Scoping Review: Community Programs for People with Leprosy

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Abstract

Objective*:* To analyze community intervention programs for people affected by leprosy in "global priority countries".

Methods*:* Scoping review of articles in the databases Pubmed, Scopus, Scielo, Lilacs and Web of Knowledge that made reference to community intervention programs aimed at people affected by leprosy in global priority countries, and which presented an evaluation of results. Analytical variables analyzed were methodological characteristics of the study, type of intervention classified according to the Community-Based Rehabilitation Matrix, indicators and results of the evaluation, and the degree of participation of the community, which was graphically represented as a spidergram.

Results*:* Thirty articles met the inclusion criteria. They were mostly related to the health component of the RBC matrix and aimed at the adult population. All evaluated the indicators used positively. The degree of participation generally ranged between *mobilization* and *collaboration*.

Conclusion*:* Community intervention programs for people affected by leprosy have a positive effect on health. There are attempts to include affected people and the community in implementing these programs, but it is not possible to establish a direct relationship with effects of their participation on health due to the study designs used. Future research using more robust methods that include leprosy patients are necessary to evaluate the effectiveness of community participation.

Keywords: leprosy, community programs, RBC matrix, health indicators, community participation

Introduction

Leprosy is recognized by WHO as a neglected tropical disease (NTD) (1). Like other NTDs, it is related to poverty and affects populations that live in isolated areas. At the end of 2017, almost 200,000 people were registered to be in treatment, and there were more than 210,000 new cases in the world. Of the new cases, 60% were multibacillary, 38% were in women and 6% had visible

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deformities or grade-2 disabilities, of which 238 occurred in children. The 22 countries considered "global priority countries" regarding the disease accounted for 95% of the global burden. Specifically, India, Indonesia and Brazil contributed 80.2% of new cases registered worldwide (2,3).

Leprosy can be prevented and cured at low cost, but care and treatment are not always accessible. If leoprosy is not diagnosed early it usually causes disabilities, often permanent, that limit the performance of people's habitual roles causing loss of social status. Discrimination, stigmatization and social exclusion of the people affected (4) may ensue.

There is growing evidence of the effectiveness of incorporating the community into programs to improve health or reduce inequalities (5-8), particularly in disadvantaged populations (9-14). Community participation was an initiative promoted in the Alma Ata Conference and is considered to be a process in which individuals, families or communities assume responsibilities related to their health and well-being. They try to identify their needs themselves, make decisions and establish mechanisms to meet them, thus contributing to their own development and that of the community (15,16). A range of approaches has emerged around this idea (7,17-19), incorporatinge different levels of participation from the simple provision of information to active decision-making by the community.

With the development of strategies such as community-based rehabilitation (CBR) (20) and more current strategies such as the 2016-2020 Global Strategies: *Moving Towards a Leprosy-Free World* (21) and the 2016-2018 Strategy on *Achieving a World Free from Leprosy* (22), WHO and the International Federation of Anti-Leprosy Associations (ILEP) recognize the importance of an integral approach (23) that takes into account the biopsychosocial vision of health and inclusion of the affected people and their communities so that interventions are effective.

These recommendations are justified by the fact that people increase their commitment to a project and improve their health when they identify their own needs and are involved in decision-making; they contribute to increasing the resources available for the program; develop collaborations with professionals, which fosters joint learning; and finally, they have the right and duty to be included in the decisions that affect their lives (24-27). The literature highlights the effect of community-based rehabilitation programs on health and well-being (28-32), including populations suffering from leprosy (33). However, evidence on the results of community programs specifically directed at people affected by leprosy and their communities and evaluations of the degree of community participation in these programs are lacking.

Consequently, this study aims to review the experiences of leprosy programs in "global priority countries" with community interventions and to produce useful information on the impact of community participation. The research focuses on the implemented programs that have been evaluated in terms of the type of intervention carried out, the results obtained and the degree of participation of people affected by leprosy and their communities.

Methods

Study design and sources

A review was carried out using the scoping review methodology (34), which comprises identifying the research question, detecting and selecting relevant studies that respond to that question, extracting information from these articles and a synthesizing the results (35,36).

The search was conducted in October 2018 in various health and social sciences databases: Pubmed, Scielo, Scopus, Lilacs and Web of Knowledge, without any time limit or language restrictions. The following key words were used to construct the search equations: *participation, leprosy, program, health impact, communit-based programs and community-based rehabilitation*.

This primary search was complemented by a manual search of the references of the articles included in the review and the electronically available issues published in the journal *Leprosy Review* since the year 2002 (Table 1).

Inclusion and exclusion criteria

Studies that evaluated community intervention programs (1) aimed at people with leprosy and (2) included population participation in any of the “global priority countries” (Table 2) were included. We considered such interventions at any stage including planning, design, coordination, implementation or service evaluation (4). Excluded articles were non-original articles, programs aimed at people not affected by leprosy or carried out in countries not considered “global priority countries”, and articles that described interventions which did not include evaluation of the results.

Study selection

After discarding duplicate articles, the first author reviewed the titles and abstracts of 277 studies identified by applying the inclusion and exclusion criteria. Sixty-five articles were selected with potential for inclusion and were reviewed in their full text. Finally, 30 articles were included that responded to the objective of this review. The classification of the doubtful articles was arrived at through consensus of the research team (Figure 1).

Data extraction and data analysis

An ad-hoc protocol was developed to extract relevant information from the articles included in the review, based on a group of variables of interest identified in the scientific literature (8,37). This information was fundamentally related to the methodological characteristics of the study, the type of intervention, evaluation indicators and results and the participation of the population (Table 3).

The extraction protocol was tested by two authors in a 10% sample. To analyze the level of concordance in the test protocol, a kappa index was calculated that offered a result of 0.347 with a standard error of 0.066 and 95% confidence intervals between 0.217 and 0.476. To improve this concordance, the protocol was revised and applied to a new 10% sample of articles. After the second test, the new concordance was testing by reviewing each extracted variable independently. A concordance level of 79% was found, confirming that the protocol permits objective extraction of information. Discrepancies between variables in the comparison process were decided by consensus by the third author.

The information extracted from each article was synthesized and organized in tables to be analyzed collectively and by each variable, in describing aggregated results and extracting conclusions.

The classification of the type of community intervention program was inspired by the Community-Based Rehabilitation Matrix (CBRM) to structure the information extracted by the studies, which allowed for comparing the different types of programs. CBRM consists of five key components (health, education, livelihood, social and empowerment). Each intervention was classified into one of these five key components based on the main objective of the intervention (38).

Rifkin’s model adapted by Draper was used to identify the level of community participation for each program. This model analyzes five indicators (leadership, planning and management, involvement of women, external support and monitoring and evaluation) based on a continuum from narrow (mobilization) to medium (collaboration) to wide participation (empowerment) with intermediate levels (18). Each indicator was scored from one to five, with one being the lowest level of participation and five the highest. A zero was assigned to indicators for which there were no data in the article. A description of the indicators of participation based on Draper´s model is shown in Table 4. To graphically represent the different levels of participation in the interventions, Rifkin’s spidergram method was used (7,16). Only programs that included information for all five indicators were taken into account. The PRISMA Declaration, a tool for authors of systematic reviews and meta-analyses which is helpful in evaluating interventions (39), guided the completion of the review and the writing of the article.

Results

Studies' general characteristics

Table 5 describes the principal characteristics of the 30 studies included (40-69). They came from seven countries belonging to two WHO regions, Southwest Asia (20 programs)(44-51,56-60,62-68) and Africa (10 programs) (40-43,52-55,61,69). The countries where most programs were implemented were India (eight interventions) (44,46,56-58,62,66,67) and Indonesia (seven interventions) (51,59,60,63-65,68).

Twenty-three programs were carried out in a particulat region or area of a country (40,41,43,45,47-49,51-55,58-61,63-69). Mixed methods were used in 16 articles (41-43,45,47,52-55,57,59-61,63,64,66). Twenty-four studies were aimed at the adult population (40-43,45,47-60,63-65,67,68).

Description of the programs

The community intervention programs (n=10) related to health (40,42-44,50,52,55,56,66,68) are primarily aimed at self-care groups for the management and prevention of ulcers and disabilities of both those with leprosy and their families (Table 6). The programs (n=3) related to education (46,62,69) are mainly focused on raising awareness of the disease in schools and in communities.(Table 7). Livelihood-related community intervention programs (n=6) (41,53,54,57,58,67) are primarily focused on improvement of socio-economic status and creation of employment opportunities, for example through micro-credits and job training (Table 8). Social programs (51,59,60,63-65) of the CBR Matrix (n=6) focused on reducing the impact of stigma related to leprosy (Table 9). Intervention programs related to empowerment (n=5) (45,47-49,61) focused on strengthening those affected and their communities and empowering them to be change agents (Table 10).

Level of community participation

Just seven studies contained information related to all five indicators (49,50,57,58,62,67,69) represented in the form of spidergrams. Figure 2 shows the different values of the indicators according to their place on the continuum of participation, and they are grouped by intervention type. All indicators were scored between mobilization (score 1) and collaboration (score 3). There were no programs for which the indicators achieved the level of empowerment (score 5). Most were at the level of mobilization (score 1), and there were several instances of the level of collaboration (score 3). There are no differences between each group of programs of note, except that the program related to empowerment (49) is the only one that presents most of the participation indicators at the level of collaboration (score 3). Also, it is significant that involvement of women is the indicator with the lowest level (score 1) in six of the seven programs (49,50,57,58,67,69).

Discussion

This review analyzed 30 studies of evaluation of community intervention projects aimed at people affected by leprosy in “global priority countries”. Most programs were related to health and for adults in regions or areas of Southeast Asia, such as India or Indonesia. They were all evaluated positively in terms of their indicators, which were very diverse and related to heterogeneous and mixed-methods designs. The barriers identified in the studies were to do with accessibility and acceptability of programs. There was scarce mention of sustainability. In terms of community participation, in general, the indicators were clustered between the levels of mobilization and collaboration.

The publications in this area of study have increased since 2015, just after the ILEP Leprosy research initiative (70) began, and coincide with two strategies 2016-2020: *Accelerating towards a Leprosy-free world* (21) and 2016-2018: *Achieving a world free from Leprosy* (22), promoted by WHO and ILEP, respectively.

The fact that programs were aimed mainly at adults shows that children are still very vulnerable and have little visibility. Although many countries do not disaggregate data or report data by age, data show that visible deformities or grade-2 disabilities in children continue to increase, indicating that there is still active transmission of the disease (2).

Although there is heterogeneity between programs in terms of area, type of interventions and indicators used, the Community-Based Rehabilitation Matrix allowed us to group the interventions with similar objectives, thus offering a global perspective of the evidence (7,18,29). The programs were primarily related to health, livelihood, and social aspects in accordance with the need for an approach aimed at rehabilitation of the physical limitations caused by leprosy, the fight against stigma and socio-economic support for those affected, their families and their communities (23). Although leprosy directly affects the education of children, and intervention in schools is important for the early detection of cases, there are few such programs (29). No indicators evaluate community participation itself, so it was not possible to know how this influences program effectiveness.

Although sustainability is considered a key variable to evaluate effectiveness (71-73), this has barely been assessed (14,74). Some authors do not recommend the total disengagement of funding agencies (14) from programs for tropical disease control; others mention institutionalization or integration of activities for control of leprosy into general health services (73-75) plus participation of communities in program development (27,73) to achieve sustainability.

An analysis of community participation according Draper's definitions (18) reveals that programs led by professionals are predominant (76,77). Second, programs are situated between those in which professionals decide the objectives and activities and mobilize resources and those in which there is collaboration with community leaders. Both mobilize resources, but without directing the program (76,77). Evidence shows that community ability to direct programs with the support of professionals constitutes the highest level of desirable participation, but the reality is usually that program management falls to professionals outside the community. They define the objectives and possible solutions that often do not represent the reality of the communities, and as a result few opportunities may be accepted or used by the communities (25). Third, although women participate occasionally in some aspects of the programs, their participation is usually not a priority objective. Women have fewer possibilities to participate than men due to low socioeconomic status and poor access to education (25,76), which contributes to maintaining inequalities in health and the triple discrimination in terms of gender, disability and stigma that women and girls with leprosy face (78-82). All programs are designed by professionals and receive external funding. At times the community is consulted and has negotiated a role. One of the reasons already mentioned for the need for community participation is for the provision of community resources to reduce economic dependence on the external agencies. But community decisions are often limited to choosing people to serve as community workers and determining how to increase the budget for activities decided upon by the planners (25). And finally, there are usually professionally designed programs with monitoring and evaluation protocols that lack transfer of results, though there are specific cases of community participation in data collection with feedback related to the results.

Our analysis places programs between mobilization and collaboration, which implies that the community mobilizes based on the advice of professionals. The community contributes time, materials and/or money but does not have the power to make decisions or to control the interventions. In complex sociopolitical situations or when resources are scarce, levels of participation could be considered adequate that although not reaching the ideal level of empowerment, involve communities in different program phases (14). Even so, it would be desirable that these programs aimed at transforming communities into active participants in acquisition of tools and knowledge, confidence, and personal experiences of effectiveness to gain the ability to identify and solve their own problems.

The use of the spidergrams allowed us to visualize the level of project participation in a simple and practical way and to show interrelationships between indicators. Spidergrams can be easily used by planners and managers as a part of the participation process and include the community in data collection, analysis and selection of the indicators (18).

There are several limitations to this study. On one hand, some articles related to community intervention programs on leprosy had to be excluded because they lacked evaluation of their indicators. It is also possible that some evaluation reports on these programs are unpublished or are considered grey literature and have not been included in this review. On the other hand, it was not possible to compare results due to the lack of evidence that evaluates and represents the level of participation of the population in the studies. And finally, both the evaluation of the indicators of participation in the programs and the classification of the interventions were interpreted by the authors, given that the information was not indicated directly in the article.

Although there is an apparent positive relationship between community interventions and the health and quality of life indicators, the designs do not permit direct attribution of program results to community participation. Community participation should be seen as a process rather as an intervention (7) and the context in which the programs are carried out must be identified and described. New research is needed that follows the best practice guidelines for participatory processes for people affected by leprosy and their communities. The barriers to effective participatory health programs must be identified, and the role of gender taken into account. And finally, we need to identify difficulties community programs face in being sustainable, and to define strategies to overcome these.

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Table 1. Search Strategy and Coverage Dates for Different Databases

Database	Search
Pubmed (1946 to present)	- ("leprosy"[MeSH Terms] OR "leprosy"[All Fields]) AND ("social participation"[MeSH Terms] OR ("social"[All Fields] AND "participation"[All Fields]) OR "social participation"[All Fields]) - ("leprosy"[MeSH Terms] OR "leprosy"[All Fields]) AND ("social participation"[MeSH Terms] OR ("social"[All Fields] AND "participation"[All Fields]) OR "social participation"[All Fields]) AND programmes[All Fields]) - ("leprosy"[MeSH Terms] OR "leprosy"[All Fields]) AND ("social participation"[MeSH Terms] OR ("social"[All Fields] AND "participation"[All Fields]) OR "social participation"[All Fields]) AND (("health"[MeSH Terms] OR "health"[All Fields]) AND impact[All Fields]) - (("residence characteristics"[MeSH Terms] OR ("residence"[All Fields] AND "characteristics"[All Fields]) OR "residence characteristics"[All Fields] OR "community"[All Fields]) AND based[All Fields] AND program[All Fields]) AND ("leprosy"[MeSH Terms] OR "leprosy"[All Fields]) - (("residence characteristics"[MeSH Terms] OR ("residence"[All Fields] AND "characteristics"[All Fields]) OR "residence characteristics"[All Fields] OR "community"[All Fields]) AND based[All Fields] AND ("rehabilitation"[Subheading] OR "rehabilitation"[All Fields] OR "rehabilitation"[MeSH Terms])) AND ("leprosy"[MeSH Terms] OR "leprosy"[All Fields])
Scielo (2002 to present)	- "leprosy" AND "social participation" - "community based program" AND "leprosy" - "community based rehabilitation" AND "leprosy"
Scopus (1970 to present)	- " leprosy" AND "social participation" - "leprosy" AND "social participation" AND " program" - "leprosy" AND "social participation" AND "health impact" - "community based program" AND "leprosy" - "community based rehabilitation" AND "leprosy"
Lilacs (1982 to present)	- "leprosy" AND "social participation" - "community based program" AND "leprosy" - "community based rehabilitation" AND "leprosy"
Web of Knowledge (1900 to present)	- " leprosy" AND "social participation" - "leprosy" AND "social participation" AND " program" - "leprosy" AND "social participation" AND "health impact" - "community based program" AND "leprosy" - "community based rehabilitation" AND "leprosy"

Table 2. Inclusion Criteria

Community intervention programs:
“Carried out with specific groups that present common characteristics, needs or interests and that aim - through active participation in some or all of the program´s phases- to support the capability of these groups to address needs, promote health and increase quality of life and social wellbeing. This concept aligns with the Community Participation Strategy." (15).

Evaluated programs:
Programs that provides at least one indicator of analysis from the evaluation of results.

People affected by leprosy:
Those who are in treatment for leprosy and those cured of the disease (83).

Community:
“a specific group of people, often living in a defined geographical area, who share a common culture, values and norms, are arranged in a social structure according to relationships which the community has developed over a period of time” (84)**.**

“Global priority countries”:
Countries that account for 95% of the disease burden of leprosy (2).

Figure 1. Prisma Flow Diagram

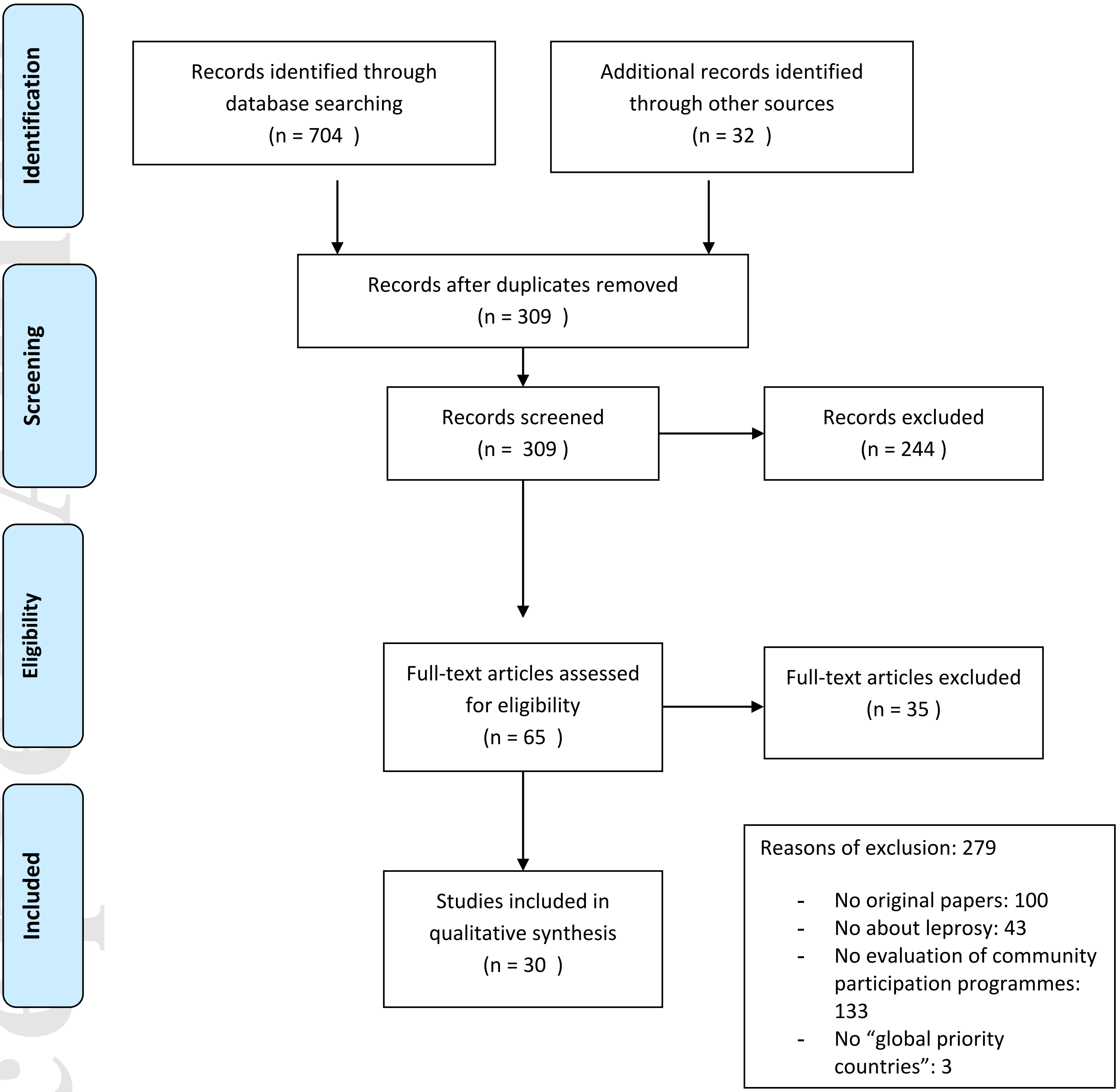


Table 3. Variables included in the extraction protocol.

Year of publication: periods 2016-2018, 2011-2015, 2006-2010, 2001-2005, 1996-2020 and 1990-1195
Review of publication
Setting and Country: intervention place: health center or specific community group, region or area and country.
Study design: community intervention (experimental or quasi-experimental), case-control, cross-sectional, qualitative and mixed methods.
Target population: child or adult population or both
Intervention type: according to key components of the Community-Based Rehabilitation Matrix, assigning the predominant key to each program within its objectives: health, education, subsistence, social or empowerment (38)
Intervention-related variables:
Intervention: intervention description
Outcome: evaluation and results variables
Evaluation: positive, negative or neutral, based on the results of the program indicators presented in the article.
Program barriers
Sustainability: yes or no, based on whether the article included explicit information on the continuity of program benefits across a long period of time and/or with the withdrawal of funding (72,73).
Level of community participation: mobilization, collaboration or empowerment (18).

Table 4. Indicators of participation based on Draper´s model (18)

Indicators of Participation	Continuum of community participation				
	Values for mobilisation	⇔	Values for collaboration	⇔	Values for empowerment
Leadership: *Professionals introducing intervention, or community of intended beneficiaries*	Health professionals assume leadership. Local leaderships does not necessarily try to widen the decision-making base in the community.		Collaborative decision-making between health professionals and community leadears. Local leadership tries to present the interests of differents groups.		Programme is led by community members who are selected through a representative process. Health professionals give leadership training if necessary. Local leadership ensures that the interests of various groups are represented in decision-making.
Planning and Management: *How partnerships between professionals and community are forged*	Health professionals tell the community how they may participate. They decide the programme´s focus, goals and activities and provide the necessary resources.		Collaboration instigated by health professionals. Community invited to participate within a predetermined remit. Activities reflect community priorities and involve local people and existing community organizations. Both professionals and community members provide resources. Some transfer of skills occurs.		Partnerships between communities and health professionals created and institutionalised. Professional´s facilitate, the community defines priorities and manages the programme. Local people learn skills they need for management and evaluation.
Women´s involvement:	The inclusion of women is not specifically sought outside their traditional roles and their active participation is not a programme objective.		Women actively participate in some aspects of the programme, but they have minor decision-making roles.		The active participation of women in positions of decision-making and responsibility is a programme objective.
External support for programme development: *In terms of finance and programme design*	Funding comes from outside the community and is controlled by health professionals. Programme components, including community participation, designed by health professionals to address health outcomes they prioritise and in ways		Majority of funding is from outside the community, but local people are asked to contribute time, money and materials. Professionals allocate resources, although they may consult community members. Programme is designed by health professionals in discussion with community		Community members work towards finding ways of mobilising resources, including through external funding and with their own resources, e.g. micro-financing. Programme is designed by community members with technical advised form professionals on request.

	they deem appropriate.		representatives. Role of each in the programme, including women and minority groups is negotiated.		The design is flexible and incorporates wide community participation, including women and minority groups.
Monitoring and evaluation: *How intended beneficiaries are involved in these activities*	Health professionals design M&E protocols, choose the outcomes and analyse the data in ways to suit their information needs. Approach is mainly one of hypothesis testing and statistical analysis of health-related outcomes. Communities may not be made aware of the findings.		Health professionals design mixed method M&E protocols and perform analyses, but community members are involved in data collection. A broad definition of "success" is used. Responses to monitoring findings are jointly decided and community feedback is both sought and given.		Communities do a participatory evaluation that produce locally meaningful findings. A variety of data collection methods are used and the community chooses the indicators for success. Professionals assist at request of community. Communities actively involved in participatory monitoring and in deciding how to respond to monitoring findings. Communities contribute to any wider external evaluations.
Score	1	2	3	4	5

Table 5. Descriptive Characteristics of the Articles According to the Main Key Components of the Intervention (Based on the Community-Based Rehabilitation Matrix (CBRM) of the WHO, 2008)

	Type of intervention according to the key component of CBR Matrix (WHO, 2008)					**Total**
	Health N = 10	**Education N = 3**	**Livelihood N = 6**	**Social N = 6**	**Empowerment N = 5**	**N 30**
Year of publication						
2015- 2018	1	0	0	6	2	**9**
2010- 2014	2	1	1	0	1	**5**
2005-2009	2	0	1	0	2	**5**
2000-2004	4	1	2	0	0	**7**
1995-1999	1	1	0	0	0	**2**
1990-1994	0	0	2	0	0	**2**
Journal						
Asia Pacific Rehabilitation Journal	2	0	1	0	1	**4**
International Journal of Leprosy	3	0	1	0	0	**4**
Leprosy Review	5	3	4	2	4	**18**
PLOS NTD	0	0	0	2	0	**2**
Others	0	0	0	2	0	**2**
Setting						
Region or Area	6	1	5	6	5	**23**
City	1	0	1	0	0	**2**
Community Group	1	1	0	0	0	**2**
Healthcare Centre	2	0	0	0	0	**2**
School	0	1	0	0	0	**1**
Country						
Ethiopia	3	0	1	0	0	**4**
India	3	2	3	0	0	**8**
Indonesia	1	0	0	6	0	**7**
Mozambique	1	0	0	0	0	**1**
Nepal	1	0	0	0	4	**5**
Nigeria	1	0	2	0	0	**3**
Tanzania	0	1	0	0	1	**2**
Study Design						
Community Intervention. Experimental	0	0	0	1	0	**1**
Community Intervention. Quasi-Experimental	2	3	0	0	0	**5**
Case-control	1	0	0	0	1	**2**
Cross-sectional	1	0	1	0	0	**2**
Qualitative	1	0	1	1	1	**4**
Mixed Methods	5	0	4	4	3	**16**
Target Population						
Adults	8	0	6	6	4	**24**
Children	0	1	0	0	0	**1**
Adults and Children	2	2	0	0	1	**5**

Table 6. Characteristics of the Interventions with the Health Key Component of the CBRM

Authorship	Intervention	Outcomes	Eval.	Barriers	Sustain.
Abera, 2003(40)	Self-care groups: education in the management and prevention of ulcers	Attitudes toward the program, health personnel response and coping mechanisms	+	Vertical organization Lack of information	No
Abera, 2003(42)	Self-care groups: education on management and prevention of ulcers to improve self-image	Level of self-image	+	No mention	No
Benbow, 2001(43)	Self-care groups: education in the management and prevention of ulcers	Group development, use of wound materials, perception of participants about the program, prevalence of ulcer	+	No mention	Yes
Chakraborty, 2006(44)	Education on self-care tips to prevent disabilities and reduce hospital admissions of those affected	Hospital admission rates, people using footwear, people practicing self-care at home, families helping with self-care at home, families attending self-care groups	+	Lack of awareness Lack of time Financial problems False beliefs	Yes
Cross, 2001(50)	Education on management and prevention of disabilities among those affected	Hospital admission rates for complicated ulcers	+	No mention	No
Deepak, 2013(52)	Self-help groups: education on ulcer management and prevention of disabilities among those affected	Group memberships, group meeting places, frequency and duration, types of training and duration, use of footwear, perceptions of benefits of the program.	+	Long distances Transportation difficulties	No
Ebenso, 2009(55)	Self-care groups: education on the management and prevention of ulcers and obtaining necessary materials for those affected.	Ulcer prevalence, re-admission interval, reason for join groups, members experience with groups, community changes due to groups, changes in activity and participation, future expectations.	+	No mention	No
Ethiraj, 1995(56)	Education for those affected and the community about the disease, self-care tips and disability prevention.	New cases with deformity; prevalence of tropic ulcers; level of leprosy awareness.	+	No mention	Yes
Porichha,	Education on self-care tips and disability	Indicators related to self-care practices, use of foot wear and	+	No mention	No

2011(66)	prevention among those affected, family members and other community actors	community support			
Crook, 1991(46)	Self-care groups: resolution of self-care problems in the community	self-perceived condition, adherence to treatment, ability to do personal care, the kind of help and services received, and acceptance and support of the person affected by leprosy	+	No mention	No

Authorship	**Core Intervention**	**Outcomes**	**Evaluation**	**Barriers**	**Sustainability**
Susanto, 2017(68)	Education of the community about the disease through activities in schools, companies and community spaces	Knowledge, attitudes and practice about the disease	+	Lack of information	No
Norman, 2004(62)	Education of school children about leprosy, signs and symptoms and training to identify possible cases	New rates case detection	+	Lack of privacy	No
Van Der Broek, 1998(69)	Education of the community about the disease and training for the detection of possible new cases	Knowledge, attitudes and beliefs about the disease	neutral	Environmental factors	Yes

Table 7. Characteristics of the Interventions Related to the Education Key Component of the CBRM

Table 8. Characteristics of the Interventions Related to the Livelihood Key Component of the CBRM

Authorship	Core Intervention	Outcome	Evaluation	Barriers	Sustainability
Abera, 2000(41)	Promotion of participation and improvement in socioeconomic integration of those affected in the community through microcredits	Change in employment patterns , economic and living conditions, social and attitudinal aspects	+	No mention	No
Ebenso, 2010(53)	Development of employment opportunities that contribute to improving the family economy of those affected through community interventions and individual interventions	Prejudicial attitudes, financial independence, accessibility to local services, desire for acceptance, sense of dignity improvement, participants perception about what elements of the program stimulate stigma-reduction	+	No mention	No
Ebenso, 2007(54)	Development of employment opportunities that contribute to improving the family economy of those affected through community interventions and individual interventions	Level of participation restriction, participants experiences of SER and effect on their living conditions	+	No mention	No
Gershon,1992(57)	Creation of opportunities for access to work for those affected and their families through economic supports and “training placement activities”	Reactions of patients and family about the disease; occupational status; socio-economic benefits.	+	No mention	No
Jagannathan, 1993(58)	Reinsertion in the labor market of those affected through job training that also supports covering local needs	Economic status.	+	No mention	No

Rao, 2000(67)	Economic empowerment and restoration of the social status of those affected	Socio-economic status.	+	Lack of awareness and participation Delays in care Long distances	No

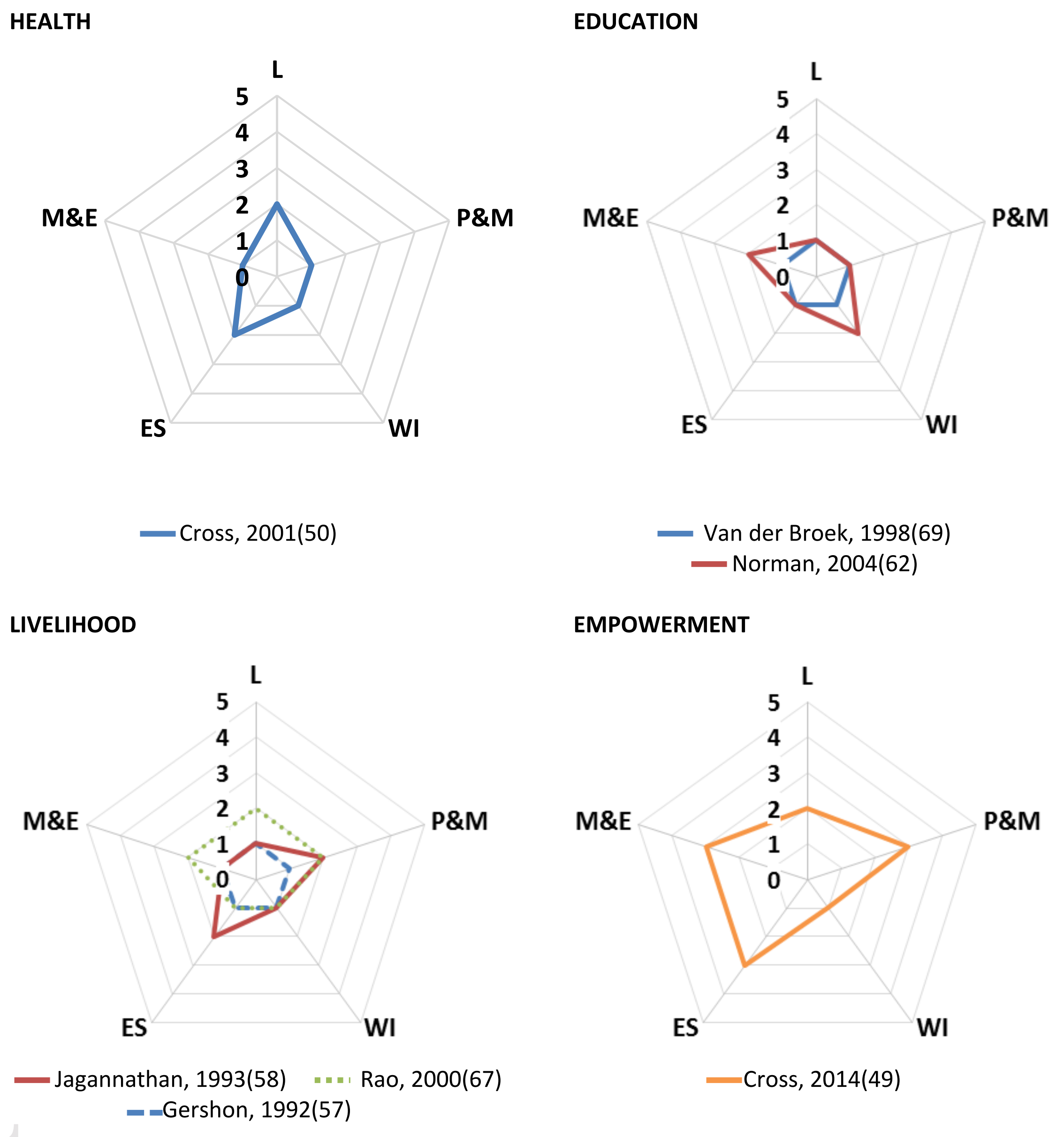
Authorship	Core Intervention	Outcome	Evaluation	Barriers	Sustainability
Dadun, 2017(51)	Counseling, socio-economic development and contact to reduce the impact of stigma related to leprosy	Stigma (individual and in the community), participation restrictions, quality of life and social distance.	+	No mention	No
Lusli, 2015(59)	Counseling to reduce stigma and its negative psychological effects on those affected by leprosy with the involvement of lay and peer counselors	Meeting´s characteristics, counselling skills, Knowledge about the disease, experiences about stigma, number of clients attended.	+	No mention	Yes
Lusli, 2016(60)	Counseling involving lay and peer counselors to reduce the impact of stigma related to leprosy	grade of experienced stigma, grade of social participation restriction, grade of quality of life	+	Lack of experience Concealment	Yes
Peters, 2016(63)	Video production using participatory processes to reduce the impact of leprosy-related stigma	Impact on the participants: participant engagement, individual confidence, capacity and sense of “can do”, stabilizing inclusive and collaborative group dynamics, participant supporting, motivating social dialogue, critical development, building collective agency, group communication action, social influence and new social awareness	+	No mention	Yes
Peters, 2015(64)	Contact intervention to reduce leprosy-related stigma	knowledge; labelling, stereotyping, separation, status loss and discrimination, public stigma	+	Concealment Physical limitations	Yes
Peters, 2015(65)	Recognition of different relevant mindsets for Leprosy-related stigma reduction	Explicit mindsets, aspirations, approaches to research and scientific validity, attitudes toward interventions, activities and timing, attitudes to leprosy and stigma and approaches to people affected by leprosy	+	No mention	No

Table 9. Characteristics of the Interventions Related to the Social Key Component of the CBRM

Table 10. Characteristics of the Interventions Related to the Empowerment Key Component of the CRBM

Authorship	**Core Intervention**	**Outcome**	**Evaluation**	**Barriers**	**Sustainability**
Cross, 2005(47)	Empowerment of those affected by leprosy to support their being agents of change in their struggle with stigma	Perception of participants about benefits of the program, level of participation restriction, number of impairments	+	No mention	Yes
Cross, 2005(48)	Empowerment of those affected by leprosy to support their being agents of change in their struggle with stigma	Level of participation restriction	+	No mention	Yes
Cross, 2014(49)	Empowerment of those affected with leprosy to support disease management and their being change agents in their communities	Leprosy related activities, enabling factors, factors that facilitate community trust, enhanced motivation factors	+	No mention	No
Choudhary, 2017(45,61)	Empowerment of those affected by leprosy for poverty alleviation	relative poverty, social restriction, physical effects and self-efficacy, order of regard for SHG activities	+	No mention	No
Mwasuka, 2018(61)	Community empowerment to strengthen early diagnosis of those affected by leprosy	New cases identified, proportion of new cases in children, proportion of MB vs PB and proportion of disability level 2	+	Lack of time Inappropriate hours Environmental factors Transportation difficulties	No

Figure 2. Participation Indicators (Spider-grams)



Indicators of Participation: L: Leadership / P&M: Planning and Management / WI: Women´s Involvement / ES: External Support / M&E: Monitoring and Evaluation

Grade of participation: 1 Mobilization, 2 Between Mobilization and Collaboration, 3 Collaboration, 4 Between Collaboration and Empowerment, 5 Empowerment.