# Cross-Cultural Validation of Two Scales to Assess Mental Health in Leprosy-Affected People in Province 1 and 7, Nepal

A Qualitative and Quantitative Study
Master Scientific Research Internship

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*"Er schuilt veel wijsheid in de klassieke lijfspreuk 'mens sana in corpore sano' (een gezonde geest in een gezond lichaam): ze herinnert ons eraan dat zowel de geest als het lichaam belangrijk is en dat de gezondheid van de een gekoppeld is aan die van de ander."*

– Quote of "Ikigai: Het Japanse geheim voor een lang en gelukkig leven"
(Miralles & García, 2016, p. 27)

## Preface

This report is part of the master programme Medicine at the VU University Amsterdam, the Netherlands. Its purpose is to cross-culturally validate two health-measurement instruments. The collected data will contribute to assessing mental wellbeing in Nepal.

This project has been a journey, and it has taught me many things about leprosy and Nepali culture. Many thanks to those who contributed and have taken part in this research. Furthermore, thank you colleagues, family members and friends for your never-ending support.

Amsterdam – October 2018

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## Abstract

**Background:** In order to assess levels of mental wellbeing among leprosy-affected people, this project aimed to test and validate the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) and the Patient Health Questionnaire (PHQ-9, depression tool) in Province 1 and 7, Nepal.

**Methods:** Herdman's framework was used to guide the cross-cultural equivalence testing of the two instruments. Ethical approval was obtained from the Nepal Health Research Council. Selection techniques involved purposive and convenience sampling. Leprosy-affected persons were selected in clinics and via clinic records. Controls were contacts of cases or community members and were randomly selected.

In the qualitative part of the study conceptual, semantic, item and operational equivalence between the Nepali and original English tool versions were assessed via the aim of semi-structured interviewing 20 subjects with (former) leprosy (cases). The data were transcribed, translated, analysed and discussed with experts before revising the tools and starting the quantitative part of the study.

In the quantitative study, we aimed for 150 structured interviews, including 100 cases and 50 non-leprosy-affected controls. Quantitative methods were used to test the psychometric properties (measurement equivalence) of the WEMWBS and PHQ-9 scales.

**Results:** The qualitative study included 20 cases (>18 years, 11:9 male:female ratio). All 14 statement items of the WEMWBS and 9 of the PHQ-9 were revised to questions, because the purpose of the statements was unclear to participants. Additional changes were made in four items because of semantic variation and in two because of item non-equivalences. These items were either not understood correctly by most respondents or they needed to be improved grammatically.

The quantitative study sample consisted of 90 cases (>18 years, 1.2:1 male:female ratio) and 50 controls (0.85:1 male:female ratio). Results showed adequate psychometric properties of both the WEMWBS and PHQ-9: Cronbach's $\alpha$ of 0.85 and 0.76 (internal consistency), 75% of hypotheses were confirmed (construct validity), no floor and ceiling effects, and good interpretability and reliability to distinguish between groups.

**Discussion:** Results provide evidence that the adapted versions of the WEMWBS and PHQ-9 have sufficient cultural validity to measure mental wellbeing and depression among Nepali people, especially among persons affected by leprosy in Province 1 and 7, Nepal. Conceptual, item, semantic, and measurement equivalence were achieved. Because of operational non-equivalence, the statements in the original tools were rephrased to questions.



*Key words: Leprosy, Stigma, Gender Differences, Psychological Health, Mental Burden, Nepal*

## List of abbreviations

| | |
|---|---|
| CBR | Community-Based Rehabilitation |
| CES-D | Center for Epidemiological Studies Depression scale |
| CI | Confidence Interval |
| EMIC-AP | Explanatory Model Interview Catalogue Stigma Scale for Affected Persons |
| HIC | High-Income Country |
| HRQOL | Health-related Quality of Life |
| ICF | Informed Consent Form |
| LF | Lymphatic Filariasis |
| LMIC | Low- and Middle-Income Country |
| MB | Multibacillary |
| NLR | Netherlands Leprosy Relief |
| NLT | Nepal Leprosy Trust |
| NMD (Toolkit) | Neglected Tropical Disease Morbidity and Disability Toolkit |
| NTD | Neglected Tropical Disease |
| PHQ-9 | Patient Health Questionnaire |
| PRIME-MD | Primary Care Evaluation of Mental Disorders |
| QOL | Quality of Life |
| SD | Standard Deviation |
| SF-20 | Medical Outcomes Study Short-Form General Health Survey |
| SI | Structured Interview |
| SSI | Semi-Structured Interview |
| WEMWBS | Warwick-Edinburgh Mental Wellbeing Scale |
| WHO | World Health Organization |

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Front page Group photo made in Tankisinwari, Morang with a leprosy-affected patient and her family

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# Introduction

## Contextual background

### Leprosy

Leprosy is one of the many neglected tropical diseases (NTDs) known today. The mildly virulent bacillus Mycobacterium leprae multiplies slowly (average incubation period: 5 years). Infection may result in permanent damage to peripheral nerves, which in turn may lead to visible secondary impairments caused by insensitive limbs and muscle paralysis (Meima, 2004). In this way, the disease carries a risk of causing chronic and progressive disability, in which the infection is cured but impairments may remain. Due to the known stigma, the condition may cause many social and psychological consequences (Lusli et al., 2015; Rafferty, 2005; Tsutsumi et al., 2007; van Brakel et al., 2012). Stigma and the related psychosocial problems are common and increase the chance of mental disorders (Mak et al., 2007).

### Stigma

According to Link & Phelan (2001), "stigma exists when elements of labelling, stereotyping, separating, status loss, and discrimination co-occur in a power situation that allows these processes to unfold". From the perspective of affected persons, three types of stigma can be distinguished: experienced, anticipated or internalized stigma (ILEP, 2011; Weiss, 2008).

The first, experienced or enacted stigma, is often called "discrimination". People are treated differently because of observed differences, such as their health condition, perceived contagiousness or ritual impurity. They experience social exclusion. It is harder for them to engage fully in society, because people avoid being close to them or being associated with them.

The second type, anticipated or perceived stigma, is the expectation or fear of negative attitudes or perceptions, also called "felt stigma". The person is aware of society's stereotypes which results in negative consequences (Livingston & Boyd, 2010).

The third type, self-stigma or internalized stigma influences a person's psychological self-esteem and dignity. Livingston & Boyd (2010) defined this as "a subjective process, embedded within a socio-cultural context, which may be characterized by negative feelings (about him-/herself), maladaptive behaviour, identity transformation, or stereotype endorsement resulting from an individual's experiences, perceptions, or anticipation of negative social reactions on the basis of their mental illness". The same processes apply to persons affected by leprosy and those affected by lymphatic filariasis (LF). The stigma in society creates negative self-perceptions for the person with a stigmatized condition. He or she may feel fear, shame, hopelessness and guilt (ILEP, 2011) and may withdraw from social contact and participation to avoid being hurt or being discriminated against (Stevelink et al., 2011).

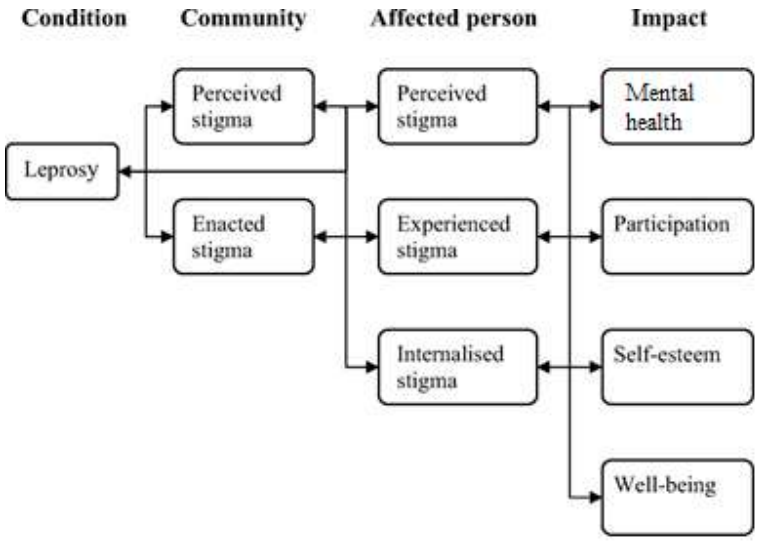


*Figure 1 Types of stigma and impact of stigma (based upon Rensen et al., 2011)*

## Mental health

Looking at the three stigma types, there are two main pathways in which these affect mental health of people affected by leprosy.

First, leprosy-affected patients are discriminated due to bodily disfigurements which are associated with stigmatizing emotions (Attama et al, 2015). Studies have shown that the more severe the (visible) physical disability, the higher the danger of mental distress (Attama et al, 2015; Leekassa et al, 2004; Mankar et al, 2011; Owoeye et al, 2009; Tsutsumi et al, 2007).

Second, felt stigma and self-stigmatization cause persons affected by leprosy to feel ashamed, possibly isolating themselves from society (Rafferty, 2005), and postponing to seek treatment. This may aggravate their condition (Kaur & Ramesh, 1994; Mankar et al, 2011; Wong, 2004). The negative self-image increases the mental burden, as patients with a more pessimistic image of themselves are less able to cope with physical impairments (Pahwa et al, 2013). In fact, the mental impact is often more severe than the physical effects (van ’t Noordende et al., 2016).

As noted above, leprosy is associated with high psychological morbidity (Attama et al, 2015; Owoeye et al, 2009; Scott, 2000; Gautam, 1994). This includes depression, generalized anxiety disorder, drug/alcohol abuse and even suicide, as well as problems in social functioning (Leekassa et al, 2004; Wong, 2004), such as divorce, high rates of unemployment, displacement from their homes, and problems involving interpersonal relations, leisure and social activities.

## Gender

With regards to the psychological burden of leprosy, it is interesting to look at how gender is associated with mental distress. Literature supports the notion that leprosy-affected women are more severely affected than men in the area of social impact, health and psychological impact (Dijkstra et al., 2017). The gender inequality caused by female inferiority and social dependence in leprosy-endemic areas plays a role in this (Ulrich et al, 1993).

## Setting of Nepal

Detecting mental wellbeing problems, including depression, and starting treatment is important in all cultures around the world to improve global health. To better understand mental health and stigma in Nepal, we will put the overall mental wellbeing in Nepal and its mental health care system in perspective.

Nepal is one of the poorest countries in South Asia.[1] In the global (and also Nepali) context is poverty a major predictor of ill-health (Rai et al., 2001; Wagstaff, 2002) and mental illness (Desjarlais & Eisenberg, 1995). In LMICs around 80% of people with severe mental disorders do not receive treatment.[2]

Even though in Nepal "mental illnesses are on the rise" (Department of Health Services, 2014), the State has not given adequate attention and resources to mental health services (Hall et al., 2016; Regmi et al, 2004; World Health Organization, 2006). Only 1% of the Government's health budget is allocated to mental health care (Regmi et al., 2004). According to a WHO report (2006), the mental health awareness of Nepali people and their treatment seeking has been increasing. However, there is a lack of attention, expertise and money in this sector. Furthermore, the stigma surrounding mental illness does not improve the situation.

Currently, the Nepal Health Research Council is conducting an ongoing project to assess the prevalence of mental disorders in Nepal.[3] They acknowledge "the need for a mental health survey representing the national population". The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) and Patient Health Questionnaire (PHQ-9) discussed in this study will contribute to this need.

When looking at leprosy, the burden of mental ill-health correlated with physical illness has a bigger impact in poorer communities due to a lack of appropriate programs and services (Desjarlais & Eisenberg, 1995). The Leprosy Control Division of the Ministry of Health & Population, Government of Nepal, focusses on disability, including physical, intellectual, mental and sensorial impairments.[4] However, the strategy and its programmes do not specifically mention mental health services.

## Conceptual background

### Theoretical framework

This study contributes to the Neglected Tropical Diseases Morbidity and Disability Toolkit (NMD Toolkit) (van 't Noordende et al, 2016). This project aims to develop a cross-NTD toolkit of instruments, as there is a lack of validated tools to assess the various aspects of impairments, mental health, disabilities, stigma and inclusion across NTDs.

We used the cultural validation model as defined by Stevelink & van Brakel (2013), describing the need for cultural validation of instruments across cultures. This is based on the Herdman framework (Herdman et al., 1998). According to Herdman et al. (1998), when adapting health-related quality of life (HRQOL) instruments cross-culturally, five types of equivalence need to be taken into account: conceptual, item, semantic, operational and measurement.

Complete cultural equivalence of an instrument is desirable, but not essential. The main goal of cultural validation is to end up with an adapted version that is culturally valid in a given culture and for a given target group.

[1] Gregson, J. (2017). Poorest Countries in the World. Retrieved 30 July 2018, from https://www.gfmag.com/global-data/economic-data/the-poorest-countries-in-the-world?page=12

[2] Nepal Health Research Council. (2018). Ongoing project: National Mental Health Survey, Nepal. Retrieved 30 July 2018, from http://nhrc.gov.np/projects/nepal-mental-health-survey-2017-2018/ %0D

[3] Nepal Health Research Council. (2018). Ongoing project: National Mental Health Survey, Nepal. Retrieved 30 July 2018, from http://nhrc.gov.np/projects/nepal-mental-health-survey-2017-2018/ %0D

[4] Government of Nepal - Ministry of Health & Population. (2018). Leprosy Control Division. Retrieved 30 July 2018, from http://mohp.gov.np/content/leprosy-control-division

*Table 1 Definitions of categories to assess cultural equivalence (Herdman et al., 1998)*

| Equivalence | Definition |
|---|---|
| Conceptual | "When the questionnaire has the same relationship to the underlying concept in both cultures" |
| Item | "When items estimate the same parameters on the latent trait being measured and when they are equally relevant and acceptable in both cultures" |
| Semantic | "Concerned with the transfer of meaning across languages, and with achieving a similar effect on respondents in different languages, […] taking into account a number of different types of meaning." |
| Operational | "When the elements [a similar questionnaire format, instructions, mode of administration and measurement methods] do not affect the results." |
| Measurement | "The extent to which the psychometric properties of different language versions of the same instrument are similar, […] primarily in terms of their reliability, responsiveness and construct validity." |

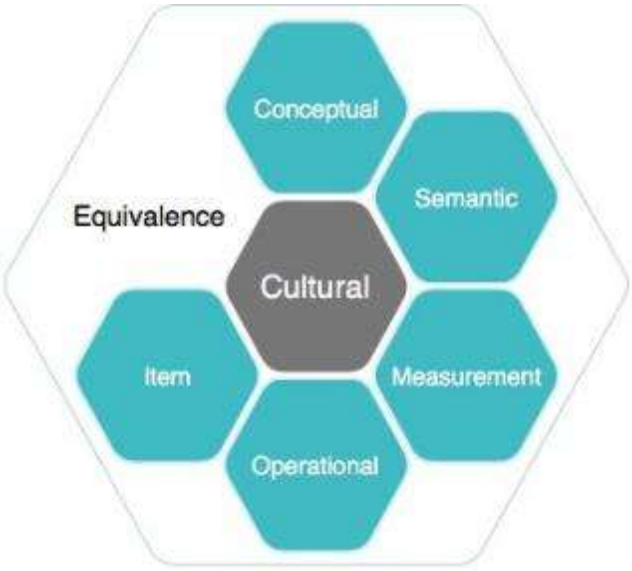


*Figure 2 Model for investigating cross-cultural equivalence in HRQOL questionnaires (based on Herdman et al., 1998). Note: We have replaced the term "functional equivalence" by "cultural equivalence", which makes more sense in our context.*

## Origin, validity and reliability of the scales

Several instruments are available to measure mental health, such as CIS-R, SRQ-20, CES-D and GDS (King, 2018). For this study, scales WEMWBS and PHQ-9 were selected for cultural validation. The tools are frequently used, had already been used in Nepal, and will help in evaluating to what extent mental health care is needed. They have already been validated in several countries and populations. However, neither tool had been validated so far for use with persons affected by leprosy in Nepal.

### WEMWBS

The WEMWBS, developed in 2007, is used for investigating, monitoring, and evaluating mental wellbeing both nationally and locally.[5] It focuses only on positive attributes of mental health such as optimism, energy and confidence. It contains 14 items, with response scales ranging from 1 (none of the time) to 5 (all of the time) (Stewart-Brown et al., 2011). This tool was shown to be valid and

[5] Warwick WMS. (2015). Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS). Retrieved 1 February 2018, from https://warwick.ac.uk/fac/med/research/platform/wemwbs/

reliable. Floor or ceiling effects did not occur, and test-retest reliability was high (ICC 0.83) (Stewart-Brown, 2008). Internal consistency was good (Cronbach's $\alpha$ 0.89) (Tennant et al., 2007).

The WEMWBS has already been validated in Brazil (Santos et al., 2015), Spain (Castellvi et al., 2014), Italy (Gremigni & Stewart-Brown, 2011), China (Ng et al., 2014), and France (Trousselard et al., 2016). See Appendix I for a copy of the WEMWBS.

### PHQ-9

The PHQ-9 is a 9-item, reliable, valid measure of depression severity (Kroenke et al., 2001). Each of the nine DSM-IV criteria of depression is scored from 0 (not at all) to 3 (nearly every day), giving a total score ranging from 0 to 27. The 9-item module was extracted from the full PHQ, which is a self-report version of a diagnostic instrument for common mental disorders: the Primary Care Evaluation of Mental Disorders (PRIME-MD).

Internal consistency was good (Cronbach's $\alpha$ 0.89 and 0.86 in two studies), as was test-retest reliability (ICC 0.84). To determine construct validity, the Medical Outcomes Study Short-Form General Health Survey (SF-20) was used. It showed a strong association between increasing PHQ-9 scores, decreasing SF-20 scores and the likelihood of a major depression.

The PHQ-9 has already been validated in South-Korea (migraine patients) (Seo & Park, 2015); New Zealand (Arroll, 2010); Ohio, USA (epilepsy patients) (Rathore et al., 2014); Chitwan, Nepal (mental illness patients) (Kohrt et al., 2016); and the Netherlands (diabetes patients) (van Steenbergen-Weijenburg et al., 2010).

Because Kohrt et al. (2016) have validated the PHQ-9 in Chitwan, Nepal, we were able to use an abbreviated procedure, just to verify that the tool and translation work well among persons affected by leprosy. In their study, some steps are omitted, such as reproducibility, so we concentrated on the missing aspects of the validation. See Appendix I for a copy of the PHQ-9.

### EMIC-AP

The Explanatory Model Interview Catalogue Stigma Scale for Affected Persons (EMIC-AP) is an existing stigma measure that was already validated in a nearby area in India (Rensen et al., 2011; Weiss, 1997),[6] and was included in this study to assess construct validity of the other two scales.

The EMIC-AP comprises items measuring perceived and experienced stigma, tapping into the most common ways stigma manifests itself. The 15-item tool encompasses questions such as "If possible, would you prefer to keep people from knowing about your leprosy?", and response options are defined as "yes, possibly, don't know, no". Scores range from 0 to 45 for leprosy-affected people, and the higher the EMIC-AP score, the higher the level of perceived stigma. See Appendix I for a copy of the EMIC-AP.

The tool has been (partly) validated at several sites, for instance in Brazil (Frota et al., 2017) and India (Rensen et al., 2011), and has been used before in Western Nepal in Nepali language (Adhikari et al., 2014).

## Objective, relevance and research questions

The objective of this study is to test the validity of the WEMWBS (14 items) and the PHQ-9 depression tool (9 items) for use with persons affected by leprosy in Province 1 and 7, Nepal. Cultural validation is necessary to ensure that instruments are well understood, relevant and acceptable, and to establish reliability and validity metrics of such instruments. They can be used after they have been shown to be cultural valid among the desired target group in the new country or setting, in this case Nepal. The data regarding these two scales will be part of the body of knowledge concerning the cross-cultural validity of instruments in the NMD Toolkit and assessment of mental health in general.

[6] Infolep. (2018). Toolkit. Retrieved 15 February 2018, from https://www.leprosy-information.org/content/emic-affected-persons

The main research question and its sub-questions are as follows:

To what extent are the Nepali versions of the WEMWBS and PHQ-9 culturally equivalent compared to the original tools?

- Conceptual: Do both cultures conceptualise (mental) wellbeing and depression in a similar way?
- Item: Are the items of the two instruments relevant and acceptable to the respondents?
- Semantic: Has the meaning behind the items been translated well and do subjects understand the items well?
- Operational: Is the same questionnaire format applicable in Nepal, such as the instructions, format of questions or items, response scales and mode of administration?
- Measurement: Do the instruments have adequate psychometric properties compared to international standards?

# Methods

## Study design

This project used a cross-sectional validation study design. The mixed methods approach contained qualitative and quantitative tools to better understand the mental health, its consequences and the mental wellbeing of leprosy-affected patients in the Nepalese context.

Qualitative methods involved semi-structured interviews (SSIs) to evaluate conceptual, semantic, item and operational equivalence. Quantitative methods used structured interviews (SIs) to test the psychometric properties (measurement equivalence) of the scales. Figure 3 shows the summary of the study design.

A Nepali interpreter trained in interviewing conducted the interviews. To minimise inter-observer variation, all interviews were conducted in Nepali by the same interviewer/translator. Interviewees were first asked to fill in a Personal Information Form (PIF, see Appendix II). The Principal Investigator was present during all qualitative interviews, and during almost all quantitative interviews.

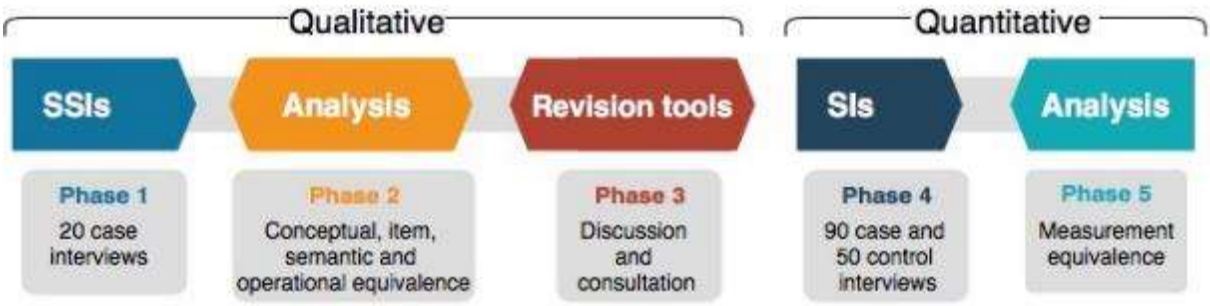


*Figure 3 Visualization of the five research phases in the cultural validation of the WEMWBS and PHQ-9 in Province 1 and 7, Nepal*

## Study sample

The study sample consisted of people affected by leprosy, living in the vicinity of the cities Biratnagar and Dhangadhi, Nepal. The control group had not been affected by leprosy.

### Inclusion criteria

People affected by leprosy were eligible to include when they:

- Were above the age of 18
- Were diagnosed, under treatment or had completed treatment
- Had sufficient command of the Nepali language
- Were capable of responding independently or by their caregivers
- Were willing to give informed consent

### Sample size and sampling method

In this study, we aimed to include 20 cases for the qualitative part and 100 cases plus 50 controls for the quantitative part, both separately selected samples and with a 1:1 male-female ratio. The quantitative sample is based on the minimum number of 100 recommended by Terwee et al. (2007).

NLR Nepal and partner organisations helped in contacting patients. Selection techniques involved purposive and convenience sampling. This is acceptable for a validation study, since the most important characteristic of the sample is known and an adequate diversity in the trait that is

being assessed is aimed for. Patients with a range of impairment severity according to the EHF score were included (van Brakel, Reed, & Reed, 1999), since impairment severity was expected to correlate with mental health status. The EHF score sums up the severity and visibility of impairment of each Eye, Hand and Foot, with 0 meaning no visible impairment, anaesthesia or vision loss; 1 only anaesthesia or vision mildly affected; and 2 both visible impairment and anaesthesia, or severe vision impairment. The total score ranges from 0 to 12.

The qualitative sample was obtained in the Koshi Zonal Hospital in Biratnagar (Province 1) and the Seti Zonal Hospital in Dhangadhi (Province 7); patients receiving treatment were included as well as patients who were previously called and invited to participate and come to the hospital. The quantitative sample was also obtained via these hospitals and their records, but also via records in Community Health Posts of Province 1 and 7.

Controls were selected via convenience sampling, provided that the demographic characteristics are roughly similar to the cases. They were family members, friends, neighbours or community members of cases, and thus were selected at the clinic, door-to-door or on the street. This group was interviewed to find a cut-off value for "normal" mental wellbeing and depression. The EMIC-AP or the community version (EMIC-CSS) was not included for controls.

## Qualitative study

### Design

The qualitative study involved 20 leprosy-affected patients participating in individual semi-structured interviews (SSI) (see Appendix III: SSI interview guide). The participants were encouraged to talk about the concepts of leprosy and their psychological health; to answer open questions about their life and their condition as well as to comment on the statements/questions of the WEMWBS and PHQ-9. This was to gain insights into the relevance of the several topics in the tools, as well as to understand the setting more (meaning the cultural background and living situation).

Results help to assess conceptual, semantic, item and operational equivalence, and to adapt the WEMWBS and the PHQ-9 to the local culture and target group. The kind of questions asked for each equivalence type were:

- Conceptual and item: Can you tell me something about how living with leprosy affects your daily life? Can you tell me something about how your condition makes you feel about yourself?
- Semantic and operational: Can you explain your answer to me (about WEMWBS and PHQ-9 questions)? Did you understand the question? Can you repeat it in your own words?

### Data management and analysis

The qualitative interviews were audio recorded. The data of the interviews were transcribed and translated by the interviewer/translator, analysed by the principal investigator by hand, and the findings and possible adjustments for the scales were discussed with an expert panel. Following the WHO translation guidelines, the "process of translation and adaptation of instruments" included: Forward translation, an expert panel, back-translation, and pre-testing.[7]

Framework analysis and coding were applied to classify the data within thematic frameworks, and interpretations of the statements were divided into being within or out of the range of what the statement was intended to mean. This indicated whether the respondent understood the question and responded appropriately or not (Statistics Division Economic and Social Commission for Asia Pacific Region, 2010). If the majority of participants interpreted the question out of scope, it was revised and adjusted.

Before accepting the revised instruments for the quantitative part, the final versions of the tools were discussed with local experts and supervisors.

[7] World Health Organization. (2018). Process of translation and adaptation of instruments. Retrieved 2 February 2018, from http://www.who.int/substance_abuse/research_tools/translation/en/

### Outcome measures

According to Stevelink & van Brakel (2013), the equivalence measurements and content validity are being categorized by the following:

- Conceptual (3): Assessment of local conceptions, appropriateness of instrument and theoretical arguments
- Item (3): Relevance and acceptability of items, items discussed in light of the findings, and adaptations made based on findings
- Semantic (5): Translation guidelines used, details translation procedure, meaning key words and phrases, and translation problems and difficulties
- Operational (3): Missing data, administration format, response scales and pre-testing

## Quantitative study

### Design

After revision, the quantitative part commenced including two phases. It consisted of the assessment of the two tools via individual structured interviews (SIs) (see Appendix III: SI interview guide). We aimed to include 100 case and 50 control interviews to validate the psychometric properties of the WEMWBS and PHQ-9. The EMIC-AP was included in the case interviews to test construct validity. The interviews took on average 15-20 minutes. After, the quantitative results were analysed, and the validity of the tools was evaluated.

### Data management and analysis

The total scores of WEMWBS and PHQ-9 (and EMIC-AP) for each subject were summed. All personal and quantitative data were entered and managed in Epi Info 7. Statistical analyses were carried out using SPSS statistical software, v25. The mean sum scores were compared between groups by means of a Student's T-test to provide a basis for interpretability. Missing values could not be included.

The data of the control group were used to establish a cut-off point for "normal" mental wellbeing and depression.

### Outcome measures

Validity statistics and psychometric properties to be calculated were measured by the following four pre-defined quality criteria:

- Internal consistency: It measures how well all the items in the tool belong together and are correlated. It explores the correlation of a given item with the sum score, indicating whether they assess the same construct. The indicator is Cronbach's $\alpha$, which would be optimal between 0.70 and 0.90 (Terwee et al., 2007).
- Construct validity: Several hypotheses were formulated to assess the construct validity of the WEMWBS and PHQ-9 (see hypotheses below). Instruments are compared with each other, and also with the EHF and EMIC-AP score. Convergent and divergent validity are aspects. If 75% or more of hypotheses are confirmed per instrument, the construct validity is supported (Terwee et al., 2007).
- Floor and ceiling effects: They are considered to be present if 15% or more of the subjects have either the lowest or the highest possible score on the WEMWBS or PHQ-9. These effects result in a lower tool's content validity as extreme items may be missing (Terwee et al., 2007).
- Interpretability: To help readers interpret the scores, the mean and standard deviation (SD) of the control group will be used as a reference, as well as the mean and 95% confidence interval of three subgroups (age, gender, EHF score).

### *Hypotheses*

Four pre-defined hypotheses per instrument to confirm construct validity are (Terwee et al., 2007):

WEMWBS

1. The mean score of the WEMWBS will be significantly lower among leprosy-affected patients than among controls.
2. The EMIC-AP score will have a negative correlation with the WEMWBS score (divergent validity, rho/ρ –0.20-0.40), i.e. the higher the EMIC-AP score, the lower the WEMWBS score.
3. The PHQ-9 score will have a negative correlation with the WEMWBS score (divergent validity, ρ –0.20-0.40) (the higher the PHQ-9 score, the lower the WEMWBS score).
4. Someone's EHF score has a negative correlation with someone's mental wellbeing.

PHQ-9

1. The mean score of the PHQ-9 will be significantly higher among leprosy-affected patients than among controls.
2. The EMIC-AP score will have a positive correlation with the PHQ-9 score (convergent validity, ρ 0.40-0.60).
3. The WEMWBS score will have a negative correlation with the PHQ-9 score (divergent validity, ρ –0.20-0.40).
4. Someone's EHF score has a positive correlation with someone's depression symptoms.

## Supervision and monitoring

The project was supervised by dr. Wim van Brakel, Head Technical Department of NLR in Amsterdam, the Netherlands, as well as by dr. Marianne van Elteren, Research Internship Coordinator of the Global Health Department, VU University Amsterdam. Furthermore, the NLR team in Nepal supervised and monitored the project on site. The team included Mr. Nand Lal Bastola, Ms. Sirjana Adhikari, and Mr. Labhi Shakya. In addition, an interpreter, Ms. Ranju Tiwari, conducted the interviews.

## Ethical considerations

Ethical approval was given by the Nepal Health Research Council, reference number 2444. Furthermore, prior to the interviews, respondents were asked to give written informed consent to participate in the study. All study data were handled with discretion. Personal identifying information (participant names) were removed from the actual data. Their anonymity was assured and they had the option to withdraw from involvement at any time during the interview. No incentives were offered other than a bus fare or compensation for lost wages, if appropriate.

# Results

## Qualitative study

### Characteristics of participants

In total, 20 cases participated in the qualitative study (see Figure 4 and Appendix VIII). The study sample consisted of 11 females and 9 males, all mostly from rural instead of urban areas (13 cases), from Province 1 (16 cases) and/or with an EHF score of 0 instead of 1-12 (17 cases). The study population shows a range of age and level of education.

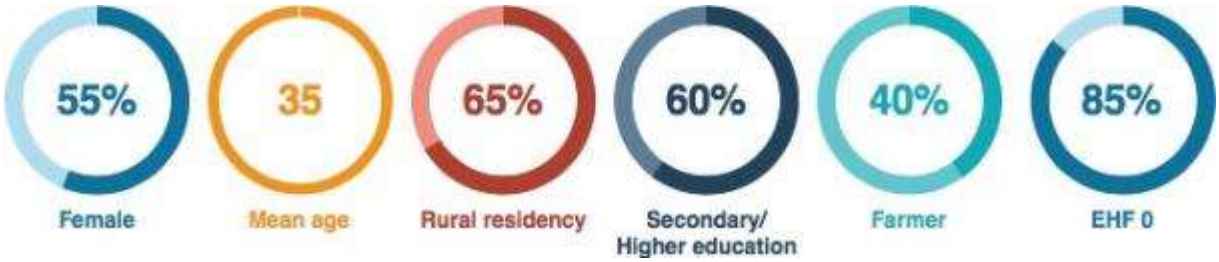


*Figure 4 Several characteristics of the qualitative research sample (n=20)*

Findings of qualitative cultural non-equivalence will be explained in the following four sub-chapters. Due to conceptual, item and/or semantic non-equivalence, several statements were adjusted. Furthermore, all statement items were changed into questions to avoid items being unclear (see Table 2). This is operational non-equivalence.

*Table 2 Adaptation of item statements of WEMWBS and PHQ-9 in Nepali culture, and the revision to questions*

| | **Original statements** | **Statement items revised** | **Items revised to questions** |
|---|---|---|---|
| | | WEMWBS | |
| 1 | I've been feeling optimistic about the future | x | Have you been feeling optimistic about the future? |
| 2 | I've been feeling useful | x | Have you been feeling useful? |
| 3 | I've been feeling relaxed | x | Have you been feeling relaxed? |
| 4 | I've been feeling interested in other people | I've been feeling interested in other people (such as family, relatives, neighbours and friends) | Have you been feeling interested in other people (such as family, relatives, neighbours and friends)? |
| 5 | I've had energy to spare | x | Have you had energy to spare? |
| 6 | I've been dealing with problems well | x | Have you been dealing with problems well? |
| 7 | I've been thinking clearly | x | Have you been thinking clearly? |
| 8 | I've been feeling good about myself | x | Have you been feeling good about yourself? |
| 9 | I've been feeling close to other people | x | Have you been feeling close to other people? |
| 10 | I've been feeling confident | I've been feeling sure of myself | Have you been feeling sure of yourself? |
| 11 | I've been able to make up my own mind about things | x | Have you been able to make up your own mind about things? |
| 12 | I've been feeling loved | x | Have you been feeling loved? |
| 13 | I've been interested in new things | x | Have you been interested in new things? |
| 14 | I've been feeling cheerful | x | Have you been feeling cheerful? |
| | | PHQ-9 | |
| 1 | Little interest or pleasure in doing things | Little interest or pleasure in doing things/"any work" | Have you been having little interest or pleasure in doing things/"any work"? |
| 2 | Feeling down, depressed or hopeless | x | Have you been feeling down, depressed or hopeless? |

| | Original statements | Statement items revised | Items revised to questions |
|---|---|---|---|
| 3 | Trouble falling asleep, staying asleep, or sleeping too much | x | Have you been having troubles falling asleep, staying asleep, or sleeping too much? |
| 4 | Feeling tired or having little energy | x | Have you been feeling tired or have you been having little energy? |
| 5 | Poor appetite or overeating | x | Have you been having a poor appetite or have you been overeating? |
| 6 | Feeling bad about yourself – or that you're a failure or have let yourself or your family down | x | Have you been feeling bad about yourself - or that you're a failure or have let yourself or your family down? |
| 7 | Trouble concentrating on things, such as reading the newspaper or watching television | Outside your routine work: Trouble concentrating on things, such as reading the newspaper, watching television or listening to music | Outside your routine work, have you been having troubles in concentrating on things, such as reading the newspaper, watching television or listening to music? |
| 8 | Moving or speaking so slowly that other people could have noticed. Or, the opposite, being so fidgety or restless that you have been moving around a lot more than usual | x | Have you been moving or speaking so slowly that other people could have noticed. Or, the opposite, have you been so fidgety or restless that you have been moving around a lot more than usual? |
| 9 | Thoughts that you would be better off dead or of hurting yourself in some way | Thoughts of hurting yourself in some way or that you would be better off dead | Have you been having thoughts of hurting yourself in some way or that you would be better off dead? |
| 10 | If you checked of any problems, how difficult have these problems made it for you to: Do your work, take care of things at home, or get along with other people? | x | x |

## Conceptual equivalence

In this chapter, the following sub-question will be answered:

1. Do both cultures conceptualise (mental) wellbeing and depression in a similar way?

It was assessed by (1) the assessment of local conceptions, (2) appropriateness of instruments and (3) theoretical arguments.

### *Assessment of local conceptions*

The main underlying concepts of mental wellbeing discussed in the qualitative interviews were the following: Optimism; usefulness; feeling relaxed/tense; interest; energy; decision-making; confidence; respect; feeling down, sad and/or hopeless; concentration; and appetite. These concepts are similar in both cultures and are now further elaborated.

Patients' **optimism** seemed to be related to the concept of improvement in the future and "to do better". For instance, one female respondent (37) answered:

*"All of the time I am feeling optimistic about my future, that one day I will be okay and I can do better to my parents and make my parents proud."*

Another related concept appeared to be happiness/feeling cheerful. Most respondents answered that they were always happy/feeling cheerful, despite their problems.

Respondent's perceived their **usefulness** in relation to their work and their performance. One woman (37) stated: *"[Yes, as] I am performing well in my work place."* If a person needed help from

others, the patient would feel less useful. Another woman (60) said: *"Sometimes I feel useful, because I cannot do my own work myself. I must have to take help from others."*

The **feeling of being relaxed or tense** was a broadly discussed concept. Feeling relaxed was correlated with feeling cheerful and *"khusi"*, meaning "happy". When patients felt the opposite of *"khusi"*, the word "tension" was often used by respondents. It could be the result of many things, for example: Having a problem in work (high work load, or unemployment); having a problem in the family (fighting, alcoholism, future of children, such as their marriage, etc.); study tension (exam); having stress about money problems and being poor; concentration problems; or having a personal problem (e.g. someone's health/physical status including fear sometimes, being in love, or being socially isolated).

Patients' **interests** involved several items: being interested in other people such as family members, relatives and neighbours; being interested in new things; and being interested in work or anything basically. Interest in others would include *"what are they doing, where are they"* (male, 34); and interest in new things was related to their work and how to improve.

Someone's **energy** level correlated with his/her daily work (mostly physical), but also with climate conditions and whether the person had had trouble sleeping. Due to the hot climate, some respondents mentioned being "lazy" and thus having low energy. Also, respondents talked about sleep problems and thus about being tired. Tension could be a reason for these problems, as e.g. one female respondent (37) mentioned: *"If I am tense, I cannot sleep well."*, and another female respondent (25) stated:

*"Sometimes I cannot sleep. I will be thinking about my disease - how did this happen to me? My husband knows about my leprosy and he's out of the home for a month, so I feel down."*

In addition, one male respondent (28) mentioned a gender-related argument about his energy level: *"I don't do a lot of work in my home. […], because my mother and sister in law are at home, so most of the time I will be busy with studying."*

The power of **decision-making** seems to be related to your position in the family, your gender, your financial status, your health, and your education. Respondents would be dealing with problems better, would be thinking more clearly and would be making up their mind better when they were the "guardian" or (male) head of the family, when they did not have financial difficulties or health problems, and when they were educated.

Men are more often the head of the household, meaning they have more responsibility for making decisions. E.g. one man (38) cited:

*"I am the head of my family, often I make up my mind about things. If I cannot, then I will talk with my elders […]. I will listen to what they have to say, and make a decision myself."*

Female participants more often reported asking family or friends for help when having a problem. One woman (32) stated: *"I alone cannot deal with the problem. Sometimes I ask help from him [husband]."*

"To think clearly" showed a correlation with someone's health and education level. One female respondent (50) who was illiterate, stated the following: *"I don't think clearly because I am uneducated and physically not well […]."* However, another educated female patient (41) also said she did not have to think clearly as *"all the people help (her)"*. Thus, to think clearly also has something to do with your independence and position in the family. This involves your gender. If you are more dependent on others or if people help you with your decisions, you do not have to think (clearly) for yourself.

Your dependence – including your gender, education, and position in family – can affect your **confidence**. E.g. one female respondent (30) mentioned her position as a single woman and being dependent on others for help [and thus being less confident]. Someone's self-confidence involved feeling good, healthy and not alone, but also included feeling bad and/or having fear.

The concept of love in Nepali culture is more experienced as the concept of **respect**. People would be feeling loved and respected by others when people would take care of them, when people would talk nicely with them, or when people would be asked for advice. E.g. one male respondent (57) stated:

*"All of the people love me. People come to me for advice about what would be better, how to face problems, and/or how to solve them."*

In addition, one female respondent (25) said she loved herself as she took care of herself.

In Nepali language, there is no word for "depression". When Nepali people were asked about how they would describe the feeling of being depressed, items were mentioned such as having stress, being anxious, feeling tense or being sad. One woman (60) said she was not depressed at all, as *"she didn't have tension"*.

When respondents talked about when they would be **feeling down, sad and/or hopeless**, remarks were made of their problems related to family, work or study, money, personal health or leprosy, or loneliness. One man (45) said: *"I feel tense because of my school so sometimes I feel down."*

However, respondents also commented on their (in)voluntary lack of time to think about their life/mental state due to their work load and other obligatory activities. E.g. one man (38) mentioned: *"[…] I am always busy in my work, so I do not get the time to think negatively.",* and another man (34) said: *"[…] I used to be hopeless that I cannot do good, so I always want to be busy doing work/things."*

Nonetheless, some respondents mentioned having had thoughts of hurting themselves or of being better off dead. They mentioned having fear/feeling tense about having leprosy, about problems in marriage or not having a child yet, or having problems in the family. Positive responses to this question were related to future improvement, having taken treatment, or having responsibility.

Participants mentioned their **concentration** on their work. One female respondent (50) told us about her concentration problems due to her work load, and others due to distractions by family (female, 18) or friends (male, 34).

The final concept was **appetite**. For some people, appetite appeared to be related with climate or taking medicine. One woman (18) mentioned having less appetite due to warmer climate conditions, whereas two others (male, 34; female, 37) stated having more appetite due to the medicine for leprosy. There was no mention of a link between mental wellbeing and someone's appetite.

### *Appropriateness of instruments, and theoretical arguments*

Both tools are appropriate to use in Nepali culture and include important concepts related to mental wellbeing. However, the concepts of **confidence** and **appetite** show some non-equivalence.

With regards to **confidence**, this is translated in Nepali as "having faith in yourself". A couple respondents mentioned they are confident because they are healthy or take medicine. For example, two female respondents stated:

*"I am confident all the time because I am taking the medicine. I trust the doctor and he told me that if there is any problem, I must come here. […]"* (50)

*"I am confident. Often when I felt sick and I was not with my family; at that time, I don't feel confident."* (18)

It seems that having faith in yourself is related to trust and a feeling that it will be okay. In the United Kingdom (country where the scale was designed), however, being confident refers more to a feeling of self-assurance, and that you appreciate your own abilities and qualities. Thus, it seems "confidence" does not have the same underlying concept across cultures.

Regarding the concept of **appetite**, a connection has not been found between feeling bad and eating less or overeating. This is different in British culture, where this connection is (more prominently) present (Reynolds & Kamphaus, 2013). Thus, appetite and depressed feelings do not seem to be related the same in both cultures and, therefore, someone's appetite is not equally relevant in the two cultures.

In summary, (mental) wellbeing and depression are conceptualised in a similar way in British and Nepali culture. Most concepts in the tools overlap in both cultures, are mutually understandable and are relevant and representative of the construct of mental wellbeing or depression. Only the concepts of confidence and appetite show some non-equivalence.

## Item equivalence

In this chapter, the following sub-question will be answered:

2. Are the items of the two instruments relevant and acceptable to the respondents?

It was measured by (1) relevance and acceptability of items, (2) items discussed in light of the findings, and (3) adaptations made based on findings.

### *Relevance and acceptability of items*

Almost all statements in the questionnaires appeared to consist of equally relevant and acceptable items in both cultures. In Nepali culture, the relevance and acceptance refer to the effects of having leprosy.

Two statements, however, showed possible item non-equivalence, as the underlying concept was not related the same to both cultures: PHQ-9 statement 7 about concentration and statement 9 about negative and suicidal thoughts. The revised items are discussed below.

Participants did not mention any other items to be added to either of the instruments.

### *Items discussed in light of the findings, and adaptations made based on findings*

#### PHQ-9

- Statement 7: "Trouble concentrating on things, such as reading the newspaper or watching television"

Respondents understood this statement, however not all respondents are literate. An expert proposed to add the clause "… or listening to music". In this way, illiterate people or people who do not read the newspaper or watch television are given a third option.

A couple of respondents mentioned they had to concentrate on work or study. For example, one stated: *"I can do my work, I am concentrated in my work. My mind doesn't roam here and there."*, and another said:

*"More than half the day I have trouble in concentrating on things because if I am doing one job then I think I also have another job to do also. So, when should I complete this job so I can do the other work? […]."*

However, this statement should be focused more on concentration on things you do for pleasure and other than routine work, as "reading the newspaper and watching television" indicates concentration in leisure time. One expert proposed to add the following clause at the start: "Outside your routine work: …". All in all, the revised statement is: "Outside your routine work: Trouble concentrating on things, such as reading the newspaper, watching television or listening to music."

- Statement 9: "Thoughts that you would be better off dead or of hurting yourself in some way"

Several patients had difficulty with the word "dead" and mentioned that this statement was direct and somewhat inappropriate. The phrasing of the item was not culturally acceptable. After consultation with an expert, it was proposed to reverse the sentence, forming the following: "Thoughts of hurting yourself in some way or that you would be better off dead". In this way, the statement is less direct and more suitable in Nepali culture.

In summary, all items of the two instruments were considered relevant and acceptable to the respondents, meaning leprosy-affected patients, and thus are appropriate for this study's purpose. To add, data do not show missing elements to be included in the scales.

Two items of the PHQ-9 have been adjusted. Statement 7 about concentration has been given an addition to clarify the focus of concentrating during leisure activities instead of concentrating during work. And statement 9 about having negative thoughts and suicidal thoughts has been rephrased to make the item culturally acceptable.

## Semantic equivalence

In this chapter, the following sub-question will be answered:

3. Has the meaning behind the items been translated well and do subjects understand the items well?

It was measured by (1) translation guidelines used, (2) details translation procedure, (3) meaning key words and phrases, and (4) translation problems and difficulties.

### *Translation guidelines used, and details translation procedure*

Following the WHO translation guidelines, this research conducted the last step "pre-testing" earlier in the process.

- Forward translation: Prior to the study, the WEMWBS scale was translated from English to Nepali by hospital staff situated in Lalgadh, Nepal (LLSC). The Nepali PHQ-9 was already translated by Kohrt et al. (2016).
- Pre-testing: Throughout 20 qualitative interviews the Nepali tools were adjusted and revised until people understood straightaway the questions being asked.
- Expert panel: To properly revise the tools before starting the quantitative part of the research, three experts were consulted during the qualitative interviews and data analysis. The discussion and consultation also resulted in some grammatical changes in the Nepali translated tools.
- Back-translation: The English back-translation of the revised Nepali scales was done by a Nepali student fluent in English and with no background information on leprosy (see Appendix V for the English back-translation).

## *Meaning of keywords and phrases*

Data concerning semantic equivalence showed that most questions were well understood. Young, literate respondents with a higher education had less difficulties answering the questions compared to older, illiterate people.

Still nine statements and one answer option, however, showed semantic cross-cultural differences, as discussed below. Of these only three parts of the WEMWBS and one part of the PHQ-9 were adjusted.

### WEMWBS

The tool mentions three statements which in Nepali culture are predominantly related to physical work. In British culture, the statements more often refer to "mental" work instead of physical, and they also imply things other than work.

- Statement 2: "I've been feeling useful"
- Statement 3: "I've been feeling relaxed"
- Statement 5: "I've had energy to spare"

This means that the basic semantic meaning of the statements is not similar across groups. However, despite this difference, the three statements may still be equally relevant in both cultures from the perspective of mental wellbeing. The items were not revised.

- Statement 4: "I've been feeling interested in other people"

Some female respondents incorrectly interpreted statement 4. They understood that when being interested in other people, you are minding other people's business, for instance on the street or people you do not know well. They would answer a, "None of the time" or answer b, "Rarely". However, when the clause "… such as family, relatives, neighbours and friends" was added, their answers would switch to answer option d, "Often" or e, "All of the time". Male respondents would answer d or e also without the additional clause.

Regarding the following two statements, respondents seemed to distinguish their answer between making decisions themselves, or ask help to e.g. family or friends.

- Statement 7: "I've been thinking clearly"
- Statement 11: "I've been able to make up my own mind about things"

One woman (24) stated for instance: *"Sometimes I have to take help from someone, and some of the time I am able to make up my mind myself."* In British culture, this distinction is not made necessarily. You can make up your own mind, whether or not you consulted with others. This is a semantic difference in both cultures, however, the statements may still be equally relevant in assessing wellbeing in both cultures. The items were not revised.

- Statement 10: "I've been feeling confident"

Some (especially illiterate) respondents understood the sentence better when the word "confident" was changed to "sure of myself", so the statement was changed to: "I've been feeling sure of myself". This change was supported by the expert panel.

- Answer option: "Rarely"

Some respondents could not explain the difference between answer b "Rarely" and answer c "Some of the time". After consulting the experts, the clause "(1-2 times)" was added. Respondents who did not understand this answer option at first, did so with this elaboration.

### PHQ-9

- Statement 1: "Little interest or pleasure in doing things"

The Nepali translation for "doing things" is "*kaam*" meaning "work". That is why, respondents mentioned their feelings about their work. For instance, one man (28) answered:

*"Not at all, there is no more work in my home. I have to clean my room and wash my clothes. Only sometimes when I am alone, I don't like to work."*

However, this sentence should address not only obligatory things (work), but also things of entertainment and joy, such as eating with family, going to the cinema, etcetera. That is why, the Nepali translation is changed to *"karya"*, meaning "any work/activity".

- Statement 4: "Feeling tired or having little energy"

This item concerns the same explanation of statement 2, 3 and 5 of the WEMWBS, about feeling useful, feeling relaxed and having energy to spare; respondents mentioned their energy level as a result of their physical work instead of "mental" work. However, the item was not revised.

### *Translation problems and difficulties*

The interviewer found it difficult sometimes to switch between the Nepali and English language to find a proper translation. This was a problem both in the field as later when entering the data on the computer.

In summary, with some minor adjustments, the meaning of the items has been translated to Nepali well and subjects understood the items well. Cross-cultural translation, however, has its difficulties. The emphasis lay on key words and phrases. Four of ten semantic variances have been adjusted.

Concerning the WEMWBS, statement 4 about interest in other people was elaborated with examples, statement 10 on confidence was changed to "feeling sure of yourself" and answer option b "Rarely" was particularised with "1-2 times". Concerning the PHQ-9, in statement 1 about having less interest in doing things, the Nepali translation for "doing things" is "work" (*"kaam"*). This word was changed to "any work/activities" (*"karya"*) to broaden the concept.

## Operational equivalence

In this chapter, the following sub-question will be answered:

4. Is the same questionnaire format applicable in Nepal, such as the instructions, format of questions or items, response scales and mode of administration?

It was measured by (1) missing data, (2) administration format, (3) response scales and (4) pre-testing.

There were no missing data, as all items were answered by participants.

The administration format was not equivalent as respondents had difficulty comprehending the items as statements. The interviewer had to repeat statements which was time consuming, and participants misunderstood items. When rephrased by the interviewer from statement to question, participants understood, indicating that the statement format was the issue rather than the translation. All items were therefore changed to questions in both scales. Interviewees of the pilot study agreed with this new better format.

Other technical methods of the data collection were comparable, as data was collected via interviews. The interviewer verbally explained the purpose, the two tools and their answer options. In general, interviewees said they understood the questions and they did not mention anything negative about the interview. For instance, one female respondent (50) mentioned: *"No the questions are not personal. You can ask such questions. I am happy to answer you."* On average, an interview (SSI) including both scales took 20 minutes, which was considered acceptable.

Regarding the response scales, respondents had no or little difficulty in understanding. However, sometimes it was found confusing that the interview used the two scales with slightly different response scales.

Regarding pre-testing of the interviews, a pilot study was conducted including four leprosy-affected patient interviews. This day was meant as a try-out to practice interviewing with a translator/interviewer.

In summary, the format of the tools indicated non-equivalence as statements had to be changed to questions. With regards to other aspects of operational equivalence, there are no remarks. The instructions, response scales and mode of administration were also applicable in Nepal.

## Quantitative study

After revision of the tools, the quantitative part of the research commenced. On average, a structured interview (SI) took around 15-20 minutes.

### Characteristics of participants

Table 3 and Figure 5 show the demographic data of the 90 leprosy-affected patients and 50 controls included in the quantitative research, recruited from Province 1 and 7 (also see Appendix VIII). Among the case group 45.6% was female, 63.6% had an EHF score of 1 or higher, and the overall mean age was 44.6 (SD 17.4). Among the control group 52.9 % was female, and the overall mean age was 39.3 (SD 14.0).

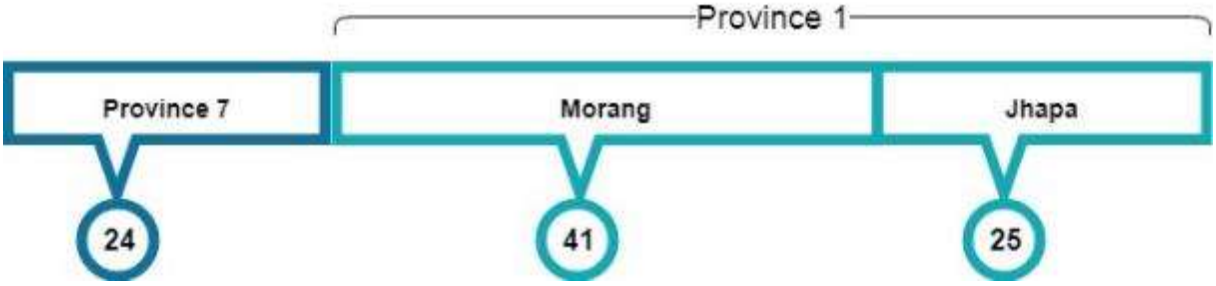


*Figure 5 Demographics of number of cases (n=90) from Province 1 and 7, Nepal, in the quantitative research part*

*Table 3 Layout of participants (n=140) in the quantitative part*

| | | **Case *N* (%)** | | | **Control *N* (%)** | | |
|---|---|---|---|---|---|---|---|
| | | **Male** | **Female** | **Total** | **Male** | **Female** | **Total** |
| **Sample** | | 48 (54.4%) | 42 (45.6%) | 90 (100%) | 23 (46%) | 27 (54%) | 50 (100%) |
| **Age (mean)** *(case n=89)* | | 48.48 (SD 19.0) | 40.15 (SD 14.2) | 44.64 (SD 17.4) | 44.43 (SD 14.1) | 34.89 (SD 12.7) | 39.28 (SD 14.1) |
| **Marital status** | Married | 38 | 36 | 74 (82.2%) | 19 | 19 | 38 (76%) |
| | Widowed | 2 | 4 | 6 (6.7%) | 2 | 2 | 4 (8%) |
| | Separated | 1 | - | 1 (1.1%) | - | - | - |
| | Unmarried | 8 | 1 | 9 (10%) | 2 | 6 | 8 (16%) |
| **Religion** | Hindu | 43 | 29 | 72 (80%) | 22 | 23 | 45 (90%) |
| | Buddhist | 3 | - | 3 (3.3%) | - | 1 | 1 (2%) |
| | Christian | 2 | 9 | 11 (12.2%) | 1 | 3 | 4 (8%) |
| | Muslim | 1 | 1 | 2 (2.2%) | - | - | - |
| | Other | - | 2 | 2 (2.2%) | - | - | - |
| **Residency** | Urban | 8 | 8 | 16 (17.8%) | 6 | 6 | 12 (24%) |
| | Rural | 41 | 33 | 74 (82.2%) | 17 | 21 | 38 (76%) |
| **Level of education** | Illiterate | 13 | 13 | 26 (28.9%) | 3 | 3 | 6 (12%) |
| | Read and write only | 14 | 16 | 30 (33.3%) | 3 | 8 | 11 (22%) |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | Primary education | 6 | 4 | 10 (11.1%) | 2 | 2 | 4 (8%) |
| | Secondary education | 16 | 7 | 23 (25.6%) | 9 | 8 | 17 (34%) |
| | Higher education (e.g. university) | - | 1 | 1 (1.1%) | 6 | 6 | 12 (24%) |
| **Income** | No income | 12 | 19 | 31 (34.4%) | 3 | 11 | 14 (28%) |
| | Less than 7000 NPR per month | 16 | 14 | 30 (33.3%) | 4 | 5 | 9 (18%) |
| | 7000 – 10,000 NPR per month | 11 | 5 | 16 (17.8%) | 4 | 5 | 9 (18%) |
| | 10,000 – 20,000 NPR per month | 9 | 2 | 11 (12.2%) | 8 | 3 | 11 (22%) |
| | More than 20,000 NPR per month | 1 | 1 | 2 (2.2%) | 4 | 3 | 7 (14%) |
| **Employment** | Farmer | 21 | 14 | 35 (38.9) | 6 | 6 | 12 (24%) |
| | Unemployed | 9 | 5 | 14 (15.6) | 2 | 3 | 5 (10%) |
| | Housewife | - | 13 | 13 (14.4%) | - | 6 | 6 (12%) |
| | Officials (employed in government) | - | - | - | 5 | 3 | 8 (16%) |
| | Other | 19 | 9 | 28 (31.1%) | 10 | 9 | 19 (38%) |
| **EHF score** *(case n=88)* | 0 | 15 | 17 | 32 (36.4%) | | | - |
| | 1 | 12 | 9 | 21 (23.9%) | | | - |
| | 2 | 6 | 4 | 10 (11.4%) | | | - |
| | ≥3 | 14 | 11 | 25 (28.4%) | | | - |
| **WEMWBS** | | 58.5 | 61.0 | **59.6** | 61.6 | 61.9 | **61.7** |
| **PHQ-9** | | 4.98 | 4.10 | **4.58** | 3.26 | 4.81 | **4.10** |
| **EMIC-AP** | | 8.55 | 10.4 | **9.40** | - | - | - |

## Measurement equivalence

In this chapter, the following sub-question will be answered:

5. Do the instruments have adequate psychometric properties compared to international standards?

It was measured by (1) internal consistency, (2) construct validity, (3) floor and ceiling effects, and (4) interpretability, including reliability to distinguish between groups.

Internal consistency of both tools was good. Construct validity was supported as 75% or more of hypotheses were confirmed per instrument. No floor or ceiling effects were observed.

To assess reliability to distinguish between groups, three subgroups (gender, age, and EHF score) were checked on mean and 95% confidence interval (CI). The control group was used as a reference. The cut-off value for age was 40 and for EHF score 3, as these figures split the cases and controls in equal groups (see Table 5 and 7) and/or showed significant differences between the made groups.

### *WEMWBS*

#### Internal consistency

The WEMWBS total score had an alpha of 0.85. When looking at the Cronbach's $\alpha$ per item, it is shown that removal of unrevised question 3 *("Have you been feeling relaxed?")* would lead to an improvement of the alpha from 0.85 to 0.88. In addition, the "Corrected Item-Total Correlation" value was low (–0.012), indicating that this item fits poorly with the rest.

*Table 4 Item-Total Statistics of the WEMWBS in Province 1 and 7, Nepal*

| Question | Corrected Item-Total Correlation | Cronbach's $\alpha$ if Item Deleted |
|---|---|---|
| 1 | 0.58 | 0.84 |
| 2 | 0.70 | 0.83 |
| 3 | –0.012 | 0.88 |
| 4 | 0.45 | 0.84 |
| 5 | 0.73 | 0.82 |
| 6 | 0.71 | 0.83 |
| 7 | 0.65 | 0.83 |
| 8 | 0.50 | 0.84 |
| 9 | 0.22 | 0.85 |
| 10 | 0.55 | 0.84 |
| 11 | 0.58 | 0.84 |
| 12 | 0.26 | 0.85 |
| 13 | 0.67 | 0.83 |
| 14 | 0.44 | 0.84 |

#### Construct validity

To establish construct validity, the four hypotheses of the WEMWBS were tested.

First, the mean wellbeing score of the case and control group were compared. As hypothesized, the case mean of 59.6 was significantly lower than the control mean of 61.7. The 95% CI of the difference between the two means was –4.68 and 0.42 ($p$=0.013).

Second, to check the correlation between the WEMWBS and EMIC-AP scale, the Spearman rank correlation coefficient was assessed. Results showed that stigma scores for leprosy-affected patients were not significantly correlated with wellbeing scores: Spearman's $\rho$ was –0.076 ($p$=0.48).

Third, the association between the WEMWBS and PHQ-9 was checked using a Spearman correlation coefficient. Spearman's ρ of –0.37 ($p$<0.01) showed a significant negative correlation, meaning the higher the depression score, the lower the wellbeing score.

Fourth, the Spearman correlation analysis of the EHF score and wellbeing showed that, as hypothesized, the two were significantly correlated: Spearman's ρ was –0.39 ($p$<0.01).

### Floor and ceiling effects

None of the participants scored the lowest (14) or highest (70) possible score. The mean score was 59.6, range from 25 to 69, with a 95% CI of 57.9 to 61.3.

### Interpretability

When comparing the WEMWBS mean scores between male and female cases and controls, it was noted that in both case and control group males show a less positive mental wellbeing relatively compared to females (58.5 vs. 61.0 and 61.6 vs. 61.9). These groups were not counterparts but independent groups. In the latter control group the difference is unlikely to be significant, which means that it is likely to be due to chance.

When the case group is split in two groups of less than 40 years old ($n$=49) and 40 or above ($n$=40), significant mean differences of the WEMWBS are found (56.4 vs 63.7, $p$<0.01), which were not found in the control group ($n$=23 under 40 and $n$=27 of 40 or above, $p$=0.17). This means people 40 years old or above who are affected by leprosy have an overall less positive mental wellbeing, compared to younger patients.

With regards to the EHF score, people with an EHF score of 3 or higher and thus, with a higher disability showed a significantly lower level of mental wellbeing ($p$<0.01).

In conclusion, the WEMWBS is reliable to distinguish between subgroups of gender, age, and EHF score.

*Table 5 Three subgroups to check reliability to distinguish between groups in assessing the WEMWBS in Province 1 and 7, Nepal. Results of case and control group are shown separately.*

*Case*

| | | ***n*** | **Mean** (95% CI) | **Independent t-test** (2-tailed) |
|---|---|---|---|---|
| **WEMWBS** | | 90 | 59.6 (57.9-61.3) | 0.10 |
| Gender | M | 49 | 58.5 (55.7-61.2) | |
| | F | 41 | 61.0 (59.1-62.9) | |
| Age | <40 | 49 | 63.7 (62.7-64.7) | 0.00 |
| | ≥40 | 40 | 56.4 (53.6-59.1) | |
| EHF | <3 | 63 | 61.4 (59.8-63.1) | 0.00 |
| | ≥3 | 25 | 54.4 (50.5-58.4) | |

*Control*

| | | ***n*** | **Mean** (95% CI) | **Independent t-test** (2-tailed) |
|---|---|---|---|---|
| **WEMWBS** | | 50 | 61.7 (60.2-63.2) | |
| Gender | M | 23 | 61.6 (59.1-64.0) | |
| | F | 27 | 61.9 (59.9-63.9) | |
| Age | <40 | 23 | 63.0 (61.3-64.6) | 0.17 |
| | ≥40 | 27 | 60.7 (58.3-63.2) | |

## *PHQ-9*

### Internal consistency

The PHQ-9 total score had an alpha of 0.76 that fell in the optimal range. Removal of any statement would not significantly improve the Cronbach's α.

*Table 6 Item-Total Statistics of the PHQ-9 in Province 1 and 7, Nepal*

| Question | Corrected Item-Total Correlation | Cronbach's α if Item Deleted |
|---|---|---|
| 1 | 0.50 | 0.73 |
| 2 | 0.35 | 0.76 |
| 3 | 0.46 | 0.74 |
| 4 | 0.55 | 0.73 |
| 5 | 0.28 | 0.77 |
| 6 | 0.57 | 0.73 |
| 7 | 0.45 | 0.75 |
| 8 | 0.32 | 0.76 |
| 9 | 0.55 | 0.73 |

### Construct validity

To establish construct validity, the four hypotheses of the PHQ-9 were tested.

First, the mean depression score of the case and control group were compared. As hypothesized, the case mean of 4.58 was higher than the control mean of 4.10. However, this difference was not statistically significant. The 95% CI of the difference between the two means was –0.60 and 1.56 ($p$=0.25).

Second, the PHQ-9 score was correlated with the EMIC-AP score. The Spearman rank correlation coefficient (ρ) was –0.46 ($p$<0.01), indicating that the higher the stigma scores, the lower the PHQ-9 scores.

Third, as discussed already as third hypothesis of the WEMWBS, the wellbeing and depression scores were compared using a Spearman correlation test. A Spearman's ρ of –0.37 ($p$=.00) showed a significant negative correlation, meaning the higher the depression score, the lower the wellbeing score.

Fourth, to check the correlation between the impairment severity (EHF score) and level of depression, the Spearman correlation coefficient was evaluated. As hypothesized, there was a significant positive correlation with a Spearman's ρ of 0.36 ($p$<0.01).

### Floor and ceiling effects

Three of the 90 cases scored the lowest (0) possible score (3.3%) and none of the participants scored the highest (27) possible score, so no floor or ceiling effects were present. The mean score was 4.58, range from 0 to 19, 95% CI 3.86-5.30.

### Interpretability

Regarding gender, female cases showed a significantly lower level of depression than male cases (4.10 vs. 4.98). However, the results in the control group went in the opposite direction, with female participants expressing more depressive symptoms than the male controls (4.81 vs. 3.26). These groups were not counterparts but independent groups.

Furthermore, when the case group was split in two age groups of less than 40 years old and 40 or above, a significant mean difference in the PHQ-9 score was found, which were not found in the control group (see Table 7). Among the cases, people 40 years old or above have an overall lower depression score compared to younger persons.

With regards to the EHF score, people with an EHF score of 3 or higher showed significantly more depressive symptoms. An independent t-test indicated a mean difference of 1.79 ($p$=0.028).

In conclusion, the PHQ-9 is reliable to distinguish between groups as significant differences were found between the three subgroups (gender, age, and EHF score).

*Table 7 Three subgroups to check reliability to distinguish between groups in assessing the PHQ-9 in Province 1 and 7, Nepal. Results of case and control group are shown separately.*

*Case*

| | | ***n*** | **Mean** (95% CI) | **Independent t-test** (2-tailed) |
|---|---|---|---|---|
| **PHQ-9** | | 90 | 4.58 (3.86-5.30) | 0.38 |
| Gender | M | 49 | 4.98 (3.79-6.17) | |
| | F | 41 | 4.10 (3.36-4.83) | |
| Age | <40 | 49 | 3.70 (3.12-4.28) | 0.022 |
| | ≥40 | 40 | 5.37 (4.15-6.58) | |
| EHF | <3 | 63 | 4.13 (3.35-4.90) | 0.028 |
| | ≥3 | 25 | 5.92 (4.25-7.59) | |

*Control*

| | | ***n*** | **Mean** (95% CI) | **Independent t-test** (2-tailed) |
|---|---|---|---|---|
| **PHQ-9** | | 50 | 4.10 (3.44-4.76) | |
| Gender | M | 23 | 3.26 (2.35-4.18) | |
| | F | 27 | 4.81 (3.92-5.71) | |
| Age | <40 | 23 | 4.30 (3.52-5.09) | 0.10 |
| | ≥40 | 27 | 3.93 (2.87-4.98) | |

# Discussion

The purpose of this study was to cross-culturally validate the WEMWBS and PHQ-9 by assessing their cultural equivalence for leprosy-affected persons in Province 1 and 7, Nepal, compared to the original tools. This was done by assessing five equivalences through qualitative and quantitative research methods.

Similar research has been done before. The WEMWBS and PHQ-9 tools have been validated and used in different groups and languages in both LMICs and HICs.[8][9] Findings support the tools' robustness in various cultural contexts (Ikink et al., 2012; Keyes, 2013).

Both tools could be used for a specific purpose. The WEMWBS is a good alternative to the quality of life instruments, especially the WHOQOL-BREF, which is often too difficult in a target group with low education (Skevington et al., 2004; A. Tsutsumi et al., 2006; Vernon-Wilson, 2013). The scope of QOL is much wider than the scope of the WEMWBS, but it could be argued that mental wellbeing would be a key outcome measure in mental health care, rehabilitation, stigma reduction and other programmes to improve quality of life (NHS Greater Glasgow and Clyde, 2013; World Health Organization, 2002).[10] Concerning the PHQ-9, measuring depression is relevant as it would affect overall QOL. It is a condition that needs to be and can be treated.

In this research, the qualitative study results showed that a good overall concept, item and semantic equivalence were achieved. However, operational equivalence was poor. After adjustments, a good operational validity was also realised. In the quantitative study, results showed a good overall measurement equivalence. The elements are discussed below whilst considering other relevant current literature.

It is important to point out the cultural rationale of changing statements. According to Herman et al. (1998), it is justified when it improves relevance, acceptability, comprehensibility and/or appropriateness of the item. Changed properties should be measured by psychometric testing.

## Conceptual equivalence

Overall, the instruments and their concepts were found to be appropriate in Nepali culture. The study supports the notion that (mental) wellbeing and depression are conceptualised in a similar way in British and Nepali culture. Most concepts in the tools WEMWBS and PHQ-9 overlap and are relevant and representative of the construct of mental wellbeing or depression in the culture among Nepali-speaking people in South Nepal. These findings are comparable with other validation studies of WEMWBS conducted in Norway (Smith et al., 2017), Spain (López et al., 2013), and the Netherlands (Ikink et al., 2012); and of PHQ-9 conducted in Western Kenya (Monahan et al., 2009), Korea (Han et al., 2008), Peru (Zhong et al., 2014), and Nigeria (Adewuya, Ola, & Afolabi, 2006).

To add, all items of the two instruments were relevant, acceptable and appropriate to the leprosy-affected respondents. No one had suggestions for elements that were missing in the scales, which support the tools' content validity. Other studies showed comparable findings (Kim et al., 2014; Santos et al., 2015; Smith et al., 2017).

However, one Dutch study by Ikink et al. (2012) found that social wellbeing was not adequately reflected in the WEMWBS, and another UK study by Taggart et al. (2013) focussing on Pakistani and Chinese groups was missing a reflection of social harmony in family and community in

[8] American Psychological Association. (2018). Patient Health Questionnaire (PHQ-9 & PHQ-2). Retrieved 26 September 2018, from http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/patient-health.aspx

[9] Warwick Medical School. (2018). WEMWBS in Other Languages. Retrieved 26 September 2018, from https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/researchers/languages/

[10] ChaMPs Public Health Network. (n.d.). Measuring mental wellbeing: Using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) to measure mental wellbeing as an outcome of your intervention. Retrieved 28 September 2018, from http://www.champspublichealth.com/writedir/2967Measuring mental wellbeing using WEMWBS-FINAL.pdf

the WEMWBS, as well as contentment and peace of mind (Keyes, 2013). Another Nepali study found that somatic complaints could be more reflected in the PHQ-9 – not just abdominal complaints (Kohrt et al., 2016).

Nevertheless, the main underlying conceptions assessed in this study while interviewing leprosy-affected Nepali people were optimism, usefulness, feeling relaxed/tense, interest, energy, decision-making, confidence, respect, feeling down, sad and/or hopeless, concentration and appetite. Other studies found overlapping concepts, e.g. Tennant et al.'s UK study (2007) used optimism, relaxation, energy, and autonomy (related to decision-making); Taggart et al.'s study (2013) on Pakistani and Chinese groups in the UK addressed self-confidence and freedom from worry (feeling relaxed); and Zhong et al.'s Peru study (2014) used concentration difficulty, low energy and appetite changes. To add, Kohrt et al.'s Nepal study (2016) reported on the frequently said term "tension" as an idiom of stress. This was also found in this study. The term could be linked to several concepts, not just: feeling relaxed/tense.

Additional conception labels mentioned in other studies were for instance, personal development and satisfying interpersonal relations (Keyes, 2013; Tennant et al., 2007), or psychomotor agitation (or retardation) (Kohrt et al., 2016; Zhong et al., 2014). This variety is perhaps due to different contextual backgrounds, maybe these missing elements show resemblance to conceptions used in our Nepali study, or the concepts did not come up in this research.

It is important to note that conceptual differences may change the relevance of some of the statements in assessing mental health in another culture compared to British culture. Conceptual differences between cultures, such as in Nepal compared to the UK, may be due to e.g. culture, work ethics, environment/climate and gender equality.

For instance, it was found that sub-themes gender and position in family were perceived differently; in Nepali culture men are more often in a position of head of the household, which also implies an inferior position of women. The lower female status is supported by literature (Asian Development Bank, 1999; Harding et al., 2013; The World Bank, 2006).

In addition, the concepts of confidence and appetite were also perceived differently in Nepali and British culture. With regards to appetite, this may be due to the fact that people had little to eat; that eating less was not an option due to their work; perhaps eating more was not an option because they did not have enough money; or that appetite changes may only be seen in more severe mood disorders which we may not have encountered. The study by Kohrt et al. (2016) found a similar result as only item 5 *("Poor appetite or overeating")* showed a low item-total correlation. Their hypothesized link was that there are high rates of parasitic and gastrointestinal infections in LICs which may affect appetite changes. Our recommendation would be to re-examine the concept and possibly rephrase the statement. If item performance does not improve, it should be deleted from the Nepali version of the PHQ-9.

## Item equivalence

Only two items of the PHQ-9 were adjusted. First, an addition was made to statement 7 *("Trouble concentrating on things, such as reading the newspaper or watching television")* to clarify the focus of being able to concentrate during leisure activities instead of being concentrated on work. This distinctive notion of work-related concentration was also used by one recent study (Burmeister et al., 2018). That is why, the supplement "Outside your routine work: …" was useful to clarify (non-work-related) concentration as meant in this study.

Secondly, statement 9 *("Thoughts that you would be better off dead or of hurting yourself in some way")* was rephrased to make the item more culturally acceptable: the strong Nepali statement concerning "suicidal thoughts" was put at the end of the sentence instead of at the beginning. In Nepal, suicide is the main cause of death for women of reproductive age (Suvedi et al., 2009). Another source found one cultural model stating suicide is more common among Nepali men in power positions (Kohrt et al., 2016). In Kohrt et al.'s study (2016) high-caste men supported exclusion of this item, however this was not done as vulnerable groups found the statement acceptable and

relevant. Possible reluctance to talk about the subject and its questionable acceptability might have influenced our findings.

## Semantic equivalence

Translating concepts developed in British culture into another language is challenging (Fernández Guerra, 2012). For instance, the word "depression" does not have a Nepali equivalent. To make the results as precise and reliable as possible, WHO translation guidelines were used and the Nepali-English translations of the interviews were discussed.

Results showed that, in the end, all 24 items were translated and revised successfully to the Nepali language and subjects understood them correctly. The meaning of four out of ten semantic variances of key words and phrases had to be adjusted.

Concerning the WEMWBS, statement 4 *("I've been feeling interested in other people")* was elaborated with examples *("… such as family, relatives, neighbours and friends")*. Some female respondents misinterpreted the original item as "minding other people's business". When adding the extra clause, a couple women changed their answer from "None of the time/Rarely" to "Often/All of the time", whereas male respondents gave the latter answer also without the addition. Perhaps this difference has something to do with Nepali culture and the lower position of women in society.

A second revision was statement 10 *("I've been feeling confident)* being changed to "I've been feeling sure of myself". This is comparable to one Spanish validation (López et al., 2013). Moreover, answer option b *("Rarely")* was specified to mean "1-2 times" due to confusion of respondents. In a similar PHQ-9 study, Monahan et al. (2009) also argued to clarify relatively vague response options by adding figures.

Concerning the PHQ-9, in statement 1 *("Little interest or pleasure in doing things")* the Nepali translation for "doing things" used first was *"kaam"*. This means '"work", in the sense of occupation. This word was changed to "any work/activities" (*"karya"*) to broaden the concept. In the study by Kohrt et al. (2016), item 1 was changed to "[…] how much do you feel that you don't enjoy things, can't enjoy yourself, can't be happy, or don't want to work?". Their revision also indicates that the concept and statement in Nepali should be broadened/adapted.

## Operational equivalence

To achieve operational equivalence in Nepal, all statements in both scales had to be changed to questions to be understood by respondents. Items were misunderstood and the interviewer sometimes had to repeat statements which was time consuming. Participants were able to comprehend the statements when rephrased to questions. This implies that the statement format rather than the translation was the issue, indicating non-equivalence in the format of the items. There were no remarks on the instructions or mode of administration.

Other validation studies with a statement format have reported similar findings to adapt questionnaire items into an interrogative format (Dadun et al., 2017; Garrels & Granlund, 2018; Kohrt et al., 2011). Results were unaffected by the change of operational method.

With regards to the response scales, it was noted that for some respondents it was confusing that the two tools used two different sets of answer options. A recommendation is to give the response scales a visual addition (e.g. a flashcard with appropriate symbols), to make them easier to understand for respondents. Adding a pictorial scale was reported to be useful in two other studies conducted in Nepal (Kohrt et al., 2011, 2016).

## Measurement equivalence

### *WEMWBS*

The Nepali version of the wellbeing tool has adequate psychometric properties compared to international standards: the construct validity was supported by confirming 75% of hypotheses. Also, no floor and ceiling effects were detected, indicating good sensitivity along the range of the scores.

Mean scores and 95% CIs for relevant sub-groups showed adequate interpretability. To add, there was sufficient evidence of reliability as groups that were expected to have different scores were indeed distinguished as having significantly different mean scores.

The internal consistency of the WEMWBS was very good ($\alpha$ = 0.85). Other validation studies conducted in South Africa, Brazil, UK, Spain, Norway, France, Korea and the Netherlands show similar results (Ikink et al., 2012; Keyes, 2013; Kim et al., 2014; López et al., 2013; Santos et al., 2015; Smith et al., 2017; Trousselard et al., 2016).

In this study, however, question 3 *("Have you been feeling relaxed?")* performed poorly. Removal of this item would further increase internal consistency ($\alpha$ = 0.88). However, this result is not found in any other validation study (Ikink et al., 2012; Keyes, 2013; López et al., 2013). We recommend therefore that the current meaning of this item should be re-examined and that the wording possibly should be rephrased. If this does not improve item performance, it should be removed from the Nepali version of the WEMWBS.

### *PHQ-9*

The depression tool in Nepali has adequate psychometric properties compared to international standards. Internal consistency was good ($\alpha$ = 0.76), as is shown in other validation studies as well (Adewuya et al., 2006; Han et al., 2008; Monahan et al., 2009; Omoro et al., 2006).

Furthermore, construct validity was supported by confirming 75% of hypotheses, no floor and ceiling effects were detected, and interpretability was sufficient as well as reliability since groups could be distinguished significantly.

Additionally, when looking at both tools, the WEMWBS and PHQ-9 are linked. This study found a significant negative correlation of mental wellbeing and depression, which is supported by several other studies (Bartram et al., 2013; Ikink et al., 2012; Keyes, 2002; Ryff & Keyes, 1995). Significant negative correlations are found of WEMWBS and various depression scales such as PHQ-9 (Smith et al., 2017), Center for Epidemiological Studies Depression scale (CES-D) (Ikink et al., 2012), or the Hospital Anxiety and Depression Scale (HADS) (Bartram et al., 2013).

## Cultural equivalence

In conclusion, as the sum of the above-mentioned five equivalences, the evidence of cultural equivalence found in this study showed that the WEMWBS and PHQ-9 are culturally valid in the Nepali context for use among persons affected by leprosy.

The validated tools should be utilized to collect data about mental wellbeing of persons affected by leprosy and to develop adequate interventions for those with below average mental wellbeing and especially those suffering from depression.

# Limitations

The qualitative sample was not ideal as 85% of the cases had an EHF score of 0, which is a very small number of participants with leprosy-affected disabilities. In addition, the actual number achieved in the quantitative sample was 90 instead of 100. This was due to difficulties in finding and visiting leprosy-affected patients together with time limitation. While this does not affect the quality of data per se, the study samples were certainly not better than they should have been.

Secondly, participants may have been too shy or embarrassed to answer personal mental wellbeing questions openly during the qualitative interviews. Participants often answered questions with "I do not know" or just a smile. Perhaps "mental health" is quite a sensitive topic to talk about for Nepali people, since it is surrounded by stigma and discrimination. To mitigate this effect, the Nepali interpreter would emphasize the safe environment and would kindly encourage participants to speak.

Another limitation was that interviews had to be conducted through a translator. The main risk is that the information acquired might not be precise. Cultural meaning can get lost in translation. It is important to note that cross-cultural translation (Baker, 2011) and the "cultural equivalence" strategy has its limitations (Higashino, 1988). To mitigate the potential effects of this, this study focussed on key words and phrases during cross-language transfer. To add, there was only one female interpreter. When interviewing a male participant, the gender difference between interpreter and interviewee might have influenced the results of the interview.

In addition, the transcription process showed some flaws as some translations seemed biased instead of literal. To militate against the bias caused, these transcriptions were discussed with the Nepali interpreter or they were excluded from data used in this report.

A way to mitigate the effect of these problems is to triangulate multiple data methods and sources. This technique was used to keep data interpretation as reliable as possible and to raise the credibility of the study.

## Recommendations

A recommendation to further improve the scales could be to assess the need of item 3 in the WEMWBS, as discussed above. Another research proposal could be to test the scales with Lymphatic Filariasis (LF) and other NTDs.

## Conclusion

The cultural validity of the WEMWBS and PHQ-9 is sufficient to assess mental health in a Nepalese setting, in particular for leprosy-affected patients. Semantic, conceptual, item, and measurement equivalence were found adequate. Operational non-equivalence was due to changing the item format from statements to questions.

Regarding scientific and societal impact, this study contributed to the NMD Toolkit validation project, a project aiming to develop a cross-NTD toolkit of instruments. To add, it may eventually contribute to put the mental wellbeing of Nepali people in perspective, to support adequate interventions in the mental health sector.

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# Appendices

## Appendix I: Original English scales

### Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS): 14 item scale

**Below are some statements about feelings and thoughts.**

Please tick (☑) the box that best describes your experience of each over the **last 2 weeks**

| STATEMENTS | None of the time | Rarely | Some of the time | Often | All of the time |
|---|---|---|---|---|---|
| I've been feeling optimistic about the future | 1 | 2 | 3 | 4 | 5 |
| I've been feeling useful | 1 | 2 | 3 | 4 | 5 |
| I've been feeling relaxed | 1 | 2 | 3 | 4 | 5 |
| I've been feeling interested in other people | 1 | 2 | 3 | 4 | 5 |
| I've had energy to spare | 1 | 2 | 3 | 4 | 5 |
| I've been dealing with problems well | 1 | 2 | 3 | 4 | 5 |
| I've been thinking clearly | 1 | 2 | 3 | 4 | 5 |
| I've been feeling good about myself | 1 | 2 | 3 | 4 | 5 |
| I've been feeling close to other people | 1 | 2 | 3 | 4 | 5 |
| I've been feeling confident | 1 | 2 | 3 | 4 | 5 |
| I've been able to make up my own mind about things | 1 | 2 | 3 | 4 | 5 |
| I've been feeling loved | 1 | 2 | 3 | 4 | 5 |
| I've been interested in new things | 1 | 2 | 3 | 4 | 5 |
| I've been feeling cheerful | 1 | 2 | 3 | 4 | 5 |

© WEMWBS

## The Patient Health Questionnaire (PHQ-9)

| Over the past 2 weeks, how often have you been bothered by any of the following problems? | Not At all | Several Days | More Than Half the Days | Nearly Every Day |
|---|---|---|---|---|
| 1. Little interest or pleasure in doing things | 0 | 1 | 2 | 3 |
| 2. Feeling down, depressed or hopeless | 0 | 1 | 2 | 3 |
| 3. Trouble falling asleep, staying asleep, or sleeping too much | 0 | 1 | 2 | 3 |
| 4. Feeling tired or having little energy | 0 | 1 | 2 | 3 |
| 5. Poor appetite or overeating | 0 | 1 | 2 | 3 |
| 6. Feeling bad about yourself - or that you're a failure or have let yourself or your family down | 0 | 1 | 2 | 3 |
| 7. Trouble concentrating on things, such as reading the newspaper or watching television | 0 | 1 | 2 | 3 |
| 8. Moving or speaking so slowly that other people could have noticed. Or, the opposite - being so fidgety or restless that you have been moving around a lot more than usual | 0 | 1 | 2 | 3 |
| 9. Thoughts that you would be better off dead or of hurting yourself in some way | 0 | 1 | 2 | 3 |
| **Column Totals** | _____ | + _____ | + _____ | |
| **Add Totals Together** | _____ | | | |

10. If you checked off any problems, how difficult have those problems made it for you to Do your work, take care of things at home, or get along with other people?

☐ Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult

## Explanatory Model Interview Catalogue Stigma Scale for Affected Persons (EMIC-AP)

**EMIC Affected persons**

**ID:**

**Tick one only for each question**

| No. | Question | Yes | Possibly | Uncer-tain | No | Score |
|---|---|---|---|---|---|---|
| | | **3** | **2** | **1** | **0** | |
| 1 | If possible, would you prefer to keep people from knowing about your leprosy? | | | | | |
| 2 | Have you discussed your leprosy with the person you consider closest to you, the one whom you usually feel you can talk to most easily? | | | | | |
| 3 | Do you think less of yourself because of your leprosy? Has it reduced your pride or self respect? | | | | | |
| 4 | Have you ever been made to feel ashamed or embarrassed because of your leprosy? | | | | | |
| 5 | Do your neighbours, colleagues or others in your community have less respect for you because of your leprosy? | | | | | |
| 6. | Do you think that contact with you might have any bad effects on others around you even after you have been treated? | | | | | |
| 7 | Do you feel others have avoided you because of your leprosy? | | | | | |
| 8. | Would some people refuse to visit your home because of this condition even after you have been treated? | | | | | |
| 9 | If they knew about it would your neighbours, colleagues or others in your community think less of your family because of your leprosy? | | | | | |
| 10 | Do you feel that your leprosy might cause social problems for your children in the community? | | | | | |
| 11 A Unmarried | Do you feel that this disease might make it difficult for you to marry? | | | | | |
| 11 B Married | Do you feel that this disease has caused problems in your marriage? | | | | | |
| 12 | Do you feel that your leprosy makes it difficult for someone else in your family to marry? | | | | | |
| 13 | Have you been asked to stay away from work or social groups? | | | | | |
| 14 | Have you decided on your own to stay away from work or social group? | | | | | |
| 15. | Because of your leprosy, do people think you also have other health problems? | | | | | |
| | | | | **Sum score** | | |

## Appendix II: Personal Information Form (PIF)

| | |
|---|---|
| Date of interview | ...../...../..... (day / month / year) |
| Respondent number | ..... |
| Medical file/dossier number | ..... / Not applicable |
| Sex | Male / Female |
| Age | ..... years |
| Marital status<br>(Tick only one) | O Married<br>O Remarried<br>O Widowed<br>O Separated<br>O Never married |
| Religion | O Hindu<br>O Buddhist<br>O Christian<br>O Muslim<br>O Other: ..... |
| Residency | Urban / Rural |
| Area of residency | ..... |
| Level of education<br>(Tick highest ever completed) | O Illiterate<br>O Read and write only<br>O Primary education<br>O Secondary education<br>O Higher education (e.g. university) |
| Level of income | O No income<br>O Less than 7000 NPR per month<br>O 7000 – 10,000 NPR per month<br>O 10,000 – 20,000 NPR per month<br>O More than 20,000 NPR per month |
| Employment status | O Farmer<br>O Teacher<br>O Officials (employed in government)<br>O Public enterprise<br>O Owner of private business / shop / restaurant, etc.<br>O Employed in business<br>O Non-paid work, such as volunteer or contributing to family income<br>O Student<br>O Housewife<br>O Retired<br>O Unemployed<br>O Other, specified: ..... |
| Severity of difficulty in vision/ hearing/ mobility/ self-care/ upper body | O No difficulty<br>O Some difficulty<br>O A lot of difficulty<br>O Cannot do at all / Unable to do<br>O Refused / Don't know |

| | |
|---|---|
| WHO Eyes, Hands and Feet impairment score:<br>(Leprosy-affected people only) | ..... |
| Occurrence of visible signs of disability<br>(Observation) | Yes / No |
| Do others know you have this condition | Yes / No |
| Age of onset of (disease-related) condition/disability | ..... years |
| Time since diagnosis | ..... years/months |
| Participates/d in CBR program | Yes / No |

(Stigma reduction) interventions participant (has) participates/d in:
.....
.....
.....
.....
.....

## Appendix III: Semi-structured (SSI) and structured (SI) interview model

Steps of the (semi-) structured interview

1. Introduce ourselves
2. Introduce study and aim of today
3. Ask informed consent, and fill in informed consent form
4. Fill in respondent's information (PIF)
5. Follow the rest of the SSI or SI guide below
    a. SSI: During qualitative part of study
    b. SI: During quantitative part of study
6. Thank and close

### SSI: Interview guide

Part 1: Welcome, introduction

*This interview consists of four parts. First, we will ask some general questions about your experiences with having to live with leprosy. Then, in part 2 and 3, we will test a list of questions about your life and how you feel about yourself. In the last part, we will ask some general questions about the interview.*

- When you think about leprosy, what are the first things that come to mind?
- Can you tell me something about how living with this condition affects your daily life?
- Can you tell me something about how your condition makes you feel about yourself?

[General questions for part 2 and 3:

- Did you understand the question?
- Can you repeat it in your own words?
- Was it about something that is important in your life?
- Do you feel it is okay to ask a question life this?]

Part 2: WEMWBS

*Now, we will ask some questions about your life. For example, have you been feeling relaxed in the past few weeks? You can choose 5 answering options: 1 means none of the time, 2 means rarely, 3 means some of the time, 4 means often and 5 means all of the time. Please feel free to ask any questions if you do not understand something.*

In the last 2 weeks…

- Question 1: Have you been feeling optimistic about the future?
- Question 2: Have you been feeling useful?
- Question 3: Have you been feeling relaxed?
- Question 4: Have you been interested in other people?
- Question 5: Have you had energy to spare?
- Question 6: Have you been dealing with problems well?
    - What kind of problems do you have?
- Question 7: Have you been thinking clearly?
    - When do you (not) think clearly?
- Question 8: Have you been feeling good about yourself?
    - When do you feel good about yourself?
    - When not?
- Question 9: Have you been feeling close to other people?
- Question 10: Have you been feeling confident?
    - When do you feel confident?
    - When not?

- Question 11: Have you been able to make up your mind about things?
    - In what condition do you make up your own mind?
- Question 12: Have you been feeling loved?
- Question 13: Have you been interested in new things?
    - What kind of new things would you be interested in?
- Question 14: Have you been feeling cheerful?

Part 3: PHQ-9

*In the third part, we will ask similar questions as in part 2. However, you can choose 4 answering options: 1 means not at all, 2 means several days, 3 means more than half the days and 4 means nearly every day.*

In the last 2 weeks…

- Question 1: Have you had little interest or pleasure in doing things?
- Question 2: Have you been feeling down, depressed or hopeless?
    - If yes, could you explain why and when?
- Question 3: Have you had troubles falling asleep, staying asleep, or sleeping too much?
- Question 4: Have you been feeling tired or have you been having little energy?
    - If yes, could you tell us when you feel this way? And why?
    - Is this due to you being affected by leprosy?
- Question 5: Have you had poor appetite or have you been overeating?
    - If yes, could you tell us when this is the case? And why?
    - Is this due to you being affected by leprosy?
- Question 6: Have you been feeling bad about yourself – or that you are a failure or have let yourself or your family down?
    - Could you give an example of when you would feel bad about yourself? Or when you would let your family down?
- Question 7: Have you been having troubles concentrating on things, such as reading the newspaper or watching television?
    - When do you have to concentrate?
    - And on what things do you concentrate?
    - Do you read the newspaper?
- Question 8: Have you been moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual?
    - When would you walk/speak slowly?
    - When would you walk/speak fast?
- Question 9: Have you had thoughts of hurting yourself in some way, or that you would be better off dead?
    - Do you feel it is okay to ask a question like this?
- Question 10: If you checked off any problems, how difficult have those problems made it for you to: Do your work, take care of things at home, or get along with other people?

Part 4: Final questions

- What did you think of this interview?
- Was a question too personal or were you unhappy to answer for any reason?
- Do you have any questions about the interview?

## SI: Interview guide

Part 1: Welcome, introduction

*This interview consists of five parts. First, we will ask some general questions about your experiences with having to live with leprosy. Then, in part 2-3-4, we will test a list of questions about your life and how you feel about yourself. In the last part, we will ask some general questions about the interview.*

- I understand you have a disease-related condition. When you think about leprosy, what are the first things that come to mind?
- Can you tell me something about how living with this condition affects your daily life?
- Can you tell me something about how your condition makes you feel about yourself?

Part 2: WEMWBS

*Now, we will ask some questions about your life. For example, have you been feeling relaxed in the past few weeks? You can choose 5 answering options: 1 means none of the time, 2 means rarely, 3 means some of the time, 4 means often and 5 means all of the time. Please feel free to ask any questions if you do not understand something.*

| |
|---|
| Instructions for interviewer: Read the statement of the WEMWBS as a question and let the participant answer by choosing 1-5. Answer possible questions of participant. |

Part 3: PHQ-9

*In the third part, we will ask similar questions as in part 2. However, you can choose 4 answering options: 1 means not at all, 2 means several days, 3 means more than half the days and 4 means nearly every day.*

| |
|---|
| Instructions for the interviewer are the same as in part 2, but now including the PHQ-9 instead of WEMWBS. |

Part 4: EMIC-AP

*In the fourth part, we will ask similar questions as in part 2 and 3. However, you can choose 4 answering options: 0 means no, 1, means don't know, 2 means possibly and 3 means yes.*

| |
|---|
| Instructions for the interviewer are the same as in part 2, but now including the EMIC-AP instead of the WEMWBS. |

Part 5: Final questions

- What did you think of this interview?
- Was a question too personal or were you unhappy to answer for any reason?
- Do you have any questions about the interview?

## Appendix IV: Informed Consent Form (ICF)

| | |
|---|---|
| Mode of administration | Verbal |
| Organization | Netherlands Leprosy Relief (NLR) |
| Title of study | Cross-Cultural Validation of Two Scales (WEMWBS and PHQ-9) to Assess Mental Health in Leprosy-Affected People in Province 1 and 7, Nepal |

Introduction

*Hello Mr./Mrs.* [name]*, thank you for taking the time to talk with us. My name is* [name] *and this is Janna Dijkstra, a student from the Netherlands, who will observe this interview. We work together with Netherlands Leprosy Relief. The purpose of this study is to adapt some questionnaires to get information about how you feel about yourself and your life. We will use the results to help improve the leprosy health services in Nepal in future.*

*Today I would like to ask you some questions about your experience with leprosy, and to test a list of questions about your life and how you feel about yourself. For example: "Have you been feeling useful in the last few weeks?" After each question, I will ask you what you think about this question. Did you understand the question? Can you repeat it in your own words? Was it about something that is important in your life? Do you feel it is okay to ask a question like this? If you feel that a question is too personal, or if you are unhappy to answer for any reason, please tell us, and we will skip this question.*

*You are free to stop the interview at any moment. This will not make any difference to the treatment you will receive in future. The interview will take about one hour. Do you have any questions so far?* [answer questions] *I would like to record this conversation to make sure I remember correctly what you have said, would that be ok with you?* [turn on recording device] *The data will only be used for the study and it will be anonymous.*

Consent of participants

- I have understood the information and the purpose of the study. The researcher has answered my questions.
- My participation is voluntary. I am free to stop with the interview at any moment.
- I consent to participate in the study, and to collect and use the information I give for the study.
- The interview will take approximately one hour. I agree for that the interview will be audio-recorded.

Name of participant:
Signature of participant: Date: __ / __ / __

Thumb print of participant:

Name of interviewer:
Signature of interviewer: Date: __ / __ / __

## Appendix V: Revised Nepali scales

### WEMWBS in Nepali

भावना र विचारहरुको बारेमा तल केही कथनहरु छन । (WEMWBS)

कृपया बाक्सामा (√) टीक लगाउनुस जस्ले तपाईको विगत २ हप्ताको अनुभवलाई बयान गर्दछ ।

| कथनहरु | कहिले पनि होईना | शायद नै (१-२ पटक) | बेला बेलामा | प्राय | सधै |
|---|---|---|---|---|---|
| १. म मेरो भविष्यको बारेमा आशावादी महसूस गरिरहेको छु | १ | २ | ३ | ४ | ५ |
| २. म आफुलाई उपयोगी महसूस गरिरहेको छु | १ | २ | ३ | ४ | ५ |
| ३. म तनावमुक्त महसूस गरिरहेको छु | १ | २ | ३ | ४ | ५ |
| ४. म अन्य व्यक्तिहरुमा पनि चासो राखिरहेको छु ( जस्तै परिवार, आफन्तहरू, छिमेकीहरू र साथीहरू ) | १ | २ | ३ | ४ | ५ |
| ५. म उर्जाशिल छु | १ | २ | ३ | ४ | ५ |
| ६. म समस्याहरुको राम्ररी सामना गरिरहेको छु | १ | २ | ३ | ४ | ५ |
| ७. म स्पष्ट रुपमा सोचिरहेको छु | १ | २ | ३ | ४ | ५ |
| ८. म आफ्नो बारेमा राम्रै महसूस गरिरहेको छु | १ | २ | ३ | ४ | ५ |
| ९. म अरु मानिसहरुसित नजिकै भएको महसूस गरिरहेको छु | १ | २ | ३ | ४ | ५ |
| १०. म आफैमा बिश्वास भएको महसूस गरिरहेको छु | १ | २ | ३ | ४ | ५ |
| ११. म आफ्नो विचार बनाउनको लागि सक्षम छु | १ | २ | ३ | ४ | ५ |
| १२. मलाई अरुले माया गरेको महसूस गरिरहेको छु | १ | २ | ३ | ४ | ५ |
| १३. म नयाँ कुरामा अभिरुचि राख्छु | १ | २ | ३ | ४ | ५ |
| १४. म हर्षित महसूस गरिरहेको छु | १ | २ | ३ | ४ | ५ |

PHQ-9 in Nepali

## बिरामी स्वास्थ्य प्रश्नावली (PHQ-9)

| बिगतदुई हप्ताभित्रमा, कति पटक निम्नलिखितसमस्याहरु मध्ये कुनै पनि समस्याहरुको सामनागर्नु पऱ्यो ? | केहि छैन | कहिले काही | आधादिनभन्दा बढी | दिनदिननै |
|---|---|---|---|---|
| १. **कुनै पनि** काम गर्नमा रुची वा खुशीमा कमी | ० | १ | २ | ३ |
| २. उदासी, निरासा वा हिनबोध | ० | १ | २ | ३ |
| ३. निदाउन कठिन, अनिदो, वा धेरै निदाउने | ० | १ | २ | ३ |
| ४. थकित महशुस वा जाँगरमा कमी | ० | १ | २ | ३ |
| ५. भोकमा कमी वा धेरै खाने | ० | १ | २ | ३ |
| ६. आफैलाई खराब महसूस गर्न – वा असफल वा आफैले हिनबोध वा परिवारलाई हिनबोध गराएको ठान्न | ० | १ | २ | ३ |
| ७. तपाईंको दैनिक कार्य बाहिर: एकाग्रतामा गाह्रो, जस्तै पत्रिका पढन, टिभी हेर्न वा संगीत सुन्न | ० | १ | २ | ३ |
| ८. विस्तारै हिडेको र बोलेको कुरा अरु मानिसहरुलाई मस्किलले थाहाहुनसक्थ्यो । वा यस्को बिपरीत-अस्वभाविक रुपमा बेचैन वा छटपटिका साथयत्रतत्र हिडन | ० | १ | २ | ३ |
| ९. कुनै तरीका बाट चोट पुऱ्याउने बिचार आउनु वा यो भन्दा राम्रो मर्नु विचार आउनु | ० | १ | २ | ३ |

जम्मा .....+.....+.....

जम्माजोड .....

१०. यदि तपाईमा उपरोक्त मध्ये कुनै समस्या देखा परयो भने, त्यसले तपाईको काममा, घरमा सरसमानको रेखदेख, वा अरु मानिससँग व्यवहार गर्नमा समस्या पर्‌यायो ।

☐ कुनै समयस्या छैन ☐ केहि हदसम्म समयस्या छ ☐ धेरै समयस्या छ ☐ अत्यन्तै समयस्या छ

## EMIC-AP in Nepali: Adapted for leprosy

EMICc adapted for Leprosy/1

EMICc ID

| क्र.स. | प्रश्नहरु | हो, छ (२) | हुन सक्छ (१) | होइन,छैन (०) | थाहा छैन (०) | स्कोर |
|---|---|---|---|---|---|---|
| १ | संम्भव भए सम्म कुष्ठरोग लागेको व्यक्तिले उसको अवस्थाको बारेमा मानिसहरुले थाहा नपाउन भन्ने चाहन्छ ? | | | | | |
| २ | यदि तपाईको परिवारको कुनै सदस्यमा कुष्ठरोग भएको भए यस समस्याले गर्दा तपाई तल परेको महशुस गर्नुहुन्थ्यो ? | | | | | |
| ३ | तपाईको समुदायमा कुष्ठरोगले गर्दा लाजमर्दो वा असहज महशुस गर्नुपरेको छ ? | | | | | |
| ४ | अन्य व्यक्तिले कुष्ठरोग लागेका व्यक्तिलाई तल पारेर सोच्छन् जस्तो लाग्छ ? | | | | | |
| ५ | कसैलाई कुष्ठरोग लागेको थाहा पाउंदा थाहा पाउनेलाई नकारात्मक असर पर्छ जस्तो लाग्दछ ? | | | | | |
| ६ | तपाईको समूदायका अन्य व्यक्तिले कुष्ठरोग लागेको मान्छेलाई बहिस्कार गर्छन जस्तो लाग्छ ? | | | | | |
| ७ | अन्य व्यक्तिहरुले कुष्ठरोग लागेका व्यक्तिका घर जान इन्कार गर्छन जस्तो लाग्छ ? | | | | | |
| ८ | तपाइको समुदायमा अन्य मानिसहरुले कुष्ठरोग लागेको व्यक्तिको परिवारलाई होच्चाउंछन् वा तल पार्छन जस्तो लाग्दछ ? | | | | | |
| ९ | कुष्ठरोगको कारणले परिवारमा समस्या ल्याउंछ जस्तो लाग्दछ ? | | | | | |
| १० | यदि परिवारको कुनै सदस्यमा कुष्ठरोग लागेको रहेछ भने त्यो कुरा परिवारले अरुलाई भन्न समस्या हुन्छ जस्तो लाग्छ ? | | | | | |
| ११ | कुनै व्यक्तिको विवाह गर्नका लागी कुष्ठरोगले समस्या ल्याउंछ जस्तो लाग्दछ ? | | | | | |
| १२ | हुदै गरेको विवाहमा कुष्ठरोगले समस्या ल्याउंछ ? | | | | | |
| १३ | कुष्ठरोग भएको व्यक्तिको नातेदारलाई विवाह गर्नमा समस्या हुन्छ जस्तो लाग्दछ ? | | | | | |
| १४ | कुष्ठरोग लागेमा काम पाउन वा खोज्न समस्या पर्छ जस्तो लाग्दछ ? | | | | | |
| १५ | मानिसहरुले कुष्ठरोग लागेका व्यक्तिबाट खानेकुरा किन्न मन पराउंदैनन् जस्तो लाग्दछ ? | | | | | |

## Appendix VI: English back-translation of revised Nepali WEMWBS and PHQ-9

### WEMWBS

**Some of the statements regarding the feelings and thoughts are given below.**

Please tick (√) one the correct option below which shows your experiences **since 2 weeks**

| STATEMENTS | Never | Maybe (1-2 times) | Sometimes | Most of the time | Every day |
|---|---|---|---|---|---|
| I am feeling optimistic towards my future | 1 | 2 | 3 | 4 | 5 |
| I feel myself helpful | 1 | 2 | 3 | 4 | 5 |
| I feel stress free | 1 | 2 | 3 | 4 | 5 |
| I keep my concern towards other people (for example my family, my relatives, my neighbours and my friends | 1 | 2 | 3 | 4 | 5 |
| I am productive | 1 | 2 | 3 | 4 | 5 |
| I am tackling my problems | 1 | 2 | 3 | 4 | 5 |
| I think clearly | 1 | 2 | 3 | 4 | 5 |
| I feel good about myself | 1 | 2 | 3 | 4 | 5 |
| I feel I am getting close to people | 1 | 2 | 3 | 4 | 5 |
| I feel faith in myself | 1 | 2 | 3 | 4 | 5 |
| I feel I am good enough to make my own decisions | 1 | 2 | 3 | 4 | 5 |
| I feel others are loving me | 1 | 2 | 3 | 4 | 5 |
| I keep my concern in new things | 1 | 2 | 3 | 4 | 5 |
| I am feeling happy | 1 | 2 | 3 | 4 | 5 |

PHQ-9

| **Since two weeks, how many times have you faced any of the problems given below?** | **Never** | **Sometimes** | **More than half** | **Every day** |
|---|---|---|---|---|
| 1. Less interest or happiness while doing any work | 0 | 1 | 2 | 3 |
| 2. Sadness, unhappiness, or dissatisfaction | 0 | 1 | 2 | 3 |
| 3. Difficulty in sleeping, sleeplessness, or sleeping too much | 0 | 1 | 2 | 3 |
| 4. Tiredness, or less energy | 0 | 1 | 2 | 3 |
| 5. Lack of appetite or extra appetite | 0 | 1 | 2 | 3 |
| 6. I feel like I am bad – or unsuccessful or dissatisfied or that I cannot make my family happy | 0 | 1 | 2 | 3 |
| 7. Outside your daily activity: Difficult to concentrate, for example when reading newspaper, watching tv or listening to songs | 0 | 1 | 2 | 3 |
| 8. People could notice my act of walking and/or talking slowly. Or opposite to this – being abnormal when walking and/or talking. | 0 | 1 | 2 | 3 |
| 9. Sometimes I feel like hurting myself or feel like killing myself/committing suicide | 0 | 1 | 2 | 3 |
| **Total** | | | | |
| **Final** | | | | |

| 10. If you have any problem regarding the above, does it affect your work, household stuff security or any problem related to social human behaviour with others? | | | |
|---|---|---|---|
| □ No problems at all | □ Some problems | □ Many problems | □ Highly problematic |

## Appendix VII: Assessing conceptual and item equivalence

### Participant quotes of qualitative study

Introductory questions about leprosy:

- No. 2 (F, 25) *"My husband works, he builds homes. He comes home once a month. I said I have leprosy now. I am afraid that he will leave me and marry to another due to leprosy. I haven't told my parents, daughter or mother-in-law."*
- No. 4 (F, 24) *"Sometimes I feel different. If other people know about my condition, they may insult me. I belief so."*
- No. 12 (M, 34) *"[Having been affected by leprosy] It has affected my life. I cannot do my work as I did before. It affects me and my family. I am the main guardian of the family. I am suffering from leprosy so my family members are facing problems such as economic problems."*

#### WEMWBS

**1. I've been feeling optimistic about the future**

Related to optimism (WEMWBS: Statement 1 and 14)

**2. I've been feeling useful**

Related to usefulness (WEMWBS: Statement 2; PHQ-9: Statement 10)

**3. I've been feeling relaxed**

Related to feeling relaxed/tense (WEMWBS: Statement 3; PHQ-9: Statement 8)

- No. 2 (F, 25) *"Yes, some of the time I feel relaxed. But sometimes I think; how did leprosy start with me? I think because I used the powder, or I did the facial. Don't do a facial or use the powder at night."* [health/disease, fear]
- No. 12 (M, 34) *"Often I am feeling relaxed. […] But sometimes I think of the fact that I am affected by leprosy now, and I cannot do anything about it. But then after a few minutes I will be ok and say that it's nothing and I will be fine."* [health/disease]

**4. I've been feeling interested in other people, such as family, relatives, neighbours and friends**

Related to interest (WEMWBS: Statement 4 and 13; PHQ-9: Statement 1)

**5. I've had energy to spare**

Related to energy (WEMWBS: Statement; PHQ-9: Statement 3 and 4)

- No. 14 (M, 28) *laughs* *"I don't do a lot of work in my home. I only clean my room, that is my daily work. I don't do anything else, because my mother and sister in law are there in home, so most of the time I will be busy with studying."*

**6. I've been dealing with problems well**

Related to decision-making (WEMWBS: Statement 6, 7 and 11)

- No. 5 (F, 15) *"Rarely I will deal with the problems. Most of the time I take help from sister and my family."* [gender, dependence, position in family]
- No. 1 (F, 32) *"I alone cannot deal with the problem. Sometimes I take help with him."* [gender, dependence, position in family]
- No. 3 (F, 50) *"If I have a small problem, rarely I deal with them. But all of the time I will talk with my sons and husband for dealing with problems."*
- No. 4 (F, 24) *"Some of the time I can deal with problems, and sometimes I take help from friends and family members […]."*
- No. 13 (M, 38) "*My mother is old, so now I am the head of my family. I must have to deal with all the problems. Often I am dealing with the problems and sometimes I take help from my wife and my parents too.*" [position in family]

**7. I've been thinking clearly**

Related to decision-making (WEMWBS: Statement 6, 7 and 11)

- No. 1 (F, 32) *"I have disease and a problem. I don't have a child so also due to this I rarely think clearly. Rest of the time I don't think clearly."* [health/disease, family]
- No. 3 (F, 50) *"I don't think clearly because I am uneducated and physically not well. My family members do all the things and what I need they bring for me, so I don't have to think about anything anymore."* [health/disease, education, gender, position in family]
- No. 6 (F, 41) *"Rarely, all of the people help me so I don't have to think anything."* [dependence, respect]
- No. 15 (M, 45) *"Up to today I have always been thinking clearly. If I don't feel good, then I don't think clearly."* [health/disease]

**8. I've been feeling good about myself**

Related to confidence (WEMWBS: Statement 8, 10 and 11; PHQ-9: Statement 6)

- No. 13 (M, 38) *"I have been feeling good all the time. I don't feel bad about my leprosy, because it will be cured after the treatment."* [health]
- No. 15 (M, 45) "*Often I feel good about myself. If the work I did is going in the right direction, then I feel good."* [work]

**9. I've been feeling close to other people**

Related to respect (WEMWBS: Statement 9, 12 and 14; PHQ-9: Statement 10)

- No. 3 (F, 50) *"I am often close to everyone but they don't know about my condition. So they are close but if I tell them about the disease, they may be far away from me. They may treat me in bad way."* [health/disease]

**10. I've been feeling sure of myself**

Related to confidence (WEMWBS: Statement 8, 10 and 11; PHQ-9: Statement 6)

- No. 3 (F, 50) *"I am confident all the time because I am taking the medicine. I trust the doctor and he told me that if there is any problem, I must come here. So if I have a problem, I will come back here again."* [health/disease]
- No. 5 (F, 18) *"I am confident. Often when I felt sick and I was not with my family; at that time I don't feel confident."* [health/disease]
- No. 6 (F, 41) *"All of the time I am feeling confident, but I am not confident about my daughter what she will do in the future. […]"* [family]
- No. 12 (M, 34) *"I have been feeling confident all of the time. When my family, my relatives and my friends are supportive, then I feel confident."* [family, respect]
- No. 13 (M, 38) *"All of the time I am confident. [I feel confident] When all of the helping hands are with me. [I don't feel confident] If I would get sick or if I would get an accident."* [respect, health/disease]

**11. I've been able to make up my own mind about things**

Related to decision-making (WEMWBS: Statement 6, 7 and 11), and related to confidence (WEMWBS: Statement 8, 10 and 11; PHQ-9: Statement 6)

- No. 1 (F, 32) *"Sometimes I am able to make up my own mind about things. But most of the time my husband makes decisions and I must have to follow him."* [gender, position in family]
- No. 4 (F, 24) *"Sometimes I have to take help from someone, and some of the time I am able to make up my mind myself."*

**12. I've been feeling loved**

Related to respect (WEMWBS: Statement 9, 12 and 14; PHQ-9: Statement 10)

**13. I've been interested in new things**

Related to interest (WEMWBS: Statement 4 and 13; PHQ-9: Statement 1)

- No. 2 (F, 25) *"I am not interested in new things. I will do my own work. I will grow vegetables and see it to the market."* [work]

**14. I've been feeling cheerful**

Related to optimism (WEMWBS: Statement 1 and 14), and related to respect (WEMWBS: Statement 9, 12 and 14; PHQ-9: Statement 10)

PHQ-9

**1. Little interest or pleasure in doing things**

Related to interest (WEMWBS: Statement 4 and 13; PHQ-9: Statement 1)

- No. 13 (M, 38) *"Not at all, I will be in my shop every day for the whole day."* [work]
- No. 14 (M, 28) *"Not at all, there is no more work in my home. I must have to clean my room and wash my clothes, but sometimes when I am alone I don't like to work."*

**2. Feeling down, depressed or hopeless**

Related to feeling down, sad and/or hopeless (PHQ-9: Statement 2 and 9)

- No. 1 (F, 32) *"I don´t feel down or depressed, because I am busy in my work."*
- No. 4 (F, 24) *"Several days I feel down and hopeless if I cannot complete my work in time […]."* [work load]
- No. 12 (M, 34) *"Several days I feel down. If I am alone, I think about how it [having leprosy] happened to me. I used to be hopeless, that I could not do good, so I always want to be busy in doing things."* [health/disease, fear]

**3. Trouble falling asleep, staying asleep, or sleeping too much**

Related to energy (WEMWBS: Statement; PHQ-9: Statement 3 and 4)

- No. 12 *"I always sleep well. Nowadays the nights are short, so I sleep 1 hour during the day."* [sleep]

**4. Feeling tired or having little energy**

Related to energy (WEMWBS: Statement; PHQ-9: Statement 3 and 4)

- No. 1 (F, 32) *"Several days I feel tired by doing my work. There is no one to help me. I have a husband but he goes to work."* [work load]

**5. Poor appetite or overeating**

Related to appetite (PHQ-9: Statement 5)

- No. 4 (F, 24) *"I don't eat less but when I sit in my shop then I eat more fast food. But I eat rice in morning and at night."*
- No. 5 (F, 18) *"Several days I had poor appetite due to climatic condition or due to warmer day."* [climate]
- No. 12 (M, 34) *"In the last two months I am eating more than before. I think this may be due to medicine and my working load."* [medicine, work load]

**6. Feeling bad about yourself – or that you're a failure or have let yourself or your family down**

Related to confidence (WEMWBS: Statement 8, 10 and 11; PHQ-9: Statement 6)

- No. 12 (M, 34) *"Sometimes I feel bad about myself because if I was not suffering from leprosy, I would be working abroad to earn money. I can earn more abroad than here."* [health/disease, work, responsibility]

**7. Outside your routine work: Trouble concentrating on things, such as reading the newspaper, watching television or listening to music**

Related to concentration (PHQ-9: Statement 7)

8. **Moving or speaking so slowly that other people could have noticed. Or, the opposite – being so fidgety or restless that you have been moving around a lot more than usual**

Related to feeling relaxed/tense (WEMWBS: Statement 3; PHQ-9: Statement 8)

- No. 1 *"Several days people notice me." "Why?" "I don't know, but they look at me." "Did they know about your leprosy?" "I didn't tell to them. Only my parents, and my husband parents know about that."* [feeling tension]

9. **Thoughts of hurting yourself in some way or that you would be better off dead**

Related to feeling down, sad and/or hopeless (PHQ-9: Statement 2 and 9)

- No. 1 (F, 32) *"Sometimes I like hurting myself." "Why?" "I don´t have a baby, and I got a disease leprosy too. And I will walk in home and I am free I think about that. I don't have a child too. My husband goes to work, and my mother in law says I don't have a baby. She said: I will marry another girl to my son. I am together with my husband for 10 years but we don't have a child."* [disease, marriage]
- No. 4 (F, 24) *"Several days I have had thoughts about hurting myself. This is because sometimes my parents scold me that I didn't do household activities, so I want to hurt myself."* [family, responsibility]
- No. 6 (F, 41) *"Several days I thoughts of hurting myself. If I take medicine and it won't be cured? Then I thought about hurting myself."* [fear]

10. **If you checked off any problems, how difficult have those problems made if for you to do your work, take care of things at home, or get along with other people?**

Related to usefulness (WEMWBS: Statement 2; PHQ-9: Statement 10), and related to respect (WEMWBS: Statement 9, 12 and 14; PHQ-9: Statement 10)

## Appendix VIII: Sample characteristics

### Qualitative sample

Demographics and layout of participants (*n*=20) in the qualitative part of the cross-cultural validation of the WEMWBS and PHQ-9 in Province 1 and 7, Nepal

| Respondent number | Sex | Age | Residency | Level of Education | Province |
|---|---|---|---|---|---|
| 1 | F | 32 | Rural | Secondary | 1 |
| 2 | F | 25 | Rural | Primary | 1 |
| 3 | F | 50 | Rural | Illiterate | 1 |
| 4 | F | 24 | Rural | Secondary | 1 |
| 5 | F | 18 | Rural | Secondary | 1 |
| 6 | F | 41 | Rural | Secondary | 1 |
| 7 | M | 63 | Urban | Secondary | 1 |
| 8 | F | 60 | Rural | Illiterate | 1 |
| 9 | F | 37 | Urban | Primary | 1 |
| 10 | M | 18 | Rural | Secondary | 1 |
| 11 | F | 27 | Urban | Secondary | 1 |
| 12 | M | 34 | Rural | Secondary | 1 |
| 13 | M | 38 | Urban | Secondary | 1 |
| 14 | M | 28 | Urban | Higher education (e.g. university) | 1 |
| 15 | M | 45 | Rural | Higher education (e.g. university) | 1 |
| 16 | M | 57 | Urban | Read and write only | 1 |
| 17 | M | 22 | Rural | Primary | 7 |
| 18 | F | 30 | Rural | Read and write only | 7 |
| 19 | M | 34 | Rural | Read and write only | 7 |
| 20 | F | 24 | Urban | Secondary | 7 |

### Quantitative sample

Demographics of participants (*n*=140) in the quantitative part

| | | **Case** | | | **Control** | | |
|---|---|---|---|---|---|---|---|
| | | Male | Female | Total | Male | Female | Total |
| Province 7 | | | | | | | |
| Kailali | Dhangadhi | 13 | 11 | 24 | 5 | 5 | 10 |
| Province 1 | | | | | | | |
| Morang | Biratnagar | 6 | 6 | 12 | 7 | 3 | 10 |
| | Kanepokhari | 6 | 4 | 10 | 4 | 5 | 9 |
| | Belaka | 6 | 5 | 11 | 4 | 3 | 7 |
| | Tankisinwari | 2 | 2 | 4 | - | - | - |
| | Dainiya | - | 4 | 4 | - | - | - |
| Jhapa | Arjundara | 1 | - | 1 | 3 | 4 | 7 |
| | Sanischare | - | - | - | - | 4 | 4 |
| | Bhadrapur | - | 3 | 3 | - | 3 | 3 |
| | Surunga | 14 | 7 | 21 | - | - | - |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Total** | **48** | **42** | **90** | **23** | **27** | **50** |
| | **%** | 53% | 47% | 100% | 46% | 54% | 100% |

Layout of participants (*n*=140) in the quantitative part

| | | **Case N (%)** | | | **Control N (%)** | | |
|---|---|---|---|---|---|---|---|
| | | **Male** | **Female** | **Total** | **Male** | **Female** | **Total** |
| **Sample** | | 48 (54.4%) | 42 (45.6%) | 90 (100%) | 23 (46%) | 27 (54%) | 50 (100%) |
| **Age (mean)** *(case n=89)* | | 48.48 (SD 19.0) | 40.15 (SD 14.2) | 44.64 (SD 17.4) | 44.43 (SD 14.1) | 34.89 (SD 12.7) | 39.28 (SD 14.1) |
| **Marital status** | Married | 38 | 36 | 74 (82.2%) | 19 | 19 | 38 (76%) |
| | Widowed | 2 | 4 | 6 (6.7%) | 2 | 2 | 4 (8%) |
| | Separated | 1 | - | 1 (1.1%) | - | - | - |
| | Unmarried | 8 | 1 | 9 (10%) | 2 | 6 | 8 (16%) |
| **Religion** | Hindu | 43 | 29 | 72 (80%) | 22 | 23 | 45 (90%) |
| | Buddhist | 3 | - | 3 (3.3%) | - | 1 | 1 (2%) |
| | Christian | 2 | 9 | 11 (12.2%) | 1 | 3 | 4 (8%) |
| | Muslim | 1 | 1 | 2 (2.2%) | - | - | - |
| | Other | - | 2 | 2 (2.2%) | - | - | - |
| **Residency** | Urban | 8 | 8 | 16 (17.8%) | 6 | 6 | 12 (24%) |
| | Rural | 41 | 33 | 74 (82.2%) | 17 | 21 | 38 (76%) |
| **Level of education** | Illiterate | 13 | 13 | 26 (28.9%) | 3 | 3 | 6 (12%) |
| | Read and write only | 14 | 16 | 30 (33.3%) | 3 | 8 | 11 (22%) |
| | Primary education | 6 | 4 | 10 (11.1%) | 2 | 2 | 4 (8%) |
| | Secondary education | 16 | 7 | 23 (25.6%) | 9 | 8 | 17 (34%) |
| | Higher education (e.g. university) | - | 1 | 1 (1.1%) | 6 | 6 | 12 (24%) |
| **Income** | No income | 12 | 19 | 31 (34.4%) | 3 | 11 | 14 (28%) |
| | Less than 7000 NPR per month | 16 | 14 | 30 (33.3%) | 4 | 5 | 9 (18%) |
| | 7000 – 10,000 NPR per month | 11 | 5 | 16 (17.8%) | 4 | 5 | 9 (18%) |
| | 10,000 – 20,000 NPR per month | 9 | 2 | 11 (12.2%) | 8 | 3 | 11 (22%) |
| | More than 20,000 NPR per month | 1 | 1 | 2 (2.2%) | 4 | 3 | 7 (14%) |
| **Employment** | Farmer | 21 | 14 | 35 (38.9) | 6 | 6 | 12 (24%) |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | Unemployed | 9 | 5 | 14 (15.6) | 2 | 3 | 5 (10%) |
| | Housewife | - | 13 | 13 (14.4%) | - | 6 | 6 (12%) |
| | Officials (employed in government) | - | - | - | 5 | 3 | 8 (16%) |
| | Other | 19 | 9 | 28 (31.1%) | 10 | 9 | 19 (38%) |
| **EHF score** *(case n=88)* | 0 | 15 | 17 | 32 (36.4%) | | | - |
| | 1 | 12 | 9 | 21 (23.9%) | | | - |
| | 2 | 6 | 4 | 10 (11.4%) | | | - |
| | ≥3 | 14 | 11 | 25 (28.4%) | | | - |
| **WEMWBS** | | 58.5 | 61.0 | **59.6** | 61.6 | 61.9 | **61.7** |
| **PHQ-9** | | 4.98 | 4.10 | **4.58** | 3.26 | 4.81 | **4.10** |
| **EMIC-AP** | | 8.55 | 10.4 | **9.40** | - | - | - |

## Personal reflection

*"[…] Een slinger van gebedsvlaggetjes […] die ik vanuit het raam kon zien. Ze waren blauw, wit, rood, groen en geel – blauw voor de ether, wit voor de lucht, rood voor het vuur, groen voor het water, geel voor de aarde […]."*

- Quote from Paolo Cognetti's "De acht bergen"

Leprosy is a burden, a disease. It can be destructive and painful. So let us do something about it. – Those who suffer from leprosy in Nepal have taught me a lesson: Don't give up, live your life, give it a try. And my lesson to the outside world would be: Be supportive, helpful, remove the prejudice, go on!

This project has been a great adventure. The journey definitely enriched and changed my life both on a practical as on a personal level.

Practical skills involved conducting research abroad. It included different aspects and competences in the fields of professional attitude, teamwork, responsibility, decision making, communication, leadership, results orientation, technical skills and cultural competency.

But living and conducting research in another country is hard and many obstacles are in the way. Who am I to assist in whatever form?

- My personal status: 23 years old, female, single, white, Dutch, rich (relatively), weak (every fortnight two days off with stomach problems), tired and sometimes exhausted (15 hour bus rides), temporary guest (three months only), inexperienced (no field work experience, no language efficiency, no statistical background).
- My assets: Only me and myself, bachelor in Medicine, uncertain about the future (my future), a little shy but enough curiosity, small woman but with high hopes, little certainty but with lots of expectations!

On a personal level the research has taught me a great deal of self-knowledge and cultural empathy. The road from compassion to communication and connection is complicated. Some of it is knowledge, some of it is patience, some of it is perseverance. So what about a modest contribution, and where do we start?

Friends and colleagues from Nepal – the translators, drivers, hospital staff, the management of the field office in Biratnagar – they all live in a beautiful country with beautiful people. As an investigator; we want to know more to assist more. Some ways you can think of are questionnaires, interviews, house visits, meeting young and old people, in particular women. And what about the role of the families, the neighbours, the village, nurses and doctors, clinics, hospitals, the government?

I am very grateful for this trip. My stay has taught me many things about the Nepali culture and about leprosy, its stigma and its consequences. The obtained cultural and professional competences will strengthen my future functioning as a doctor. Many thanks to all those who made this inspiring expedition so colourful.