.</li> <li>For simple or complicated ulcers, greater reductions were seen in the 1st year compared to 2nd or 3rd years</li> <li>Healed ulcers were the most important factor in increasing confidence in self-care practice</li> </ul> <p>Study 2</p> <ul style="list-style-type: none"> <li>87% of people in leprosy villages vs 50% of people in the general community continued to practice self-care</li> <li>There were more support mechanisms for people in the leprosy village including a nurse and social welfare support from the local government.</li> <li>74.2% of participants in the leprosy village and 84% of participants in the general community continued to wear appropriate footwear</li> <li>38% of participants not practicing self-care presented with ulceration or foot cracks vs 25% among those practicing self-care</li> </ul>
Study 1: Li J, Mu H, Ke W, Bao X, Wang Y, Shen LM and Cross H. Study 2: Li J, Mu H, Ke W, Bao X, Wang Y, Wang Z, Zeng B and Cross H	<ul style="list-style-type: none"> <li>Initiated and implemented by the National Centre for Leprosy Control Nanjing in collaboration with provincial and non-governmental organisations</li> <li>Program included self-care of eyes, hands and feet, comprehensive therapy for those with complicated ulcers and early detection and treatment of nerve function impairment.</li> <li>Free footwear was provided to those conducting self-care with foot ulcers.</li> <li>Health workers monitored and followed-up on activities simultaneously with other tasks.</li> <li>Specialised services were provided at skin disease prevention stations</li> </ul>	<ul style="list-style-type: none"> <li>Seventy-two public health workers from nine pilot counties attended prevention of disability training before the start of the project</li> <li>Public health workers had difficulties detecting to early nerve function impairment in the patients with neuritis.</li> <li>They were also not able to determining the appropriate dosage of prednisolone in complex situations.</li> <li>Additionally, health workers reported low confidence and limited professional skills in dealing with difficult disabilities, particularly difficult disabilities</li> <li>Most local governments provided matched funds for the POD project, funds were used to improve standards of living</li> </ul>	<ul style="list-style-type: none"> <li>Participants in the self-care component reported reductions in wounds on hands (80%), cracks on feet (83%) and reduction in wounds on feet (35%).</li> <li>Locally acceptable and available footwear was provided and among participants 61% reduction in cracks and 21% reduction in wounds</li> <li>Participants followed for 2 years reported a greater reduction in wounds (44%) compared to 1 year (16%)</li> <li>Regularity in self-care for eyes, hands, and feet increased in the first year and plateaued after 1 year</li> <li>An increase in regular performance only occurred after three monthly reinforcements, one meeting was not sufficient</li> </ul> <p>Study 1</p> <ul style="list-style-type: none"> <li>88.5% of all red eyes, 83% of hand ulcers and 62.8% of foot simple ulcers healed completely.</li> <li>There was no significant change in number of people with vision impairment</li> <li>95% reduction in hand and foot crack cases, normally reported at 3rd to 6th month</li> <li>The first year of the POD project was important, as it was during this time that people adopted self-care behaviour.</li> <li>For simple or complicated ulcers, greater reductions were seen in the 1st year compared to 2nd or 3rd years</li> <li>Healed ulcers were the most important factor in increasing confidence in self-care practice</li> </ul> <p>Study 2</p> <ul style="list-style-type: none"> <li>87% of people in leprosy villages vs 50% of people in the general community continued to practice self-care</li> <li>There were more support mechanisms for people in the leprosy village including a nurse and social welfare support from the local government.</li> <li>74.2% of participants in the leprosy village and 84% of participants in the general community continued to wear appropriate footwear</li> <li>38% of participants not practicing self-care presented with ulceration or foot cracks vs 25% among those practicing self-care</li> </ul>

Table 3. (Continued)

Authors (Year)	Design	Fidelity/Adaptation	Outcomes
Benbow C and Tamiru T	<ul style="list-style-type: none"> <li>Membership in self-care groups was voluntary; members had to provide their own self-care materials and actively participated in meetings</li> <li>Shoes were available at the subsidized cost of \$1.25 to group members</li> <li>Ideal meeting size was between 8 and 10 members and at least 50% of members had to be present for meetings to hold</li> <li>Groups chose their group leader who was responsible for management of the group</li> <li>The group together with the facilitator decided on meeting locations</li> <li>Meetings were expected to hold every 1 or 2 weeks and last 1.5 to 2 hours</li> <li>After 6 months, groups could decide to continue or stop self-care groups</li> <li>No formal training for ALERT staff that worked as facilitators or group leaders. ALERT staff developed guidelines that other facilitators used.</li> </ul>	<ul style="list-style-type: none"> <li>Training was incorporated, first as a 4-day training workshop and then further developed into four-day course</li> <li>No formal training was provided for group leaders</li> <li>Data monitoring forms were not systematically reported and varied based on facilitator skill</li> <li>Group sizes varied and were bigger in leprosy villages and urban areas as (8–15 people) as opposed to rural areas (3–6 people)</li> <li>All groups but 4 chose to meet in-group member's houses, 2 met in health centres because of stigma and 2 in homes of people without leprosy</li> <li>All groups met every 4 weeks, 10% did not meet more often, 80% met every 2 weeks, 10% met weekly</li> <li>96 groups formed, 72 groups continued to meet after 6 months, 9 amalgamated due to small group numbers, 15 groups did not develop past the storming phase.</li> <li>25 educational training sessions and workshops were delivered to 235 participants.</li> <li>Sessions targeted individuals at all levels including health workers, community members, health extension workers, people with disabilities and supervisors.</li> </ul>	<ul style="list-style-type: none"> <li>An informal follow-up in two district communities showed that all wounds present at intake were smaller at follow-up.</li> <li>The majority of group members (80–95%) had well hydrated skin, clean and well-trimmed wounds, wounds covered and wore footwear.</li> <li>Participants reported feelings of belonging to a group, improved self-respect, dignity and confidence to participate socially.</li> </ul>
Hounscome N, Kinfe M, Semrau M, Ali O, Tesfaye A, Mengiste A, Bremne S, Ahmed A, Fekadu A and Davey G	<ul style="list-style-type: none"> <li>Patients with LF, podocontosis and leprosy identified from health records and recruited by health extension workers.</li> <li>Activities were delivered at one three levels: <ul style="list-style-type: none"> <li>healthcare organisation level; training,</li> <li>Healthcare facility (training and outpatient secondments)</li> <li>Community level (community awareness raising, stigma reduction workshop, community conversation facilitators, self-help group training, and training for CHWS).</li> </ul> </li> <li>Patients were provided with foot hygiene supplies and treatment was initiated as appropriate.</li> <li>Patients were also assessed by a mental health professional and medication provided as needed.</li> </ul>	<ul style="list-style-type: none"> <li>Total cost of healthcare supplies was £12,263 and £52 per person</li> <li>80.2% of participants did not seek professional help with respect to their lower limb disorder</li> <li>People in hospitals contributed an average of £24 per year to their care and £11 on medication, £9 on purchasing hygiene and care products (out of pocket expenses)</li> <li>40% of households had to borrow money in the past year</li> <li>Significant improvement in dermatologic quality of life, 46% decrease in the mean Dermatology Life Quality Index</li> <li>Improvement in self-reported disability 35% decrease in the mean score</li> <li>Statistically significant reductions in number of days with symptoms over the last month, days off usual activities or work and days with reduced activity due to lower limb disorder</li> </ul>	

Table 3. (Continued)

Authors (Year)	Design	Fidelity/Adaptation	Outcomes
van't Noordende AT, Wubie Aycheh M, Tadesse T, Hagens T, Haverkort E, Schippers AP	<ul style="list-style-type: none"> <li>A family-based intervention was developed based on exploratory qualitative data.</li> <li>Intervention focussed on three key components (i) self-management of disabilities (ii) awareness raising (iii) socio-economic empowerment.</li> <li>Self-management was the main component and included information on inspection, foot hygiene, ointment and advice on appropriate footwear.</li> <li>Participants also received basic tools to practice self-care.</li> <li>The intervention included people affected by leprosy, LF or podocytosis and their family members.</li> <li>Family members had to live in the same household and know about the condition of their family member</li> <li>A Self Care Training Centre (SCTC) developed by the Nepal Leprosy Trust.</li> <li>SCTC facilitator and two full-time assistants provided demonstrations and advice on all self-care activities, with a major emphasis on safe methods of daily labour.</li> <li>Participants had access to: land for small scale farming, two dormitories (one female and one male) and kitchen</li> <li>Participants attended a 14-day training session.</li> <li>The control group was obtained from hospital main files.</li> </ul>	<ul style="list-style-type: none"> <li>74 different group meetings were organised over eight sessions.</li> <li>Groups met on different days and 78% of participants attended at least three sessions.</li> <li>The intervention intended to distribute printed materials in the communities but due to time, constraints they distributed after the follow-up assessment had been completed.</li> <li>Ultimately, due to differences in distribution of diseases per district, each of the conditions and their families and their family attended different sessions.</li> </ul>	<ul style="list-style-type: none"> <li>No change in participants with eye impairments</li> <li>Non-significant decrease in number of participants with hand impairments, significant decrease in foot impairments among persons affected by leprosy.</li> <li>Severe limitations significantly decreased amongst all persons affected.</li> <li>Participants were positive about participating in the family-based intervention and the interventions had improved their knowledge about the three conditions and of self-management.</li> <li>Non-significant increase in family quality of life scores for persons affected and family members but significant for other sub-groups.</li> <li>Mean stigma scores significantly decreased between baseline and follow-up.</li> </ul>
Cross H and Newcombe I	<ul style="list-style-type: none"> <li>A Self Care Training Centre (SCTC) developed by the Nepal Leprosy Trust.</li> <li>SCTC facilitator and two full-time assistants provided demonstrations and advice on all self-care activities, with a major emphasis on safe methods of daily labour.</li> <li>Participants had access to: land for small scale farming, two dormitories (one female and one male) and kitchen</li> <li>Participants attended a 14-day training session.</li> <li>The control group was obtained from hospital main files.</li> </ul>	<ul style="list-style-type: none"> <li>No significant differences between study and control groups in terms of leprosy status and gender but a difference in age.</li> <li>On comparisons of admissions, the study group reported less admissions than the control (<math>p = 0.03</math>). <math>OR = 1.8</math> (95% <math>CI = 0.15-0.01</math>).</li> <li>People with impaired feet who did not undergo the SCTC training were 1.8 times as likely to be admitted for treatment of a complicated ulcer as people who participated in the program.</li> <li>An intense period of self-care training affects positive behaviour.</li> </ul>	

Table 3. (Continued)

Authors (Year)	Design	Fidelity/Adaptation	Outcomes
Cross H and Sah AK	<ul style="list-style-type: none"> <li>The project had two primary aims, poverty reduction and social responsibility.</li> <li>The core of the project was the development of self-efficacy gained because of positive effects of self-care practice.</li> </ul>	<ul style="list-style-type: none"> <li>Not clear what the activities of the original project were but participants reported 12 leprosy related activities.</li> <li>These were group meetings self-care, raising social awareness, examination of suspect leprosy cases and referral to health facilities, facilitating access to government resources, ensuring access to referral centres for treatment of complications, home visits, advocacy, follow-up of current cases, assistance to secure disability cards, stigma reduction activities, counselling.</li> <li>Facilitators received training from the training centre.</li> <li>They also received a bicycle and labelled bags with which to carry project documents, this produced a sense of status.</li> <li>Before 2006, the groups were given all the ulcer care material and staff performed wound-care.</li> <li>After 2006, only footwear and crutches were supplied. Members learned to use locally available materials to perform self-care.</li> <li>Some self-care group and hospital staff members incorrectly believed that the groups would replace hospital care.</li> </ul>	<ul style="list-style-type: none"> <li>All facilitators actively implemented group meetings, self-care and activities to reduce stigma.</li> <li>A majority of participants conducted activities related to raising social awareness regarding leprosy related issues, examination and referral of suspected cases, counselling, compliance.</li> <li>Only 8 facilitators followed-up with current cases to ensure compliance.</li> <li>High continuation of self-care activities was explained by their conviction in the benefits and efficacy of the intervention which gave them confidence to explain to others.</li> <li>Provision of resources such as bicycles (ease of transportation), labelled bags (sense of status), and economic support for income generation and savings and loan program (ease financial constraints).</li> <li>Status as leprosy affected was an advantage.</li> </ul>
Ebenso J, Mnyywa L and Ebenso B	<ul style="list-style-type: none"> <li>Self-care groups began in 2004 by a physiotherapist at the hospital and were first managed by hospital staff.</li> <li>In 2006 SCGSs ownership of the meeting shifted to the group members. They were responsible for their care and the care of group members.</li> <li>Materials were adapted and translated from the ALERT Ethiopian study.</li> <li>Facilitators were either community health assistants or community members.</li> </ul>	<ul style="list-style-type: none"> <li>Minimal reduction in number of ulcers when the health staff drove ulcer care.</li> <li>A decrease in ulcer prevalence, occurrence and hospital admission was noted when participants began self-care practices</li> <li>Participants also reported good experiences with self-care groups.</li> <li>Initial inertia and resistance to the self-care concept by health staff and group members.</li> </ul>	

Table 3. (Continued)

Authors (Year)	Design	Fidelity/Adaptation	Outcomes
Gidado M, Ohasanya JO, Adesigbe C, Huiji J and Tahir D	<ul style="list-style-type: none"> <li>Self-care group was introduced to the community during meeting in which the importance of self-care groups, the voluntary nature and non-provision of financial incentives for membership were emphasised.</li> <li>Two months later the group began.</li> <li>Baseline data was collected with routine leprosy monitoring forms and each patient was assessed for ulcer, impairment and visible deformity on the eyes, hands or feet.</li> <li>The group met fortnightly and sat in a circle. Group members inspected each other.</li> <li>A health care worker was always in attendance at the meetings</li> </ul>	Not applicable	<ul style="list-style-type: none"> <li>50% of the ulcers were healed out home using the self-care group and two patients 33% healed their ulcers.</li> <li>Group members observed general improvement in hygiene, protective footwear utilization and willingness to support each other.</li> <li>Group members who had healed ulcers described their process of healing and responded to the complaints of group members with their own experiences.</li> </ul>
Souza, NMN, Belmonte ML, Alves MGT, Nascimento RD, Gomes MF and Santos DCM	<ul style="list-style-type: none"> <li>Self-care group that serves as a reference service for the treatment of patients affected by leprosy as well as a research project at the University of Pernambuco</li> </ul>	Not applicable	<ul style="list-style-type: none"> <li>Affiliation and belonging: Group members were able to share their thoughts and experiences.</li> <li>Cooperation: Group members conducted activities together, shared knowledge and engaged in shared income-generating workshops and activities.</li> <li>Pertinence: Self-care group coordinator played a significant role in keeping the groups running.</li> <li>Communication: Various approaches to communication (listeners versus expressive) and conflict about lack of commitment from members. Learning occurred through activities mostly related to self-care.</li> <li>Tele: No major conflicts observed but some sub-groups formed within the larger groups.</li> <li>Positive outcomes were reported for family support, understanding the importance of self-cleaning in reducing deformity, improved social relationships with other members during the duration of the group (group support).</li> <li>While information on stigma, rights and self-confidence was provided there was no clear change in stigma perception.</li> </ul>
Syahpuri, VN	<ul style="list-style-type: none"> <li>'Payung Meureuleuy' self-care group was founded in 2012 and assisted 84 patients with leprosy disabilities.</li> <li>During that year, they provided explanations, discussions and practice to the members to improve the understanding of leprosy self-care and confidences.</li> <li>The program had six months of active learning and practice.</li> </ul>	<ul style="list-style-type: none"> <li>Deformity care was incorporated using available equipment including adapted sandals. These were created by families and workers from the health office.</li> </ul>	

Table 3. (Continued)

Authors (Year)	Design	Fidelity/Adaptation	Outcomes
Susanto T, Dewi EI, Rahmawati I;	<p>Design</p> <ul style="list-style-type: none"> <li>• SCGs with routine monthly activities for those affected by leprosy in families and communities under the supervision of public health nurses at the local PHCs</li> </ul>	<p>Fidelity/Adaptation</p> <p>Not applicable</p>	<p>Outcomes</p> <ul style="list-style-type: none"> <li>• Participants who had spent more than 6 months in treatment and received good information from PHCs, reported good understanding and perception of leprosy.</li> <li>• Some participants also showed a lack of understanding of the disease as evidenced by ill-defined descriptions.</li> <li>• Adherence was related to lack of confidence in the treatment provided by PHC's understanding of MDT short and long-term treatment regimens and efforts to reduce side effects of treatment.</li> <li>• Participant's ability to do self-care related to their ability to meet basic human needs, control their living environment.</li> <li>• Acceptance and support were related to family support during treatment, public social acceptance, provision of adequate information and health services from PHCs and flexibility to return to work after recovery.</li> <li>• 86.2% of people in rural and urban areas reviewed in the self-care programme were practicing self-care.</li> <li>• Initially ulcers were present in 516 and healed in 364 (70.5%) of people.</li> <li>• The success rate was significantly higher in urban areas compared to rural areas (<math>p &lt; 0.0001</math>).</li> <li>• 847 people were provided with MCR footwear, 81% of which came from the funds generated from the community by the health workers.</li> </ul>
Madhavan K, Vijayakumaran P, Ramachandran L, Manickam C, Rejmohan R, Mathew J and Krishnamurthy P	<ul style="list-style-type: none"> <li>• Government general health staff implemented prevention of disability services with technical support from the NGO project, which trained a core team of trainers from the government.</li> <li>• Hands-on training was given to all staff which included a demonstration in self-care.</li> <li>• Workers were to visit villages as part of their twice a month routine visits.</li> <li>• They recorded findings in their personal records.</li> <li>• None of the required items were supplied from the health services, rather individuals used materials available at home.</li> </ul>	<p>Day trainings were delivered in POD camps covering theory (Day 1) and demonstration (Day 2).</p>	<ul style="list-style-type: none"> <li>• Self-care groups in both provinces reported benefits in group membership, key among these were better knowledge of disabilities and rights, ability to fight for rights and socialising and meeting with friends.</li> <li>• Group membership increased over time and only a few people had left the groups due to ill health, transportation challenges and death. Only one person was reported to leave the groups due to conflict.</li> <li>• The main challenges raised by group members were the need for training, economic assistance and funds for income generating activities</li> </ul>
Deepak S, Hansine P and Braccini C	<ul style="list-style-type: none"> <li>• Self-care groups were started by provincial health services and NGOs in both provinces</li> </ul>	<ul style="list-style-type: none"> <li>• Groups evolved over time with particular changes to meeting membership, location and frequency.</li> <li>• Between the two provinces, there was inconsistent provision of training, materials and footwear with a statistically significant difference in access to sandals.</li> </ul>	<ul style="list-style-type: none"> <li>• Self-care groups in both provinces reported benefits in group membership, key among these were better knowledge of disabilities and rights, ability to fight for rights and socialising and meeting with friends.</li> <li>• Group membership increased over time and only a few people had left the groups due to ill health, transportation challenges and death. Only one person was reported to leave the groups due to conflict.</li> <li>• The main challenges raised by group members were the need for training, economic assistance and funds for income generating activities</li> </ul>

in the patients with neuritis. Second, they were also not able to determine the appropriate dosage of prednisolone in complex situations. Li *et al.*<sup>24</sup> also reported a positive adaptation in regards to intervention funding, which involved local government authorities deciding to provide matched funds for the project and to improve the living standards of people living with leprosy.

#### PROCESS OUTCOMES

Three articles reported on process level outcomes.<sup>26,28,37</sup> Madhavan *et al.*<sup>37</sup> found that village health nurses (VHN) identified leprosy cases not included on the government leprosy register but noted that transportation was a potential barrier to health workers effectiveness. Smith *et al.*<sup>26</sup> reported on possible dosage effects and found that three monthly reinforcements were needed to produce an improvement in self-care practice. They also found that self-care practice improvement in the first year reduced followed by a plateau in the subsequent two years. Li *et al.*<sup>24</sup> recorded a similar finding with the greatest reductions in simple and complicated ulcers in the first year of the intervention than in the subsequent two years. However, two studies noted continuation of self-care practices.<sup>25,26</sup>

#### CLINICAL OUTCOMES

Seven studies reported a clinical outcome and they all reported positive improvement in the number and/or site of lesions on the hands and feet.<sup>24-27,29,33,34</sup> Smith *et al.*<sup>26</sup> reported that because they continuously recruited participants, some of their participants did not contribute to both baseline and follow-up data. The only controlled study (Cross and Newcombe<sup>32</sup>) found that an intensive 14-day training course led to an almost 50% reduction in subsequent admissions among the intervention group. Madhavan *et al.*<sup>37</sup> noted ulcer healing in 70% of participants, with those in urban areas reporting a higher rate of healing than those in rural areas.

#### PSYCHOSOCIAL OUTCOMES

Three studies<sup>24,26,35</sup> highlighted factors that facilitate or impede, self-care practice. Susanto *et al.*<sup>35</sup> found that ability to perform self-care was correlated with a better understanding of leprosy. They also found that factors such as individuals' ability to meet basic human needs and control their living environment were associated with more diligent self-care.<sup>35</sup>

### Discussion

This review synthesized evidence on the implementation of self-care programs for people with leprosy. Our findings suggest that programs which focus on teaching and supporting regular self-care practice report reduction in cracks, wounds, ulcers and hence potentially disability. However, it is important to reflect on our findings in light of the recent review of Casado *et al.*<sup>21</sup> as well as challenges and opportunities presented by the study, intervention design and reporting standards of included studies.

First, comparing our review to that of Casado *et al.*<sup>21</sup> they included 30 papers which covered self-care groups ( $n = 10$ ), education programs ( $n = 3$ ), livelihood related community intervention programs ( $n = 6$ ), stigma reduction programs ( $n = 6$ ) and interventions related to empowerment ( $n = 5$ ).<sup>21</sup> In our review, we found all 10 of the self-care articles described in the above review, five of which met our inclusion criteria. We also included 9 articles that had not been included. We attribute the inclusion of additional articles to our focus

on all self-care interventions regardless of setting. This broader scope allowed us highlight additional organisational concerns for self-care interventions. Additional information on organising and managing a self-care program is presented in Celiktemur *et al.*<sup>40</sup> However, as in Casado *et al.* we also noted challenges with study design as well as intervention design, implementation and reporting.

The major flaw in study design was that none of the included interventions utilised the gold standard of a randomized control trial. Randomising people into self-care versus no self-care is not likely to be acceptable to researchers or people. However, there are still many questions about the effectiveness of self-care interventions for example the intensity of programs and individual components of self-care itself. The nine quantitative studies used a cohort rather than repeat cross-sectional design. Thus, they used an extremely weak design where each person acted as their own control and hence where the counterfactual cannot be estimated.

In relation to intervention design, we noted that all programs were conceptualised and implemented by NGOs, ministries or departments of health. While this top-down approach is necessary, where people lack resources and know-how, it is still very important to generate a sense of ownership of self-care interventions. There is substantial evidence in the field of health promotion and health programs which show that community ownership is key in the sustainability of interventions.<sup>41–43</sup> Some interventions attempted to address ownership by requiring participants to provide their own self-care tools or allowing group members to adapt group meetings as desired.

This review suggests that a key implementation challenge is the availability of human resources needed to deliver the interventions. A recurring problem was the availability of a trained health workforce to conduct home visits and self-care training. The studies also faced issues related to confidence of health care workers, transportation for health workers, availability of wound and ulcer care materials that influenced intervention implementation.

Finally, concerning the reporting of intervention design and implementation, there is a need for further elucidation of self-care interventions. Most articles provided little information on the specifics of the intervention. Gaining in-depth understanding of intervention developer's assumptions and detailed intervention description are important for pragmatic and academic reasons. The lack of detailed descriptions limits the possibility of cross learning between countries and programs. The need for greater description of the intervention group, intervention design and intervention developers' assumptions are included in the recommendations proposed by Jaarsma *et al.*<sup>44</sup>

#### LIMITATIONS

For this study, a limited search strategy was employed, focusing on only three databases and limiting the search terms to self-care and leprosy. Given the broad range of terminologies used to describe programs that are essentially self-care, we might have missed some relevant studies. However, given that self-care is the primary term utilised in leprosy we decided to explore self-care specific literature.

#### Conclusion

The findings of this review suggest that self-care interventions for people with leprosy can lead to reductions in cracks, wounds and ulcers. However, more research is required to address pending questions about the mechanisms by which self-care interventions can accomplish their objectives and be sustainable. Above all more programme designs are needed to test strategies

to implement self-care programmes in communities (for example self-care versus self-help) and to test various components of the self-care itself (for example different types of footwear).

### **Ethics approval**

Not required.

### **Competing interests**

The authors have no competing interests.

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### **Authors' contributions**

OI: Conducted the literature search and review. OI, RJJ: contributed to the development and editing of the manuscript.

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