

The need for an integrated, contextual, and holistic, minimum essential data collection tool for leprosy and lymphatic filariasis disability in India

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Summary

Aim To develop an integrated, contextual, and holistic, minimum essential data collection tool to reliably assess, and obtain a broad overview of issues needing attention among people suffering with WHO Grade 2 leprosy disability and WHO Grade 3 and above lymphatic filariasis (LF) disability in India, to enable the design of integrated and customized interventions to improve their situations.

Process A review of universal tools measuring activity limitations, stigma, participation restrictions, mental wellbeing, quality of life, and community stigma, was carried out for their applicability to leprosy and LF disability. A focus group discussion was conducted with field staff who had used these tools, to learn from their experiences. Questions for the minimum essential data tool were formulated based on their applicability and relevance to people with severe leprosy and LF disabilities, their context, and to our aim.

Results A hybrid quantitative and qualitative minimum essential data tool was developed, integrating leprosy and LF disability related issues to holistically assess situations, capture lived experiences, and enable participation of persons with leprosy and LF disability in designing solutions for the issues which impact them most.

Conclusions Integrated approaches are cost-effective and efficient when customized for the local context and the people impacted. Our tool will be piloted in Bihar, India to assess its reliability in the estimation of needs, and its effectiveness in designing interventions using a person-centered approach, to improve situations for people

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living with leprosy and LF disability within the cultural and environmental context of rural India.

Keywords: Assessment, leprosy, lymphatic filariasis, disability, integration

Introduction

Disability is an umbrella term for impairments, activity limitations, and participation restrictions caused by a disease or health condition.¹ Neglected tropical diseases (NTDs) are a group of 20 diseases that affect more than one billion people globally.² Many NTDs result in permanent disability and disfigurement, with devastating human and socio-economic consequences for those affected. While NTDs differ significantly in their prevalence and disease burden according to their geographic presence, one factor remains the same, they predominantly occur among the poorest, and most vulnerable and marginalized populations in low and middle income countries. In India, leprosy and lymphatic filariasis (LF) are the major potentially disabling and high morbidity NTDs responsible for immeasurable distress to those affected. India accounts for approximately one-third of the global prevalent cases of leprosy and LF, which are focused in areas of urban and rural poverty.³

Disability refers to the interaction between individuals with the condition, and the personal and environmental factors unique to their situation (e.g. negative attitudes, inaccessible transportation and public buildings, limited social supports).¹ Leprosy and LF disabilities have multidimensional consequences for affected individuals in India. People with leprosy and LF disability have to manage lifelong care for their disabilities, often in severely resource constrained settings. They experience deep seated stigma, prejudice, discrimination, and ostracism which often extends to their family members. The stigmatizing deformities and disabilities result in productivity losses and recurring out-of-pocket medical expenses causing significant financial hardship for some of the poorest people in India.^{4,5} All these factors greatly impact the quality of life of affected individuals.

Background

American Leprosy Missions, LEPRO Society, and the Health Informatics Rapid Lab, Public Health Foundation of India are collaborating in a 3-year integrated WASH and NTDs project in a resource constrained, leprosy and LF endemic district in Bihar, India. One of the project objectives is to improve surveillance and care for people with leprosy and LF disabilities.

During this project period, we plan to assess the actual situations of persons with World Health Organization (WHO) Grade 2 leprosy disability, and WHO Grade 3 and above LF disability, with respect to their lived experiences regarding activity limitations, stigma, participation restrictions, mental wellbeing, and quality of life, along with any prevalent community stigma that may exist in connection with these diseases. The purpose of this assessment is to holistically assess situations to obtain a broad overview of the issues needing attention. Our next step after piloting the tool would be to design customized, integrated interventions which we could pilot using a lean experimentation model. The same tool would be used to evaluate the interventions for effectivity, providing an evidence base for integrated approaches and interventions that work for similar disability related issues.

As we studied the available universal tools, and discussed them with field staff, we realized the operational difficulties involved in administering multiple tools to the same individuals. Additionally, there seemed little advantage in using separate tools with focus on leprosy or LF

specific impairments for similar disability related issues when the cultural and geographic context of the people affected was the same. Finally, considering that activity limitations, stigma, participation restrictions, mental wellbeing, and quality of life are not experienced as separate constructs by a person living with the disability, we decided to collect this information in a combined, practical, and contextual format.

We aimed for a single, context-specific tool, applicable to people with disability from both diseases, culturally appropriate for rural India's economically disadvantaged and more traditional populations, with questions that were easy to relate to and answer. This lean but reliable tool would have to be able to give us the minimum essential data to assess situations and enable the design of interventions. In keeping with our people-centered approach, involving the people most impacted by the disability is critical to developing customized interventions. We therefore decided to develop a hybrid tool comprising a short quantitative section that could be scored, and a qualitative section giving opportunity for people to express themselves about issues pertinent to them, and what they perceive as workable solutions. This paper highlights our rationale and the process we followed for developing a minimum essential data collection tool for leprosy and LF disability in India.

Aim

To develop an integrated, contextual, and holistic, minimum essential data collection tool to reliably assess, and obtain a broad overview of issues needing attention among people suffering with WHO Grade 2 leprosy disability and WHO Grade 3 and above LF disability in India, to enable the design of integrated and customized interventions to improve their situations.

Process

REVIEW OF TOOLS

We explored the literature through a scoping review to learn which tools, validated as being universal and cross-cultural, had been used in the measurement of activity limitations, stigma, participation restrictions, mental wellbeing, and quality of life among people with NTDs. The databases searched were Google Scholar, PubMed Advanced, PsycINFO, and Web of Knowledge.

The Stigma Assessment and Reduction of Impact (SARI) scale, Explanatory Model Interview Catalogue (EMIC), 5-Question Stigma Indicators for Affected Persons (5-QSI-AP), and the Social Distance Scale (SDS) have been used to assess stigma related to leprosy and LF. The Screening of Activity Limitation and Safety Awareness (SALSA) scale and the Participation Scale (P-Scale) have been used to assess activity limitations and participation restrictions respectively, related to leprosy and LF.⁶ Apart from these, the Self-Reporting Questionnaire (SRQ), Warwick–Edinburgh Mental Wellbeing scale (WEMWBS), Patient Health Questionnaire (PHQ-9) for mental wellbeing, World Health Organization Disability Assessment Schedule (WHODAS 2.0), and World Health Organization Quality of Life Brief version (WHOQOL-BREF) have been used in assessments for mental wellbeing and quality of life among people affected by leprosy and LF. Disease specific tools like the Lymphatic Filariasis Specific Quality of Life questionnaire (LFSQQ) have been used in comparison with other tools in LF.⁷

FOCUS GROUP DISCUSSION

A focus group discussion (FGD) comprising eight field staff, seven men and one woman, each with more than 20 years of leprosy and LF field experience was held. The participants were well acquainted with the disability-related issues we were researching, were professionally trained in disability management, and had previous experience in using universal tools—specifically, the P-Scale, the SALSA scale, the Stigma scales, and the WHOQOL-BREF scale—in leprosy and LF research projects in the Indian states of Bihar, and Jharkhand. They were invited to discuss their experiences of using these tools with reference to critical areas that needed to be included, whether they found the questions were easy for the respondents to understand and respond to, whether they found any questions culturally inappropriate or difficult for the respondent to answer, and what they did in such cases.

Their observation was that nuanced questions on any issue, while distinct in the English language, were almost indistinguishable when translated into the local language for the respondents' understanding and context. Questions like these appeared repetitive, which they found confused the respondents. For example, three questions in succession in the P-Scale ask, *'Do you visit other people in the community as often as other people do?'*, *'Do you move around inside and outside the house and around the village/neighbourhood just as other people do?'*, and *'In your village/neighbourhood, do you visit public places as often as other people do (e.g. schools, shops, offices, market and tea/coffee shops)?'* On translation, these questions are worded alike for the local context and understanding. Another observation was that pertinent cultural issues with a bearing on leprosy and LF disability were not addressed by the tools. For example, two situations that are realities in the Indian context are discrimination experienced by family members of the person with leprosy or LF disability, and discrimination experienced by people with leprosy and LF disability in healthcare settings. These were not addressed by the stigma tools. An essential activity of daily living like squatting for defecation, usual in the Indian context, was not covered in the activity limitation tools.

They found some questions in the universal tools contextually or culturally inappropriate. For example, in the P-Scale: *'Do you make visits outside your village as much as your peers do?'* We were informed that in most of rural India, travel out of the village irrespective of an NTD, is a rarity for most villagers. *'In your home, do you do household work?'*, here again, in most of rural India irrespective of an NTD, it is not customary for men to do household work. Therefore, the answers *'No'* to these questions do not constitute participation restrictions but a normal way of life, yet could lead to misrepresentation on analysis of the universal tool. In the case of the question, *'In family discussions, does your opinion count?'*, we were told that a question like *'Does your family respect you and treat you well?'* is far more likely to suggest participation restrictions within the family than asking if their opinion counts. Other examples of contextually or culturally inappropriate questions were from the SDS: *'How would you feel about renting a room in your home to someone with leprosy/LF disability?'* We were informed that villagers in the poorer NTD endemic areas do not have a room to rent. *'How would you feel having someone with leprosy/LF disability as a neighbour?'* They felt that this was not an appropriate question to ask when people in villages have been living as neighbours for years. The question, *'How would you feel about introducing someone with leprosy/LF disability to a young man/woman you are friendly with?'* was felt to be inappropriate in the traditional Indian context. The FGD participants also felt that questions in the quality of life tool such as, *'How satisfied are you with yourself?'*, *'To what extent do you have the opportunity for leisure?'* did not reflect a traditional rural way of thinking, and were difficult for people with severe disabilities to relate to.

From their experience of interviewing people using the different tools, the FGD participants advised us to use simple and non-confusing response options for our quantitative questionnaire, which people in rural settings would feel comfortable with. They also advised us to start our questionnaire with questions that were less distressing, and only then move on to issues that might be more painful for people to discuss. The participants of the FGD welcomed the idea of developing a single, integrated, contextual, and holistic, minimum data collection tool for use in programme locations where leprosy and LF disabilities were encountered together.

SELECTION, ADAPTATION, AND TRANSLATION OF QUESTIONS

The criteria we used to select the tools for our review were: *Are they used in NTDs? Do they cover the domains of activity limitations, stigma, participation restrictions, mental wellbeing, and quality of life? Are the questions applicable to persons with leprosy and LF disabilities?* Based on our criteria we selected six tools from our review for the domains to be assessed, specifically, activity limitations, stigma including community stigma, participation restrictions, mental wellbeing, and quality of life, and which are included in the NTD Toolkit.⁸ Using these tools as a frame of reference, we started developing our questionnaire. We found that every tool had been well researched and that we would be able to build on this foundation, along with the combined field and technical expertise of the field staff and researchers, all of whom have first-hand, on the ground experience with people with severe leprosy and LF disabilities in different parts of rural and urban India, and some of whom themselves experience leprosy and LF disability. We discussed each question in the selected tools with respect to relevance and applicability to the people, their context, and to our aim. We listed our reasons for adapting or rejecting questions from the referenced tools and formulated new contextual questions that we felt would serve our purpose better. We tried to avoid questions which would create bias due to the cultural context, questions which the interviewees would find difficult to relate to because of their more traditional and collectivist way of thinking, and questions which would be identically worded on translation.

To help formulate a working definition of quality of life for people with leprosy and LF disabilities for the 3-year integrated WASH and NTDs project in Bihar, we had informally interviewed five women and one man with WHO Grade 2 leprosy disabilities, and two men with WHO Grade 3 and above LF disabilities, ages ranging from the early twenties to the late fifties and with lived experiences of disability ranging from 3 years to 50 years, to understand what they perceive as a reasonably good quality of life for themselves, within their cultural and environmental context, despite their disability. Their shared life experiences also guided what our minimum essential data collection tool should include to facilitate development of interventions to improve such situations and in effect, contribute to improving the quality of life of people with similar experiences. For example, we needed to know about difficulties with essential activities of daily living like squatting for toilet, to be able to address a vital yet neglected area.

Following is a brief description of our review of the tools.

Activity limitations

We referenced the SALSA scale and adapted questions that were relevant and inclusive of both leprosy and LF disabilities for our context. Our focus was on key everyday activities of people in rural India. Therefore, pertinent activities of daily living such as squatting for toilet, sitting cross-legged as is customary, bending, lifting and carrying as during cultivation and fetching water from wells, etc. were added.

Stigma

We referenced the 5-QSI-AP (leprosy) scale. We found four questions relevant to our context and adapted these. We formulated new questions addressing stigma extending to family members of the affected individual, and stigma experienced by affected individuals through the discriminatory attitudes and actions of staff in health care settings. A set of questions for community stigma was developed referencing the Social Distance Scale (leprosy). We found three aspects relevant to our context which we adapted, and formulated two which were more contextual: ‘*Would you have a meal together with someone who has leprosy/LF?*’ and, ‘*Would you buy vegetables, food or other items from someone who has leprosy/LF?*’.

Participation restrictions

We referenced the P-Scale (Short). We adapted three questions, and combined three questions regarding restriction of movement within the village, which on translation were almost identical, into one question. In keeping with gender neutrality, we avoided questions that in the local context, could be slanted towards a particular gender.

Mental wellbeing

We referenced the Warwick–Edinburgh Mental Wellbeing Scale (WEMWBS) and found three questions useful for our purpose, which we adapted. On translation, some questions in this tool appeared to be almost identical to those in the quality of life (QOL) tool. The questions in the mental wellbeing and QOL tool generated the most discussion when we considered their applicability to traditional culture in terms of feeling accepted, respected, loved and needed. We therefore focused on how individuals are made to feel by family, friends, and others, and their fears concerning their futures.

Quality of life

We referenced the WHOQOL-BREF scale and found six questions useful for our purpose, which we adapted. We formulated new questions pertinent to quality of life for people with leprosy and LF disability: ‘*Are you satisfied with the aids, adaptive equipment etc. you have to help you manage your activities of daily living e.g. proper footwear, compression wear, other aids and adaptations according to the disability?*’, ‘*Are you satisfied with your ability to practice selfcare (can you do it yourself or do you need help, can you practice selfcare every day, do you have the things you need for self-care – basin, mug, soap, water, dressing, ointment)?*’, and ‘*Does the physical environment in and around your home allow you to function comfortably in spite of your disability e.g. to walk, climb, sit, squat, move around comfortably in and around the house and in and around the village?*’

We narrowed down our questions to a total of 30 for the quantitative tool, which we felt would give us pertinent and reliable information without tiring the interviewee. We then formulated uniform response options of ‘*All of the time; Some of the time; Rarely; and Never*’, and adjusted the scoring to make it uniform for the whole tool. We decided to exclude the ‘*Don’t know*’ response option present in many of the universal scales, as people with severe leprosy and LF disability do know what they have experienced, though they may not have opportunity to freely share their experiences. Since we want to develop customized interventions, it is important that we are sensitive and understand what people have experienced or are experiencing, and learn from what they perceive as solutions to their issues. This is where the qualitative section of our tool facilitates our person-centered and customized approach. The

time frame for all the questions was with reference to what a person had experienced over the past year since for example, in rural India where employment is seasonal, restricting the time frame to six months or less might elicit a misleading response to employment related questions. While the quantitative tool is designed to flow uninterruptedly and sequentially starting with questions about activity limitations and ending with questions about quality of life, it does have separate subscales for activity limitations, stigma, participation restrictions, mental wellbeing, and quality of life, which can be scored separately, as well as one overall score.

Field staff who spoke the local language, participated in the translation, and different translated versions of the same questions were discussed to ensure easy understanding for the target population.

Field test

We then tested the translated tool on a small sample. Two field staff used the questionnaire to interview two people with Grade 2 leprosy disability and six people with Grade 3 and above LF disability living in the community, in the states of Jharkhand and Bihar. The feedback on the design and content of the tool was very encouraging. The interviewees showed no hesitation in answering any of the questions and were happy to be able to share through the qualitative section. Feedback from the data collectors was to reword and change the tone of some of the questions. Another feedback was that all known disease-related data should be gathered beforehand from the project case sheets, and to only ask the interviewee about present complications like ulcers, reactions, or acute adenolymphangitis over the past year.

Results

Based on our reviews, discussions, and feedback from the field test, we limited our quantitative questionnaire to relevant and gender neutral questions with uniform response options, supplemented by a qualitative section for in-depth exploration. We were able to develop a single, integrated and holistic, hybrid quantitative and qualitative tool to obtain a minimum package of data that could highlight the leprosy and LF disability related issues needing attention, with information through the qualitative section that could guide customization of integrated approaches and interventions in the context of traditional and rural communities in India.

Discussion

Leprosy and LF are chronic NTDs with a comparable spectrum of disability related issues and requirement for lifelong care when severe disability is present. The issues surrounding these stigmatizing diseases are well documented and continue to be experienced by affected people living in economically disadvantaged communities and traditional cultural settings.^{9,10} The WHO International Classification of Functioning, Disability and Health (ICF) is a framework that provides a standard language to understand the effects of a health condition on functioning and disability. Changes or losses in body functions and structures (physical or mental) are referred to as 'impairments', difficulties experienced in performing activities are 'activity limitations', and restrictions to participation in family, school, work, and community life are referred to as 'participation restrictions'. Environmental factors can be physical (terrain, building design), attitudinal, and/or social factors (attitudes, laws) that affect functioning and disability.¹ According to WHO, mental health is a state of wellbeing in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.¹¹ WHO defines

‘quality of life’ as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.¹² While there are many universal tools available to measure activity limitations, stigma, participation restrictions, mental wellbeing and quality of life as separate constructs, people with disabilities experience the sum of all these constructs, and their experiences lie within the context of their cultures, value systems, and environments. There is a dearth of tools that holistically capture the significant social, economic, and psychological impact that similarly disabling and stigmatizing diseases have on affected individuals within their particular local cultural context.¹³ By integrating these constructs into one tool for leprosy and LF disability, we were firstly able to minimize the number of questions, as similar questions recur in separate construct tools. Secondly, we were able to integrate the tool for everyday activities of living rather than for precise impairments particular to any one disease. Finally, we were able to ensure inclusion of relevant questions when it came to how people live in the context of rural India.

Another drawback of universal tools is that the conceptualization of English terms in other languages is often limited to literal translation that makes it difficult to capture nuanced meanings and experiences.¹⁴ We have given some examples under our review of tools, where nuanced questions in English sound exactly the same when translated for the local understanding and context.

Many tools in use for measuring activity limitations, stigma, participation restrictions, mental wellbeing and quality of life as separate constructs in leprosy and LF, do not take into account the differences between the disease and the disease-related disability. It is widely recognized, and has been our own experience in the field, that affected individuals and their families usually suffer the negative socioeconomic, health related, and psychological consequences of leprosy and LF after these diseases have progressed to cause visible deformities and disabilities.^{15,16} Hence our focus on improving the situations for people living with these disabilities.

Many of the quantitative tools in use were originally developed in English, and designed by researchers and academicians to be cross-cultural and universally applicable. Global trends in public health are to integrate similar disease conditions for efficient ways of programme delivery and use universal tools for high-level data collection. Universal tools look for consistency and standardization, but we cannot ignore localization. We have given examples of how some questions in universal tools can elicit misleading responses when the cultural context is not taken into consideration. While global interconnectedness has increased, the world remains local to the people who live within their own cultures and environments. The way in which people perceive themselves as accepted, respected, loved and needed is also dictated by local culture. Hence, interventions that are meaningful to them need to be designed for their context. We therefore, formulated our questions based on their applicability and sensitivity to our target population, who are men and women with severe leprosy and LF disabilities, with varying degrees of physical and financial dependence on their families, and living within traditional Indian rural social and cultural norms.

Our single, holistic, and minimum essential data collection tool integrates leprosy and LF disability in the context of traditional and rural communities in India. The quantitative section can give a broad overview of the issues needing attention, and information through the qualitative section of the tool can guide customization of integrated approaches and interventions that we plan to pilot through a lean experimentation model as a next step. The same tool will be used to evaluate these interventions, providing an evidence base for integrated

approaches/interventions that work for similar disability related issues. Our tool is meant to be applicable to people with any NTD-related disability that engenders activity limitations, stigma, and participation restrictions. To begin with, we are focusing on people with severe leprosy and LF disability, as they form the largest group of people with NTD-related disability in India. Our pilot study using the tool would inform us if this minimum essential data package could be useful to guide service providers (health, water and sanitation, social welfare etc.) who operate in the same regional context as the people with the problems. A tool developed for the Indian context may also be applicable for Nepal and Bangladesh. Pilot studies using our tool in these countries would give us more information to strengthen these assumptions. The process of development of our tool may also provide new perspectives to local researchers working on contextual tools in other regions of the world.

Conclusion

With the increasing shift towards integrated approaches as being cost-effective and efficient, along with the understanding that the most effective interventions are shaped by the local context and the people most impacted, we have developed a tool that integrates leprosy and LF disability in the context of traditional rural communities in India. Our tool can holistically assess situations, highlight issues needing attention, capture lived experiences, and enable participation of persons with leprosy and LF disability in designing solutions for the issues which impact them most.

We will pilot our tool in Bihar, India to assess its reliability and effectiveness in the estimation of needs, and in enabling design of integrated and customized interventions using a person-centered approach, to improve the situations for people living with severe leprosy and LF disability within the cultural and environmental context of rural India. The data collection tool described here is currently in draft form and will be published after pilot testing has been completed and appropriate revisions have been made.

Authorship and contribution

The conceptualization of the tool, in-depth review of existing tools, the focus group discussion, and the development of the new tool was done by SA, AJ, and RKS. The literature search was done by SA and AJ. Translation of the tool was done by RKS and his team. The paper was written by SA and AJ. The guarantor is SA.

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Ethics approval

Ethics approval was not required for this research.

Patient consent statement

No patient consent was required.

Conflict of interest statement

All authors report no conflict of interest.

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