BMJ Open

Investigating the sustainability of self-help programmes in the context of leprosy and the work of leprosy missions in Nigeria, Nepal and India: a qualitative study protocol

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To cite: Choudhury S, Ilozumba O, Darlong J, *et al*. Investigating the sustainability of self-help programmes in the context of leprosy and the work of leprosy missions in Nigeria, Nepal and India: a qualitative study protocol. *BMJ Open* 2023;**13**:e070604. doi:10.1136/bmjopen-2022-070604

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2022-070604).

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Received 01 December 2022
Accepted 03 May 2023

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ABSTRACT

Introduction Leprosy occurs among very poor people who may be stigmatised and pushed further to the margins of society. Programmes to improve social integration and stimulate economic development have been implemented to help break the vicious cycle of poverty, reduced quality of life and ulcer recurrence. These involve forming groups of people, with a common concern, to provide mutual support and form saving syndicates—hence the term 'self-help groups' (SHGs). While there is literature on the existence and effectiveness of SHGs during the funded periods, little is known about their sustainability. We aim to explore the extent to which SHG programme activities have continued beyond the funding period and record evidence of sustained benefits.

Methods and analysis In India, Nepal and Nigeria, we identified programmes funded by international non-governmental organisations, primarily aimed at people affected by leprosy. In each case, financial and technical support was allocated for a predetermined period (up to 5 years).

We will review documents, including project reports and meeting minutes, and conduct semistructured interviews with people involved in delivery of the SHG programme, potential beneficiaries and people in the wider environment who may have been familiar with the programme. These interviews will gauge participant and community perceptions of the programmes and barriers and facilitators to sustainability. Data will be analysed thematically and compared across four study sites.

Ethics and dissemination Approval was obtained from the University of Birmingham Biomedical and Scientific Research Ethics Committee. Local approval was obtained from: The Leprosy Mission Trust India Ethics Committee; Federal Capital Territory Health Research Ethics Committee in Nigeria and the Health Research Ethics Committee of Niger State Ministry of Health; University of Nigeria Teaching Hospital and the Nepal Health and Research Council. Results will be disseminated via peer-reviewed journals, conference presentations and community engagement events through the leprosy missions.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Interviews will be conducted with two groups of people, 'insiders' (people who were directly involved in the self-help group (SHG) programmes during the funded period) and 'outsiders' (those who were aware of the programmes and who might have evidence or information of their sustainability) to capture a wider perspective of SHG sustainability.
⇒ Comparative analysis of data from across the four geographical areas in Asia and Africa will allow us to refine existing theory on sustainability of SHG programmes for people with leprosy, disability, other conditions causing ulcers or marginalised people, once funding has ceased.
⇒ The primary limitation of this study is that we will conduct retrospective interviews which will rely on participants memories of events over several years ago, resulting in recall bias.
⇒ The researchers conducting the interviews and analysing the data are paid with funding from the leprosy non-governmental organisations which were responsible for implementing the interventions.

INTRODUCTION

Leprosy tends to occur among very poor people and can result in leprosy-related ulcers and deformity. Leprosy may lead to stigmatisation and people being pushed further to the margins of society.[1] In order to help break the vicious cycle of poverty, low mood and ulcer recurrence, programmes to improve social integration and stimulate economic development have come into being.[2] These programmes are community based and involve the formation of groups of people who can provide mutual support; hence the term 'self-help groups' (SHGs).[3]

Self-help groups and other types of group activities

SHGs have much in common with 'women's groups' in the context of maternity care,[4–6] and 'peer support groups' in the context of HIV[7 8] and diabetes care.[9] However, it is the inclusion of some form of economic assistance that distinguishes SHGs from other types of group-based mutual support.[10–21] The term 'self-help group' is somewhat elastic but it is commonly used to describe groups that include activities specifically aimed at economic advancement.[22 23] Biscaye and colleagues use a wider definition based on voluntary membership, self-governance of the group, regular meetings, member contributions of assets such as time and labour (but not money) with the aim of improving welfare.[24] In this article, we will use SHG in the narrower sense of including a specific economic component, but we will also allude to literature based on the broader definition above.

The economic activities included in SHGs borrow heavily from those used in economic microdevelopment projects generally. These include assistance in setting up savings groups, provision of some initial 'seed-corn' money/business loans provided by the donor organisation,[25] non-conditional and conditional cash transfers, training in marketable skills and farming methods (eg, use of optimal seeds/fertilisers) and support in setting up bank accounts and joining national business networks.[26] SHGs often include other (ie, non-economic) activities including self-care[27 28] and WASH (Water, Sanitation and Hygiene).[29] In India, the SHGs we have encountered are female only, while in Nepal and South East Nigeria they are mixed gender. In North Central Nigeria groups are female only, male only or mixed gender.[30]

We have observed that SHGs brought into existence to support people affected by leprosy have widened their remit to include people with disabilities due to conditions other than leprosy, marginalised people, single women and, increasingly, people who are very poor but who have no medical condition. As a general rule, SHGs do not come into being spontaneously; while they are community-based organisations, they come into being through the activities of organisations external to the local community.[31] The funding for SHGs often comes from Non-Government Organisations (NGOs) such as the Leprosy Missions. A key factor of SHGs, and the topic of this paper, relates to the duration of this external funding. We have found that funding for self-help programmes tends to be time limited. This raises the question of the sustainability of SHGs beyond the funding period. There is an implicit assumption that SHGs will become self-sustainable. Finding out whether, or under what circumstances, self-sustainability is achieved is the purpose of the study described here.

Sustainability of SHGs

Sustainability of SHGs can be considered as long-term continuation of the core activities without external support.[32] Empirical literature on sustainability of SHGs is very sparse and we are therefore conducting a review to close the gap in the literature. So far, we have not found any studies of sustainability of SHGs concerned with leprosy or funded by a Leprosy Mission/NGO. Given the lack of studies specific to the leprosy domain, we extended our review to include health in general and found one study that investigated factors that might promote SHG sustainability after external financial support was withdrawn. This study found that community support, strong leadership, an appetite to acquire new knowledge and strong belief in value of SHGs among members of the groups were associated with sustained activities.[31] Biscaye and colleagues cast the net still wider and carried out a systematic review on the effectiveness of SHGs using, as mentioned above, a broad definition of self-help that was not limited to groups that included an economic component. Again they found little evidence on sustainability and any evidence that came to light was weak and based mainly on anecdote rather than systematic study.[24]

Since the literature on sustainability of SHG programmes is limited, an evaluation is critical in determining how effective programmes are in achieving their goals over the longer term and whether activities continue once the funding ends. Having reviewed the available literature, we can construe that sustainability can be observed in two (non-exclusive) ways: first, at the level of process (the extent to which the characteristics/elements of programmes are sustained, ie, groups continue to meet) and second, at the level of outcome, such as well-being, health, social integration and economic progress.[27 33]

The theory that SHGs acquire skills and become independent over time would seem more in keeping with a policy of gradual, rather than an abrupt, withdrawal of funding. Yet funding was not tapered in the cases with which we are familiar. It must be assumed that the capacity for self-sustainability accrues over time. If so, it could be argued that to guillotine funding abruptly at a predetermined point in time is not the optimal strategy. Nor have we found any evidence to support a 5-year intervention period as opposed to any other preset period. Finally, there is evidence within the behavioural psychology literature, that sudden withdrawal of support can be deeply demotivating, leaving the recipients worse off than if the intervention had not been promulgated in the first place.[28] In short, it cannot be taken as inevitable that this type of limited duration intervention does more good than harm. With this in mind, we set up the study described here to explore sustainability and how it might be affected by intervention design and context, including funding and implementing organisations in the larger system context, and the level and duration of funding provided.[29]

In this study, we aim to explore the extent to which SHG programme activities have continued in the time beyond the funding period. This falls under our full programme of work in the National Institute for Health Research, Research and Innovation for Global Health Transformation (RIGHT) leprosy grant, whose overall aim is to improve self-care in the community for patients

who are at risk of recurring leprosy ulcers. Previous SHGs were implemented in all four of our study sites described below. We are therefore in a position to evaluate the sustainability of all four SHG intervention programmes.

OBJECTIVES

The objectives of this work programme are to:

1. Explore the extent to which the programmes were sustained with respect to process, structure and outcome.
2. To investigate what might facilitate or hinder sustainability.

METHODS AND ANALYSIS

Study sites

This study is focused on four sites: South East Nigeria, North Central Nigeria, Nepal and India. In each of these four study areas, we have identified historic programmes which established time bound SHGs. The funding for the programmes came from a variety of sources: the Australian Government, the Leprosy Mission Australia, the Swedish International Developmental Agency (SIDA) through the Swedish Missions Council (SMC) and the German Leprosy and Tuberculosis Relief Association. In each case, financial and technical support was allocated for a predetermined period of up to 5 years, between 2009 and 2019 and then withdrawn. There were two programmes in Nepal—one ran from 2009 to 2014, followed by another, in a different geographical area, from 2014 to 2019. A two-phased programme was funded from 2013 to 2018 in India. In North Nigeria, two programmes were implemented from 2013 to 2018. In South East Nigeria, SHG projects were implemented from 2010 to 2016.

An internal operational evaluation was conducted at the end of the funding period in each case but, to the best of our knowledge, no further study into sustainability has been carried out.

Study design

We will seek to retrieve and analyse any documents, including project reports and meeting minutes related to the purpose and planning of the SHG projects. This activity will be followed by semi-structured interviews.

Patients and the public

Patients and the public are not involved directly in the design and conduct of this retrospective study.

Collation and analysis of programme documents

Programme managers or equivalent members of staff at the implementing organisation will be contacted and asked for programme descriptions, project reports and meeting minutes related to the purpose and planning of the SHG projects dating back to the planning stage. We aim to identify and summarise the original purpose of the SHG projects and plans for SHGs from these documents. We will gather any evaluation reports, produced internally and externally, to gain a holistic understanding of the SHG projects. We also aim to gather any evidence of groups continuing to meet or any activities that are still on-going.

Semistructured interviews

Semistructured qualitative interviews will be conducted with two groups of people—'insiders' and 'outsiders'. We aim to obtain perspectives from people who might be able to describe programmes, and provide any evidence on short-term effects and sustainability of programme activities or benefits. We also aim to elicit views on facilitators and/or barriers to sustainability and on how these may be overcome.

Sampling strategy

Our study will adopt two purposive sampling strategies in each site; identification of participants who meet specific criteria and snowballing.[34] Purposive sampling will help identify suitable people who may still be part of an SHG or the implementing organisation to interview. Snowball sampling will involve contacting people identified in conversations with our initial contacts. We will record the number of designated interviewees who are uncontactable or decline.

Insiders

'Insiders' are people who were directly involved in the SHG programmes during the funded period.

The 'insider' groups will consist of people who were:

- staff responsible for overall management (governance of the project) of the SHG programmes.
- staff responsible for local implementation.
- group members who have engaged with SHGs.
- Family members of people who attended SHGs.

'Outsiders'

'Outsiders' are peripheral parties who were aware of the programmes and who might have evidence or information of their sustainability.

The 'outsider' groups will include:

- Staff in funding agencies with knowledge of the programme/project.
- People in official positions who are likely to have known about the SHG programmes and its effects. Examples include government officials, the administrator at a local health facility, Community Health Workers and local public health officials, disability officers bank managers.
- Community leaders/ex-community leaders (including those elected to leadership positions) with awareness of local SHGs.

Data collection

The study team will examine the SHG within their own organisations in India and North Central Nigeria. However, the researchers collecting the data were not involved in the implementation of the SHG programme. In Nepal, the organisation is working with a researcher from the local university to collect data. In South East

Nigeria, the data will be collected using a consultant. All data collection will be monitored and supervised by researchers at the University of Birmingham and Warwick who are not members of the project implementation organisation. Interviews will be conducted using the interview topic guide (online supplemental appendices 1 and 2). All participants will be asked about the topics, although how the questions are asked will be adapted to the particular participant. For example, project directors and people from funding organisations will be asked questions on financial contributions to the project, whereas members of SHGs will be asked what type of financial/economic activities they are aware of. One particularly important question relates to any evidence of economic activity that may plausibly be attributed to the intervention. Interviewers will elicit the activities; explore how they have developed over time and ask how or to what extent they may be attributed to the intervention. We will probe the effect that the SHGs may have had on the broader community and vice versa. We will ask those managing the intervention about the overall management structure of the intervention and ask group members their perceptions of this.

We will sensitively explore with interviewees about relationships between members of the SHGs, including group leaders and facilitators, as these have been shown to influence group success.[35] Anyone in an administrative position will be asked whether they can identify any written material covering current or past activities of the groups.

Interviews will be conducted by local research staff, trained in qualitative interviews, in the language spoken by the participants or with the use of an interpreter. The qualitative training for the local researchers included interview techniques with role play to practice introductions, consent taking, how to ask questions and prompts, how to deal with distress or concerns raised and how to end the interview. Further training will focus on data analysis. Regular meetings with the qualitative team will be held to monitor progress and to provide feedback on the quality and content of data collection as it proceeds. Interviews with staff in funding agencies and people in the highest official position in the organisations, such as the country directors, who are able to speak and understand English, will be conducted by the Chief Investigator.

We anticipate conducting 25–40 insider interviews and 6–25 outsider interviews at each study site. Interviews will continue until data saturation is reached at each study site and no new themes appear to be emerging at each study site.[36] This will be determined through conducting blocks of interviews from each target group and coding and analysing these transcripts.

Analysis of interviews

All interviews will be audio recorded and transcribed and translated into English. Field notes will similarly be translated. The individual site data will be analysed by researchers at each site, following training, using Braun and Clarke thematic analysis.[37] The analysis will begin with the researchers familiarising themselves with the data early on through reading the interview transcripts and field notes. Data from the first few transcripts will be coded line by line by two researchers independently. This will help identify any discrepancies in the assigned codes, develop and refine the coding framework and establish intercoder consistency. Coding will be applied to all interview data and emerging codes will be incorporated. We will identify the contextual factors that participants consider influencing sustainability, and how what happened in the groups influenced sustainability. Additionally, comparative analysis will be conducted between the 'insider' and 'outsider' groups at each study site. Data from across the four study sites will be triangulated to explore similarities and differences in sustainability outcomes across the different contexts, paying attention to the impacts of factors such as culture, the local process of establishing SHGs and local structure of the SHGs and gender composition between the various study sites.

Reflections on anticipated outcomes

This is a retrospective study based largely on memory. Moreover, people will be, to some extent, emotionally 'invested' in the programmes. To mitigate recall bias, we will ask for examples of SHG activities and outcomes—for example, successful businesses that were formed and their trajectory. To mitigate bias from internal meeting Minutes and reports, we will be gathering any evaluation reports available, which may have been conducted internally or externally.

We anticipate new insights that prompt action. For example, we may find that the SHGs were highly active in the short term, but that actions were seldom sustained such that they are now mostly a distant memory. Such a finding could influence donors to make longer-term investments and/or taper investments more gradually. It could encourage research funders to set funds aside for evaluation of sustainability even when short-term benefits have been demonstrated. We may make more nuanced observations. For example, we may find that, even within one area, some SHGs continue to operate and generate new enterprises, while others dissolve. In that case, we might be able to discern likely facilitators—factors in the implementation of the intervention or its context that are conducive to success.

Our findings will not be leprosy specific. For a start, people affected by leprosy are in the minority in the SHGs in all of our participating countries of this project. Moreover SHGs, or similar structures given different names, have become ubiquitous over many low-income and middle-income countries. We plan to learn general lessons concerning SHGs or similar initiatives.

Data storage and security

Data will be stored on institutional network drives with firewalls and security measures in place. Hard copy records will be stored in a locked cabinet in a secure

location. Each study site will have their own unique set of keys to access data locally.

ETHICS APPROVAL, CONSENT TO PARTICIPATE AND DISSEMINATION

The research will be performed in accordance with the Declaration of Helsinki for Human Research of the World Medical Association. Written informed consent will be obtained from all participants; or thumb/fingerprints will be requested in lieu of a signature if necessary. Approval has been granted by the University of Birmingham Biomedical and Scientific Research Ethics Committee (BSREC). Each site has also obtained site specific local approval, that is,:

- In India from The Leprosy Mission Trust India Ethics Committee.
- In NC Nigeria from the Federal Capital Territory Health Research Ethics Committee in Nigeria and the Health research ethics Committee of Niger State Ministry of Health.
- In SE Nigeria from the University of Nigeria teaching Hospital.
- In Nepal from the Nepal Health and Research Council.

We plan to disseminate the results via peer-reviewed journals, conference presentations and community engagement events through the leprosy missions.

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Acknowledgements We acknowledge the contribution of other members of the NIHR RIGHT grant team including members in The Leprosy Mission Nigeria, The Leprosy Mission Nepal, The Leprosy Mission Trust India, The Leprosy Mission England and Wales and the German Leprosy and TB Relief Association.

Contributors SC, OI, JD, KG, PAT, SU, DS, IBN, LU, AM, JS, FG and RJL: contributed to the development and editing of the manuscript. RJL: director of the NIHR RIGHT funded project at University of Birmingham, contributed to the conception of this article and critically evaluated the intellectual content.

Funding This research was funded by the National Institute for Health Research (NIHR: 200132) using UK Aid from the UK Government to support global health research. RJL is also funded by NIHR Applied Research Collaboration (ARC) West Midlands. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK Department of Health and Social Care.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting or dissemination plans of this research.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

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