Cross-cultural validation of the Patient Health Questionnaire (PHQ-9) and the Mental Wellbeing Scale (WEMWBS) among people affected by lymphatic filariasis, in India.

Name: N. Ceelen

Student number: 2619331 Number of words: 8910

Internship organization: Netherlands Leprosy Relief Foundation

Name on-site supervisor: Dr. W. van Brakel Name VU-supervisor: Dr. M.R. de Boer Master program: Health Sciences

Specialization: International Public Health

Number ECs: 27

Submission date: 19-09-2019



Abstract

Introduction: Lymphatic filariasis (LF) is considered to be the main cause of long-term physical disability worldwide according to the World Health Organization. LF causes physical, psychological, and social suffering. It is important to quantify the severity of the disability due to the disease in order to implement and evaluate morbidity management and stigma reduction programs. Until now, no instruments have been validated to measure depression and mental wellbeing as comorbidity of LF in India.

Objective: To cross-culturally validate the Patient Health Questionnaire (PHQ-9) and the Mental Wellbeing Scale (WEMWBS) among people affected by LF-related lymphedema, in India.

Methods: A cross-sectional mix methods study design was used. For the cross-cultural validation of the two scales, the cultural equivalence framework was used. First, a small qualitative pilot study was performed, for assessing the semantic, conceptual, item, and operational equivalences, through semi-structured interviewing. After that, the scales were quantitively validated. For this measurement equivalence was assessed through structured interviewing. Here, four psychometric properties were tested namely: interpretability, floor and ceiling effects, construct validity and interpretability.

Results: The qualitative study included eight participants affected by LF. Both the PHQ-9 and WEMWBS showed adequate conceptual and item equivalence. To improve semantic and operational equivalence, adjustments were made in both scales and all statements were changed into questions. The quantitative study included 101 cases and 62 controls. This study showed that both scales had excellent psychometric properties. Internal consistency of the PHQ-9 and WEMWBS was high (Cronbach's α : 0.86 and 0.86), construct validity was supported, no floor and ceiling effects were found and appropriate median values have been given to aid interpretability of the scores.

Conclusion: After making some adjustments, the PHQ-9 and WEMWBS are considered culturally valid in Jharkhand and similar Hindi-speaking settings among people affected by LF-related lymphedema to measure depression and mental wellbeing.

Introduction

Lymphatic filariasis (LF) severely affects public health, especially in tropical areas (1). It is a mosquito-transmitted parasitic infection, with humans as the only reservoir. The mosquitos are infected with parasitic worms, either Wuchereria bancrofti, Brugia malayi or Brugia timori. The larvae of these worms are transmitted to humans by several bites of an infected mosquito (2). It is the obstruction of the lymphatic drainage system caused by the adult worms that causes the eventual problems of LF. These eventual problems are hydrocele and lymphedema of lower limbs, breasts, and female genitals (2). In 2019, there are an estimated 15 million people with lymphedema and another 25 million men with hydrocele worldwide (3). Moreover, an estimated 40 million people are chronically disabled due to LF globally. Therefore, the World Health Organization (WHO) considers the disease to be the single main cause of long-term physical disability worldwide (4). Because the clinical damage is largely irreversible, the proportion of disabled people may still increase when the infection is controlled (1, 5). India accounts for 42% of the burden of LF worldwide, with 250 districts in the country declared endemic for LF (6, 7). A highly affected state in the country is Jharkhand since 17 out of 24 districts are identified to be endemic (7).

It is well known that LF causes social suffering, such as stigma (4, 6, 8). Weiss, Ramakrishna (9) defined health-related stigma as; 'a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group'. A study conducted in India showed that many patients affected by LF experienced stigma and discrimination (10). Participants of several studies reported being teased in public about their physical impairment (4, 11, 12). Evidence suggests that stigma is often due to the fear of contagion and the misunderstanding of the causes of LF (4, 13). Self-stigmatization is also prevalent among LF patients (14). Stigma of LF can affect both the individual health status and public health negatively because it creates barriers for health-seeking behaviour and for adhering to the recommended treatment (8, 12, 15). Moreover, stigma leads to social disconnectedness which affects mental health (8).

According to the WHO, mental health is defined as 'a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community' (16). Here, mental health is more than the absence of a mental disorder (16). The definition of mental wellbeing is less clear because there is limited research about this definition (17). The Royal Society in the UK describes mental wellbeing as 'a positive and sustainable mental state that allows individuals, groups, and nations to thrive and flourish' (17). Several studies showed a significant association with LF and physical health, mental health, and quality of life (8, 18, 19). Also, patients affected by LF frequently report that they experience embarrassment, depression, and social isolation (8, 12, 19). Recent research estimated that co-morbid depression occurred in 50% of cases of LF patients (20). Therefore, depression has been acknowledged as a prevalent disability in those with LF (20). Depression is defined as 'a common mental disorder that presents with depressed mood, loss of interest or pleasure, decreased energy, feelings of guilt or low self-worth, disturbed sleep or appetite, and poor concentration' (21).

It is important to quantify the severity of the disability due to the disease in order to implement and evaluate morbidity management programs (MMP) and stigma reduction programs (20, 22). Aspects that need to be quantified are, for example, mental wellbeing, depression, social participation, stigma, physical impairment, and activity level. The numbers of LF-related disability are crucial for advocacy and creating awareness among health policymakers (22). Advocacy is considered to be an important part in ensuring the implementation of programs (22). Therefore, quantifying the severity of the disability will be helpful in planning and evaluating MMP and stigma reduction programs (10, 22).

The Patient Health Questionnaire-9 (PHQ-9) and the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) can be used to measure depression and mental health among patients with a variety of diseases. The PHQ-9 is an instrument that helps screening for depression and the severity of depression, based upon the diagnosis of DSM-IV depressive disorders (23, 24). The WEMWBS measures aspects of mental health in the last two weeks (25). The PHQ-9 and WEMWBS have already been used and validated in various cultures and target groups (25-36). In India the PHQ-9 has been validated among Indian adolescents in Kolkata (37), people with vision impairments in South-India (38), and among adults of urban areas also in South-India (39). Moreover, in Nigeria, the PHQ-9 has already been used, but not validated, among individuals with LF to assess the prevalence of depression (40). The WEMWBS, in contrast, has not yet been validated in India.

In addition, no instruments have been validated to measure depression and mental wellbeing as comorbidity among people affected by LF in India. Most instruments have been developed in high-income countries and tested in different settings (41). Developing a new instrument for measuring depression and mental wellbeing among people affected by LF in India is unnecessary because it is expected that the construct of depression will be seen in the same way as in countries where these instruments have already been validated. Therefore, an existing instrument can be translated for use in India. However, instruments that are translated should be tested before being used with another target group or in another culture. This is called cross-cultural validation, which implies the extent to which an existing validated instrument, like the PHQ-9 or WEMWBS, is equally suitable in India as well (41). Cross-cultural validation of scales is important, because definitions and understandings of concepts may vary in different cultures (41). Therefore, the aim of this study is to cross-culturally validate the Patient Health Questionnaire (PHQ-9) and the Mental Wellbeing Scale (WEMWBS) among Hindi-speaking people affected by lymphatic filariasis-related lymphedema, in India.

Methods

Study design

A cross-sectional mix methods study design was used for the cross-cultural validation of the PHQ-9 and WEMWBS. First, a small qualitative pilot study was performed to test both measurements scales for example on language, appropriateness, and relevance. Since the PHQ-9 was already validated and used in Hindi (37-39), and the WEMWBS already translated but not validated in Hindi (42), a full qualitative validation was not required. After the qualitative part, both measurement scales were tested quantitatively.

Study population

The study population consisted of people affected by LF-related lymphedema living in Jharkhand, India. A control group was included as well.

The following inclusion and exclusion criteria applied to both the quantitative and qualitative part: **Inclusion criteria**

- People affected by LF-related lymphedema
- People aged eighteen years and above
- People who spoke Hindi
- People who were willing to give informed consent
- People who lived in Jharkhand, India

Exclusion criteria

- People who were not able to give the answers independently
- People who had another disability besides the LF-related lymphedema

Moreover, these inclusion and exclusion criteria applied to both the case and control group, the only difference between the two groups was that the control group consisted of people not affected with LF, these people were for example contacts of cases and community members.

Sample size and sampling methods

For the qualitative part, we aimed to include 5-10 participants affected by LF-related lymphedema, because this was feasible within the timeframe of this study. For the quantitative part, we aimed to include 100 people affected with LF-related lymphedema with a control group of 50 people. According to Terwee et al, the minimum sample size has to be the number of items used in the questionnaire multiplied by 7, with a minimum number of 100 participants. Also, every subgroup should consist of at least 50 participants (43).

The recruitment of participants was done in cooperation with the Netherlands Leprosy Relief (NLR) Foundation in India. The NLR Foundation in India has a register of all the cases affected by LF who are in treatment at the NLR. The NLR team asked local health workers to contact these cases since local health workers have close contact with all the cases living in the specific districts where local hospitals are localized. These local health workers invited the participants to visit a hospital where they were interviewed. Sometimes participants were interviewed at their home if only a few participants were present at the hospital that day. However, interviewing participants at their home was time-consuming, and therefore not preferred. Not all cases in treatment at the NLR Foundation were approached. Occasionally, meetings for self-care were already arranged. In that case, the participants were interviewed at that place. Sometimes places relatively close to the NLR office or places where a lot of participants could be interviewed at the same time were chosen. For the control group, the recruitment of participants was in cooperation with the NLR Foundation as well. Sometimes controls were interviewed at the hospitals where cases were interviewed at the same time or at homes where cases were interviewed. Thereby, controls were interviewed randomly on the street not far from the NLR office. So the sampling method used was convenience sampling for both parts, with the purpose of getting a large sample size.

Conceptual framework

Cultural equivalence framework

For the cross-cultural validation of the two scales, the cultural equivalence framework was used, a modified version of the Herdman framework (41). This framework consists of five types of equivalences: conceptual, item, semantic, operational and measurement equivalence. Cultural equivalence is an umbrella concept, combining the five equivalences (41). The first four equivalences are tested through qualitative research and the fifth one mostly via quantitative research (44). Table 1 in Appendix I explains the definitions of each of the categories of equivalence and in figure 1 these equivalences are illustrated in relation to each other.

The fifth equivalence, measurement equivalence, was evaluated by testing the psychometric properties of the instruments. The main purpose of this part is to guarantee that the culturally adapted scales have acceptable psychometric properties (44). According to Terwee et al, the psychometric properties are: construct validity, criterion validity, content validity, internal consistency, floor and ceiling effects, interpretability, responsiveness, and reproducibility which consist of agreement and reliability (43). Content validity is the only psychometric property that is qualitatively investigated. Table 2 in Appendix I explains the definitions of the different psychometric properties and in figure 1 these psychometric properties are visualized in relation to each other and the equivalences.

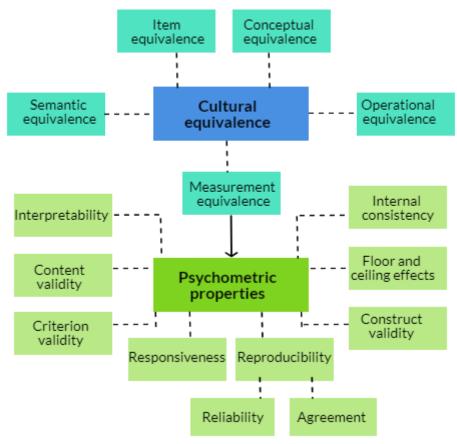


Figure 1. Cultural equivalence framework of Stevelink and Van Brakel (41) and psychometric properties according to Terwee et al (43).

For this study, three of the psychometric properties were not investigated, namely: criterion validity, reproducibility, and responsiveness. First, for criterion validity, there needs to be a golden standard which was not available for the two scales, since the diagnosis of a psychiatrist is considered as golden standard. Second, reproducibility was not within the scope of this study. And third, responsiveness requires a longitudinal research design which was also not within the scope of this study. Therefore, these three psychometric properties were not further investigated.

Translation process

Both measurements scales, the PHQ-9 and WEMWBS, were already translated into Hindi, so a forward-translation into Hindi was not necessary (42, 45). An expert, who had knowledge about LF and depression, who spoke English and Hindi, first back-translated both scales to check the translated scales. After that, the same expert compared the English and Hindi version of both scales. Moreover, a back-translation was also done by an independent interpreter in India who did not have knowledge about depression and LF.

Measurement scales

PHQ-9

The Patient Health Questionnaire-9 (PHQ-9) is a screening tool that assesses symptoms of depression and the severity of depression, which is based upon the diagnosis of DSM-IV depressive disorders (29). The PHQ-9 was developed in the UK, see Appendix II for this scale in English and Hindi. The PHQ-9 consists of nine items and was developed as a self-report questionnaire, but was not used as a self-report questionnaire in this study. The questionnaire measures whether the symptoms were present in the last two weeks (24). The nine items consist of the following topics subsequently:

interest loss, depressed mood, trouble sleeping, feeling tired, change in appetite, guilt, self-blame, or worthlessness, trouble concentrating, feeling slowed down or restless, and thoughts of being better off dead or hurting oneself. Each answer option is scored from 0 to 3 (0 = Not at all, 1 = Several days, 2 = More than half the days, 3 = Nearly every day), with a summed score that ranges from 0 to 27 (46).

WEMWBS

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS), also developed in the UK, measures mental wellbeing (47). This scale is provided in Appendix III in English and Hindi. The WEMWBS was originally developed as a self-report questionnaire, which consists of 14 items. The scale consists of positively phrased items which cover both eudaimonic (e.g., the experience of meaning) and hedonic (e.g., the experience of pleasure or satisfaction) aspects (25, 48, 49). The answer options of the scale are scored from 1 to 5 (1 = None of the time, 2 = Rarely, 3 = Some of the time, 4 = Often, 5 = All of the time). The sum scores range from 14 to 70, a higher score means higher levels of mental wellbeing (48).

BDI

A third measurement scale, the Beck Depression Inventory (BDI), was conducted during the quantitative part of this study, to test construct validity. The BDI used in this study consisted of 16 items and is originally a self-report instrument, which aims to assess particular symptoms of depression (23). The answer options of the scale range from 0 to 3 and the maximum score is 63 (50). The BDI was chosen to assess the construct validity of the two other scales because the BDI was already validated among students and adolescents in India (51, 52). See Appendix IV for this scale in English and Hindi.

Qualitative validation

Data collection

To confirm the first four equivalences, conceptual, item, semantic, and operational equivalence, a small qualitative pilot study was performed, through semi-structured interviewing. See Appendix V for this semi-structured interview guide. Hereby, the content validity was investigated as well, because this is part of the four equivalences. Multiple interpreters, who spoke Hindi and English, conducted the interviews. These interpreters were trained beforehand to become familiar with the topics that were discussed. Before performing the interviews, personal information of all participants was collected (for example age, gender, marital status, education level, employment status, residence, severity of lymphedema etcetera). This was necessary for the purpose of describing the socio-demographics of the participants. The personal information form can be found in Appendix VI. The severity of the lymphedema in this personal information form was based on the WHO severity score and was assessed by a local health worker (53). Subsequently, both measurement scales, the PHQ-9 and WEMWBS, were conducted and questions were asked about the statements. These questions were based on the first four equivalences (41). First, for the conceptual equivalence questions were asked about the concepts 'depression' and 'mental wellbeing', and participants were asked to explain the statements in their own words. This was to investigate if both cultures, the UK where the scales were developed and the Hindi culture where the scales were validated in this study, conceptualise the concepts of the scales associated with 'depression' and 'mental wellbeing' in the same way. Second, for the item equivalence participants were asked if they found the statements acceptable and relevant. Third, for the semantic equivalence, participants were asked if they understood the statement, whether they could repeat the statement in their own words, and whether they had suggestions to improve the statement. And finally, for the operational equivalence, the participants were asked whether or not the answer options were clear to them and whether or not they understood that the scales were about the last two weeks. Per statement of both measurements scales the questions were asked. Moreover, the interviews were audio-recorded.

Data management and analysis

First, the semi-structured interviews were transcribed and translated by a partner from the NLR Foundation. After that, the data was managed and analysed by the researcher by using MAXQDA 2018. Each of the four equivalences, conceptual, item, semantic, and operational equivalence, were analysed. Firstly, segments were given codes and the four equivalences were used as these codes. Secondly, codebooks were made based on the four equivalences. And thirdly, the categorized data per equivalence were examined and interpreted. Analysing the interviews was done during data collection. This way, improvements on both scales were done and tested in the next interviews. After analysing all interviews, adaptations were made if necessary on both measurement scales with help of the NLR team in India, an independent partner from NLR, a student assistant from the Netherlands as recommended by the participants.

Quantitative validation

Data collection

For the quantitative part, the participants were asked to give the same personal information as mentioned in the qualitative part. After that, the PHQ-9 and WEMWBS were conducted through structured interviewing, by the same interviewers as for the qualitative part. In the quantitative part also the Beck Depression Inventory (BDI) was conducted. This scale was assessed to check the correlation between both scales (the PHQ-9 and WEMWBS) and the BDI, for the measurement of the construct validity. The BDI was also back-translated into English by an independent interpreter before using the scale.

Data management and analysis

For the statistical analysis, SPSS Version 24 was used and Epi Info was used to import the data to SPSS. Questionnaires with >10% missing data were excluded from the analysis. If the missing data was less than 10%, person-mean substitution was performed (54). Normality of the total sum scores of the three scales was checked, separate for cases and controls, before performing the statistical analyses.

The measurement equivalence, consisted of the different psychometric properties, was being assessed with the following tests:

- Internal consistency: Cronbach's alpha was calculated. A coefficient of 0.7 or higher was considered as acceptable.
- Construct validity: predefined hypotheses were tested, see textbox 2 and 3. When at least 75% of the hypotheses was confirmed a positive rate was given. If normally distributed, independent t-tests and Pearson's correlation coefficients were used for testing the hypotheses. If not normally distributed, the Mann-Whitney U test and Spearman's correlation coefficient were used.
- Floor and ceiling effects: to determine floor and ceiling effects it was investigated whether
 more than 15% of the participants achieved the lowest or highest possible total score of the
 scale. If this was the case floor and ceiling effects were present.
- Interpretability: mean values and standard deviation (SD) scores were calculated if normally distributed, otherwise the median and interquartile range (IQR) were calculated of at least four relevant subgroups (e.g. groups based on gender, age, or severity of disability).

Textbox 2. Hypotheses concerning the PHQ-9

- The median score of the PHQ-9 is expected to be at least 2 points higher in the group of people with LF-related lymphedema compared to the control group.
- The scores of the PHQ-9 are expected to have a moderate to high positive correlation with the scores of the BDI ($\rho = 0.50 0.80$).
- The scores of the PHQ-9 are expected to have a moderate negative correlation with the scores of the WEMWBS ($\rho = -0.50 0.70$).
- The median score of the PHQ-9 is expected to be higher among people with high severity of LF-related lymphedema (grade 3) in comparison to people with low severity of LF-related lymphedema (grade 1). The difference in medians between the two groups is expected to be at least 1.

Textbox 3. Hypotheses concerning the WEMWBS:

- The median score of the WEMWBS is expected to be at least 4 points lower in the group of people with LF-related lymphedema compared to the control group.
- The scores of the WEMWBS are expected to have a mild to moderate negative correlation with the scores of the BDI ($\rho = -0.30 -0.60$).
- The scores of the WEMWBS are expected to have a moderate negative correlation with the scores of the PHQ-9 (ρ = -0.50 -0.70).
- The median score of the WEMWBS is expected to be lower among people with high severity of LF-related lymphedema (grade 3) in comparison to people with low severity of LF-related lymphedema (grade 1). The difference in medians between the two groups is expected to be at least 2.

Ethical considerations

Ethical approval was obtained by the Research Committee under the Rights of Persons with Disabilities Act before performing this study. All participants of the study were informed about the research verbally and were asked to give written informed consent to participate in this study. For the informed consent form see Appendix VII. Personally identifying information (like participant names) were excluded from the data and all data were treated with strict confidentiality. Small incentives were given to the participants, like candy, and traveling costs were compensated.

Results

Qualitative study

Characteristics of participants

In total, eight semi-structured interviews were conducted. The socio-demographic information of the participants is described in Table 3. The sample of the qualitative study consisted of seven women and one man. The age of the participants ranged from 29 to 55. One participant had completed primary education, the other participants were illiterate. All participants lived in rural areas. There was a range in the WHO severity grade of the LF-related lymphedema (grade 1, 2 or 3).

Table 3. Socio-demographics of the participants of the semi-structured interviews.

Respondent number	Sex	Age	Level of education	Residency	Severity grading	Mental disorder	Employment status
1	Male	41-50	Primary education	Rural	2	No	Farmer
2	Female	29-40	Illiterate	Rural	1	No	Housewife
3	Female	41-50	Illiterate	Rural	2	No	Housewife
4	Female	51-55	Read and write	Rural	1	No	Housewife
5	Female	29-40	Illiterate	Rural	3	No	Housewife
6	Female	29-40	Illiterate	Rural	2	Yes	Housewife
7	Female	41-50	Illiterate	Rural	2	No	Housewife
8	Female	41-50	Illiterate	Rural	1	No	Housewife

Assessing conceptual equivalence

The most important concepts of depression that were discussed during the semi-structured interviews of the PHQ-9 were: 'better off dead', 'appetite', and 'sleep disturbance'.

All participants were familiar with the word 'depression'. Some participants indicated that they felt this way due to their disease. They mentioned that due to problems in their body or pain, they cannot do any work and this makes them feel sad and depressed. One participant said:

"[Because of] my swollen leg, I face problems in doing my work. I have pain in my legs... In that case I feel sad." (Female, age 41-50)

One participant thought feeling depressed meant weakness. In addition, over half of the participants indicated that they thought that they would be better off dead. Participants indicated that they thought they would be better off dead because of problems and pain in their body, or because they were living alone or because they were unable to work. One participant explained:

"Yes. If I have problems in the body, I feel that it would have been better to die. But if there is no problem I wish to survive longer." (Female, age 41-50)

Only one participant mentioned 'appetite' as a concept of depression. Most participants did not connect depression to poor appetite or overeating. Some participants linked 'appetite' to having enough food: "No. Hunger is not an issue. I take meals in the morning, noon and evening. When I feel hungry, then I have a little food. Then I drink water. There is no problem regarding meals" (Female, age 51-55). Only one participant indicated that he/she did not feel hungry and could not eat properly due to tension and worries.

Two participants related 'sleep disturbance' to worries and stress. One participant said: "Can't sleep properly due to worries, how children will get married? What will happen to me?" (Female, age 29-40). Three other participants linked 'sleep disturbance' to pain and problems in their bodies because of their disease.

The main concepts of 'mental wellbeing' that were discussed during the semi-structured interviews of the WEMWBS were: 'optimism', 'interests', 'feeling happy', and 'tension'.

A few participants linked 'optimism' to hope and to being cured. To the question if participants feel optimistic about the future, one participant answered: "I am hopeful. I am not too old. I wish to be cured" (Female, age 41-50). Two participants linked 'optimism' to their disease. One participant indicated he/she was disappointed because of his/her disease and because of that did not felt optimistic about the future.

When participants were asked if they had interest in new things a few participants linked this to new work. They did not relate interest in new things to mental wellbeing or thought of new things in general. The answer they gave was that they were interested in new work, but that they could not do new work due to their disease. For instance, one participant answered: "I have interest in work, but due to problems in my legs, I can't do work. I have pain in hands and legs" (Female, age 29-40). One participant was planning to do new work.

The participants' concepts about the term 'feeling happy' varied. One participant felt happy when her wishes were fulfilled, one participant felt happy when she achieved something, one participant only felt happy when there were no problems in his/her body, and another felt happy when the children were happy.

And lastly, a few participants indicated that they felt 'tension' when they had a general problem and some felt 'tension' due to their disease. Two participants mentioned that they felt tension when they felt idle. One participant said: "When I am engaged in any work don't feel tension, but when I am idle I feel tension" (Female, age 29-40)

In conclusion, the questionnaires have the same relationship to the underlying concepts in both cultures. However, the concept 'appetite' in statement 5 of the PHQ-9 was seen differently. Most participants did not relate poor appetite or overeating to depression, while poor appetite or overeating in the UK are seen as signs of depression.

Assessing item equivalence

All participants indicated that they found the statements acceptable and relevant. This applied to both the PHQ-9 and the WEMWBS. One participant explained:

"Interviewer: We asked you many questions. Do you feel we should not have asked any particular question, because it was not appropriate?

Participant: No. Nothing like that. I enjoyed the questions" (Female, age 51-55)

No adjustments were made in either scale regarding item equivalence.

Assessing semantic equivalence

In the PHQ-9, in four out of 10 statements (1, 2, 4, and 7) adjustments were made because problems like the misapprehension of statements or them being too abstract, occurred. Table 4 in Appendix VIII shows the revised statements.

- <u>Statement 1</u>: 'Little interest or pleasure in doing things'. The original meaning of this statement is 'little interest or little pleasure in doing things'. However, most participants thought that they could choose between 'little interest in doing things' or the opposite 'pleasure in doing things'. This was not clear to the participants. Therefore, an additional word 'little' was added to the statement before 'pleasure'. In addition, half of the participants had difficulties with the meaning of 'doing things' (*kaam*) in this statement. 'Doing things' was found to be too abstract and it was difficult for the participants to think of examples that covered the word 'things'. For this reason, the example 'or work' (*karya*) was added to this statement.
- <u>Statement 2</u>: 'Feeling sad, depressed, or hopeless'. Half of the participants did not understand this statement and in particular the Hindi word for 'depression'. The interviewer explained that the Hindi word for depression (*udas rahna*) in this scale was a very difficult word. Therefore, the Hindi word was changed to an easier Hindi term for 'depression' (*dawab mey rahha*).
- <u>Statement 4</u>: 'Feeling tired or having very little energy'. Most of the participants did not understand the meaning of the word 'energy' (*urja*). In this statement, the word 'energy' was changed to a different word (*takat*), which means 'power in the body/mind'.
- <u>Statement 7</u>: 'Problem in concentrating in reading newspaper, watching TV etc.' Almost none of the participants could read. For this reason 'reading the newspaper' was not relevant to them. During the interview, the interviewer changed 'reading the newspaper' to different things if the participants could not read. In this statement, an extra example 'or listening to music' was added to have more examples also for people who cannot read.

In the WEMWBS, 6 out of 14 statements were adapted (2, 4, 5, 7, 9, 13), see Table 5 in Appendix VIII for the revised statements.

- <u>Statement 2</u>: 'I am feeling useful'. Most of the participants did not understand the word 'useful' (*upyogi*). This word was too abstract. The participants found it hard to imagine in what way or

when they could be useful. When the interviewer added examples, for instance, 'feeling useful in your work or family' some participants understood the statement. In this statement 'or needed' (awashyak) was added to make useful more clear and also examples 'for instance in your work, for your community or family' were added to the statement to make it less abstract.

- <u>Statement 4</u>: 'I am feeling interested in other persons'. For some participants the word 'interest' (*ruchi*) was unclear. Additionally, 'in other persons' was sometimes unclear too. One female participant thought it was about being interested in men other than her husband. To make the statement more clear examples were added. After 'other persons' the examples 'like your neighbours, friends or family were added.
- <u>Statement 5</u>: 'I have a lot of energy'. In this statement the word 'energy' (*urja*) was not clear, the same changes were made discussed in statement 4 of the PHQ-9.
- <u>Statement 7</u>: 'I am thinking clearly'. Many answers were given that were not in line with the meaning of the statement. For example, one participant answered: "Yes. I think cure of the disease would have been better" (Female, age 29-40). The participants misunderstood the word 'clearly' (spast) in this statement. This word was changed into the word 'properly' (sahi parkar se), which the participants understood.
- <u>Statement 9</u>: 'I am feeling close to others'. Most participants understood this question. Only for a few participants the word 'close' was not clear. The word 'close' (*kareeb*) was changed into 'near' (*nikat*). When this word was used all participants understood the statement.
- <u>Statement 13</u>: 'I am showing interest in new things'. Again, 'new things' (*nai chijo*) was not clear and too abstract for the participants. Therefore, 'or changes' (*pariwartan*) was added to the statement. Here, no examples were added to make 'new things' more clear. For the reason that if people are interested in for instance new work, it might mean that they are not happy in their current work, which would make the statement negative, while the WEMWBS consists of positive framed statements.

Assessing operational equivalence

No missing data were found in the PHQ-9 and WEMWBS. All participants understood the different answer options and the two week reference period of both measurement scales. However, most of the interviewers changed the statements into questions to make the statements more clear for the participants. For that reason and for the reason that the scales were validated as interviewer-administered questionnaires, all statements were changed into questions.

Quantitative study

Characteristics of participants

Table 6 shows the socio-demographic information of the participants in the quantitative study. A total of 163 participants were included in this study, consisting of 101 cases and 62 controls. In the case group 76.2% was female and in the control group this was 62.9%. More than half of the case group was illiterate (62.4%) and all participants had a lower education. In the control group there was a range in education level. Moreover, almost all participants of the case group lived in rural areas (88.1%), in the control group this was 64.5%. The median PHQ-9 score of the case group (9.0) was 6 points higher than in the control group (3.0). The median WEMWBS score of the case group (54.0) was 10 points lower than that of the control group (64.0).

Table 6. Socio-demographic information of the participants of the quantitative study.

Variables		Case	Control
		n = 101	n = 62
Gender	Male (%)	24 (23.8%)	23 (37.1%)
	Female (%)	77 (76.2%)	39 (62.9%)
Age group	18-28 (%)	2 (2.0%)	10 (16.1%)
	29-40 (%)	23 (22.8%)	25 (40.3%)
	41-50 (%)	29 (28.7%)	14 (22.6%)
	51-55 (%)	8 (7.9%)	6 (9.7%)
	>55 (%)	39 (38.6%)	7 (11.3%)
Residency	Urban (%)	12 (11.9%)	22 (35.5%)
	Rural (%)	89 (88.1%)	40 (64.5%)
Marital status	Unmarried (%)	2 (2.0%)	5 (8.1%)
	Married (%)	81 (80.2%)	57 (91.9%)
	Separated (%)	-	-
	Widowed (%)	18 (17.8%)	-
Education level	Illiterate (%)	63 (62.4%)	14 (22.6%)
	Read and write only (%)	17 (16.8%)	4 (6.5%)
	Primary education (%)	16 (15.8%)	19 (30.6%)
	Secondary education (%)	5 (5.0%)	16 (25.8%)
	Higher education (%)	-	9 (14.5%)
Level of income	No income (%)	27 (26.7%)	5 (8.1%)
	<3000 Rupees per month (%)	42 (41.6%)	22 (35.5%)
	3000-5000 Rupees per month (%)	14 (13.9%)	13 (21.0%)
	5000-8000 Rupees per	10 (9.9)	10 (16.1%)
	month (%)	10 (5.5)	10 (10.170)
	>8000 Rupees per month (%)	8 (7.9%)	12 (19.4%)
Religion	Christian (%)	1 (1.0%)	2 (3.2%)
	Hinduism (%)	99 (98.0%)	57 (91.9%)
	Muslim (%)	-	3 (4.8%)
	Other (%)	1 (1.0%)	-
Mental disorder	Yes (%)	-	4 (6.5%)
	No (%)	101 (100%)	58 (93.5%)
WHO severity grading	1 (%)	53 (52.5%)	-
	2 (%)	37 (36.6%)	-
	3 (%)	11 (10.9%)	-
		median (IQR)	median (IQR)
PHQ-9 total score		9.0 (2.0-14.0)	3.0 (0.0-7.3)
WEMWBS total score		54.0 (45.0-60.0)	64.0 (59.5-68.0)
		mean (95%-CI)	mean (95%-CI)
BDI total score		10.4 (9.2-11.6)	-

Measurement equivalence PHQ-9

Internal consistency

A Cronbach's alpha of 0.86 was found, which indicates a high reliability. There was no indication that deleting any item would improve the Cronbach's alpha, see Table 7.

Table 7. Item-total statistics PHQ-9 and WEMWBS.

Item PHQ-9	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
1	0.43	0.86
2	0.73	0.82
3	0.57	0.84
4	0.63	0.84
5	0.65	0.83
6	0.67	0.83
7	0.45	0.85
8	0.45	0.85
9	0.67	0.83
Item WEMWBS	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
1	0.29	0.88
2	0.58	0.85
3	0.34	<mark>0.87</mark>
4	0.48	0.86
5	0.62	0.85
6	0.63	0.85
7	0.63	0.85
8	0.59	0.85
9	0.48	0.86
10	0.59	0.85
11	0.69	0.85
12	0.45	0.86
13	0.64	0.85
14	0.67	0.85

Construct validity

First, the median score of the PHQ-9 of the case group was compared to the median score of the control group and was as expected higher with a difference of 6 points in medians. Thus this hypothesis was confirmed. Secondly, a moderate to high positive correlation between the PHQ-9 and BDI was found with a Spearman's ρ of 0.68. This hypothesis was also confirmed. For the third hypothesis, a moderate negative correlation between the PHQ-9 and WEMWBS was found with a Spearman's ρ of -0.54, which had been expected. Finally, for the fourth hypothesis, the people with high severity had a 4 point higher median in comparison to the people with low severity, confirming the hypothesis. In conclusion, all four predefined hypotheses were confirmed, thus in this study construct validity was sufficient.

Floor and ceiling effects

No floor and ceiling effects were found. Out of 101 cases, 14 persons had the lowest possible score (13.9%) and no one had the highest possible score.

Interpretability

The medians and interquartile ranges (IQRs) of the PHQ-9 were calculated of five subgroups from the case group, see Table 8. Females scored slightly higher, with a small difference of 1 point in medians (9.0 vs 8.0, respectively). The cases with the lowest age (18-40) scored lower compared to the cases with an older age (41-44 and >55) (5.0 vs 10.0 and 9.0, respectively). Moreover, people who lived in

rural areas had a higher median (6.0) compared to people who lived in urban areas (9.0). A large difference in medians was found between people who were not educated and people who were educated, the median of the people who had no education was five points higher (10.0 vs 5.0). And lastly, people with low severity of the LF-related lymphedema (grade 1) had a higher median (9.0) compared to people with grade 2 (5.0), and people with grade 3 had the highest median (13.0) compared to people with grade 1 and 2.

Table 8. Differences in medians of the PHQ-9 and WEMWBS score of five subgroups.

PHQ-9		n	Median (IQR)
Total		101	
Gender	Male	24	8.0 (10.0)
	Female	77	9.0 (13.0)
Age group	18-40	25	5.0 (13.0)
	41-55	37	10.0 (13.0)
	>55	39	9.0 (12.0)
Residency	Urban	12	6.0 (7.0)
	Rural	89	9.0 (13.0)
Education level	No education	80	10.0 (13.0)
	Education	21	5.0 (6.0)
WHO grading severity	1	53	9.0 (10.0)
	2	37	5.0 (13.0)
	3	11	13.0 (15.0)
WEMWBS		n	Median (IQR)
WEMWBS Total		n 101	Median (IQR)
-	Male	•	Median (IQR) 49.0 (13.0)
Total	Male Female	101	
Total		101	49.0 (13.0)
Total Gender	Female	101 24 77	49.0 (13.0) 55.0 (19.0)
Total Gender	Female 18-40	101 24 77 25	49.0 (13.0) 55.0 (19.0) 59.0 (21.0)
Total Gender	Female 18-40 41-55	101 24 77 25 37	49.0 (13.0) 55.0 (19.0) 59.0 (21.0) 53.0 (17.0)
Total Gender Age group	Female 18-40 41-55 >55	101 24 77 25 37 39	49.0 (13.0) 55.0 (19.0) 59.0 (21.0) 53.0 (17.0) 50.0 (16.0)
Total Gender Age group	Female 18-40 41-55 >55 Urban	101 24 77 25 37 39 12	49.0 (13.0) 55.0 (19.0) 59.0 (21.0) 53.0 (17.0) 50.0 (16.0) 58.5 (18.0)
Total Gender Age group Residency	Female 18-40 41-55 >55 Urban Rural	101 24 77 25 37 39 12 89	49.0 (13.0) 55.0 (19.0) 59.0 (21.0) 53.0 (17.0) 50.0 (16.0) 58.5 (18.0) 53.0 (16.0)
Total Gender Age group Residency	Female 18-40 41-55 >55 Urban Rural No education	101 24 77 25 37 39 12 89	49.0 (13.0) 55.0 (19.0) 59.0 (21.0) 53.0 (17.0) 50.0 (16.0) 58.5 (18.0) 53.0 (16.0) 53.5 (15.0)
Total Gender Age group Residency Education level	Female 18-40 41-55 >55 Urban Rural No education Education	101 24 77 25 37 39 12 89 80 21	49.0 (13.0) 55.0 (19.0) 59.0 (21.0) 53.0 (17.0) 50.0 (16.0) 58.5 (18.0) 53.0 (16.0) 53.5 (15.0) 59.0 (26.0)

Measurement equivalence WEMWBS

Internal consistency

For the WEMWBS a Cronbach's alpha of 0.86 was found, which shows a good internal consistency. When deleting statement 1 and 3 of the measurement scale the Cronbach's alpha increases slightly to 0.88 and 0.87, see Table 7.

Construct validity

For the first hypothesis, the median scores of the WEMWBS between the case group and the control group were compared and the case group had a 10 points lower median in comparison with the control group, which confirmed the hypothesis. The second hypothesis was confirmed as well. A mild to moderate negative Spearman's correlation coefficient of -0.51 was found between the WEMWBS

and BDI. For the third hypothesis, Spearman's correlation coefficient showed, as mentioned before, a moderate negative correlation (ρ = -0.54) between the PHQ-9 and WEMWBS, as expected. The last hypothesis was not confirmed. The median score of WEMWBS among people with high severity of LF-related lymphedema (grade 3) was 6 points higher than among people with low severity (grade 1). This result contradicted the expected hypothesis. Here, three out of the four predefined hypotheses were confirmed.

Floor and ceiling effects

No floor and ceiling effects were found. None of the participants scored the lowest possible score and 11 participants out of 101 participants scored the highest possible score (10.9%).

Interpretability

Again, medians and IQRs were calculated of five subgroups from the case group, see Table 8. Females scored higher on the WEMWBS than males (55.0 vs 49.0, respectively). The cases with the lowest age range (18-40) had the highest median score (59.0), subsequently the age group with a range of 41-55 (53.0), and the lowest score was found in the highest age group of 55 years and older (50.0). Furthermore, people who lived in urban areas scored higher than people who lived in rural areas (58.5 vs 53.0) and people who were educated scored higher compared who people who were not educated (59.0 vs 53.5). And finally, cases with high severity of lymphoedema (grade 3) had the highest median score (57.0).

Discussion

The aim of this study was to cross-culturally validate the Patient Health Questionnaire (PHQ-9) and the Mental Wellbeing Scale (WEMWBS) among Hindi-speaking people affected by LF-related lymphedema, in India. Both the PHQ-9 and WEMWBS showed adequate conceptual and item equivalence. Small adaptations were made in both scales to improve the semantic and operational equivalence and all statements were changed into questions. This study showed that both scales had excellent psychometric properties. Internal consistency of the PHQ-9 and WEMWBS was high (Cronbach's α : 0.86 and 0.86), construct validity was found to be sufficient, no floor and ceiling effects were found and appropriate median values have been given to aid interpretability of the scores.

Qualitative validation

Conceptual equivalence

For the conceptual equivalence the measurement scales had the same relationships to the underlying concepts in the Hindi and British culture and thus conceptual equivalence was achieved. The same results were found in other validation studies of the PHQ-9 in Western Kenya (55), in Nepal (56), and South Asians living in the UK (57). Only statement 5 about 'appetite' of the PHQ-9 appeared not to have the same relationship to depression in de cultural setting in Jharkhand. That this concept was seen differently in a South Asian culture than in the British culture was also found in two other studies in Nepal (31, 56). According to Dijkstra, this might be due to the fact that poor people may not have enough food or money to buy food (56). This could be a reason why the concept 'appetite' was not linked to depression. However, we choose to not delete statement 5 of the PHQ-9 because first of all, deleting one statement of the scale would change the total scoring of the scale. Second of all, the small qualitative pilot study consisted only of eight participants, which is too small for deleting a whole item. And third of all, the Cronbach's alpha did not get higher when deleting this item, investigated in the quantitative validation. With regards to the WEMWBS, comparable results were found in the literature. Validation studies in Spain (25) and Nepal (56) also found that conceptual equivalence was achieved.

Item equivalence

For the item equivalence, all statements were found to be acceptable and relevant for both measurement scales. For the PHQ-9 and WEMWBS, the same results were found in the literature. According to a study among South Asians living in the UK, the statements of the PHQ-9 were found relevant and acceptable (57). Additionally, in a study conducted in Nepal item equivalence of the WEMWBS was found to be equivalent and no statements needed to be revised (56). However, in this study conducted in Nepal, two items of the PHQ-9 were revised, because of their lack of acceptability and relevance. These statements were statement 7 about trouble concentrating on things and statement 9 about hurting yourself or better be off dead. For statement 7 examples were added in this Nepali study, in this current study this was also done, however this was for improving the semantic equivalence. For statement 9 no adaptations were made in this study. In the Nepali study, several participants had difficulty with the word 'dead' in this statement and found the statement too direct and therefore somewhat inappropriate. We expected that the word 'dead' would also be a sensitive word in India, however this was not found in this study. One reason that this was not found in our study may be that the participants gave socially desirable answers on the questions if they found the statement acceptable and relevant. It was noticeable that participants gave short answers on these questions, mostly with 'yes'. Thereby, the interviewers were no experts in interviewing and did not always probe and often asked closed questions.

Semantic equivalence

To achieve semantic equivalence adjustments were made to both scales. In the PHQ-9 four statements (1, 2, 4, and 7) and in the WEMWBS six statements (2, 4, 5, 7, 9, and 13) were adapted (see Table 4 and 5 in Appendix VIII). The reasons for the adaptations that were made were that the statements were misunderstood or too abstract. In two other studies conducted in Western Kenya and Spain, investigators found that the statements 3, 5, and 8 of the PHQ-9 were unclear for the participants because these describe opposite symptoms (55, 58). This was not found in our study, this may be due to cultural differences. In one study conducted in Nepal also statement 1 of the PHQ-9 was adapted to make the statement more broad (56). In this Nepali study also statement 4 of the WEMWBS was adapted, for the same reason as in this current study, examples were added to both (56). In this Nepali study, fewer statements were adapted to improve the semantic equivalence (56). So even though Nepal is also a country in South-Asia, the adaptations made regarding the semantic equivalence did not fully correspond, probably because it is still very culture and language dependent.

Operational equivalence

To improve the operational equivalence all statements were changed into questions because in this way the statements were more easily understood by the participants. This was also found in the literature in two other validation studies, where the statements were changed into questions for the same reason (31, 56). The answer options were clear for the participants, and the two week reference period of the scales was also understood. We found no missing data among the responses, this could be another indication that the format of the items worked well. In one other validation study of the PHQ-9, conducted in Western Kenya, the participants understood the answer options, but the participants found it confusing to evaluate the answer options in relation to the last two weeks (55). Moreover, in another study of the PHQ-9 the participants had difficulties with the answer options because no exact numbers were given (only 'not at all', 'several days', etc.) (31).

Quantitative validation

Measurement equivalence PHQ-9

This current study showed that the PHQ-9 has satisfactory psychometric properties. Internal consistency was high with a Cronbach's alpha of 0.86. A similar internal consistency was found in

other validation studies of the PHQ-9, with Cronbach's alphas ranging from 0.78 to 0.90 (24, 26, 28, 29, 34, 37, 46, 59-61). For construct validity, all predefined hypotheses were confirmed. As expected, the PHQ-9 and the WEMWBS correlated negatively with a Spearman ρ of -0.54 and the PHQ-9 correlated positively with the BDI with a Spearman ρ of 0.68. Other validation studies found comparable correlations between these measurement scales (37, 46, 47, 56). No floor and ceiling effects were found, which confirmed the findings in other validation studies (55, 56, 61). That there are no floor and ceiling effects found means that cases with the highest or lowest possible score can be distinguished from each other, which increases the reliability of the scale. Because when floor or ceiling effects are present, there is a high probability that extreme items are missing, a consequence of this is that cases with the highest or lowest possible score cannot be distinguished from each other (43). For the interpretability, the median scores of the different subgroups distinguished from each other. Interpretability was investigated to show differences between different subgroups and thereby make the scores easier to interpret. According to Terwee et al, interpretability is defined as 'the degree to which one can assign qualitative meaning to quantitative scores' (43).

Measurement equivalence WEMWBS

Our study showed that the WEMWBS has good psychometric properties. Internal consistency was excellent with a Cronbach's alpha of 0.86, which corresponds with reports in the literature (30, 33, 35, 62-65). However, when deleting two items (1 and 3) the Cronbach's alpha increases slightly to 0.88 and 0.87. In one Nepali study it was also found that removal of item 3 leads to an increase of the Cronbach's alpha (56). The total-item correlation values of item 1 and 3 were 0.29 and 0.34, respectively. If the item-total correlation value is less than 0.3 it means that the item does not correlate well with the overall scale. Items with a low item-total correlation may have to be removed (66). Because of the small qualitative pilot study it is recommended to re-examine the meaning of these two items in the Hindi culture and rephrase the wording. If rephrasing does not improve the items, removal of the two items can be considered. Of the predefined hypotheses of the WEMWBS 75% was confirmed. Here, one hypothesis was not confirmed. We expected that the median scores of the cases with low severity lymphedema (grade 1) would be higher than scores of cases with high severity (grade 3). However, this result contradicted the expected hypothesis. A reason for this could be that only a few cases had severe lymphedema (11 cases) compared to the cases with low severity (53 cases). As expected, the WEMWBS correlated negatively with both the PHQ-9 and BDI, which confirms findings in the literature (47, 56, 62, 63). Neither floor nor ceiling effects were found. As for the PHQ-9 discussed above, this means that cases with the highest or lowest possible score can be distinguished from each other, which increases the reliability. The same was found in the literature (25, 62-65). Moreover, appropriate median values have been given to aid interpretability of the scores.

Strengths and limitations

This research had some limitations, which should be taken into account. Firstly, the interviewers were not very experienced and did not always follow the instructions of the training and interview guide. For example, the interviewers sometimes explained statements during the semi-structured interviews, which was not the intention of these interviews. In addition, they did not always probe and often asked closed questions. To improve the semi-structured interviews extra training was given after three interviews. However, it is possible that information is missing in the qualitative part, because of the lack of experience of the interviewers. Information that is missing could be in the conceptual and item equivalence because those were equivalent in this current study which did not fully correspond with the literature. In addition, it has not become entirely clear if it would have been better to delete the statement about 'appetite'. Secondly, only male interviewers conducted the interviews. It would have been better to have a female interviewer as well, who could interview female participants. It could be that female participants gave socially desirable answers, because they were interviewed by a male, since there are still differences between men and women in India

(67, 68). However, only male interviewers were used, because they had a good relationship of trust with the participants. For this reason, the NLR team in India recommended to only use team members as interviewers, instead of using persons not known to the participants. Thirdly, convenience sampling was used as sampling method for both parts. Purposive sampling would have been a more appropriate sampling method, to get a more heterogeneous group. A lot more women than men were interviewed and also the literacy rate was very low. This could lead to a lower reliability of the measurement scales. However, in this current study this did not cause any problems. Thereby, the study sample of this study is representative for the target group because lymphedema is more common among women and their education level is often lower in Jharkhand (69, 70), which is a strength of this study because the equivalences differ between settings and populations. Therefore, the study sample needs to be representative for the setting and population in which the scales will be used (43). And lastly, the use of a translator is also a limitation. Since translation is an interpretative act, it is possible that meaning gets lost during the translation process (71).

Recommendations for future research

More extensive qualitative validation is recommended, because of the small qualitative pilot study in this research to re-examine item 1 and 3 of the WEMWBS, which had low total-item correlation values, for the consideration of removing these items. Moreover, the concept 'appetite' could be further investigated in this more extensive qualitative validation. Thereby, experienced interviewers are recommended for this more extensive qualitative validation. Another recommendation is to investigate the reproducibility and responsiveness of the two scales, which were not investigated in this study. Moreover, we advise to always pilot the measurement scales, before using them in another setting and population in India, because there are many different dialects of the Hindi language (72). Therefore, it is important to always pilot the measurement scales also in Hindispeaking districts.

Conclusion

To our knowledge, this is the first study to validate the PHQ-9 and WEMWBS among people affected by LF-related lymphedema in India. Both the PHQ-9 and WEMWBS showed adequate conceptual, item, and measurement equivalence. To improve the semantic and operational equivalence small adjustments were made. In conclusion, the PHQ-9 and WEMWBS were shown to be culturally valid in Jharkhand and similar Hindi-speaking settings to measure depression and mental wellbeing among people affected by LF-related lymphedema. These scales can now be used to implement and evaluate MMP and stigma reduction programs for people affected by LF-related lymphedema.

References

- 1. Nathan AA, Dixit M, Babu S, Balakrishnan AS. Comparison and functional characterisation of peripheral blood mononuclear cells isolated from filarial lymphoedema and endemic normals of a South Indian population. Tropical Medicine & International Health. 2017;22(11):1414-27.
- 2. Webber R. Communicable diseases: a global perspective: Cabi; 2016.
- 3. World Health Organization. Lymphatic filariasis 2018 [Available from: https://www.who.int/news-room/fact-sheets/detail/lymphatic-filariasis.
- 4. Zeldenryk LM, Gray M, Speare R, Gordon S, Melrose W. The emerging story of disability associated with lymphatic filariasis: a critical review. PLoS neglected tropical diseases. 2011;5(12):e1366.
- 5. Hoerauf A, Albers A. Onchocerciasis and Lymphatic Filariasis. Pigmented Ethnic Skin and Imported Dermatoses: Springer; 2018. p. 133-48.
- 6. Cassidy T, Worrell CM, Little K, Prakash A, Patra I, Rout J, et al. Experiences of a community-based Lymphedema management program for lymphatic Filariasis in Odisha state, India: an analysis of focus group discussions with patients, families, community members and program volunteers. PLoS neglected tropical diseases. 2016;10(2):e0004424.
- 7. Shilpa K, Shalini S, Shamim H, Vivek K, Singh S. Trend of MDA coverage and compliance in the four endemic districts of Jharkhand: a secondary data analysis. Healthline, Journal of Indian Association of Preventive and Social Medicine. 2014;5(1):9-13.
- 8. Stocks ME, Freeman MC, Addiss DG. The effect of hygiene-based lymphedema management in lymphatic filariasis-endemic areas: a systematic review and meta-analysis. PLoS neglected tropical diseases. 2015;9(10):e0004171.
- 9. Weiss MG, Ramakrishna J, Somma D. Health-related stigma: rethinking concepts and interventions. Psychology, health & medicine. 2006;11(3):277-87.
- 10. Suma T, Shenoy R, Kumaraswami V. A qualitative study of the perceptions, practices and socio-psychological suffering related to chronic brugian filariasis in Kerala, southern India. Annals of Tropical Medicine & Parasitology. 2003;97(8):839-45.
- 11. Ahorlu CK, Dunyo SK, Koram KA, Nkrumah FK, Aagaard-Hansen J, Simonsen PE. Lymphatic filariasis related perceptions and practices on the coast of Ghana: implications for prevention and control. Acta Tropica. 1999;73(3):251-61.
- 12. Person B, Bartholomew LK, Gyapong M, Addiss DG, van den Borne B. Health-related stigma among women with lymphatic filariasis from the Dominican Republic and Ghana. Social Science & Medicine. 2009;68(1):30-8.
- 13. Person B, Addiss D, Bartholomew LK, Meijer C, Pou V, Gonzálvez G, et al. "Can it be that god does not remember me": a qualitative study on the psychological distress, suffering, and coping of Dominican women with chronic filarial lymphedema and elephantiasis of the leg. Health care for women international. 2008;29(4):349-65.
- 14. Akoto-Bamfo PM. Barriers to High Coverage during Mass Drug Administration for the Control of Lymphatic Filariasis in Ayawaso Sub-Metro in the Greater Accra Region, Ghana: University of Ghana; 2014.
- 15. Weiss MG, Ramakrishna J. Stigma interventions and research for international health. The Lancet. 2006;367(9509):536-8.
- 16. World Health Organization. Promotion of mental well-being 2019 [Available from: http://www.searo.who.int/entity/mental_health/promotion-of-mental-well-being/en/
- 17. Clarke A, Friede T, Putz R, Ashdown J, Martin S, Blake A, et al. Warwick-Edinburgh Mental Well-being Scale (WEMWBS): validated for teenage school students in England and Scotland. A mixed methods assessment. BMC public health. 2011;11(1):487.
- 18. Krishna Kumari A, Harichandrakumar K, Das L, Krishnamoorthy K. Physical and psychosocial burden due to lymphatic filariasis as perceived by patients and medical experts. Tropical Medicine & International Health. 2005;10(6):567-73.

- 19. Litt E, Baker MC, Molyneux D. Neglected tropical diseases and mental health: a perspective on comorbidity. Trends in parasitology. 2012;28(5):195-201.
- 20. Ton TG, Mackenzie C, Molyneux DH. The burden of mental health in lymphatic filariasis. . Infectious diseases of poverty. 2015;4(1):34.
- 21. World Health Organization. Depression: A global public health concern. WHO Dep Ment Heal Subst Abus. 2012:1-8.
- 22. Harichandrakumar K, Krishnamoorthy K, Kumari AK, Das L. Health status of lymphatic filariasis assessed from patients using seven domains five levels (7D5L) instrument. Acta tropica. 2006;99(2-3):137-43.
- 23. Han C, Jo SA, Kwak J-H, Pae C-U, Steffens D, Jo I, et al. Validation of the Patient Health Questionnaire-9 Korean version in the elderly population: the Ansan Geriatric study. Comprehensive psychiatry. 2008;49(2):218-23.
- 24. Wang W, Bian Q, Zhao Y, Li X, Wang W, Du J, et al. Reliability and validity of the Chinese version of the Patient Health Questionnaire (PHQ-9) in the general population. General hospital psychiatry. 2014;36(5):539-44.
- 25. López MA, Gabilondo A, Codony M, García-Forero C, Vilagut G, Castellví P, et al. Adaptation into Spanish of the Warwick–Edinburgh Mental Well-being Scale (WEMWBS) and preliminary validation in a student sample. Quality of Life Research. 2013;22(5):1099-104.
- 26. Arrieta J, Aguerrebere M, Raviola G, Flores H, Elliott P, Espinosa A, et al. Validity and Utility of the Patient Health Questionnaire (PHQ)-2 and PHQ-9 for Screening and Diagnosis of Depression in Rural Chiapas, Mexico: A Cross-Sectional Study. Journal of clinical psychology. 2017;73(9):1076-90.
- 27. Bass M, Dawkin M, Muncer S, Vigurs S, Bostock J. Validation of Warwick-Edinburgh mental well-being scale (WEMWBS) in a population of people using secondary care mental health services. Journal of Mental Health. 2016;25(4):323-9.
- 28. Gholizadeh L, Ali khan S, Vahedi F, Davidson PM. Sensitivity and specificity of Urdu version of the PHQ-9 to screen depression in patients with coronary artery disease. Contemporary nurse. 2017;53(1):75-81.
- 29. Hanwella R, Ekanayake S, de Silva VA. The validity and reliability of the Sinhala translation of the Patient Health Questionnaire (PHQ-9) and PHQ-2 screener. Depression research and treatment. 2014;2014.
- 30. Kim S, Jung H-Y, Na K-S, Lee SI, Kim S-G, Lee AR, et al. A validation study of the Korean version of warwick-edinburgh mental well-being scale. Journal of Korean Neuropsychiatric Association. 2014;53(4):237-45.
- 31. Kohrt BA, Luitel NP, Acharya P, Jordans MJ. Detection of depression in low resource settings: validation of the Patient Health Questionnaire (PHQ-9) and cultural concepts of distress in Nepal. BMC psychiatry. 2016;16(1):58.
- 32. Azah M, Shah M, Juwita S, Bahri I, Rushidi W, Jamil Y. Validation of the Malay version brief patient health Questionnaire (PHQ-9) among adult attending family medicine clinics. INTERNATIONAL MEDICAL JOURNAL-TOKYO-. 2005;12(4):259.
- 33. Santos JJAd, Costa TAd, Guilherme JH, Silva WCd, Abentroth LRL, Krebs JA, et al. Adaptation and cross-cultural validation of the Brazilian version of the Warwick-Edinburgh mental well-being scale. Revista da Associação Médica Brasileira. 2015;61(3):209-14.
- 34. Shin J, Park S-Y, Cho S, Chiu Y-L, Bang H, Bernstein KS. Validation of Patient Health Questionnaire-9 Korean version (PHQ-9K) scale for screening depression among Korean Americans in community settings. Journal of Theory Construction & Testing. 2010;14(2):45.
- 35. Trousselard M, Steiler D, Dutheil F, Claverie D, Canini F, Fenouillet F, et al. Validation of the Warwick-Edinburgh mental well-being scale (WEMWBS) in French psychiatric and general populations. Psychiatry research. 2016;245:282-90.
- 36. Vaingankar JA, Subramaniam M, Chong SA, Abdin E, Edelen MO, Picco L, et al. The positive mental health instrument: development and validation of a culturally relevant scale in a multi-ethnic Asian population. Health and quality of life outcomes. 2011;9(1):92.

- 37. Ganguly S, Samanta M, Roy P, Chatterjee S, Kaplan DW, Basu B. Patient health questionnaire-9 as an effective tool for screening of depression among Indian adolescents. Journal of Adolescent Health. 2013;52(5):546-51.
- 38. Gothwal VK, Bagga DK, Sumalini R. Rasch validation of the PHQ-9 in people with visual impairment in South India. Journal of Affective Disorders. 2014;167:171-7.
- 39. Poongothai S, Pradeepa R, Ganesan A, Mohan V. Reliability and validity of a modified PHQ-9 item inventory (PHQ-12) as a screening instrument for assessing depression in Asian Indians (CURESÁ65). JAPI. 2009;57:1Á6.
- 40. Obindo J, Abdulmalik J, Nwefoh E, Agbir M, Nwoga C, Armiya'u A, et al. Prevalence of depression and associated clinical and socio-demographic factors in people living with lymphatic filariasis in Plateau State, Nigeria. PLoS neglected tropical diseases. 2017;11(6):e0005567.
- 41. Stevelink S, Van Brakel W. The cross-cultural equivalence of participation instruments: a systematic review. Disability and rehabilitation. 2013;35(15):1256-68.
- 42. Warwick Medical School. WEMWBS in Other Languages 2018 [Available from: https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/researchers/languages/.
- 43. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. Journal of clinical epidemiology. 2007;60(1):34-42.
- 44. Herdman M, Fox-Rushby J, Badia X. A model of equivalence in the cultural adaptation of HRQoL instruments: the universalist approach. Quality of life Research. 1998;7(4):323-35.
- 45. Pfizer. Screener Overview n.d. [Available from: https://www.phqscreeners.com/select-screener/36.
- 46. Seo J-G, Park S-P. Validation of the Patient Health Questionnaire-9 (PHQ-9) and PHQ-2 in patients with migraine. The journal of headache and pain. 2015;16(1):65.
- 47. Smith OR, Alves DE, Knapstad M, Haug E, Aarø LE. Measuring mental well-being in Norway: validation of the Warwick-Edinburgh Mental Well-being Scale (WEMWBS). BMC psychiatry. 2017;17(1):182.
- 48. Maheswaran H, Weich S, Powell J, Stewart-Brown S. Evaluating the responsiveness of the Warwick Edinburgh Mental Well-Being Scale (WEMWBS): Group and individual level analysis. Health and Quality of Life Outcomes. 2012;10(1):156.
- 49. McMahan EA, Estes D. Hedonic versus eudaimonic conceptions of well-being: Evidence of differential associations with self-reported well-being. Social Indicators Research. 2011;103(1):93-108.
- 50. Adewuya AO, Ola BA, Aloba OO. Prevalence of major depressive disorders and a validation of the Beck Depression Inventory among Nigerian adolescents. European Child & Adolescent Psychiatry. 2007;16(5):287-92.
- 51. Basker M, Moses PD, Russell S, Russell PSS. The psychometric properties of Beck Depression Inventory for adolescent depression in a primary-care paediatric setting in India. Child and Adolescent Psychiatry and Mental Health. 2007;1(1):8.
- 52. Kushwaha JK. Beck depression inventory: Hindi translation and psychometric properties for the students of higher education. Journal of Research in Humanities and Social Science. 2016;4(9):39-49.
- 53. World Health Organization. Lymphoedema staff manual: treatment and prevention of problems associated with lymphatic filariasis. Geneva: World Health Organization; 2001.
- 54. Hawthorne G, Hawthorne G, Elliott P. Imputing cross-sectional missing data: comparison of common techniques. Australian & New Zealand Journal of Psychiatry. 2005;39(7):583-90.
- 55. Monahan PO, Shacham E, Reece M, Kroenke K, Ong'Or WO, Omollo O, et al. Validity/reliability of PHQ-9 and PHQ-2 depression scales among adults living with HIV/AIDS in western Kenya. Journal of general internal medicine. 2009;24(2):189.
- 56. Dijkstra J. Cross-Cultural Validation of Two Scales to Assess Mental Health in Leprosy-Affected People in Province 1 and 7, Nepal: VU University Amsterdam; 2018.

- 57. Lloyd C, Roy T, Begum S, Mughal S, Barnett A. Measuring psychological well-being in South Asians with diabetes; a qualitative investigation of the PHQ-9 and the WHO-5 as potential screening tools for measuring symptoms of depression. Diabetic Medicine. 2012;29(1):140-7.
- 58. Zhong Q, Gelaye B, Fann JR, Sanchez SE, Williams MA. Cross-cultural validity of the Spanish version of PHQ-9 among pregnant Peruvian women: a Rasch item response theory analysis. Journal of affective disorders. 2014;158:148-53.
- 59. Gelaye B, Williams MA, Lemma S, Deyessa N, Bahretibeb Y, Shibre T, et al. Validity of the patient health questionnaire-9 for depression screening and diagnosis in East Africa. Psychiatry research. 2013;210(2):653-61.
- 60. Liu S-I, Yeh Z-T, Huang H-C, Sun F-J, Tjung J-J, Hwang L-C, et al. Validation of Patient Health Questionnaire for depression screening among primary care patients in Taiwan. Comprehensive psychiatry. 2011;52(1):96-101.
- 61. Marc LG, Henderson WR, Desrosiers A, Testa MA, Jean SE, Akom EE. Reliability and validity of the Haitian Creole PHQ-9. Journal of general internal medicine. 2014;29(12):1679-86.
- 62. Ikink JG, Lamers S, Bolier J. De Warwick-Edinburgh Mental Well-being Scale (WEMWBS) als meetinstrument voor mentaal welbevinden in Nederland. University of Twente, unpublished thesis; 2012.
- 63. Koushede V, Lasgaard M, Hinrichsen C, Meilstrup C, Nielsen L, Rayce SB, et al. Measuring mental well-being in Denmark: Validation of the original and short version of the Warwick-Edinburgh mental well-being scale (WEMWBS and SWEMWBS) and cross-cultural comparison across four European settings. Psychiatry research. 2019;271:502-9.
- 64. Tennant R, Hiller L, Fishwick R, Platt S, Joseph S, Weich S, et al. The Warwick-Edinburgh mental well-being scale (WEMWBS): development and UK validation. Health and Quality of life Outcomes. 2007;5(1):63.
- 65. Waqas A, Ahmad W, Taggart F, Muhammad Z, Bukhari MHH, Sami SA, et al. Validation of Warwick-Edinburgh Mental Well-being Scale (WEMWBS) in Pakistani healthcare professionals. PeerJ PrePrints; 2015. Report No.: 2167-9843.
- 66. Field A. Discovering statistics using IBM SPSS statistics: sage; 2013.
- 67. Batra R, Reio Jr TG. Gender inequality issues in India. Advances in Developing Human Resources. 2016;18(1):88-101.
- 68. Khera P. Macroeconomic Impacts of Gender Inequality and Informality in India: International Monetary Fund; 2016.
- 69. World Health Organization. Lymphatic filariasis: managing morbidity and preventing disability: an aide-mémoire for national programme managers. 2013.
- 70. Census 2011. What is literacy rate of Jharkhand? 2019 [Available from: https://www.census2011.co.in/questions/13/state-literacy/literacy-rate-of-jharkhand-census-2011.html.
- 71. Van Nes F, Abma T, Jonsson H, Deeg D. Language differences in qualitative research: is meaning lost in translation? European journal of ageing. 2010;7(4):313-6.
- 72. Kadyan V, Singh A, Wadhwa P, editors. Hindi dialect (Bangro) spoken language recognition (HD-SLR) system using Sphinx3. Proceeding of International Conference on Intelligent Communication, Control and Devices; 2017: Springer.

Appendix

I. Table 1 and Table 2

Table 1. Definitions of categories of equivalence according to Stevelink and Van Brakel (42).

Equivalence	Definition
Conceptual	'Achieved when the questionnaire has the same relationship to the underlying concept in both cultures, primarily in terms of domains included and the emphasis placed on different domains.'
Item	'Item equivalence exists when items estimate the same parameters on the latent trait being measured and when they are equally relevant and acceptable in both cultures.'
Semantic	'The transfer of meaning across languages, achieving a similar effect on respondents who speak different languages.'
Operational	'The possibility of using a similar questionnaire format, instructions, mode of administration and measurement methods.'
Measurement	'The psychometric properties of the adapted version of the participation measures are equivalent.'
Cultural	'The extent to which an instrument is equally suitable for use in two or more cultures.'

Table 2. Definitions of the psychometric properties according to Terwee, Bot (44)

Equivalence	Definition
Construct validity	'The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured.'
Internal consistency	'Internal consistency is a measure of the extent to which items in a questionnaire (sub)scale are correlated (homogeneous), thus measuring the same concept.'
floor and ceiling effects	'Floor or ceiling effects are considered to be present if more than 15% of respondents achieved the lowest or highest possible score, respectively.'
interpretability	'Interpretability is defined as the degree to which one can assign qualitative meaning to quantitative scores.'
Reproducibility	Agreement: 'The extent to which the scores on repeated measures are close to each other (absolute measurement error).' Reliability: 'The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error).'
Criterion validity	'The extent to which scores on a particular questionnaire relate to a gold standard.'
Content validity	'The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire.'
Responsiveness	'The ability of a questionnaire to detect clinically important changes over time.'

II. PHQ-9 – English and Hindi PHQ-9 English:

PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME:				
	DATE:			
Over the <i>last 2 weeks</i> , how often have you been bothered by any of the following problems? (use "a" to indicate your answer)	Not at all	Several days	Note that half	Neath 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 or 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 are 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
	add columns		+	+
(Healthcare professional: For interpretation please refer to accompanying scoring card.)				
10. If you checked off <i>any</i> problems, how <i>difficult</i> have these problems made it for you to do your work, take care of things at home, or get along with other people?		So	ot difficult at al mewhat difficu ery difficult tremely difficu	

रोगी स्वास्थ्य प्रश्नावली – 9 (PHQ-9)

पिछले 2 सप्ताहों में, आप इन समस्याओं में से किसी से भी कितनी बार परेशान रहे/रही हैं? (अपना उत्तर बताने के लिए "√" का प्रयोग करें)	मिल्कुल नहीं	कई दिन	आग्ने से अधिक दिन	लग [्] f
1. कुछ करने में बहुत कम दिलचस्पी या मज़ा आना	0	1	2	
2. उदास, अवसादग्रस्त या निराश महसूस करना	0	1	2	
3. नींद आने या सोये रहने में परेशानी, या फिर बहुत अधिक सोना	0	1	2	
4. थकान महसूस करना या बहुत कम ऊर्जा होना	0	1	2	
5. भूख कम लगना या ज़्यादा खाना	0	1	2	
6. अपने बारे में बुरा महसूस करना - या ऐसा महसूस करना कि आप नाकाम इंसान हैं और आपने खुद को और अपने परिवार को नीचा दिखाया है	0	1	2	
7. अखबार पढ़ने या टेलीबिज़न देखने जैसी चीज़ों पर ध्यान देने में परेशानी	0	1	2	
8. इतना धीमे चलना-फिरना या बोलना कि लोगों का ध्यान जाये? या इसका उल्टा - इतना अस्थिर या बेचैन होना कि आप सामान्य से काफ़ी ज़्यादा हिलते-डुलते और चलते-फिरते रहे हैं	0	1	2	į
9. ऐसे विचार कि आप मर जाते तो अच्छा होता या किसी ढंग से ख़ुद को नुक्सान पहुंचाना	0	1	2	

अगर आपने किन्हीं समस्याओं पर निशान लगाया है, तो बतायें कि इन समस्याओं ने आपके लिए काम करना, घर पर चीज़ों की देखभाल करना, या दूसरे लोगों के साथ मेल-जोल रखना कितना मुश्किल किया है?

बिल्कुल मुश्किल **	थोड़ा-बहुत	बहुत	बेहद
नहा	मुश्किल	मुशिकल	मुश्किल

III. WEMWBS – English and Hindi WEMWBS – English:

Below are some statements about feelings and thoughts.

Please tick (1) 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

Warwick-Edinburgh Mental Well-being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.

WEMWBS - Hindi:

Warwick Edinburgh Mental Health Scale (Hindi Version)

नीचे भावनाओं और विचारों के बारे में कुछ वाक्य दिए गये हैं। हर एक वाक्य को ध्यान से पढ़े और उन जवाबों पर निशान लगाइए जो पिछले दो हफ़्तों में इन भावनाओं और विचारों के मामले में आपके अनुभव को व्यक्त करते हैं।

STATEMENTS	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
में भविष्य के बारे में आशावादी महसूस कर रहां/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं अपने आपको उपयोगी महसूस कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं अपने आपको तनाव मुक्त महसूस कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मुझे दूसरे लोगों में रूचि महसूस हो रही है।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मुझमें बहुत ऊर्जा है।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
में समस्याओं का सामना अच्छी तरह कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
में स्पष्ट रूप से सोच रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं अपने बारे में अच्छा महसूस कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं खुद को दूसरों के करीब महसूस कर रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मुझे खुद में आत्मविश्वास महसूस हो रहा है।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं चीज़ों के बारे में अपना मन बना पा रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मुझे लगता है कि लोग मुझे प्यार करते हैं।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं नयी चीज़ों में रूचि दिखा रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा
मैं अपने आपको खुश/आनंदित महसूस कर पा रहा/रही हूँ।	कभी नहीं	बहुत कम	कभी कभी	अक्सर	हमेशा

(Developed by Dr Sandeep Grover, Dr Pradyumna and Dr Subho Chakrabarti form Department of Psychiatry, Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh, India)

IV. BDI – English and Hindi

BDI – English:

Instructions: Following are group of statements conveying the same thought in varying degree of intensity, which are being experienced by students during higher. Read group of statement carefully and encircle the digit provided before the statement which defines your occurring thoughts completely.

		vided before the statement which defines your occurring thoughts completely.
S. No.	One	thoughts given varying degree of intensity
1	0-	I do not feel sad.
	1-	I feel sad.
	2-	I am sad all the time and I can't snap out of it.
	3-	I am so sad and unhappy that I can't stand it.
2	0-	I am not particularly discouraged about the future.
	1-	I feel discouraged about the future.
	2-	I feel I have nothing to look forward to.
	3-	I feel the future is hopeless and that things cannot improve.
3	0-	I do not feel like a failure
J	1-	I feel I have failed more than the average person
	2-	As I look back on my life, all I can see is a lot of failures
	3-	I feel I am a complete failure as a person
4	0-	I get as much satisfaction out of things as I used to
7	1-	I don't enjoy things the way I used to
	2-	I don't get real satisfaction out of anything anymore
	3-	I am dissatisfied or bored with everything
5	0-	
3		I don't feel disappointed in myself
	1-	I am disappointed in myself
	2-	I am disgusted with myself
	3-	I hate myself
6	0-	I don't feel I am any worse than anybody else
	1-	I am critical of myself for my weaknesses or mistakes
	2-	I blame myself all the time for my faults
7	3-	I blame myself for everything bad that happens
7	0-	I don't cry any more than usual.
	1-	I cry more now than I used to.
	2-	I cry all the time now
	3-	I used to be able to cry, but now I can't cry even though I want to.
8	0-	I am no more irritated by things than I ever was
	1-	I am slightly more irritated now than usual
	2-	I am quite annoyed or irritated a good deal of the time
	3-	I feel irritated all the time
9	0-	I have not lost interest in other people
	1-	I am less interested in other people that I used to be
	2-	I have lost most of my interest in other people
	3-	I have lost all of my interest in other people
10	0-	I make decision about as well as I ever could
	1-	I put off making decisions more than I used to
	2-	I have greater difficulty in making decisions more than I used to
	3-	I can't make decision at all anymore
11	0-	I don't feel that I look any worse than I used to
	1-	I am worried that I am looking old or unattractive
	2-	I feel there are permanent changes in my appearance that make me look unattractive
	3-	I believe that I look ugly
12	0-	I can work about as well as before
	1-	It takes an extra effort to get started at doing something
	2-	I have to put myself very hard to do anything
	3-	I can't do any work at all.

13	0-	I can sleep as well as usual
	1-	I don't sleep as well as I used to be
	2-	I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
	3-	I wake up several hours earlier than I used to and cannot get back to sleep
14	I don't get more tired than usual	
	1-	I get tired more easily than I used to.
	2-	I get tired from doing almost anything
	3-	I am too tired to do anything
15 0- I haven't lost much weight, if any, lately		I haven't lost much weight, if any, lately
	1-	I have lost more than two Kg.
	I have lost more than four Kg.	
	3-	I have lost more than seven Kg.
16 0- I have not noticed any recent change in my interest in sex.		I have not noticed any recent change in my interest in sex.
	1-	I am less interested in sex than I used to be.
	2-	I have almost no interest in sex.
	3-	I have lost interest in sex completely

APPENDIX-B

Hindi-Beck Depression Inventory (H-BDI)

निर्देश: नीचे कुछ कथनों के समूह दिए गयें है। एक समूह एक ही विचार को विभिन्न तीव्रता के अनुसार प्रकट करता है जो कि छात्रों द्वारा उच्च शिक्षा के दौरान अनुभव किया जा सकता है। कृपया कथनों के समूह को ध्यानपूर्वक पढिए तथा उक्त कथन के सामने लिखे अंक पर घेरा बनाइए जो आपके आने वाले विचार को पूर्ण रूप से व्यक्त करता है।

Φ.	आने वाले विचार				
सं.	311 411 1441				
1	 मैं दुखित महसूस नहीं करता हूँ। 				
	1. मैं दुखित महसूस करता हूँ।				
	 मैं हर समय दुखित होता है और मैं इससे उबर नही पाता है। 				
	 मैं इतना ज्यादा दुखित और अप्रसन्न हुँ कि इसको सहन नहीं कर सकता। 				
2	 मैं विशेषकर भविष्य के बारे में हतोत्साहित नहीं हूँ। 				
	 मैं भविष्य के लिए इतोत्साहित महसूस करता हूँ। 				
	2. मैं महसूस करता हुँ कि मेरे पास आगे करने को कुछ नही है।				
	 मैं महसूस करता हूँ कि भविष्य निराशाजनक है और चीजें सुधर नहीं सकती है। 				
3	0. मैं असफल महसूस नहीं करता हूँ।				
	 मैं महसूस करता हूँ कि मैं एक औसत आदमी से ज्यादा असफल रहा। 				
	 जब मैं अपनी पिछली जिन्दगी देखता हूँ तो उसमें बहुत सारी असफलताएँ देखता 				
	हूँ। 3. में महसूस करता हूँ कि मैं पूर्ण रूप से असफल आदमी हूँ।				
	3. म महसूस करता हूं कि म पूर्ण रूप स असफल आदमा हूं।				
4	 मैं वस्तुओं से उतनी ही संतुष्टि प्राप्त करता हूँ जितना कि पहले करता था। 				
	 मुझे वस्तुओं से वैसा आनन्द नही मिलता जैसा कि पहले मिलता था। मैं किसी चीज से किसी प्रकार की वास्तविक संतुष्टि प्राप्त नही करता हूँ। 				
	 म किसा चार्ज स किसा प्रकार का वास्तावक सतुाष्ट प्राप्त नहा करता हू। मैं सभी चीजों से असंतुष्ट तथा ऊब चुका हूँ। 				
5	 में अपने आप में निराशा महसूस नहीं करता हूँ। 				
	1. मैं अपने आप में निराशा महसूस करता हूँ।				
	2. मैं अपने आपसे निराश हूँ।				
	3. मैं अपने आपसे घृणा करता हूँ।				
6	 मैं ऐसा महसूस नहीं करता कि मैं किसी और से ज्यादा खराब हूँ। 				
	 मैं अपनी किमयों और खामियों के बारे में आलोचनात्मक हूँ। 				
	2. मैं हर समय अपने आप को अपनी गलतियों के लिए दोषी ठहराता हूँ।				
	 मैं अपने आपको दोषी ठहराता हूँ उन सबके लिए, जो कुछ भी मेरे साथ बुरा होता 				
	है।				
7	0. मैं जल्दी रोता नहीं हूँ।				
	 मुँ आजकल जल्दी रोंने लगता हूँ, पुढले की अपेक्षा। 				
	2. मैं आजकल हर समय रोता रहता हूँ।				
_	3. मैं रोने के लिए तत्पर हूँ पर मैं रो नहीं सकता, यहाँ तक कि ऐसा चाहने पर भी।				
8	0. मैं उतना ज्यादा चिडचिड़ा नहीं हूँ, जैसा कि पहले था।				
	1. मैं आजकल पहले से ज्यादा चिडचिंडा हूँ।				
	 मैं अधिकतर समय गुस्से में या चिडचिडेपन में रहता हूँ। 				
_	3. मैं हर समय चिडचिंडा महसूस करता हूँ।				
9	 मैं दूसरे लोगों से मिलने—जुलने का आनन्द नही खोया हूँ। 				

^{*}Corresponding Author: Jitendra Kumar Kushwaha¹

48 | Page

	 मैं पहले की अपेक्षा, दूसरे लोगों से कम मिलता—जुलता हूँ। 				
	 मैं दूसरे लोगों से मिलने—जुलने का आनन्द नहीं खो चुकाँ हूँ। 				
	 मैं दूसरे लोगों से मिलने—जुलने का आनन्द, पूर्णरूप से खो चुका हूँ। 				
10	 मैं वैसा ही निर्णय करता हूँ जैसा पहले करता था। 				
	 मैं वैसे निर्णय लेना बन्द कर दिया हूँ जैसा कि पहले करता था। 				
	मुझे निर्णय लेने में, पहले से ज्यादा कठिनाई का सामना करना पडता है।				
	 अब से मै किसी प्रकार का निर्णय नहीं ले सकता हूँ। 				
11	 मैं ऐसा महसूस नही करता हूँ कि मेरा रूप पहले से ज्यादा खराब है। 				
	 मैं चिन्तित हूँ कि मैं बुद्दा या बदसूरत दिखायी देता हूँ। 				
	 मैं महसूस करता हुँ कि मेरे चेहरे पर स्थायी परिर्वतन हुए है जो कि मेरे रूप को 				
	बदसूरत बनाते है।				
	 मेरा विश्वास है कि मैं बडा बदसूरत दिखता हूँ। 				
12	 मैं पहले की तरह काम क्र सकता हूँ। 				
	 मुझे कोई काम शुरू करने और करते रहने के लिए अब ज्यादा प्रयास करना पडता 				
	 मुझे कोई भी करने के लिए अपने आप से ज्यादा प्रयास करना पडता है। 				
	3. मैं कोई काम नहीं कर सकता हूँ।				
13	0. मैं पहले की तरह अच्छे से सो सकता हूँ।				
	 मैं पहले की तरह अच्छे से सो नहीं पाता हूँ। 				
	 मैं हमेशा समय की अपेक्षा से 1-2 घण्टें पहले जग जाता हूँ और बहुत किटनाई से 				
	दुबारा नींद आती है।				
	 मैं हमेशा समय की अपेक्षा से कई घण्टें जग जाता हूँ और फिर दुबारा से नींद नहीं आती है। 				
44	141 11111 4				
14	 मैं थकान महसूस नहीं करता हूँ। मैं पहले की अपेक्षा जल्दी थक जाता हूँ। 				
	 म पहल का अपना जल्दा थक जाता हूं। मैं कुछ भी करने में थकान महसूस करता हूँ। 				
	 मैं इतना ज्यादा थका हुआ हूँ कि कुछ भी नहीं कर सकता। 				
15	 यदि ऐसा कुछ है तो हाल ही में मेरा वजन कम नही हुआ है। 				
13	 मेरा 2 किलो वजन घट गया है। 				
	2. मेरा ४ किलो वजन घट गया है।				
	 मेरा 7 किलो वजन घट गया है। 				
16	0. हाल ही में मेरी यौन—किया की इच्छा में कोई परिवर्तन नही आया है।				
	1. मैं पहले की अपेक्षा यौन–किया के लिए कम इच्छुक हूँ।				
	2. मैं यौन-किया करने की इच्छा लगभग खो चुका हूँ।				
	 मैं यौन–किया करने की इच्छा पूरी तरह से खो चुका हूँ। 				
	- ID				

^{*}Corresponding Author: Jitendra Kumar Kushwaha¹

V. Semi-structured interview guide

Interview guide

Semi-structured Interviews

Introduction

Hello Mr./Ms. [name], thank you very much for your time and doing an interview with us. This is Nikky from the Netherlands. She will observe the interview, and may take some notes. She does not speak Hindi but speaks English. My name is [name interpreter], and I will take this interview with you. We work together for the Netherlands Leprosy Relief Foundation.

In this interview we will ask you some questions related to your life, your experiences with being affected by lymphatic filariasis, and your mental wellbeing. The duration of the interview will be approximately 45 minutes. There are no wrong answers, and your experiences and opinions are most important; only these matter to us. If there is something you do not understand, please ask me to stop and I will take time to explain. If you have questions later, you can ask them at any time. Do you have any questions so far?

Informed consent

We would now kindly like to ask you to sign the following form [discuss informed consent, Appendix V]. We would like to record the interview, are you okay with this?

Explanation of the interview

The interview consists of 4 parts. The first part involves general questions, the second part focuses on your experiences of living with lymphatic filariasis. The third part is mainly about terms of mental wellbeing. In the last part, statements will be read out loud, and we will ask you questions about these statements. The reason why I will ask you these questions, is to make both questionnaires understandable for everyone in Hindi. The results of this interview will be used to improve health services for lymphatic filariasis.

Personal information

Now we would like to ask you some general questions; for example, about your age, living area etc. [filling in personal information, Appendix 7].

Questions concerning LF

- 1. I understand you have been affected by lymphatic filariasis, could you tell me what you know about lymphatic filariasis?
 - When did it start, how did you find out about the condition?
- 2. Could you tell me in if the condition (or disability) affects your daily activities? If so, in what way?
- 3. Could you tell me in what way the condition (or disability) affects your functioning in daily life? (Probing: are people affected by lymphatic filariasis treated differently than other people in the community?)
- 4. Could you tell me something about how the condition is making you feel?

Questions concerning PHQ-9 and WEMWBS

- 5. Could you please tell me what you think depression is?
 - > Are there any words which come into your mind when you hear the word 'depression'?
 - Are there any other words in your local language for the word 'depression'?
- 6. Could you please tell me what you think mental wellbeing is?
 - Are there any words which come into your mind when you hear the word 'mental wellbeing'?
 - Are there any other words in your local language for the word 'mental wellbeing'?

From now on, I will read out a statement and will kindly ask you some questions about this. [PHQ-9 and WEMBWS statements will be read out loud and after each statement the following questions 7-11 will be asked]:

- 7. Did you understand the statement?
 - If not: could you tell me what was difficult to understand about the statement?
 - Are there any words that you do not understand? What are they? How would you change it to make it clear?
 - ➤ Is there anything about this statement/question that is confusing? What? How would you change it to make it clear?
- 8. Why did you choose this answer?
- 9. Could you repeat the statement by using your own words?
- 10. Could you tell me if the statement was about something important in your life?
- 11. Was it easy or difficult to answer this statement? If respondent did not feel good about the statement ask:
 - Could you tell me what part of the statement made you feel like this?
 - ➤ Whv?
 - Do you have any suggestions how this statement could be changed?
- 12. Did you understand the different answer possibilities?

We now have some questions about the whole instrument (PHQ-9/WEMWBS).

- 13. Was this instrument relevant to you personally? Why (not)?
- 14. Does this instrument say anything that might offend or embarrass someone in your community?
- 15. Is there anything about this instrument that you really like? What and why?
- 16. Is there anything about this instrument that you don't like? What and why?
- 17. Could you please rate the ease of answering the questions of the PHQ-9/WEMWBS? (scale: 1st smiley/colour very difficult 5th smiley very easy)











18. Could you explain why you chose to rate it like this?

We are almost at the end of the interview now. "[Interviewer gives a short summarization of the most important findings of the interview]"

19. Did I understand you correctly?

Then I would like to ask some final questions:

- 20. Is there something that you think is important that hasn't been discussed yet?
- 21. Do you have any questions for us?

The interview is now finished. Thank you very much for your time. We really appreciate that you wanted to participate in this study.

VI. Personal information form

Personal information form			
Please tick one of the boxes after each			
question.			
Date of interview	/ (day/month/year)		
Respondent number			
Gender	☐ Female		
	□ Male		
To which of the following age groups do	☐ From 18 up to 28		
you belong?	☐ From 29 up to 40		
	☐ From 41 up to 50		
	☐ From 51 up to 55		
	□ Over 56.		
What state do you live?	☐ The state of Jharkhand		
Time state as you live.	Other:		
	- Other		
Could you specify the area where you live?	☐ Urban area		
could you specify the area where you live.	□ Rural area		
	indial area		
Are you married?	☐ Married		
ric you married:	Remarried		
	☐ Widowed		
	□ Separated		
	☐ Never married		
What is your living situation?	Living with parents		
what is your living situation:	Living with partner		
	Living with partner		
	☐ Living alone		
	☐ Living with others		
What is your level of education?	☐ Illiterate		
·	☐ Read and write only		
	☐ Primary education		
	☐ Secondary education		
	☐ Higher education (e.g. university)		
	- The codedion (e.g. dinversity)		
What is your employment status?	☐ Student		
	□ Farmer		
	☐ Employed in business		
	☐ Official (in government)		
	☐ Housewife/homemaker		
	☐ Working for someone paid		
	☐ Unemployed due to health reasons		
	☐ Unemployed due to other reasons ☐ Other:		
What is your level of income?	□ No income		
what is your level of illcome!			
	Less than 3000 Rupees per month		
	□ 3000-5000 Rupees per month		

	5000-8000 Rupees per month More than 8000 Rupees per month
What is your religion?	Buddhism
	Hinduism
	Muslim
	Christian
	Other
Are you diagnosed with a mental disorder?	Yes
	No
Have you ever participated in a self-help	Yes
group?	No
WHO grading severity lymphedema	1
	2
	3

VII. Informed consent

INTRODUCTION

We kindly ask you to participate in a practical research and thank you in advance for your participation. We will be very grateful if you want to participate. Participation is completely voluntary. To participate, your permission is required. Before you decide whether you want to participate (in this study) or not, you will receive an explanation of what the research entails.

TITLE OF STUDY

Cross-cultural validation of the Patient Health Questionnaire (PHQ-9) and the Mental Wellbeing Scale (WEMWBS) among people affected by lymphatic filariasis, in India.

PRINCIPAL INVESTIGATOR

Name: Nikky Ceelen Name translator:

PURPOSE OF STUDY AND STUDY PROCEDURES

The purpose of this study is to culturally validate the PHQ-9 and WEMWBS. Therefore, we will kindly ask you some questions about your experience with lymphatic filariasis, your life and how you feel about yourself. The questions will be asked verbally. Examples of questions are: 'do you have little interest or pleasure in doing things?' or 'do you feel tired or having less energy?'. If you find a question too personal you can indicate this, then we can skip the question. Lastly, the interview will be recorded, but we will not share your information to anyone outside the research team.

CONFIDENTIALITY

Your responses to this interview will be anonymous.

These measures are taken to ensure confidentiality:

- Assigning code names/numbers for participants that will be used on all research notes and documents
- Notes, interview transcriptions, and any other identifying participant information will only be shared with the research team.

VOLUNTARY PARTICIPATION

Your participation in this study is voluntary. It is up to you to decide whether or not to take part in this study. If you decide to participate, you will be asked to sign this form. After signing the form, you are always capable of withdrawing from the study without having to give a reason. Withdrawing from this study will not affect the relationship you have, if any, with the researcher. If you withdraw from the study before data collection is completed, your data will be destroyed. Do you have any questions about the form or study?

CONSENT

I have read and I understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time. I understand that I will be given a copy of this consent form. I voluntarily agree to take part in this study.

Participant's signature	Date		
Investigator's signature	Date		

VIII. Table 4 and 5

Table 4. Adjustments of items PHQ-9

	Original statement English version	Statement Hindi version	Adaptions of statements	Final questions
1	Little interest or pleasure in doing things	Little interest or pleasure in doing things	Little interest or little pleasure in doing things or work.	Have you been having little interest or little pleasure in doing things or work?
2	Feeling down, depressed, or hopeless	Feeling sad, depressed or hopeless	Feeling sad, depressed (easier word was used in Hindi) or hopeless.	Have you been feeling sad, depressed or hopeless?
3			X	Have you been having problems with sleep, staying asleep or otherwise, sleeping too much?
4	Feeling tired or having little energy little energy		Feeling tired or having less power in your body/mind.	Have you been feeling tired or have you been having less power in your body/mind?
5	Poor appetite or overeating	Feeling less hungry or eating too much/overeating	Х	Have you been feeling less hungry or eating too much/overeating?
6	Feeling bad about yourself—or that you are a failure or have let yourself or your family down	Feeling bad about yourself- or feeling that you are a failed person and you have let down yourself and your family	Х	Have you been feeling bad about yourself- or feeling that you are a failed person and you have let down yourself and your family?
7	Trouble concentrating on things, such as reading the newspaper or watching television	Problem in concentrating in reading newspaper, watching TV etc.	Problem in concentrating in reading newspaper, watching TV or listening to music.	Have you been facing problems in concentrating in reading newspaper, watching TV 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	Walking or speaking so slowly that these draw others attention. Or just the opposite of these. You are very unstable, restless and waffle excessively or move excessively	Х	Have you been walking or speaking so slowly that these draw others attention? Or just the opposite of these. Have you been very unstable, restless and waffle excessively or moving excessively?
9	Thoughts that you would be better off dead, or of hurting yourself in some way	Thoughts that it would have been better to die or hurt yourself in any way.	Х	Have you been having thoughts that it would have been better to die or hurt yourself in any way?
Sum- mary item	If you checked off 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?	If you checked off 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

Table 5. Adjustments of items WEMWBS

	Original statement English version	Statement Hindi version	Adaptions of statements	Final questions
1	I've been feeling optimistic about the future	I am feeling optimistic about the future	Х	Have you been feeling optimistic about the future?
2	I've been feeling useful	I am feeling myself useful	I am feeling useful/needed, for instance in my work, community or family.	Have you been feeling useful/needed, for instance in your work, for your community or family?
3	I've been feeling relaxed	I am feeling myself tension free	Х	Have you been feeling yourself tension free?
4	I've been feeling interested in other people	I am feeling interested in other persons	I am feeling interested in other persons, like my neighbours, friends or family.	Have you been feeling interested in other persons, like your neighbours, friends or family?
5	I've had energy to spare	I have a lot of energy	I have a lot of power in my body/mind.	Have you been having a lot of power in your body/mind?
6	I've been dealing with problems well	I am facing problems properly	Х	Have you been facing problems properly?
7	I've been thinking clearly	I am thinking clearly	I am thinking properly.	Have you been thinking properly?
8	I've been feeling good about myself	I am feeling good about myself	Х	Have you been feeling good about yourself?
9	I've been feeling close to other people	I am feeling myself close to others	I am feeling <mark>near</mark> to others.	Have you been feeling near to others?
10	I've been feeling confident	I am feeling self- confident	X	Have you been feeling self-confident?
11	I've been able to make up my own mind about things	I am able to make an opinion about things	Х	Have you been able to make an opinion about things?
12	I've been feeling loved	I think that people love me.	Х	Have you been thinking that people love you?
13	I've been interested in new things	I am showing interest in new things	I am showing interest in new things or changes.	Have you been showing interest in new things or changes?
14	I've been feeling cheerful	I am feeling happy/delighted	Х	Have you been feeling happy/delighted?