

Measuring health-related stigma – a literature review

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Suggested keywords:

assessment, attitude, discrimination, HIV/AIDS, leprosy, measurement, scales, stigma

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Abstract

A literature review was conducted to review work done on measuring health-related stigma. References were obtained through a PubMed (Medline) and ScienceDirect search and through examining relevant bibliographies. The Internet was searched and relevant publications and reports downloaded. Collaborating partners of the International Consortium on Stigma Research contributed some draft reports and instruments. Sixty-three papers were selected that addressed the issue of measurement of stigma or related constructs and that contained a sample of the instrument or items used. Three unpublished studies were also included in the review.

The different approaches used or recommended to assess health-related stigma can be broadly grouped in four categories. First, assessing the experience of actual discrimination and/or participation restrictions on the part of the person affected; second, assessment of perceived or internalised stigma; third, assessment of attitudes and/or practices towards the people affected and, fourth, screening for discriminatory and stigmatising practices in (health) services, legislation, media and educational materials. Within each of these approaches, different research methods have been used, including questionnaires, qualitative methods, indicators and scales. The characteristics of each of the selected instruments are described and compared.

The studies reviewed indicate that stigma related to chronic health conditions such as HIV/AIDS, leprosy, tuberculosis, mental health and epilepsy is a global phenomenon, occurring in both endemic and non-endemic areas. Stigma has a severe impact on individuals and their families, as well as on the effectiveness of public health programmes. Despite enormous cultural diversity across the world, the areas of life affected are remarkably similar. They include marriage, interpersonal relationships, employment, education, mobility, leisure activities and attendance at social and religious functions. This suggests that development of generic instruments to assess health-related stigma may be possible. Data obtained with such instruments would be useful in situational analysis, advocacy, monitoring and evaluation of interventions against stigma and research to better understand stigma and its determinants.

The conclusions from this review are that 1) the consequences of stigma affect the quality of life of individuals, as well as the effectiveness of public health programmes, 2) many instruments have been developed to assess the intensity and qualities of stigma attached to leprosy, mental illness, epilepsy, disability and HIV/AIDS, but often these have been condition-specific and, 3) the similarity in the consequences of stigma in many different cultural settings and public health fields suggest that it would be possible to develop a generic set of stigma assessment instruments. To achieve this aim, existing instruments should be further developed or adapted, avoiding duplication and building on and collaborating with current projects with similar aims.

Introduction

Stigma is a phenomenon associated with many chronic health conditions, including leprosy, HIV/AIDS, mental illness, epilepsy, disability and tuberculosis. Stigma and its psychosocial consequences cause indescribable suffering to those who are stigmatised (Frist 1996; Jacoby et al. 2004; Kaur & van Brakel 2002; Nyblade et al. 2003) In addition, stigma has indirect but strongly negative implications for public health efforts to combat the diseases concerned. (Link & Phelan 2001; Nicholls et al. 2003; Piot 2001; Weiss & Ramakrishna 2001) Both personal effects and negative public health impact are surprisingly similar for a wide range of chronic stigmatised conditions. The effects are summarised in Table 1. The effects on the affected individual include psychological stress, depression and other psychiatric morbidity, fear, marital and relationship problems, other social participation restrictions such as loss of employment or reduced employment opportunities and reduced education opportunities, increased (risk of) disability and advanced disease. Many negative effects on public health programmes and interventions have been reported. Important examples are delay in diagnosis and treatment, resulting in continuing risk of disease transmission in case of infectious diseases and in more severe morbidity and poorer treatment prognosis in most conditions (Jaramillo 1998; Ngamvithayapong et al. 2000; Nicholls et al. 2003; Piot & Coll Seck 2001). Concealment may result in continued risk behaviour and failure to embrace preventive behaviour in conditions such as HIV/AIDS and TB (Adetunji & Meekers 2001; Rahlenbeck 2004) and in poor treatment adherence or default from treatment, as has been reported in leprosy, TB, HIV/AIDS, mental illness and epilepsy (Conrad 1985; Heijnders 2002; Sumartojo 1993; Weiser et al. 2003). In TB and HIV/AIDS, poor treatment adherence increases the risk of the development of drug resistance (Bangsberg et al. 2000; Bangsberg et al. 2004; Wahl & Nowak 2000).

Many studies have documented stigma associated with a wide variety of chronic health conditions in the past few decades, particularly in mental health, epilepsy, leprosy, HIV/AIDS and other chronic, disabling conditions. Despite this knowledge and the far-reaching consequences of stigma, comparatively little progress has been made in systematically addressing stigma, and the often resulting discrimination, in public health programmes. Many stigma reduction interventions have been carried out, but their effectiveness is often not known (see paper van der Meij & Heijnders). This is partly because tools to measure the impact have not been available, particularly not in developing country settings. The lack of progress in this area is due in part to the difficulty of reliably measuring complex psychosocial phenomena such as stigma. Quite a number of scales and indicator sets have been developed, but these usually apply to stigma in one particular health field only. It would seem beneficial if stigma assessment instruments were to be developed that could be applied across a range of public health areas. This would allow assessment of stigma reduction strategies and interventions and comparison between different approaches. In addition, good instruments are essential for stigma research. Link et al. stated, "Essential to the scientific understanding of stigma is our capacity to observe and measure it." (2004, in press). Since a number of instruments have been developed in the past, it may not be necessary to design new instruments, but merely to adapt or validate existing instruments for use in additional target groups and cultural settings.

Definitions

In the literature we find many definitions of stigma and related phenomena. For the purpose of this review we will adopt the following working definitions.

Stigma

1. A social process that exists when elements of labelling, stereotyping, separation, status loss, and discrimination occur in a power situation that allows them (Link & Phelan).
2. A social process or related personal experience characterised by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group. In health related stigma, this judgment is based on an enduring feature of identity conferred by a health problem or health related condition. (Weiss and Ramakrishna).

Enacted stigma

Actual experiences of discrimination

Perceived (or internalised or felt) stigma

1. The devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself. (Corrigan, 1998)
2. The fear of being discriminated against (Siyam'kela 2003)

Discrimination

Unjustifiably different treatment given to different people or groups¹ Any measure entailing a distinction among persons depending on their confirmed or suspected health status (Carael et al. 2000).

Participation restriction

Problems an individual may experience in involvement in life situations (ICF, WHO, 2001).

Stereotype

A belief that all members of a group possess the same characteristics or traits exhibited by some members of that group.

Indicator

An indicator is the measure used to assess if an objective has been achieved or what progress has been made.

We will use the term *measurement* in a broad sense including both quantitative and qualitative aspects of the phenomenon measured. Some prefer to use 'assessment' since this does not have the same quantitative connotations. However, many publications refer to the 'measurement of stigma', even when qualitative aspects are included. Using the current broad meaning of 'measurement', both terms can be used interchangeably.

Purpose

The purpose of the paper is to review published reports of instruments developed to assess and measure health-related stigma and discrimination in the fields of HIV/AIDS, leprosy, tuberculosis, mental health, epilepsy and a number of other health conditions. The review may provide the basis for the development or adaptation of a set or generic tools to assess stigma in different health conditions in a variety cultural settings.

Methods

To review the work done to date on measuring stigma related to leprosy, a literature study was done. References were collected through a PubMed (Medline) and ScienceDirect search on the keywords stigma or discrimination combined with 'scales', 'measurement' or 'assessment'. The same search was used for title words. In addition, relevant bibliographies were scanned for additional references. The Internet was searched for reports and publications not formally published in scientific journals. Collaborating partners of the International Consortium on Stigma Research contributed several draft reports and instruments. Only English language papers and reports that included the scale items, questions or indicators used or developed, or for which these were available separately, were included in the review. Generally, only papers describing the actual development of the instrument(s) have been reviewed. In a few instances, where additional studies offered further validation of a particular instrument or validation in different health field, these have been included.

Results

Sixty-three papers were selected that addressed the issue of measurement of stigma or related constructs. Five studies as yet unpublished or still in progress were also included in the review. The available instruments will be presented separately for each public field, before attempting to draw out any common features. However, first we will look briefly at the different approaches used to assess stigma and at the types of tools that have been developed.

The different approaches have been used or recommended to assess health-related stigma can be broadly grouped in four categories:

1. Experience of actual discrimination and/or participation restrictions on the part of the person affected. People with a (potentially) stigmatised health condition are interviewed about any actual experiences of discrimination they have had.
2. Assessment of perceived or internalised stigma
People with a (potentially) stigmatised health condition are interviewed about feelings of

¹ Manser & Thompson (eds.). (1999) Combined Dictionary Thesaurus. Ediburgh, Chambers

fear, shame, guilt, etc. they may experience.

3. Assessment of attitudes and/or practices towards the people affected
Members of the community (general public) or of specific groups (e.g. care providers) are interviewed about attitudes they or others have towards people with a particular health conditions. Similarly, (reported) behaviour towards such people may be documented.
4. Screening for discriminatory and stigmatising practices, services, legislation and materials
 - Health services
Health services are audited to look for arrangements and practices that may be stigmatising or destigmatising.
 - Legislation
Legislation is reviewed for laws that may be stigmatising or discriminatory and to check whether anti-discriminatory legislation is in place.
 - Media
A systematic review is done of news coverage during a certain period looking for articles or programmes conveying stigmatising or destigmatising messages.
 - Educational materials
A systematic review is done of educational materials used in schools and other education facilities relating to stigmatised conditions to see whether they convey stigmatising or destigmatising messages.

Within each of these approaches, different research methods may be used. The most commonly used methods include:

- **Questionnaires**
Questionnaire may be closed or open or interview guides. Often these contain items collecting data about knowledge, attitudes and reported practices (KAP).
- **Qualitative methods**
Assessment based on qualitative methods, such as key informant interviews, focus group discussions and participant observation.
- **Indicators**
Indicators are often used in sets. They provide separate information for each indicator. Together they may give a profile of stigma and discrimination, but they cannot be summarised in one measure, unless they have been developed as a scale.
- **Scales**
Scales are quantitative instruments intended to give a numerical result that indicates the severity or extent of the phenomenon measured.

The instruments reviewed for this paper are listed in Table 2. The condition-specific instruments will be reviewed by public health field, first the infectious diseases, followed by mental health, epilepsy and other disability.

Generic instruments

Only one instrument, the stigma scale derived from the Explanatory Model Interview Catalogue (EMIC), has been used with a number of different health conditions to measure stigma in terms of negative community attitudes (Weiss et al. 1992). The original scale contained 12 items and is only one part of a catalogue of instruments used to study different cultural and epidemiological aspects of a health condition. Responses are coded on a 0-3 ordinal scale (0 = no, 1 = uncertain, 2 = possibly or conditionally and 3 = yes). The EMIC stigma scale only covers certain areas of life that may be affected by stigma, namely, concealment, avoidance, pity, shame, being made fun of, respect and marriage (prospects). In addition, its psychometric properties are only partly known. In particular, data on construct validity, stability and responsiveness to change are lacking, while test-retest reliability has only been evaluated on a sample of 18 subjects. In my opinion, the strength of this instrument lies 1) in its simplicity and 2) in the fact that its utility has been demonstrated in different cultural settings and with very different health conditions. The first study was on mental health and leprosy in India (Weiss et al. 1992). Subsequently, the instrument has been used with various modifications to assess attitudes to a number of other conditions, including depression (Raguram et al. 1996), onchocerciasis (Brieger et al. 1998; Pan-African Study Group on Onchocercal Skin Disease

1995;Vlassoff et al. 2000), tuberculosis (Weiss et al. 2004) and Buruli ulcer (Stienstra et al. 2002).

Two other scales designed to be generic instruments measuring stigma-related constructs are the The Child Attitude Toward Illness Scale (CATIS) (Austin & Huberty 1993;Heimlich et al. 2000) and the Participation Scale (van Brakel et al., submitted). The CATIS is a 13-item instrument validated for use with children aged 8-12 and with adolescents (Austin & Huberty 1993;Heimlich et al. 2000). The psychometric properties were generally very good in samples of children with epilepsy and with asthma. The Participation Scale is based on the terminology and structure of the International Classification of Functioning, Disability and Health (ICF)(World Health Org 2001). It consists of 18 items with a two-step, 5-point response scale. Criterion validity was checked against an experts score. The Spearman correlation coefficient was 0.44 (N=227, $p = 0.005$). Convergent validity was assessed by correlating the Participation Score with a measure of impairment severity (Spearman correlation coefficient 0.39 (N=724), $p < 0.001$). Internal consistency was very high, with a Cronbach's alpha of 0.92 and an item to total correlation range of 0.33 – 0.74. Construct validity was confirmed by factor analysis. The first factor (participation) explained over 90% of the variability. Inter-interviewer reliability (Intra-class correlation coefficient) was very good at 0.80 (N=296) and intra-interviewer stability after the 4 weeks scored 0.84 (N=210). Discrimination between people affected by leprosy or disability and controls (people without leprosy or disability) was excellent. Responsiveness to change was satisfactory with a statistically significant difference in scores between baseline data and post life-change data (N=67).

Leprosy

While very few actual scales have been developed, many studies have assessed attitudes to people affected by leprosy, using a variety of questionnaires. Large studies investigating attitudes in the general population were done in Sarawak (Chen 1986), Ethiopia (Tekle-Haimanot et al. 1992), Myanmar (Myint et al. 1992), India (Gopal 1998;Raju & Kopparty 1995) and Nepal^a (de Stigter et al. 2000). Only two scales have been developed, but neither specifically targeting stigma. The Dehabilitation Scale of Anandaraj (1995) covered social participation and self-esteem, while the recently developed Participation Scale measures the effects of stigma, among other factors, on (social) participation of people affected by leprosy, disability or other stigmatised conditions (van Brakel et al., submitted – see above). The 'Dehabilitation Scale' is a 52-item instrument covering four areas related to stigma, family relationships, vocational conditions, social interaction and self-esteem (Anandaraj 1995). The items consist of positive or negative statements, with 5-point Likert-type response scales (strongly agree to strongly disagree). The results are summed, divided by the maximum possible score and multiplied by 100 to get the "score-quotient". No published studies were found using this scale.

Dr. P.K. Gopal developed a questionnaire designed to identify target groups for socioeconomic rehabilitation (Gopal 1998). It contains 14 items related to attitude or practice that were to be answered with yes/no. If the respondent answered 'yes' on 50% or more of the items, (s)he was considered in need of socioeconomic rehabilitation. A large study (53,000) was conducted in India using this questionnaire, but the results have not been formally published.

HIV/AIDS

Ten out of the 14 instruments reviewed were developed for use in the United States. Only the best validated and least specialised instruments are discussed here. The AIDS Attitude Scale (Froman et al. 1992;Froman & Owen 1997;Froman & Owen 2001) has been used in a number of studies since 1992. The earlier version was developed to measure attitudes to AIDS among health care personnel, while the most recent version was adapted to assess attitude among the general public. Validity has been well established. Another scale measuring public attitudes is the Attitudes towards AIDS scale developed in Brazil (Moriya et al. 1994). It consists of 25 items and psychometric properties have been shown to be good. A different type of instrument is the 'Protocol for identification of discrimination against PLWH' developed by UNAIDS, an indicator

^a van Brakel WH, Bhatta I, Anderson AM, Engelbrektsson U. Preliminary results from a Leprosy Elimination Campaign conducted in Parwat District, West Nepal. Paper presented at the 2nd international conference on the elimination of leprosy, New Delhi, India, 11-13 October 1996.

based on a checklist of 37 possible ways discrimination may have occurred (2000). The checklist documents actual, verified instances of discrimination against PLWHA. After very thorough investigation by several expert field teams, the items for which instances of discrimination can be found is decided. The number of items for which *no* evidence of discrimination is found is divided by 37 to give the “degree of non-discrimination”. The authors stress that the Indicator and the protocol are not scientific devices. The Discrimination Indicator has not yet been used in studies and its psychometric properties are unknown. The 40-item HIV Stigma Scale developed by Berger et al. measures stigma perceived and experienced by PLWHA (Berger et al. 2001). The items are formulated as statement and responses are given on a 4-point agreement scale. The psychometric properties of the scale have been tested in a large sample of diverse background. The results were very good. Apparent overlap between items and the high alpha coefficient (0.96) suggest that the instrument could perhaps be shortened without losing validity. The Policy Project, South Africa, developed the Siyam’kela indicator set (2003). The 41 indicators in the set measure stigma and discrimination both from the perspective of PLWHA and of the community. Each indicator asks for the number of PLWHA who have experienced a particular type of discrimination or the number of people who have a particular opinion about or feeling towards PLWHA. The Siyam’kela set intends to provide a profile of stigma, not a summary measure. The psychometric properties of the indicators have not been tested. In February 2004, the USAID Inter-Agency Working Group on Stigma and Discrimination (IWG S&D) met to discuss and refine a similar list of indicators related to HIV/AIDS stigma and discrimination.² The resulting set is currently being piloted in Tanzania. The indicators have been included in the indicator list.

Tuberculosis

In the field of tuberculosis studies investigating TB-related stigma have mainly used qualitative research methods (Johansson et al. 2000; Long et al. 2001; Rubel & Garro 1992). Jaramillo carried out a survey in Colombia exploring the correlates of prejudice, as an attitudinal component of this stigma. Results show that local beliefs about the transmission of the disease are the main significant predictor of the negative attitudes (Jaramillo 1998). Macq et al. are developing an instrument to assess stigma related to tuberculosis in Nicaragua (2004, submitted). Another current research project in Thailand, led by the University of Carolina, aims to develop a new measure of stigma in patients co-infected with TB and HIV (Van Rie et al.).

Other stigmatised infectious diseases

A few studies have measured stigma related to onchocerciasis (Brieger et al. 1998; Vlassoff et al. 2000) and Buruli ulcer (Stienstra et al. 2002), but these have used a stigma scale derived from the EMIC described above. Other infectious diseases known to be associated with stigma are lymphatic filariasis (Gyapong et al. 1996) and leishmaniasis.

Mental illness

The field of mental health perhaps has the oldest instruments available for measuring stigma. Assessment has focussed on the attitudes of the general public towards people with mental illness, as well as on internalised stigma as experienced by the people affected. One of the earliest scales found in the literature was the Opinions about Mental Illness (OMI) scale (Cohen & Struening 1962; Struening & Cohen 1963). The 51-item version had good construct validity and international consistency. Taylor & Dear further developed the OMI, by adding a subscale to measure community mental health ideology (1981). The ‘Community Attitudes to Mental Illness (CAMI) measures attitudes in the general population and has 40 items covering 4 sub-scales on authoritarianism, benevolence, social restrictiveness and community mental health ideology. Psychometric properties were tested and found to be adequate in several samples in the USA and Canada. Angermeyer and Matschinger developed the Emotional Reaction to Mental Illness Scale to examine to what extent personal experience with mental illness might influence attitudes towards the mentally ill (Angermeyer & Matschinger 1996). The instrument assesses emotional reactions toward persons with mental illnesses. Two vignette descriptions were used, one describing schizophrenia and the other depression. The original scale consisted of 18 items, with a 5-point response scale, each assessing a single emotional response. The final instrument included the four items for each component, aggressive emotions (e.g., anger), pro-social reactions (desire to help, sympathy) and feelings of anxiety (e.g. fear). According to

² HIV/AIDS-related Stigma and Discrimination Indicators Development Workshop Report. February 10, 2004

Link et al., "This instrument's key strengths are its assessment of affective experiences of the stigmatizer which have previously been under-assessed, its demonstrated reliability, and its validity in demonstrating a predicted pattern of relationships with the construct of previous contact with mentally ill people." (2004, in print).

An instrument aimed at measuring perceived stigma among people with mental illness is the Internalised Stigma of Mental Illness scale (ISMI), developed by Ritsher et al. (2003). The ISMI comprises 5 sub-scales with in total 29 items phrased as statements. The sub-scale domains are alienation, stereotype endorsement, discrimination experience, social withdrawal and stigma resistance. Construct validity and other psychometric properties were extensively tested in a sample of 127 mental health outpatients with a variety of diagnoses at a Veterans Administration medical centre. The results were very good, but additional validation would be required with people from different backgrounds. Particularly women were underrepresented in the sample (6.4%). Corrigan et al. have developed a series of scales designed to assess attitudes, affect and behavioral intentions related to a hypothetical person with mental illness (2001a;2001b;2002;2004). The General Attribution Questionnaire consists of 20 questions about a person or persons with mental illness. Responses are coded on 9-point opinion scales (ranging from 'not at all' to 'very much'). The psychometric properties of the instrument are not clear. The same is true for the Attribution Questionnaire-27 (AQ-27) and the Attribution Questionnaire-Short Form (AQ-SF). These use vignettes that paint word pictures of a particular person with mental illness and then ask questions about attitudes and emotions concerning this person. Different vignettes are used, e.g. male, female, danger/no danger and controllability of cause/no controllability. If vignettes describing people affected by other stigmatised conditions were used, the AQ-27 and AQ-SF may also be suitable as generic instrument. However, the validity of this would need to be evaluated. The Psychiatric Disability Attribution Questionnaire comprises 6 sets of 6 statements (mixed) on attitudes to and opinions about people with 6 different conditions (cocaine addition, AIDS, cancer, psychosis depression and mental retardation) (Weiner et al. 1988). The items represent controllability, stability and pity. Link et al constructed a twelve-item scale measuring the extent to which a person believes that mental health patients will be devalued and discriminated against (Link & Phelan 2002). Other investigators have assessed people's attitudes towards mental health in Ethiopia and Nicaragua (Alem et al. 1999;Penayo et al. 1988;Shibre et al. 2001;Shibre et al. 2003) and in India (James et al. 2002;Raguram et al. 1996;Raguram et al. 2004), but, except for the studies done by Raguram, copies of the instruments used were not available.

Epilepsy

In the field of epilepsy, perceived or internalised stigma has been the major area of study. The oldest study identified is the one by Ryan et al. (1980). Their 21-item scale was validated for use with older adolescents and adults. Westbrook et al. designed a 3-item scale to measure perceived stigma specifically among adolescents (1992). Ten years later, a 5-item questionnaire was used in a large survey of attitudes to epilepsy among high students in the United States (Austin et al. 2002). Austin and colleagues also developed two scales to measure stigma-related experiences among children with epilepsy (Austin et al. 2004;Austin & Huberty 1993). In 2004, Austin and colleagues published two new short scales to assess stigma experience among children, one to be administered to the children themselves and one for their parents. Both scales were found to have strong psychometric properties (Austin et al. 2004). Jacoby developed an 8-item scale to assess perceived stigma among adults with epilepsy (Jacoby et al. 1993). The scale uses 'Yes/No' responses. In another study, she used a brief 3-item scale, modified from one designed by Hyman for use with stroke patients (1971). Convergent validity and internal consistency were found to be satisfactory (Jacoby 1994). Baker et al. used the instruments developed by Jacoby in a large study to compare perceived stigma among people with epilepsy between 15 countries in Europe (Baker et al. 2000). Cramer et al. developed an instrument to assess health-related quality of life among adolescents with epilepsy, containing 10 stigma-related items (Cramer et al. 1999). Validity and reliability were reported to be good. A large study in Ethiopia compared stigma in a rural community related to epilepsy with that of leprosy using a questionnaire with 8 items relating to stigma (Tekle-Haimanot et al. 1992). Aziz et al. conducted a cross-sectional study in Pakistan to assess knowledge, attitudes, stigma and handicap among people with epilepsy. Their 15-item questionnaire contained 12 questions related to stigma and attitudes with Yes/No answers.

Other disability

Investigators working in general rehabilitation have developed many scales assessing constructs related to stigma, such as handicap and (social) participation, but we did not find a scale designed specifically for measuring stigma related to disability in general. Stigma is a major cause of handicap and participation restrictions (van Brakel et al., submitted). Most scales assess perceived stigma and experiences of participation restrictions. The recently developed Participation Scale has been validated for use with people with non-leprosy-related disability also (see above). The Perceived Handicap Questionnaire (PHQ) measures perceived handicap across five of the six life domains that make up the construct of Handicap (physical independence, mobility, occupation, social integration and economic self-sufficiency) (Kuptniratsaikul et al. 2002; Tate et al. 1994). The instrument contains one item per domain. The self-administered London Handicap Scale (LHS) assesses the impact of chronic disease on all six handicap 'dimensions' of the International Classification of Impairment, Disability and Handicap (WHO 1980), the five mentioned above and 'orientation' (Harwood et al. 1994; Lo et al. 2001). The instrument has six items and is "meant for comparisons between groups of subjects" (Harwood et al. 1994). Because of the way questions and response levels are formulated, the validity of the instrument in low and middle-income countries is questionable. The Impact on Participation and Autonomy Questionnaire (IPAQ) measure participation as defined in the International Classification of Functioning, Disability and Health (ICF) (Cardol et al. 1999; Cardol et al. 2001; World Health Org 2001). The scale has 31 items covering 6 of the 9 Participation domains of the ICF. In addition, 8 items probe 'problem experience'. More recently, the Assessment of Life Habits (LIFE-H) was developed (Noreau et al. 2002). The LIFE-H exists in a short and a long form, containing 77 items and 240 items, respectively. The response scales assess level of accomplishment, level of assistance and level of satisfaction. The validity and other psychometric properties of the above handicap and participation scales generally have been well established.

Items commonly used in the above instruments

Many areas of life may be affected by stigma. In the terminology of the new WHO International Classification of Functioning, Disability and Health (ICF), the consequences of stigma would manifest to a large extent as participation restrictions (World Health Organisation 2001). The ICF recognises nine life domains in which participation may be restricted (World Health Organisation 2001). These are learning and applying knowledge, general tasks and demands, communication, mobility, self care, domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life. Other aspects of life affected by stigma are well-being or quality of life, self-esteem and emotions.

Table 3 list the attitude, discrimination, self-esteem, perceived stigma and other stigma items used in three or more of the public health fields included in this review. They have been grouped according to the ICF domains where possible or otherwise in appropriate other categories. Items related to particular issues often were formulated in several different ways. These include questions or statements, actual experience or perceived stigma, community perspective or the perspective of the affected person. However, underneath these differences, the similarities are striking. As many as 35 items have been used in 3 or more public health fields to assess stigma or related constructs. Among the top 16, occurring in at least 4 fields, are items related to marital problems, social avoidance, concealment of the condition, shame and embarrassment, thinking less of oneself, visiting or being visited by others, family members having problems to get married, not being allowed to play with children, reduced employment opportunities, people thinking less of the affected person and fear of the person with the condition.

Discussion

In conditions like leprosy, HIV/AIDS and schizophrenia, the consequences of the stigma attached to the condition may be worse than the condition itself. While the presence of stigma is often well recognised, the magnitude or intensity of such stigma, and the often resulting discrimination, is difficult to quantify. The question, "How strong is the stigma against HIV/AIDS or leprosy in this community?" is likely to be answered with vague statements, such as 'very

strong', 'not so strong' or 'less strong than before'. Because of the strong negative impact of stigma on public health, a lot of resources are invested in stigma reduction. It is therefore very important to be able to assess the impact of such interventions.

Despite enormous cultural diversity, the areas of life affected by stigma are remarkably similar in different countries and health conditions. They include marriage, interpersonal relationships, mobility, employment, access to treatment and care, education, leisure activities and attendance at social and religious functions. This similarity suggests that it may be possible to develop a set transcultural generic instruments to assess the intensity of stigma and discrimination related to a condition like leprosy in a given community.

'Stigma' has many components. Stigmatising attitudes in a community play a major role, but are not the only source of stigma. Other important sources are the media, health and social services, the educational system and legislation. Therefore, a comprehensive assessment will need a combination of quantitative and qualitative approaches including an assessment of the attitudes and practices of members of the community, an 'audit' of the media, the (health) services provided, information contained in educational materials and legislation. Stigma should be assessed from the community perspective as well as the perspective of the affected persons and their family. The latter should include an assessment of perceived stigma and of the impact of stigma of social participation, quality of life, health seeking behaviour and, if relevant, treatment adherence.

Public attitudes

The analysis of items in attitude scales developed in the various areas of public health suggests that a generic scale would be feasible. Results of studies that have used the stigma scale derived from the EMIC, as well as the performance of several generic handicap and participation scales support this hypothesis. The most promising instruments include the stigma scale derived from the EMIC (Weiss et al. 1992), the questionnaire used for impact assessment of media campaigns in Nepal (van Brakel 1997), the AAS-G (Froman & Owen 2001), the Siyam'kela indicator set, the indicator set currently field-tested in Tanzania (see Table 2), the CAMI (Taylor & Dear 1981), the Attribution Questionnaire (Corrigan et al. 2004) and the scales developed by Angermeyer and Matschinger (1996;2003). A stigma scale and other interview-based instruments would assess *reported* attitudes and practices, which are not necessarily an accurate reflection of the real situation. They therefore should be complemented and validated with the help of qualitative methods, such as key informant interviews, focus group discussions and in-depth interviews with people affected.

Actual discrimination

Far fewer examples are available of instruments developed to measure actual discrimination. Link et al. noted this as a gap in stigma research in mental health (2004, in press). The one instrument specifically developed for this purpose is 'Protocol for identification of discrimination against PLWH' developed by UNAIDS (2000). The indicator sets developed by the Policy Project (see HIV/AIDS section above) also contain items specifically querying discrimination experience. These instruments are currently being field-tested and reports of results are not yet available. The Participation Scale (van Brakel, submitted) and other measures of handicap and participation also contain many relevant items on discrimination experience (see Table 2). Since reducing discrimination is the target of many interventions, information on actual discrimination is crucial for evaluation of the impact of measures such as media campaigns, legislation, etc. Such information would also allow an assessment of the extent in which reported stigma is perceived or based on actual experience.

Perceived stigma

Perceived stigma may affect the lives of the people concerned in same way as enacted stigma. It also may cause the same negative effects on public health programmes as enacted stigma. Accurate assessment of perceived stigma, both at the individual and group level, is an essential component of stigma measurement. The most promising instruments are the HIV Stigma Scale (Berger et al. 2001), the Internalised Stigma of Mental Illness scale (Ritsher et al. 2003), the scale developed by Jacoby (Jacoby et al. 1993) and the children and parents scales developed by Austin et al. (Austin et al. 2004).

The impact of stigma on the person affected

Stigma affects people psychologically. It often lowers self-esteem and can cause or aggravate psychiatric morbidity. Both enacted and perceived stigma restrict social participation in a wide range of areas. Ultimately, stigma reduction efforts must mitigate these negative effects. Measurement of self-esteem, depression and social participation are therefore highly relevant to monitor the impact of stigma reduction interventions. Many instruments have included items or sub-scales measuring these effects. The best-validated instruments are the Participation Scale (van Brakel et al., submitted), the Syam'kela indicator set, the Self-Efficacy Scale (Tedman et al. 1995), the QOLIE-AD-48 (Cramer et al. 1999), the CATIS (Austin & Huberty 1993), the Impact on Participation and Autonomy Questionnaire (Cardol et al. 1999), the Assessment of Life Habits (Noreau et al. 2002) and the CHART (Whiteneck et al. 1992).

Stigmatising arrangements in health and social services

Stigma and discrimination occurring in health and social services are particularly harmful for public health programmes dealing with stigmatised conditions. They are a major problem for people affected by mental illness, HIV/AIDS and leprosy and need to be addressed as a matter of priority and therefore should be part of stigma assessment. No specific instruments assessing this type of stigma were found, but relevant items are included in the UNAIDS protocol on measuring discrimination (2000) and the Policy Project indicator sets.

Stigmatising descriptions or images in media and educational materials

The images portrayed in the media and in educational materials potentially play a powerful role in perpetuating or mitigating stigma. They can serve as an indicator of changing attitudes towards people with stigmatised conditions and are themselves powerful change agents. An audit of such materials therefore would be an important part of stigma assessment. However, we could not find any instruments developed for this purpose. A few relevant items are included in the UNAIDS protocol.

Purpose of stigma assessment

The data collected with such instruments would be very useful for a number of purposes.

1. Understanding the situation of people affected by a given condition in a particular area or country, as part of a situational analysis in preparation for a public health programme.
2. Monitoring and evaluation of the impact of interventions to reduce stigma in the community. The efficacy of different strategies and interventions could be compared.
3. Evaluating the cost-effectiveness of various interventions to reduce stigma or to mitigate the impact of stigma.
4. Providing data for advocacy work. Data on stigma would strengthen the case of people involved in advocacy on behalf of those stigmatised. Such data would awaken the interest of the public to the plight of those affected by the stigma.
5. Research. Reliable generic instruments to measure stigma in a comprehensive way would enable further research to increase our understanding of the dynamics and causes of stigma, with the purpose of designing more effective stigma reduction interventions. Comparing stigma intensity between different people groups and communities would help us discover factors that have helped some to overcome stigma or factors that increase the risk of stigmatisation in others.

Conclusions

1. The consequences of stigma are far-reaching, affecting the quality of life of countless individuals, as well as the effectiveness of many public health programmes.
2. Many instruments have been developed to assess the intensity and qualities of stigma attached to leprosy, mental illness, epilepsy, disability and HIV/AIDS, but often these have been condition-specific.
3. The similarity in the consequences of stigma in many different cultural settings and the crosscutting applicability of many items from stigma instruments suggest that it would be possible to develop a generic set of stigma assessment instruments.
4. To achieve this aim, existing instruments should be further developed, avoiding duplication and building on and collaborating with other current projects with similar aims.

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Table 1: Comparison of the effects of stigma on individuals, community and public health programmes and interventions in different fields of public health.

Effect on the individual and/or community	Leprosy	HIV/AIDS	TB	Mental illness	Epilepsy	Disability	Buruli ulcer	Oncho cerciasis
Emotional stress and anxiety	X	X	X	X	X	X	X	X
Problems in marriage or in getting married	X	X		X	X	X	X	X
Problems in friendships and social relationships	X	X	X	X	X	X	X	X
Problem with employment or in getting a job	X	X		X	X	X		X
Reduced educational opportunities	X	X		X	X	X		
Increased inequities between those affected and those who are not	X	X		X	X	X		
Concealment of the disease after diagnosis	X	X	X	X	X			
Poor(er) prognosis	X	X	X	X				
Other participation restrictions (e.g. economic dependency, denied access to loans and credit, etc.)	X	X		X	X	X	X	
Isolation	X	X	X	X	X	X		X
(Increased) psychological and psychiatric morbidity	X	X	X	X	X	X		X
Lack of motivation to continue treatment, or	X	X	X					
Motivation to continue treatment	X		X	X	X			
Increased disability	X	X	X	X				
Increased gender differences	X	X	X					
Empowerment, e.g. positive self image and confidence developed in resistance to discrimination	X	X		X	X	X		
Effect on public health programmes and interventions								
Delay in presentation for treatment	X	X	X	X		X		
Poorer treatment prognosis; more complicated and more expensive treatment	X	X	X	X		X		
Continued transmission	X	X	X					
Failure of prevention		X						
Poor adherence and default	X	X	X	X				
Risk of drug resistance	X	X	X					
Increased burden on the health services	X	X	X			X		
Poor image of the public health programme	X	X	X	X				

Table 2: Overview of instruments to assess stigma or stigma-related concepts in different fields of public health, arranged in order of publication.

Country	Authors and year	Type of instrument (name) and target population	No. of items*	Response scale	Psychometric properties tested	No. of subjects
Generic						
India	(Brieger et al. 1998;Raguram et al. 1996;Raguram et al. 2004;Stienstra et al. 2002;Vlassoff et al. 2000;Weiss et al. 1992)	Scale (Explanatory Model Interview Catalogue (EMIC)) – people affected by stigmatised conditions Adaptations of the stigma scale of the EMIC have been used in different studies.	6, 13, 19	Yes/Possibly or uncertain/No	Validity (convergent), internal consistency, reliability	56 leprosy 19 vitiligo 12 controls (tinea versicolor)
USA	(Austin & Huberty 1993;Heimlich et al. 2000)	Scale (Child Attitude Toward Illness Scale (CATIS)) – children with chronic disease	13	5-point very good-very bad or very often-never scale	Validity (convergent, divergent, construct), internal consistency, reliability	136 children 8-12 with epilepsy 133 children with asthma 197 adolescents with epilepsy
Nepal, India and Brazil	van Brakel et al., 2004 (submitted to SS&M)	Scale (Participation Scale) – people affected by leprosy, disability or other stigmatised conditions	18	Yes / Sometimes / No, followed 4-point severity scale	Validity (content, criterion, convergent, construct), internal consistency, reliability, stability, dynamicity	Phase II: 691 Phase III: 683 Mixed leprosy, other disability and controls
Leprosy						
India	(Ramu et al. 1975)	Questionnaire – general public	2	Yes/No/Don't know		25 'normal' individuals in rural south India
Malaysia-Sarawak	(Chen 1986)	List of statements – general public	12	Approve / disapprove of given statements		388 community of different ethnic background
Nigeria	(Awofeso 1992)	Questionnaire – nurses	5	5-point agreement scale		278 nurses
Ethiopia	(Tekle-Haimanot et al. 1992)	Questionnaire – people affected by leprosy	8	Yes/No/Don't know		1313 leprosy, 1257 epilepsy
Myanmar	(Myint et al. 1992)	Questionnaire – people affected by leprosy and general public	9	4-point agreement scale		251 leprosy 251 community
USA	(Booth & Ashbridge 1993)	Questionnaire – professionals	5	Yes/No/Don't know		149 non-professional; 55 professional
India	(Raju & Kopparty 1995)	Questionnaire – general public	8	3-point scale (positive, neutral, negative)		599 Orissa, 600 Andhra Pradesh
India	(Anandaraj 1995)	Scale (Dehabilitation scale) – people affected by leprosy	52	5-point agreement scales	Validity (content, construct), internal consistency	???

Country	Authors and year	Type of instrument (name) and target population	No. of items*	Response scale	Psychometric properties tested	No. of subjects
Nepal	van Brakel et al., 1996 ^a	Questionnaire – general public	8	Yes/No/Don't know or multiple answer categories		534 community before campaign 534 community after
India	(Gopal 1998)	Questionnaire – people affected by leprosy	14	Yes/No		53,000 people affected by leprosy
Tanzania	(van den Broek et al. 1998)	Checklist with open questions – general public	5	Open questions with checklist		1064 school children, 344 general public
Bangladesh	(Croft & Croft 1999)	Questionnaire – general public	4	Yes/No/Don't know		50 'cases' 50 controls
Nepal	(de Stigter et al. 2000)	Semi-structured interview – general public		4 categories: usual behaviour, eating limitations, individual negative behaviour, social-public limitations, segregation		192 community
India	(Sharma et al. 2001)	Questionnaire , as well as qualitative methods – people affected by leprosy and general public	4	3-option 'scales'		36 Panchayat reps 16 leprosy in Madhya Pradesh
India	(Arole et al. 2002)	Questionnaire , open-ended questions and other qualitative methods	18	Yes/No		25 leprosy FGD with family members PRA with community
Guyana	(Briden & Maguire 2003)	Questionnaire – health care staff	9	2-4-item response scales		185 non-leprosy
HIV/AIDS						
USA	(Blumenfield et al. 1987)	Questionnaire – nurses	10	True / False		107 nurses 191 nurses
USA	(Shrum et al. 1989)	Scale (AIDS Attitudes Scale (AAS)) – college students	54		Validity (content, construct), internal consistency	164 phase I 135 phase II
USA	(1992;Froman & Owen 1997)	Scale (AIDS Attitude Scale (AAS)) – nurses and other health care personnel	21	6-point agreement scale	Validity (content, construct), internal consistency, stability	167 nurses
USA	(Schondel et al. 1992)	Scale (Attitude Towards Volunteer Motivation) – volunteers working with PLWHA	55	5-point agreement scale	Validity (content, convergent, construct), internal consistency, discrimination	150 youth services volunteers 247 AIDS volunteer organisation
USA	(Dubbert et al. 1994)	Scale (Nursing Willingness	13	11-point willingness	Validity (content, construct,	571 nurses

^a van Brakel WH, Bhatta I, Anderson AM, Engelbrektsson U. Preliminary results from a Leprosy Elimination Campaign conducted in Parwat District, West Nepal. Paper presented at the 2nd international conference on the elimination of leprosy, New Delhi, India, 11-13 October 1996.

Country	Authors and year	Type of instrument (name) and target population	No. of items*	Response scale	Psychometric properties tested	No. of subjects
		Questionnaire – nurses		scale	convergent, divergent), internal consistency, stability	
USA	(Harrison et al. 1994)	Scale (AIDS Attitude and Conservative Views Scale) – nurses	14	5-point willingness or agreement scale	Validity (content, construct), internal consistency	225 nurses
Brazil	(Moriya et al. 1994)	Scale (Attitudes towards AIDS) – general public	25		Validity (content, construct), internal consistency, discrimination	
USA	(Mulford & Lee 1996)	Scale (AIDS victim blaming scale) – general public	17	5-point agreement scale	Validity (construct, convergent)	824 students
	(UNAIDS 2000)	Protocol / indicator (Protocol for identification of discrimination against PLWH) – different aspects of society	37	3-category response scales (multiple options possible)		
USA	(Berger et al. 2001)	Scale (HIV Stigma Scale) – PLWHA	40	4-point agreement scale	Validity (content, convergent, construct), internal consistency, reliability (stability)	318 PLWHA of different ethnic background
USA	(O'Hea et al. 2001)	Scale (Attitudes towards women with HIV/AIDS scale (ATWAS)) – general public	27	5-point agreement scale	Validity (content, convergent, construct), internal consistency	225 students
USA	(Froman & Owen 2001)	Scale (AIDS Attitude Scale (AAS-G)) – general public	21	4-point agreement scale	Validity (content, construct), internal consistency, stability, reliability	160 community members 96 community members 62 community members
South Africa	(Siyam'kela 2003)	Indicator set (Siyam'kela HIV/AIDS stigma indicators) – PLWHA and general public	41	Number of people doing or not doing something		205 in FGD (43% PLWHA) 32 in-depth interviews
USA / Tanzania	UNAIDS/ICRW/Policy Project/Synergy Project/MUCHS ³	Indicator set – PLWHA and general public				978 community members 200 PLWHA 100 health care providers
UK?	Skevington & O'Connell	Scale (WHO-QOL-HIV) - PLWHA	33		Validity (content, construct), internal consistency	900 HIV-positive and well respondents
Tuberculosis						
Vietnam	(Johansson et al.	Qualitative methods – people with and			N.A.	16 focus group discussions

³ MUCHS = Muhimbili University College of the Health Sciences; part of an ongoing stigma indicator field-testing project in Tanzania

Country	Authors and year	Type of instrument (name) and target population	No. of items*	Response scale	Psychometric properties tested	No. of subjects
	2000)	without tuberculosis				
Nicaragua	Macq 2004 (paper submitted)	Scale – people affected by tuberculosis	35	4-point agreement scale	Under development	82 people affected by tuberculosis
Mental Health						
USA	(Cohen & Struening 1962; Struening & Cohen 1963)	Scale (Opinions about Mental Illness (OMI)) – general population	51		Validity (construct), internal consistency	1194 hospital staff
Canada	(Taylor & Dear 1981)	Scale (Community Attitudes to Mental Illness (CAMI)) – general population	40		Validity (content, convergent, construct), internal consistency, discrimination	321 students 54 community members 1090 community households
Germany	(Angermeyer & Matschinger 1996)	Scale (Emotional Reaction to Mental Illness Scale) – general population	12	5-point scale	Validity (content, construct), internal consistency, reliability	2 surveys of community members
USA	(Ritsher et al. 2003)	Scale (Internalised Stigma of Mental Illness (ISMI)) – people with mental illness	29	4-point agreement scale	Validity (content, convergent, divergent, construct), internal consistency, reliability	127 mental health outpatients
USA	Corrigan	Scale (Family Stigma Questionnaire (FSQ)) – family members of persons with mental illness	7	7-point agreement scale using vignettes		850 family members
USA	(Corrigan et al. 2001a)	Scale (General Attribution Questionnaire (G-AQ-20)) – general public	20	9-point 'opinion' scale		
USA	(Corrigan et al. 2001b; Weiner et al. 1988)	Scale (Psychiatric Disability Attribution Questionnaire (PDAQ)) – general public	36 (6 conditions)	7-point agreement scale		
Germany	(Angermeyer & Matschinger 2003)	Scale – general public	8 + 9 + 7	5-point, 9-point and 5-point scales indicating degree of trueness and certainty	Validity (content, convergent, divergent, construct), internal consistency, reliability	5025 general population
USA	(Corrigan et al. 2004)	Scale (Attribution Questionnaire – 27 or Attribution Questionnaire-Short Form) – general public	27 (8 Short Form)	9-point 'opinion' scale using vignettes		
Epilepsy						
USA	(Ryan et al. 1980)	Scale – people with epilepsy	21		Validity (convergent,	445 older adolescents and

Country	Authors and year	Type of instrument (name) and target population	No. of items*	Response scale	Psychometric properties tested	No. of subjects
					divergent, construct)	adults with epilepsy
USA	(Westbrook et al. 1992)	Scale – adolescents with epilepsy	8	Often/sometimes/rarely/never	Validity (convergent), internal consistency	64 adolescents
UK	(Jacoby et al. 1993)	Scale – people with epilepsy	8	4-point scale (a lot, some, a little, not at all)	Validity (content, construct), internal consistency	75 adults with epilepsy 696 adults with epilepsy
UK	(Jacoby 1994)	Scale – people with epilepsy	3	2-option agreement scale	Validity (convergent), internal consistency	607 adults with epilepsy
UK	(Tedman et al. 1995)	Scale Self-Efficacy Scale – adults with epilepsy	12	5-point agreement scale	Validity (content, face, convergent, divergent, construct), internal consistency, reliability	52 adults with epilepsy 48 controls
Pakistan	(Aziz et al. 1997)	Questionnaire – people with epilepsy	12	Yes/No		241 people with epilepsy
USA	(Cramer et al. 1999)	Scale (QOLIE-AD-48) – people with epilepsy	10		Validity (content, convergent, construct), internal consistency, reliability	197 adolescents
USA	(Austin et al. 2002)	Questionnaire – adolescents	5	5-point agreement scale		19,441 high school students
USA	(Austin et al. 2004)	Scale (Child scale) – children with epilepsy Scale (Parent scale) – parents of children with epilepsy	9 6	5-point frequency scale 5-point agreement scale	Validity (convergent, divergent, construct), internal consistency	171 'Chronic sample' 171 'Chronic sample' 210 'New-onset sample'
Disability						
USA	(Tate et al. 1994)	Scale (Perceived Handicap Questionnaire (PHQ)) – people with disability	5			163 spinal cord injury patients
UK	(Harwood et al. 1994)	Scale (London Handicap Scale (LHS)) – people with disability	6	6 levels of severity	Validity (content, convergent, divergent), reliability	89 stroke patients
Netherlands	(Cardol et al. 1999)	Scale (Impact on Participation and Autonomy Questionnaire (IPAQ)) – people with disability	31	5-point quality scale (excellent – very poor)	Validity (content, convergent, construct), internal consistency, reliability	126 adults with disability
Canada	(Noreau et al. 2002; Noreau et al. 2004)	Scale (Assessment of Life Habits (LIFE-H)) – people with disability	69 or 240	10-point severity scale	Validity (content, convergent, divergent), internal consistency intra and inter-tester reliability	49 children and adults with spinal cord injury 482 spinal cord injury patients
USA	(Walker et al.	Scale (Craig Handicap Assessment	32 long	Different scales; actual	Validity (content, convergent),	135 spinal cord injury patients

Country	Authors and year	Type of instrument (name) and target population	No. of items*	Response scale	Psychometric properties tested	No. of subjects
	2003;Whiteneck et al. 1992)	Reporting Technique (CHART) – people with disability	form; 19 short	time spent, actual financial resources	reliability	1110 people with disability
Skin disease						
USA	(Neil 2001)	Scale (the Stigma Scale) – general population	11	5-point agreement scale	Validity (content, construct), internal consistency, reliability	150 community

* Only items measuring attitude and/or practice have been counted here

Table 3: Commonly used stigma instrument items grouped according to ICF domains

Domain*	Item	Mental health	Epilepsy	HIV/AIDS	Leprosy	TB	Buruli ulcer	Onchocerciasis	Disability	Generic	Fields**
Interpersonal interactions and relationships	Problems in / quality of an ongoing marriage / problems with spouse or partner	I	I	I	II		II	III	II	II	7
Interpersonal interactions and relationships	Affected people are concealing the condition / keep it a secret	II	III	II	III		I	I	I		7
Interpersonal interactions and relationships	People avoid someone with this condition / distance themselves socially	III	I	III	I		I	II		I	6
Interpersonal interactions and relationships	Problems for the affected person to get married	III	I		I		I	I		I	5
Interpersonal interactions and relationships	Is the person with the condition treated with respect by family, community members, health workers	I	I		III	I			I		5
Interpersonal interactions and relationships	Allowed to or problems to play with / be around / look after children	I	I	II	III						4
Interpersonal interactions and relationships	Do friends avoid you / is your relationship with your friends affected negatively?		III	I	II				II		4
Interpersonal interactions and relationships	Problems for the children or relative of the affected person to get married	I			II			I		I	3
Interpersonal interactions and relationships	Negative attitude of relatives / abandoned by family			I	I	I					3
Interpersonal interactions and relationships	Does the opinion of the affected person count in (family) discussions	I			I				I		3
Interpersonal interactions and relationships	It is easier to avoid new friendships than worry about telling someone that I have this condition	II		II		I					3
Major life areas	Do you have an equal opportunity as your peers to find work?	I	I	I	II				I		5
Major life areas	Loosing work or diminished employment prospects		I	III	III	I					4
Major life areas	Working with / employing an affected person	I	I		III						3
Major life areas	Are you able to work as hard as your peers do/has your ability to work been affected by your condition?		II		I				III		3

Domain*	Item	Mental health	Epilepsy	HIV/AIDS	Leprosy	TB	Buruli ulcer	Onchocerciasis	Disab	Generic	Fields**
Major life areas	Has your condition affected your educational plans or opportunities?										3
Community, social and civic life	Visiting or being invited by friends, family and/or others			II	IIII				III		5
Community, social and civic life	Being socially active								II		4
Community, social and civic life	Attending social / community functions and/or meetings			II	IIII						3
Community, social and civic life	Anyone with (a history of) this condition should be excluded from taking public office / difficult to function as a leader							II			3
Domestic life	Does the affected person do household work (the way they want)								II		3
Domestic life	Having equal opportunity to buy or rent accommodation										3
Self-esteem / self-efficacy	I'm not as good a person as others because of my condition / think less of yourself							II			5
Self-esteem / self-efficacy	Others would think less of the person because of his/her condition	II						II			4
Self-esteem / self-efficacy	Having this condition has spoiled my life										3
Self-esteem / self-efficacy	I'm a person of worth; I can have a good, fulfilling life, despite my condition										3
Self-esteem / self-efficacy	I feel comfortable being seen in public with a person who has / is known to have this condition										3
Fear of contagion or of being affected	Being afraid of (persons with) this condition	II									4
Fear of contagion or of being affected	Being afraid you or other may catch the condition from an affected person			II							3
Fear of contagion or of being affected	An affected person should be isolated / live separately	III		II	IIII						3
Shame / embarrassment	Is the condition associated with shame or embarrassment	II			II			II			7
Blame / guilt	I feel guilty because I have this condition			III							3
Pity	People feel sorry for a person with this condition / Others pity you							II			4
Perceived stigma	Others would think less of the family										3

Domain*	Item	Mental health	Epilepsy	HIV/AIDS	Leprosy	TB	Buruli ulcer	Onchocerciasis	Disability	Generic	Fields**
Stereotyping	It is possible/easy to tell if a person has this condition										3

* Domains of the ICF or stigma components

** Number of public health fields that have included an item of this type in one or more instruments

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