Approaches and tools for measuring disability in low and middle-income countries

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Accepted for publication 15 November 2007

Summary
Purpose To review the current state-of-the-art of measuring disability in the context of countries where leprosy is endemic.
Background Estimates of the prevalence of disability are often based on scanty data, collected with a myriad of different instruments. This is true for all four components of the International Classification of Functioning, Disability and Health (ICF); 1) body functions and structures, 2) activities and participation, 3) personal factors and 4) environmental factors, and for disability-related quality of life. There is an urgent need for data on leprosy-related disability, as well as for data on disability due to other causes. Data is needed as baseline for rehabilitation programmes, individual interventions, for programme monitoring and evaluation and for advocacy.

Results Measurement instruments and qualitative data collection techniques now exist which are directly applicable in the context of most leprosy-endemic countries. We discuss several instruments compatible with the ICF conceptual framework. A validated generic instrument for measuring impairment is currently not available. For measuring activity and participation, we recommend the WHODAS, the SALSA scale and the Participation Scale. We recommend an inclusive focus, where people with leprosy-related disability are seen as a sub-group of people with disability in the wider context, since many of their needs are the same as those of others. The need for validation and collection of normative reference data is also discussed.

Conclusions Programmes and research projects should choose an appropriate set of tools and methods and seek to apply these systematically. This choice should be guided by data on the validity of these tools in the concerned context. Instruments should be revalidated formally in every new context. Similarly, locally relevant normative data should be collected and applied to ensure that decisions are based on valid interpretations and conclusions.

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Introduction

The number of people with various types of disability in the world is not known. Often, an overall figure of 650 million is quoted.† However, this figure is based on rough estimates, since systematic data on the prevalence of disability are not available, particularly not from many developing countries. In addition, widely varying definitions and criteria for ‘disability’ have led to large discrepancies in estimates. Considering the aforementioned issues, the World Health Assembly Resolution 58.23 (May 2005), on ‘Disability, including prevention, management and rehabilitation,’ requests WHO to produce a World Report on Disability and Rehabilitation based on the best available scientific evidence. This report, which is being produced jointly by WHO and the World Bank is expected to be launched in 2009. It will provide governments and civil society with a comprehensive description and analysis of the importance of disability and the responses provided and make recommendations for action including action on approaches for measuring disability. The availability of this knowledge will play an important role in shaping policy and enhancing the lives of people with disabilities including persons with leprosy related disability.

Leprosy is one of the leading causes of preventable disability in many developing countries.1–6 WHO estimated the number of people with leprosy-related disability to be 1·5–2 million in 1996.7 Again, this figure is based on estimates and extrapolations, since accurate and up-to-date data are rarely available.

Leprosy affects the peripheral nervous system and, if not treated in time, leads to irreversible sensory, motor and autonomic neuropathy in a substantial proportion of cases.5,6,8–10 This in turn leads to secondary impairments, such as wounds due to burns or high pressure on the sole of the foot, contractures of fingers and toes and visual impairment. These impairments lead to limitations in activities of daily living2 and/or restrictions in social participation.11 The latter may also result from the fear of the diagnosis ‘leprosy’ directly, even in the absence of any visible impairments.12

Disability in leprosy has a number of special characteristics. First, it is preventable in principle. If leprosy is detected early and treated with multidrug therapy (MDT), permanent nerve damage can usually be prevented.13 A proportion of patients will develop further episodes of nerve damage, even during and after treatment, particularly in patients who already have nerve function impairment at diagnosis.5,6,14 If detected in time, treatment with corticosteroids can often reverse this impairment.6,15 Second, since leprosy mainly affects the peripheral nerves, primary impairments easily lead to secondary impairments, unless the person affected looks after him/herself very carefully.16–18

Third, leprosy and leprosy-related disabilities provoke strong negative social reactions.12,19–21 This stigma may be ‘enacted’22,23 or ‘felt’24 and may lead to self- (or internalised) stigma.25,26 The impact of these different types of stigma on social participation is remarkably similar, also under different circumstances, such as different cultures and stages of development.27

Data on the various forms of disability, their determinants, impact and response to interventions is very scarce. This is at least in part due to the inherent difficulty of measuring phenomena like impairment, activities of daily living, stigma, social participation and quality of life. The scarcity of data hampers planning services for prevention of disability and rehabilitation, and hinders advocacy efforts for the rights

of people affected by leprosy. However, in recent years, new instruments have been developed both within and outside the field of leprosy. The present paper examines the conceptual framework for measuring disability and reviews tools and instruments currently available for this purpose.

Overview of Approaches to Measurement of Disability

General Disability

There is great heterogeneity in conceptual frameworks used in disability measurement. Although a trend towards their standardisation is evident, international comparisons are currently unreliable because of the heterogeneity of the concepts and indicators of morbidity and quality of life. For example the different approaches used to generate prevalence estimates include:

Self-identification: Respondents are asked a variant of the question ‘Do you have a disability?’ Prevalence rates of between 1 and 3% are commonly obtained in this way. A more functional approach (e.g. ICF-based) yields estimates of between 10% and 20% in the same population.

Diagnosable conditions: The respondent is asked if they have any of the conditions listed, i.e. epilepsy, cerebral palsy, polio, leprosy, etc. Data is limited by the knowledge of respondents on their diagnosis, which may be influenced by variables such as education, access to health services and socio economic status.

Impairment focus: ‘Diagnosis’ and ‘treatment’ of the problem a person presents with are based on impairments that are found during physical examination. There may be little or no attention for the impact of a particular impairment on a person’s functioning in terms of activities or social participation, or of the impact of environmental factors.

Activities of daily living: The respondent indicates if they experience difficulties in performing tasks related to basic activities: dressing, brushing hair, bathing.

Social participation: The respondent is questioned about the influence of a health condition on their ability to perform their social role, i.e. going to school, working.

Information on activity limitations and participation restrictions is important. These data need to be complemented with information on difficulty in functioning at the level of the body for planning of rehabilitation programmes and individual level interventions.

Leprosy-related Disability

Until recently, surveys of leprosy-related disability were limited almost entirely to assessment of impairments and to Knowledge, Attitude and Practice (KAP) surveys. Mostly, such studies implicitly used a medical model of disability, seeing the physical impairments as the key issue. This is illustrated by the so-called ‘WHO Disability Grading’ (Table 1), which is a leprosy-specific measure of severity of impairment of eyes, hands and feet, unrelated to other conceptual frameworks of disability.

Various authors have recommended use of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) as a conceptual framework. This led to the development of the Green Pastures Activity Scale (GPAS), an instrument to assess activities of daily living relevant in low and middle-income countries. Attention to the
WHO-introduced conceptual framework of disability increased following an international Workshop on Measuring Disablement in New Delhi in 2000, which set in motion the development of two ICF-based instruments – the SALSA (Screening Activity Limitation and Safety Awareness) Scale and the Participation Scale.\textsuperscript{27,51}

\textbf{International Classification of Functioning, Disability and Health}

\textbf{WHAT IS IT?}

The International Classification of Functioning, Disability and Health (ICF) is a framework developed by WHO to describe, measure and compare functioning and disability at individual and population levels.\textsuperscript{52} ‘A person’s functioning and disability is conceived as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors’ (ICF page 12).\textsuperscript{54}The ICF consists of two parts comprised of four core components:

- Part 1: Disability and functioning
  - 1. Body functions and structure
  - 2. Activities and participation
- Part 2: Contextual factors
  - 3. Personal factors
  - 4. Environmental factors.

Body functions and structures refer to physiological functions and anatomical parts of the body (i.e. organs, joints). Activities relate to the execution of certain tasks with limitations occurring when an individual has difficulties executing one or more activities. Restrictions in participation are problems experienced by the individual in the context of their environment. See example below:

\begin{table}[h]
\centering
\begin{tabular}{|l|l|}
\hline
\textbf{Hands and feet} & \textbf{Eyes} \\
\hline
\textbf{Grade 0} & No anaesthesia, no visible deformity or damage \\
\textbf{Grade 1} & Anaesthesia present, but no visible deformity or damage \\
\textbf{Grade 2} & Visible deformity or damage present \\
\hline
\textbf{Grade 0} & No eye problem due to leprosy; no evidence of visual loss \\
\textbf{Grade 1} & Eye problems due to leprosy present, but vision not severely affected as a result of these (vision: 6/60 or better; can count fingers at six meters) \\
\textbf{Grade 2} & Severe visual impairment (vision: worse than 6/60; inability to count fingers at six meters), also includes lagophthalmos, iridocyclitis and corneal opacities \\
\hline
\end{tabular}
\caption{WHO ‘disability’ grading system, 1998\textsuperscript{95}}
\end{table}
Personal factors (i.e. sex, age) are not classified in the ICF because of the large social and cultural variations (page 8, ICF manual). The environment encompasses the physical, social and attitudinal environments in which people live and which influence a person’s activities and participation.

Each component of the ICF is comprised of different domains and within each domain are categories which are units of classification. By selecting codes and adding qualifiers (i.e. numeric codes) it is possible to specify the extent of functioning or disability in each category or the extent to which the environment is a facilitator or an obstacle. Body functions and structures are interpreted by physiological changes for which there are a number of different measurement tools. Activities and participation are operationalised using constructs called capacity and performance. The gap between an individual’s inherent capacity level and a lower actual performance in the real-life environment reflects barriers created by the environment.

### ADVANTAGES OF USING THE ICF

The ICF provides a consistent and complete conceptualisation of ‘disability’ and a framework for its operationalisation. The ICF was adopted by the World Health Assembly in 2001 (resolution WHA 54.21). It provides a sound international and inter-professional conceptual basis for understanding health and health related states. It has also been well received by professionals and, importantly, by people with disabilities. It is relevant and equitable for all health conditions irrespective of cause or nature and can cover a person’s life span.

The ICF shifts the focus from traditional health indicators (i.e. mortality rates) to measures that take into consideration how people live with their health conditions and the different levels of interventions (i.e. individual or societal) that can be made to enhance the quality and productivity of the person’s life. This makes the application of ICF universally relevant not only for all people with disabilities but to all people irrespective of culture or gender.

The focus is inclusive having moved away from the individual towards the situation of the individual within a range of health and related domains (i.e. education, social interactions and transportation). This concept of health and disability as a neutral, multidimensional and universal concept is a powerful tool for developing mutual understanding, reducing stigma associated with ill health and disability and an important advocacy tool that highlights the need to address the social aspects of disability.

### LIMITATIONS OF USING THE ICF

The coding for environmental factors does not describe the interactions between the person and their environment but helps to identify whether the environment is a facilitator or
A DEFINITION OF DISABILITY RELEVANT TO MEASUREMENT

Disability is a complex multidimensional experience, which is seldom static. Environmental factors (e.g. physical environment and community attitudes) are central to the understanding of the disability experience. A definition of disability must be flexible enough to describe disability in all its aspects, be etiologically neutral, be applicable to a range of applications and take into consideration the environment.

When these characteristics are subsumed in the definition and it can be operationalised in a manner that can produce comparable data on a continuum of functioning, it would be ideally suited for measurement.

A definition that holds these characteristics is the simplified ICF definition which defines disability as ‘difficulty in functioning at the body, person or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors.’

This definition can be used to describe and measure functioning and contextual factors of both leprosy-related disabilities and disability in the wider context. It does not however enable measurement of wellbeing, quality of life (QoL) and levels of personal satisfaction with life, which are personalised evaluations of functioning. QoL is a useful measure for health policy and planning and can be collected independently of the presence or extent of disability. This paper will discuss a number of instruments relevant to the ICF conceptualisation of disability and this simplified definition.

WHAT DISABILITY DATA ARE NEEDED FOR LEPROSY SERVICES?

Leprosy-related disability has five components that overlap, but also have clear distinct features in the eyes and upper and lower extremities. The resulting sensory, motor and autonomic impairment may lead to repeated injury, bone infection, muscle weakness and contractures. Depending on the location, these may lead to blindness, shortening of fingers and toes and, eventually, even amputation. Deterioration of impairment is a life-long risk in those with permanent nerve damage.

Attempts are made to intervene in these processes at various stages. Early diagnosis and treatment are advocated to prevent permanent nerve impairment in the first place. The success of this is assessed using the proportion of new cases with visible impairment (Grade 2 in the WHO disability system – see Table 1) among all new cases as a proxy indicator. This is the most basic disability information needed and is collected, recorded and reported in many leprosy control programmes around the world. Once patients have been diagnosed, nerve function should be monitored at regular intervals to enable early detection and treatment of deterioration. Information of sensory and motor status of the concerned nerves should be measured using a ballpoint pen or monofilament test for touch sensation and a manual voluntary muscle test for motor function. Results are to be recorded on patient cards. Usually, this information is only used for local patient management and is not reported to higher levels. It would be important, however, also to record and report data on the impairment status of patients at the time of release from treatment (RFT), particularly on a cohort basis. This would allow monitoring and evaluation of the efficacy of prevention...
of disability (POD) interventions and provide data to estimate the need for post-treatment resources for POD and rehabilitation. Therefore, programmes and institutions should decide on appropriate cohort-based indicators and implement data collection and reporting that allows calculation of these. At an individual level, information may also be needed on occupation and other determinants of the risk of disability, since these would point to required POD interventions.

The second component of disability on which data are needed concerns the strongly interlinked concepts of activity and social participation. Such data are needed for planning and management of rehabilitation services, as well as in the context of research. Data on activity related to leprosy are very scarce, but a range of activities has been shown to be affected.2,51 Although ‘social aspects of leprosy’ have been studied for a long time,20,62–66 specific data on participation have only recently become available.11,12,27 Topics on which data are urgently needed include determinants of leprosy-related activity limitations and participation restrictions, the efficacy of rehabilitation and advocacy interventions, stigma and discrimination, the status of the people affected in relation to various human rights and the integration of rehabilitation of people affected by leprosy into general CBR programmes. Managers of rehabilitation services would also need periodic data on the progress of clients in terms of activities and participation.

The third and fourth components of disability data required for leprosy concern ‘contextual factors,’ which can be divided into personal and environmental factors. Negative attitudes and other aspects of stigma and discrimination are included in the latter, being part of the social environment of a person affected by leprosy. Other key factors include education, social status and available health and social services and policies. Very little has been done to map these factors systematically, let alone study their association with the risk of disability in well-designed studies. Since these contextual factors play a crucial role in the development of rights-based policies and interventions, they have come into focus much more prominently than before.

Quality of life (QoL) may be considered the fifth component requiring data. Although not conceptualised within the ICF, QoL is strongly influenced by stigma and discrimination, as well as by other aspects of disability, such as visible impairment and poverty, but data specifically related to leprosy are scarce.67–70 QoL is a client-relevant concept that has been shown to be important as an outcome measure in various treatment and rehabilitation programmes other than leprosy.

Choice of Measurement Tools Applicable in Low-Income Countries

IMPAIRMENT MEASURES

Cohort-based indicators of impairment status or severity may be based on the WHO Disability Grading system (see Table 1). The maximum grade of the six sites evaluated is most commonly used as the individual indicator of impairment status. The big disadvantage of this measure is its lack of responsiveness to change.42 The same was shown in an unpublished study in Myanmar (Lwin, Master’s thesis, 2006) and Nigeria.71 An improvement on this is the EHF score, which uses the sum of the six sites as an indicator of severity.3,6,10 The EHF score is more responsive to change,42 but still uses the crude grading categories of the WHO Grading system. However, reliability of the grading system and of the EHF score has been shown to be good, provided adequate training is given.72,73 The strongest point in its
favour is undoubtedly the near universal use of the WHO grading system in leprosy control
programmes around the world. This means that EHF-based cohort indicators could be
calculated with no extra effort in terms of patient examination and recording of data, provided
a disability assessment at RFT is included.

The most sophisticated impairment monitoring system in current use is the Impairment
Summary Form (ISF). The ISF-based impairment indicator has good validity when
compared to an expert clinical examination and is much more responsive to change than
those based on the WHO maximum grade and the EHF score (Lwin, unpublished thesis). In
addition, the ISF provides information on where a given impairment is located (eyes, hands
or feet), making it suitable for monitoring of individuals and allowing it to be used to assess
the efficacy of interventions specific to eyes, hands or feet. At present, no ICF-based
impairment assessment system is in use in leprosy, although one could be devised, based on
the generic grading system that is part of the ICF. It would seem wise, however, not to
develop another leprosy-specific tool at a time when everyone is attempting to integrate
leprosy work into general health care and rehabilitation programmes.

**ACTIVITY MEASURES**

Two instruments to measure activities have been developed that are suitable for use in most
leprosy-endemic countries. The Green Pastures Activity Scale (GPAS) was developed as a
generic instrument for use under circumstances that prevail in Nepal and assesses a wide
range of activities of daily living. It was designed to cover the Disability domain of the
ICIDH and was shown to have good measurement properties. More recent is the ICF-based
SALSA scale, which was designed specifically to assess both level of activity and safety
awareness in people with peripheral neuropathy, such as leprosy or diabetes. The SALSA
scale was developed simultaneously in five countries and has good psychometric properties.
The safety awareness aspect of the SALSA is unique and very relevant in the context of
leprosy.

To measure functioning and disability in a manner conceptually compatible with the ICF,
the World Health Organization’s Disability Assessment Schedule II was developed. The
WHODAS II can be used to measure, with parity, the level of disability across various
conditions. It provides an overall disability score and a profile of functioning across six
domains including: understanding and communicating, getting around, self care, getting
along with others, house hold and work activities, participation in society. The WHODAS II
is available in different versions that have undergone extensive psychometric, reliability and
validity testing. It can be used to identify needs, match patients to interventions, track
functioning over time and to measure clinical outcomes and treatment effectiveness (Ustun
et al. submitted). The WHODAS was recently used as part of a Rapid Disability Appraisal
toolkit in a field study in Indonesia, which included people affected by leprosy (van Brakel
et al. in preparation).

**PARTICIPATION MEASURES**

The construct of ‘participation’ was introduced during the revision process of the ICIDH. It
‘succeeded’ the construct of ‘handicap’ and covers similar domains. In the late nineties,
Cardol et al. reviewed instruments assessing handicap and concluded that ‘a generic person-
perceived handicap questionnaire could not be identified.’ They went on to develop the
Impact on Participation and Autonomy Questionnaire (IPAQ) measuring participation as conceptualised in the framework of the ICF. The scale has 31 items covering six of the nine Participation domains. However, several years later, after reviewing 27 instruments, Wilkie et al. still concluded that ‘None of the identified instruments consisted entirely of participation items.’ Around the same time, Perenboom and Chorus also reviewed instruments measuring participation, concluding that the ‘two instruments closest to solely involve items on participation level are the Perceived Handicap Questionnaire (PHQ) and the London Handicap Scale (LHS).’ The PHQ measures perceived handicap across five life domains, using only one item per domain. The self-administered London Handicap Scale (LHS) assesses all six handicap ‘dimensions’ (orientation, physical independence, mobility, occupation, social integration and economic self-sufficiency). The LHS is also short (only six items). However, the authors state that the scale is not intended for assessment of individual subjects’ handicap, but is ‘meant for comparisons between groups of subjects,’ which clearly limits the use of the scale.

Anandaraj developed an instrument to measure ‘dehabilitation’ among people affected by leprosy, a concept related to participation restriction. It also contained items measuring self-esteem, which relates more to quality of life than to the ICF participation component. More recently, three other participation instruments have been developed. The first is the Assessment of Life Habits (LIFE-H), based on a conceptual framework close to that of the ICF, the Disability Creation Process. The LIFE-H exists in two formats, the General Short Form (77 items covering 12 categories of activities of daily living and social participation), and the Long Form, consisting of 240 items. The second participation instrument is the 11-item ‘Keele Assessment of Participation’ (KAP).

The third instrument, the Participation Scale, was developed specifically to measure participation in low and middle-income countries. It was developed simultaneously in seven languages in India, Nepal and Brazil. Psychometric properties were shown to be good. The scale is generic and is particularly suitable for use with people affected by stigmatised conditions, such as leprosy and HIV/AIDS. It has been used to evaluate the impact of a stigma reduction project and to study risk factors for participation restrictions. Other programmes are using the instrument in ongoing rehabilitation services to help select people for services, to monitor progress and to evaluate the impact of interventions at the individual level.

Measures of Contextual Factors (Particularly Environment)

Disability is now seen as a dynamic experience influenced by contextual factors (personal and environmental) in interaction with a person’s health condition. The environmental factors covered under ICF include all aspects of our living environment, e.g. products and technology, the natural environment and human made changes, support provided by others, attitudes of individuals and society and services systems and policies, i.e. education health, etc. Environmental factors can be either barriers or facilitators, depending on whether they induce or aggravate disability or rather reduce it. Facilitators may be the availability of a ramp, positive attitudes and, or inclusive policies, systems and services. Environmental factors such as inaccessible buildings, negative attitudes and the absence of rehabilitation services or discriminatory policies that exclude and isolate people are barriers. Any measure of disability must include an assessment and description of the environmental factors and their role as facilitators and barriers.
There are three generic instruments that may be used for measuring environmental factors. These are the Measure of the Quality of the environment;†† The Craig hospital Inventory of Environmental Factors (CHIEF) and the Facilitators and Barriers Survey. Both the CHIEF and Measure of the Quality of the Environment instruments use a standard questionnaire to identify if potentially relevant environmental factors are a ‘problem’ or ‘influence’ daily life. The CHIEF-SF (12 questions) focuses on the frequency reported by individuals whilst the Measure of the Quality of the Environment (109 questions) looks more at the extent to which items are reported as facilitators or obstacles. The Facilitators and Barriers Survey is a longer instrument (66 questions; 133 items) with eight different question forms. This instrument covers the questions outlined in the other two instruments and also investigates health care settings and services. Further studies are required to explore the utility of these instruments in determining the frequency and impact of relevant environmental factors on people affected by leprosy.

QUALITY OF LIFE (QOL) MEASURES

Although a large number of QoL instruments have been developed, very few are suitable for use in leprosy-endemic countries. The most widely used instrument is WHO Quality of Life (WHOQOL) scale, sometimes in the abbreviated version (WHOQOL-BREF). Tsutsumi found good psychometric properties using the WHOQOL-BREF among people in Bangladesh. Joseph and Rao confirmed the ability of the instrument to show differences in QoL between people affected by leprosy and a control group in South India. Further studies are needed to explore the utility of QoL measures in rehabilitation and to study the relationship between QoL and participation.

VALIDATION AND NORMATIVE DATA

‘What is the best instrument for this particular purpose?’ is usually a question about validity. In other words, which measure will best reflect what we want to measure? Most of the above mentioned instruments have been validated in at least one context and with one group of people. This means that they have been shown to have adequate measurement properties to be used as an instrument. However, too often validation is incomplete; i.e., not all relevant properties have been examined. Even more commonly, they have been investigated in one context, with one particular target group, but not in others. Before choosing an instrument, this should be carefully checked. Important measurement properties (also called psychometric properties) are:

- **Validity**: Does the instrument measure what it is intended to measure? This includes *face validity* (does the items ‘look’ right, do they seem appropriate for what you intend to measure?), *content validity* (do items cover the different aspects of the construct or phenomenon you want to measure? E.g. all relevant aspects of activities of daily living), *construct validity* (does it give results that ‘fit’ with other instruments measuring the same or a similar construct?), *criterion validity* (do the results agree with some external criterion, e.g. expert opinion, gold standard measure?) and *divergent validity* (do the results disagree with instruments that measure something different?).

Reliability: Is the instrument internally consistent (do the items in the scale measure the same construct?)? This is assessed with a statistic called ‘Cronbach’s alpha’ and by examining ‘item-to-total’ correlations. Do the results agree between assessors (often called ‘inter-tester agreement/reliability’); does one assessor get the same result if he/she assesses the same subject twice? Is the result stable over time, if the subject does not change?

Discrimination: The ability of the instrument to distinguish between different groups, e.g. a group of people with a particular type of disability and a control group without that disability.

Responsiveness to change: Do the results obtained with the instrument reflect relevant changes in the situation of the target group? This is an essential characteristic if a measure is to be used for monitoring over time.

These key characteristics are partly dependent on the instrument itself, but also differ according to context and target group. Therefore, one cannot assume that an instrument shown to be valid, e.g. in North America, will be valid also in India. Therefore, instruments need to be revalidated whenever they are used in a significantly different context or with a very different target group. This is not an easy task, but provided the instrument is good and will provide valuable data, it is worth the effort. Without it, we are never sure whether the data we generate are valid and reliable. The above is true, not only for multi-item scales, but also for questionnaires, in which each individual item could be considered to be a 1-item scale, which needs to be valid, reliable, etc., if we want to base important decisions on the outcome.

Normative values

Normative values do not refer to what is ‘normal’, but to the norm of a particular measure in a population. In case of (semi-)quantitative data, this may be expressed as an average (mean or median), as the mean plus two standard deviations or as a percentile of values found in a reference group (e.g. 95th). Normative data may need to be reassessed in a new context or target group if this context or group is likely to be different from the one for which normative data have been published.

With a few exceptions, biological measurements and psychometric scores, such as scores derived from instruments that measure activities, participation or QoL, will have normative values or ranges that differ in different contexts. For example, normal thresholds of touch sensation have been shown to differ between people in the US and a mixed population in India. The same is true for the distribution of participation scores between South Asia and South Sulawesi (van Brakel et al. in preparation). It is important, therefore, to conduct a normative study to determine appropriate reference values, cut-offs or ranges for a given population, if such data do not exist already. We suggest a minimum study size of 50 persons. They should be people without the characteristic to be studied, but with a similar distribution of relevant characteristics such as age, sex and social status.

Generic versus leprosy-specific instruments

The question of whether one should use a generic or a condition-specific measure depends on the purpose of the assessment and on the characteristic one seeks to measure.
Generic instruments have the advantage of being more comparable, but are often less sensitive to pick up differences or changes than condition-specific instruments. For example, the WHODAS can be used in a general disability context, but the SALSA scale will have better sensitivity and specificity to assess activity limitations among people affected by leprosy. As another example, if the purpose is to collect data on QoL related to use of a prosthesis and compare this to QoL related to wheelchair use, a generic QoL scale such as the WHOQOL should be used. However, if QoL is used as an outcome measure in a trial of different prosthetic designs, a prosthesis-related instrument such as the Trinity Amputation and Prosthesis Experience Scales (TAPES) or the Prosthesis Evaluation Questionnaire (PEQ) is likely to offer better sensitivity and discriminatory power.93,94

Conclusions

There is a vast need for data on leprosy-related disability, as well as for data on disability due to other causes. This is true for all four ICF components, body functions and structures, activities and participation, personal factors and environmental factors, and for quality of life. Measurement instruments and qualitative data collection techniques now exist which are directly applicable in the context of most leprosy-endemic countries. An inclusive focus is recommended, where people with leprosy-related disability are seen as a sub-group of people with disability in the wider context, since many of their needs are the same as those of others. Programmes and research projects should choose an appropriate set of tools and methods and seek to apply these systematically. This choice should be guided by data on the validity of these tools in the concerned context. Instruments should be validated formally, if this has not already been done. Similarly, locally relevant normative data should be collected and applied to ensure that decisions are based on valid interpretations and conclusions.

Acknowledgements

The views expressed are those of the authors alone and not necessarily those of the organizations they represent.

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