Depression and mental wellbeing in people affected by leprosy in southern Nepal

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Abstract

Background
Leprosy is still one of the most important causes of preventable disability throughout the world. In Nepal, 3.054 new cases of leprosy were reported in 2016. As well as potentially experiencing physical impairment, many people with leprosy also experience stigmatization and may suffer from mental health problems.

Objectives
This study has two main objectives: (a) Establishing a baseline of the mental wellbeing status and level of depression in the leprosy-affected population of southern Nepal, and (b) Examining factors that influence mental wellbeing and depression amongst people affected by leprosy in southern Nepal.

Methods
A cross-sectional survey was conducted to establish the baseline level of depression and mental wellbeing status and to investigate what factors influence the mental wellbeing and level of depression amongst leprosy-affected people in southern Nepal. The survey consisted of three interview-administered questionnaires: the Patients Health Questionnaire 9 (PHQ-9) to measure the level of depression, the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) to examine mental wellbeing status, and the 5-Question Stigma Indicator – affected persons (5-QSI-AP) to measure the level of stigma.

Results
The results show that people affected with leprosy in southern Nepal have a significantly lower level of mental wellbeing and a higher level of depression than the general population. Furthermore, multivariate regression analysis shows that both mental wellbeing and depression are affected by the level of perceived stigma, gender and disability grade. In addition to these factors, mental wellbeing is affected by what caste the person belongs to.

Discussion
This study shows that there is a need for mental health care interventions on different levels. The factors identified in this study might be useful in identifying individuals with extra needs. Finally, these findings indicate further research on specific and practical interventions in order to improve the mental health of leprosy-affected people.

List of abbreviations and acronyms

ANOVA	Analysis of variance
CF	Conceptual Framework
DSM-IV	The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
DSM-V	The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
EMIC	Explanatory Model Interview Catalogue
LF	Lymphatic Filariasis
LLSC	Lalgadh Leprosy Hospital & Services Centre
MDD	Major Depressive Disorder
NLR	Netherlands Leprosy Relief
NLT	Nepal Leprosy Trust
NTD	Neglected Tropical Disease
OR	Odds ratio
PHQ-9	The Patients Health Questionnaire 9 items
PRIME-MD	Primary Care Evaluation of Mental Disorders
SHG	Self-help groups
TB	Tuberculosis
VU	Vrije Universiteit
WEMWBS	Warwick-Edinburgh Mental Wellbeing Scale
WHO	World Health Organization
5-QSI-AP	5 - Question Stigma Indicator – Affected Persons

Introduction and background

Neglected Tropical Diseases (NTDs) are a diverse group of diseases caused by parasitic, viral and bacterial infections that prevail in tropical conditions, and can be found in 149 countries. Out of these many NTDs, the World Health Organization (WHO) selected NTDs based on their transmission characteristics and treatment possibilities, to be the focus of a concerted international effort to address these conditions and their impact. Currently 20 NTDs are selected and together they affect more than 1 billion people worldwide. These NTDs are the chosen targets of the WHO NTD Roadmap, which has as its main objective to eradicate at least two of the NTDS by 2020 (Savioli, 2012).

Leprosy, also known as Hansen's disease, is one of the 20 NTDs selected by the WHO to be targeted for elimination in the Roadmap. Leprosy is caused by *Mycobacterium leprae,* which multiplies slowly and therefore can have an incubation period over 20 years, although the average incubation period is 2-5 years (WHO, 2018). Granulomatous inflammation due to *Mycobacterium leprae* typically affects the peripheral nerves, eyes, skin and mucosa of the upper respiratory tract (WHO, 2018). The leprosy-related impairments are classified using the WHO three-grades system.

Currently, if patients are early given multi-drug therapy (MDT) most impairment can be prevented or minimised (Cunha De Souza et al., 2016; WHO, 2006). However, leprosy is often diagnosed too late and irreversible nerve damage has already occurred. Furthermore, during or even after MDT episodes of increased inflammatory activity can cause damage in the skin and nerves, a so-called leprosy-reaction (Lienhardt & Fine, 1994; Rajendra Kumar et al., 2004). After an initial decline in the number of new cases in the first years of this millennium, the number of cases detected annually has now stabilised. Therefore, leprosy is still an important cause of preventable disability throughout the world (Britton & Lockwood, 2004).

In 2016, 214,783 new cases of leprosy were diagnosed worldwide. More than 75% of these are found in the South Asia Region. The southern part of Nepal, the Terai region, and the neighbouring north-eastern part of India are epidemiological hotspots for leprosy. In Nepal, 3.054 new cases of leprosy were reported in 2016 (WHO, 2016).

As well as potentially experiencing physical impairment, many people with NTDs are also affected by stigmatization associated with these diseases. Hofstraat & van Brakel found that people with 10 different NTDs are affected by stigma (2016). Furthermore, there is also an extensive body of literature regarding the stigmatization of people affected by leprosy. Several studies show that people affected by leprosy often experience rejection, hate, insults and unsympathetic reactions (Brouwers, Brakel, & Cornielje, 2011; Heijnders & Van Der Meij, 2006; Van Brakel, 2006; van Brakel et al., 2012). Moreover, Adhikari et al. showed high levels of perceived stigma in leprosy affected people in western Nepal (2014).

In addition to stigma, and often as a result of stigmatisation, people affected by NTDs may also experience mental health problems and reduced mental wellbeing. Hotez reports that many NTDs can cause severe physical disability and permanent disfigurements, which can lead to a decline in mental wellbeing (2008). Moreover, various studies have demonstrated that this link with mental health problems also applies to people affected by leprosy. A study in Bangladesh by Tsutsumi et al. demonstrated that leprosy impacts the mental health status of people affected by this disease (2007). Furthermore, Leekassa et al. showed that people affected by leprosy have a sevenfold increased risk of mental disorders compared to patients with other skin diseases (2004).

Several studies have indicated or described a relationship between stigmatization and mental health problems (Leekassa et al., 2004;

Senturk & Sagduyu, 2004; Zodpey, Tiwari, & Salodkar, 2000). However, to our knowledge no studies have investigated perceived stigma, mental wellbeing and depression in southern Nepal. Only a few (qualitative) studies have examined the factors that affect the mental wellbeing status and level of depression in people affected by leprosy in Nepal.

Therefore, this study has two main aims: (a) Establishing a baseline of the mental wellbeing status and level of depression in the leprosy-affected population of southern Nepal, and (b) Examining factors that influence mental wellbeing and depression amongst people affected by leprosy in southern Nepal. The finding of this study can be used for advocacy purposes and to improve (mental) health care for persons affected by leprosy in Nepal and elsewhere.

Contextual background

Lalgadh Leprosy Hospital & Service Centre

The Nepal Leprosy Trust (NLT) is an UK-based Christian organization that aims to eliminate leprosy from Nepal, and provides services to people affected by leprosy and their families. One of the two major projects of the NLT is the Lalgadh Leprosy Hospital and Service Centre (LLSC). The construction of LLSC began in 1990 and the hospital received its first patients in 1993 (Nepal Leprosy Trust, 2018). Currently, the LLSC employs 103 Nepali staff, of whom 26% are themselves affected by leprosy or from a leprosy-affected family. Furthermore, the LLSC is one of the busiest centres specialized in leprosy in the world, with an annual patient-flow of about 1200 leprosy patients. In the period of July 2015 to July 2016, more than 500 patients with leprosy were admitted to the hospital. LLSC is located in the Dhanusha district and has a catchment area that encompasses the districts of Dhanusha, Mahottari, Sarlahi and Sindhuli (LLSC, 2018).

Self help groups

As well as offering inpatient services, the LLSC also provides outpatient services and runs community health projects. One of these community projects is the formation, mobilization and support of self help groups (SHGs). The SHGs are part of the Stigma Elimination Programme (STEP), which became operational in 2002. Cross & Choudhary evaluated this program in 2005 and concluded that STEP had a significant positive effect on the social participation of leprosy-affected people in southern Nepal (2005).

At the start of the STEP program, the number of SHGs was 10. Today there are 101 SHGs with a total of 2,461 participants (LLSC, 2018). Each of these SHGs consists of about 20 members with various backgrounds, including leprosy-affected persons. Most people become aware of the presence of SHGs via word of mouth in their village or from medical staff when visiting LLSC. People with all sorts of impairments and diseases are welcome to participate in SHGs, including disabled children. In addition, people can participate in SHGs if they are marginalized, for example single mothers with young children. Participation is not restricted by other characteristics such as caste, gender or age.

Every group has its own facilitator who leads the meetings, and a treasurer who is responsible for the money saved by the group. The groups meet on average twice a month at a central place in the village, such as a health centre or a community house. The community staff of LLSC visits these groups once a month to monitor their progress and discuss difficulties in the group.

The SHGs practice several activities. First of all, they promote self-care, which includes soaking of hand and feet to hydrate the skin and application of oil to keep the moisture inside the skin for leprosy-affected persons. This helps to prevent the occurrence of cracks and formation of ulcers. Second, participants talk about the problems they face in their daily life and support each other in difficult times. Third, the group saves money, with every participant depositing a small amount of money per month. As a result the members of the group can get a loan from these savings with a low interest. These loans can be used for investments such as the purchase of a water buffalo or the opening of a small shop. Finally, participants make villagers aware of leprosy and educate them about the symptoms of leprosy.

Theoretical background

Stigma

The link between stigma and NTDs is not a new phenomenon. The earliest writing about lepraphobia goes back to 1250 before Christ in Egypt. More than 80,000 people infected with leprosy were placed in a compound on the edge of the Sahara Desert (Kilwein, 1995). The concept of stigma was first formally described by Erving Goffman in *Stigma: Notes on the Management of Spoiled Identity*, which inspired a profusion of research on the nature, sources, and consequences of stigma. In this book stigma is defined as '*The phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of other spoils normal identity'* (1963 p.3).

Despite its important role in the research into stigma, some criticism on the work of Goffman was expressed (Scambler, 2009). Weiss et al. stated that Goffman's definition of stigma is not fully applicable to health-related research, especially in low-income settings, and proposed another definition of stigma. They defined stigma as '*a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perceptions or reasonable anticipation of an adverse social judgment about a person or group'* (2006). This definition is applicable to health problems in an international context and will therefore be used in this study.

Stigma can be approached in two ways; from the point of view of people that are stigmatized or from the perspective of the people that stigmatize, thus the community (Weiss, 2008). These two approaches can be seen in *Figure 1*. In this study we will only focus on people who are affected by leprosy and are therefore stigmatized.

Affected persons can face three types of stigma. These types of stigma are also shown in *Figure 1*. First, perceived stigma, which is also called felt stigma. Perceived stigma is the perception or anticipation of an adverse social judgment about a person or group (Weiss, 2008). Second, experienced stigma is the experience of discrimination, i.e., differential treatment on account of a health condition. Third, internalised or self-stigma, which means a lower personal value and sense of self because of the incorporation and acceptance of the negative evaluation of the society (Livingston & Boyd, 2010). In this study we will measure only perceived stigma in affected persons, which are indicated with an asterisks in *Figure 1*.

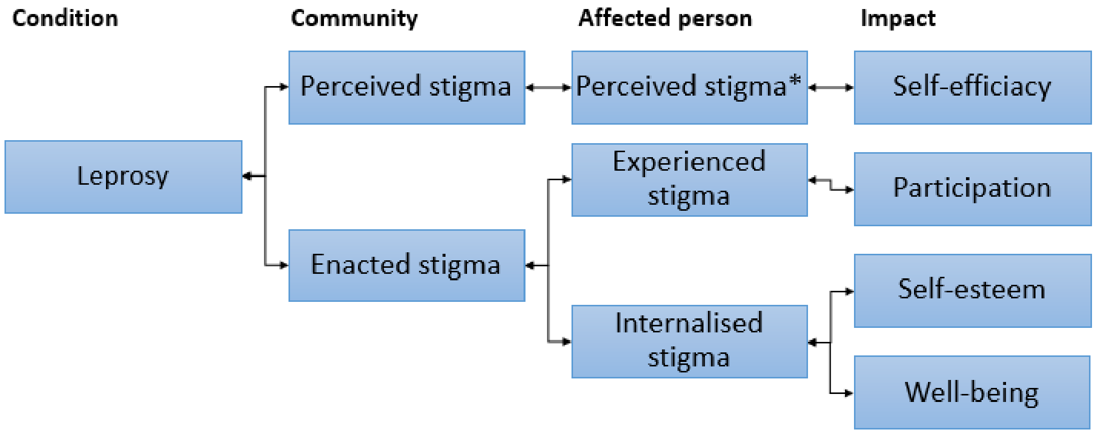

***Figure 1**: Different perspectives, types and impact of stigma (adapted from Rensen et al., 2011)*

Mental health, illness and wellbeing

Mental health is defined by the WHO as '… *a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community. In this positive sense, mental health is the foundation for individual well-being and the effective functioning of a community'* (2016). Mental health can be both positive and negative; positive mental health is also called mental wellbeing. For this study the adapted definition of mental wellbeing used for the development of the Warwick-Edinburgh Mental Well-being Scale will employed. The definition is *' Mental wellbeing is the ability to maintain a sense of autonomy, agency, self-acceptance, self-esteem, personal growth and purpose in life and the capability to develop and maintain mutually beneficial relationships.',* which was adopted from Ryan and Deci. (Ryan & Deci, 2001; Taggart, Stewart-Brown, & Parkinson, 2015)

Although there is some discussion in the literature regarding whether mental illness and mental wellbeing represent two different dimensions or two ends of one spectrum, for this study mental wellbeing and mental illness are considered as two different dimensions. This corresponds with the finding that analysis of instruments covering both mental wellbeing and mental illness often suggests two correlated, but independent, underlying factors. For this study we will adopt the definition of mental illness used for the development of the WEBMWBS: '*Mental illness is a term used to encompass all mental disorders – these are illnesses that affect mood, emotions, and the ability to function effectively and appropriately'* (Taggart et al., 2015).

Depression

The most common mental disorder is depression, which can be described as '*an enduring sadness that is accompanied by loss of interest in people and activities and an inability to execute daily activities'* (WHO, 2017). The duration and intensity of depression can vary greatly, and when depression is long-lasting and has a severe intensity, it can become a serious health condition. Furthermore, depression can cause great suffering, and at its worst can lead to suicide (WHO, 2017). The *Diagnostic and Statistical Manual of Mental Disorders* is a document in which international experts define and classify mental disorders. The *Diagnostic Manual of Mental Disorders, Fifth Edition (DSM-V)* is the latest version. However, many questionnaires and studies are based on the criteria of *DSM, Fourth Edition (DSM-IV)*. The DSM-IV describes 9 criteria, of which at least 5 should be met in order to diagnose a person with a Major Depressive Disorder (MDD) (American Psychiatric Association, 1994*)*. These 9 criteria can be found in *Figure 2*.

1. Most of the day an irritable or depressed mood and this nearly every day. This can be indicated by observation made by others or by subjective report by the patient itself.
2. Most of each day, decreased pleasure and interest in most activities.
3. Change in appetite and a significant weight change of 5%.
4. A change in sleep: which can be either insomnia (sleeplessness) or hypersomnia (excessive sleepiness)
5. Changes in activities: Psychomotor agitation, which includes restlessness, or retardation, which is the slowing down of thoughts or physical movements.
6. Loss of energy and feelings of fatigue
7. Excessive or inappropriate feelings of guilt and/or feelings of worthlessness
8. Reduced ability to concentrate or think and an increase in indecisiveness
9. Thoughts of suicide or death, or a plan in mind to commit suicide

Figure 2*: The 9 criteria used to diagnose a Major Depressive Disorder (MDD) (adapted from American Psychiatric Association, 1994)*

Mental health and stigma

The below unpublished conceptual model (*Figure 3*) describes the relation between stigma related to NTDs and mental distress in people affected by NTDs. This model was developed by Dr. Julian Eaton, a psychiatrist specialized in mental health related to NTDs, and Dr Mirja Koshorke, a research psychiatrist at the National Institute for Mental Health in London (Koschorke & Eaton, 2018).

In this model, stigma, discrimination and social exclusion are key components. Stigma, discrimination and social exclusion cause increased participation restrictions, disability, and internalised stigma. Next, increased participation restrictions and disability, and internalised stigma can lead to mental distress and increase the likelihood of depression, anxiety and other disorders. As a result, there is reduced help seeking, treatment uptake and adherence. This reduced help seeking, treatment uptake and adherence can result in poor prognosis and treatment outcomes, causing higher visibility of illness. Visibility of the illness impacts the level of stigma, and discrimination and social exclusion may be increased. Besides this “vicious circle,” another smaller negative feedback loop takes place. Stigma, discrimination and social exclusion may also result in limited resources for NTD management and negative attitudes amongst health care staff. This results in low training levels and poor quality of treatment, which will subsequently lead to poor prognosis and treatment outcomes, and higher visibility of illness. The visibility of illness can cause an increase in stigma, discrimination and social exclusion (Koschorke & Eaton, 2018).

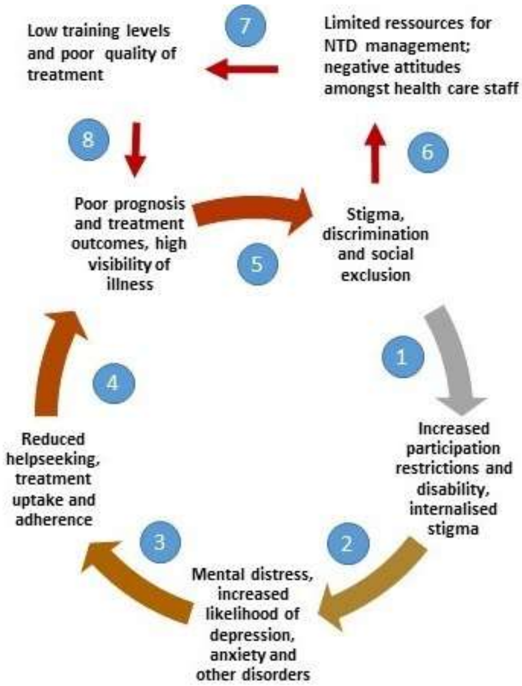

Figure 3 *Mental health, stigma and neglected tropical diseases: links between factors relevant to people affected by NTDs (Koschorke & Eaton, 2018).*

This study will focus on understanding the associations between stigma, discrimination and social inclusion; increased participation restrictions and disability; internalised stigma and mental distress; and increased likelihood of depression, anxiety and other disorders that are described by the model presented in *Figure 3*. Three important aspects of the cycle will be measured: First of all, perceived and experienced stigma from the perspective of the affected person; second, the mental wellbeing of the person affected by leprosy; and third, depression in affected persons. From this conceptual framework, the following two research questions have been derived: (a) What is the mental wellbeing status and prevalence of depression among persons affected by leprosy in southern Nepal? (b) What factors influence the mental wellbeing status and the level of depression among persons affected by leprosy in southern Nepal.

Methods

Study design

The study design was a cross-sectional survey. This survey consisted of three different questionnaires related to mental well-being, depression and stigma. This present study was part of a mixed-methods study, that used both qualitative and quantitative tools. The qualitative part of the study was performed by Wiebrich van Netten.

Study population

For this research, the study population was comprised of people affected by leprosy in southern Nepal. To investigate this study population, data was collected from people affected by leprosy who participated in SHGs. People were included in this study if they were affected by leprosy, were over 18 years of age, and had participated in a SHG for more than three months. People were excluded from participation in the study if they had another major comorbidity (e.g. polio, HIV/AIDS), were not able to speak Maithili fluently or were not resident in the LLSC catchment area. To obtain reference data for comparison of the level of depression and mental wellbeing status, people from the general population were included in a reference group. This group had the same inclusion and exclusion criteria except that they were not affected by leprosy and did not participate in SHGs.

Sample size and sampling method

The sample size calculation was done by using EpiCalc2000 (Brixton Health). The calculation showed that a minimal sample size of 80 participants was needed to obtain a prevalence estimate of depression with a precision of +/- 5% and a confidence level of 95%. A minimum of 50 subjects were to be recruited from the general population to obtain normal values for the PHQ-9 and WEMWBS. To examine the mental wellbeing status and the level of depression 142 people affected with leprosy were included in this study. The stigma survey was conducted by 86 of these leprosy-affected people to determine the level of perceived stigma. The reference group consisted of 54 persons from the general population. The sampling method of this study was random sampling.

Data collection

For the data collection three questionnaires were used related to mental well-being, depression and stigma. The Patients Health Questionnaire (PHQ-9) is an interview-administered version of the Primary Care Evaluation of Mental Disorders (PRIME-MD) and diagnostic instrument for common mental disorders. This questionnaire has a good internal consistency (Cronback's a = 0,835), an desirable content validity and a satisfying 1-month test-retest reliability of r = 0,875. (Ganguly et al., 2013; Kroenke & Spitzer, 2002). Furthermore during our study the PHQ-9 was being validated in people affected by leprosy in southern Nepal by Dijkstra (2018). A cut-off point of a score of 10 was used in this study, since it was reported that a score equal or higher than 10 has a 88% sensitivity and a specificity of 88% for major depression (Kroenke & Spitzer, 2002).

To measure mental wellbeing, the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) was used. The WEMWBS was developed to monitor mental wellbeing in the general population (Waqas et al., 2015). A cross cultural evaluation showed that the WEMWBS has a good internal consistency (Cronback's a = 0.91 in the population sample) and a high test-retest reliability at one week of 0,83 (Tennant et al., 2007). This was supported by various studies, which demonstrated the validity and reliability of this questionnaire in different contexts (Clarke et al., 2011; Stewart-Brown et al., 2011). Furthermore, this questionnaire is already used in LLSC and has been proven useful in this setting. This questionnaires was also being validated in leprosy-affected people in southern Nepal by Dijkstra during our study (2018). For this study a score of 45 or lower on the WEMWBS was considered to represent poor mental wellbeing, since several studies support this cut-off point (Bianco D. 2011, Alves O. 2017).

Despite the fact that the WEMWBS and PHQ-9 are related, these questionnaires measure a different outcome. The PHQ-9 measures depression, a potential treatable disease, and can therefore be of immediate importance for interventions. In contrast to the WEMWBS, which is an overall mental health outcome. Therefore both these questionnaires were considered as a valuable part of the study.

To determine the level of perceived stigma, the 5-Question Stigma Indicator – Affected Persons (5-QSI-AP) was used. The 5-QSI-AP is mentioned in the "suggested actions'' section of the *Global Leprosy Strategy 2016-2020* as an easy-to-use questionnaire for stigma assessment (WHO, 2015). This questionnaire is based on the EMIC stigma scale, which is a commonly used questionnaire (Rensen et al., 2011).

Pre-testing:

Before the start of the study, the questionnaires and informed consent form were translated in Maithili and back translated in English, with help of a local (hired) interpreter and researcher(s) from the LLSC. Hereafter, a pilot study was conducted to test the questionnaires. During this pilot, the questions or the questionnaires were read out loud, one by one. After each question, the participant was asked whether he/she understood the statement, whether he/she had any suggestions to improve the statements and whether he/she thought that there were any sensitive statements which made him/her feel uncomfortable. After the pilot study, the questions of the questionnaires were adapted when needed. Finally, the pilot study was also used to practice working with an interpreter.

Data analysis

All the scores were entered in Epi Info (Epi Info version 7.2). Subsequently, the dataset was exported to SPSS (IBM SPSS Statistics 25) and Excel (Excel 2016 Office) for further analysis. Descriptive statistics were used to get an overview of the demographic characteristics (e.g. gender and age) and a t-test or a non-parametric Mann-Whitney U test was carried out to compare these characteristics between the two groups. To compare more than two groups ANOVA analysis was performed and for the analysis of categorical data the Chi-square test or Fisher's exact test was executed. To examine the association between two continuous variables, such as the total questionnaire scores, linear regression analysis was performed. To examine factors associated with the mean depression and mental wellbeing scores, multivariate linear regression was used (Terwee et al., 2007).

Ethical considerations

The participants that were approached for this study are affected by leprosy. These people are vulnerable and therefore might be less capable of protection their own rights. In addition, this study included questions about mental wellbeing and unpleasant experiences, both very personal and sensitive topics. Before any data was collected, participants were informed about the study. The participants were informed about the intentions of the study and what they could expect. It was clearly stated that no incentives nor compensations for wages would be used in this study. Subsequently, written informed consent was requested by using the informed consent form in Maithili. In case participants needed medical help, they were referred to Lalgadh Leprosy Hospital & Services Centre. Before the start of the research, ethical approval from the Nepal Health Research Council and ethical approval of the VU University Amsterdam was acquired.

Results

Demographic characteristics

Table 1 shows the demographic characteristics of both people affected with leprosy and that of the reference group, which includes people selected from the general population who have similar demographic characteristics.

Table 1 shows that the group with leprosy-affected people consisted of 142 people with a mean age of 56.7, with a roughly equal distribution among the sexes. The reference group included 54 people with a mean age of 61.1 and included more women (64.8%) than men. Although the mean age and gender distribution were different between the two groups, this difference was not significant at the 5% level (p = 0.068 and p = 0.070). In both groups, the majority of people lived in a rural area, were illiterate and did household work. The second most common occupation was agricultural labour (36.6% of the sample population and 31.5% of the general population). Most of the people in both groups were Hindu, currently married and belonged to a low caste. The majority of the people affected with leprosy come from the district Mahottari, and in the reference group most people come from the district Dhanusha. Analysis shows that this difference is significant (p = 0.002) but that the variable district was independent from the PHQ-9 or WEMWBS scores. Therefore these scores have not been adjusted for the difference in district. The demographic characteristics of the smaller sample of leprosy-affected people (*n* =86) who completed the stigma survey are not (significantly) different from the larger sample of leprosy-affected people (*n* =142).

Leprosy-associated characteristics

The average number of months since respondents were diagnosed with leprosy was 171 months, which is more than 14 years. More than 20% of the people affected with leprosy also have a close relationship with a leprosy-affected person.

	Leprosy-affected n (%)	**Reference n (%)**
Number of people	142	54
Mean age	56.7	61.1
Male	73.0 (51.4)	20 (37.0)
Living in rural area	127 (89.4)	50 (92.6)
Education		
Illiterate	119 (83.8)	49 (90.7)
can read/write	9 (6.3)	0 (0.00)
primary school	7 (4.9)	3 (5.60)
secondary school	5 (3.5)	0 (0.00)
higher education	2 (1.4)	2 (3.7)
Occupation		
employed	7 (4.9)	0 (0.00)
self-employed	16 (11.3)	6 (11.1)
unemployed	0 (0.00)	0 (0.00)
student	0 (0.00)	0 (0.00)
Household work	67 (47.2)	31 (57.4)
agricultural labour	52 (36.6)	17 (31.5)
Religion		
Hinduism	135 (95.1)	53 (98.1)
Buddhism	2 (1.4)	10 (1.90)
Christianity	0 (0.00)	0 (0.00)
Muslim	5 (3.5)	0 (0.00)
Other	0 (0.00)	0 (0.00)
Marital status		
never married	1 (0.7)	0 (0.00)
currently married	110 (77.5)	41 (75.9)
living together	0 (0.00)	0 (0.00)
divorced	2 (1.4)	0 (0.00)
widowed	29 (20.4)	13 (24.1)
Caste		
high	15 (10.6)	2 (3.70)
middle	17 (12.0)	7 (13.0)
low	110 (77.5)	45 (83.3)
District***		
Dhanusha	56 (39.4)	33 (61.1)
Mahottari	65 (45.8)	10 (18.5)
Sarlahi	21 (14.8)	11 (20.4)

Table 1: *Demographic characteristics in numbers and percentages for people affected with leprosy (n = 142) and the reference group (n = 54).*
**= $p \leq 0.05$, **= $p \leq 0.01$, ***= $p \leq 0.001$.*

Figure 4 shows the distribution of disability grades among people affected with leprosy. Disability grade of 0 indicates no disability (impairments) grade 1 is sensory impairment and a disability grade of 2 indicates visible disfigurement such as contractures of digits, wounds, loss of digits and blindness.

Figure 4 shows that 31% of the people affected with leprosy had a disability grade of 0, thus minor deformities. The majority of the people (52.8%) had a disability grade of 1, which indicates significant deformities. Only 16.2% of the people affected by leprosy in this study had a disability grade of 2 and therefore visible deformities. The leprosy-associated characteristics, which includes months diagnosed, disability grade and close relationship with leprosy affected person, were not significantly different between the smaller and bigger sample of the leprosy affected people (respectively *n*= 86 and *n* = 142).

Level of depression and mental wellbeing status

The results show that the mean total PHQ-9 score is 7.54 among people affected with leprosy and 3.61 in the reference group. The difference between these scores is highly significant (*p* = 0.000). Furthermore, the mean total WEMWBS score is 49.0 in leprosy-affected people and 58.3 in the reference group, again a highly significant difference (*p* = 0.000).

Figure 5 shows the prevalence of depression, thus a total score on PHQ-9 higher or equal to 10, and the prevalence of people that have a low mental wellbeing, thus a total score on WEMWBS lower or equal to 45. Finally, the prevalence of thoughts about self-harm or suicide in both groups is shown, which is a score of 1 or higher on question 9 of the PHQ-9 questionnaire. This means that people thought in the past two weeks on several days (score of 1), more than half of the days (score of 2) or nearly every day (score of 3) that they would be better off dead or hurting themselves in some way.

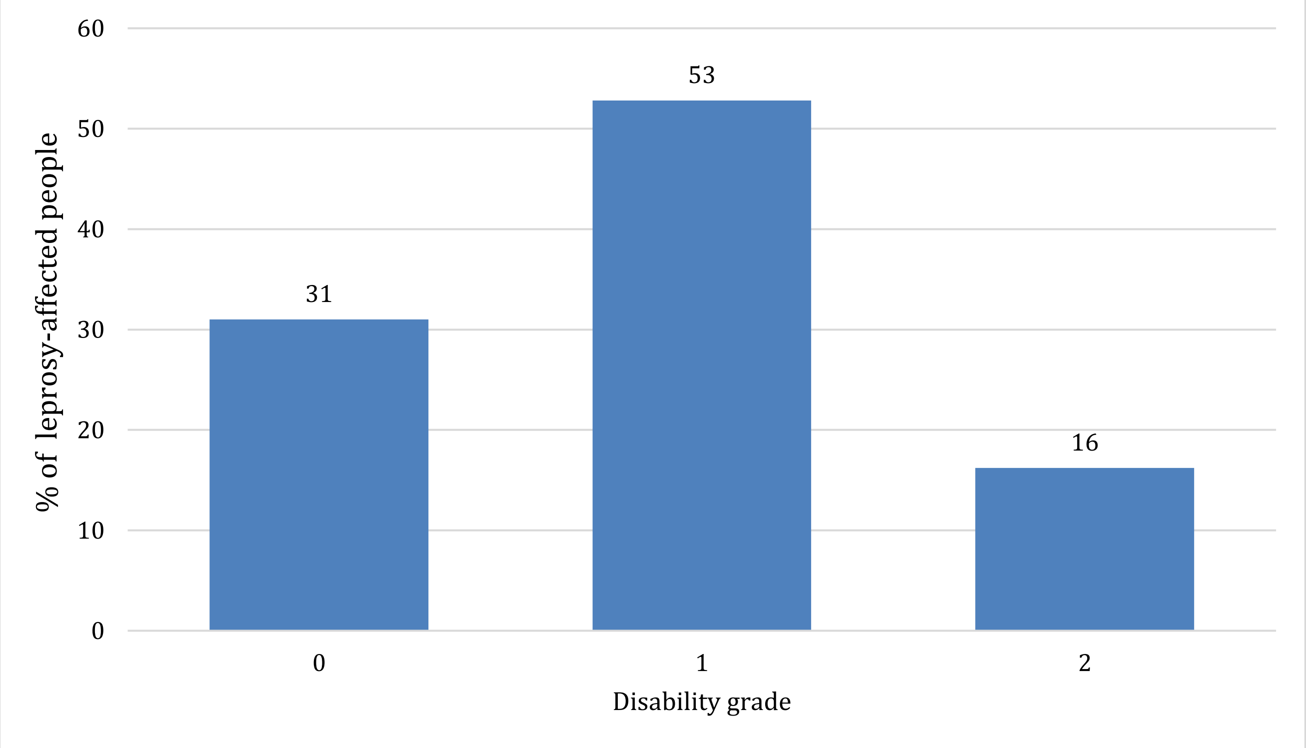

Figure 4: *Distribution of disability grade among leprosy-affected people in percentages (n = 142).*

Figure 5 shows that the prevalence of depression amongst people affected with leprosy is 24.6% (95% CI 16.9 - 31.1) in comparison to 0.00% in people from the reference group. The difference between these groups is highly significant with a *p* -value of 0.000. The prevalence of poor mental wellbeing is also significantly higher in people affected with leprosy (38.0% with 95% CI 30.1 - 45.9) than in the reference group (9.30% with 95% CI 1.27 -16.7). Half of the people affected with leprosy said they have thoughts of suicide or self-harm (50.0% with 95% CI 41.8 - 58.2). In the reference group, more than 20% of the people reported to have had suicidal or self-harm ideation (20.4% with 95% CI 9.3 to 30.7). The difference between the leprosy-affected and reference group is again highly significant, with a *p*-value of 0.000.

For further analysis a Haldane-Anscombe correction was applied to the data related to prevalence of depression. This correction was needed because the prevalence of depression in the reference group was equal to zero. For this correction 0.5 was added to each of the relevant cells and then the odds ratio was calculated over these adjusted cell counts.

After this correction, the results show that people affected with leprosy have a more than 50-fold risk of depression compared to people of the reference group (*OR* = 52.6, *p* = 0.000). The risk of poor mental wellbeing is also much higher in people affected with leprosy, this risk is 6 times higher than in the reference group (*OR* = 6.02, *p* = 0.000).

Relation mental wellbeing and depression

Figure 6 shows the correlation between the mean total WEMWBS score (*x*-axis) and the mean PHQ-9 score (*y*-axis) for people affected with leprosy (*n* = 142). This figure shows that there is a strong negative correlation between the mean total PHQ-9 score and the mean total WEMWBS score in people affected with leprosy (*r* = 0.70, *p* =0.000). The higher the PHQ-9 score, which is a measure for depression, the lower the WEMWBS score, which means a poor mental wellbeing. Because, the mean total PHQ-9 scores and the mean total WEMWBS scores are highly correlated, these variables will not be included in the respective models examining factors that contribute to depression and poor mental wellbeing.

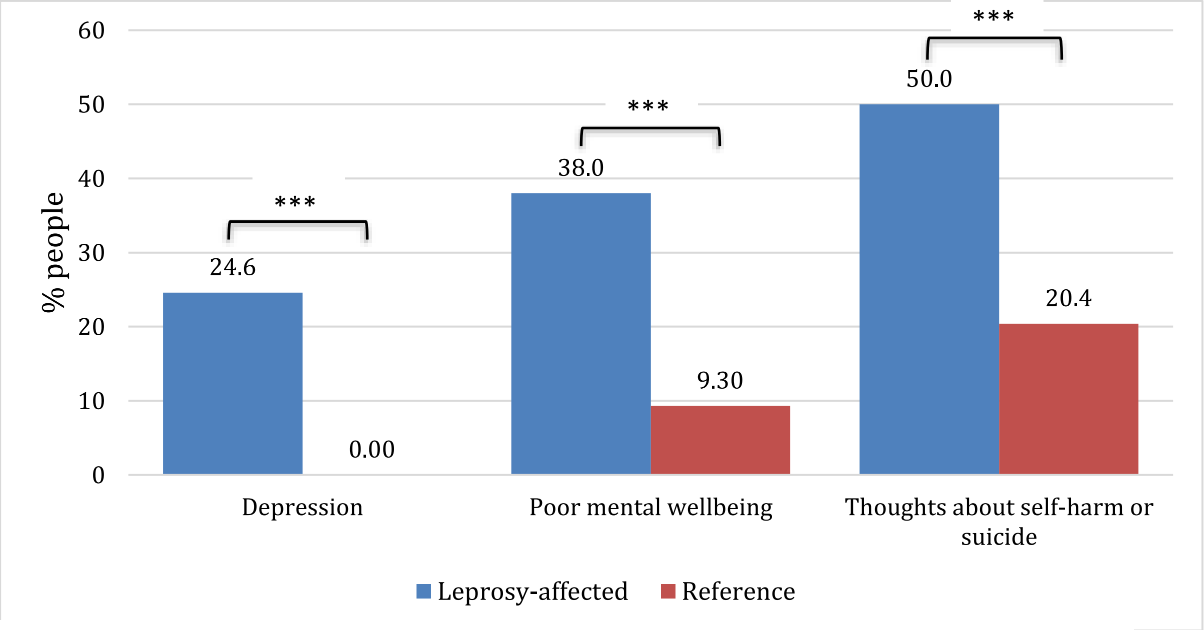

Figure 5: *Prevalence of people with depression (total PHQ-9 score ≥ 10), poor mental wellbeing (total WEMWBS score ≤ 45) and thoughts about self-harm or suicide (score PHQ-9 question 9 ≥ 1) in the leprosy-affected (n = 142) and reference group (n = 54).*

Factors influencing depression

Table 2 shows the results of the multivariate linear regression analysis for the mean total PHQ-9 score, which is a measure of depression, in people affected with leprosy. This analysis shows variables that significantly influence the mean total PHQ-9 scores, and therefore affect the level of depression.

Table 2 shows that the mean total 5-QSI-AP score, which is an indicator for the level of perceived stigma, significantly affects the mean total PHQ-9 score. For every extra point on the 5-QSI-AP scale, the mean total PHQ-9 score rises by 0.787 (p = 0.000). Furthermore, the results show that the mean total PHQ-9 score increases with 2.73 points if the participant is a woman (p = 0.004). Moreover, people with a disability grade of 2 have on average a 3.11 point higher mean total PHQ-9 score than people with a disability grade of 0 or 1 (p = 0.007). Finally, Muslims have a significant higher mean total PHQ-9 of 7.88 points (p = 0.001). The mean total PHQ-9 score was not significantly affected by the other variables, which included age, area of residence, level of education, occupation, marital status, caste and district.

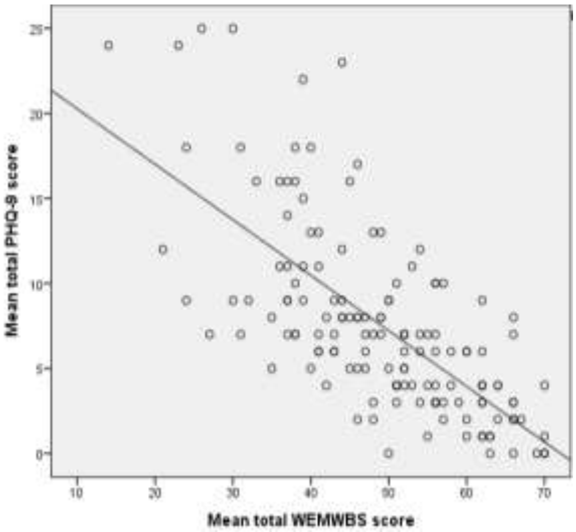

Figure 6: *correlation between the mean total WEMWBS score (x-axis) and the mean total PHQ-9 score (y-axis) in people affected with leprosy (n=142).*

Factors in mental wellbeing

Table 3 shows the results of the multivariate linear regression analysis of the mean total WEMWBS score, which is a measure of mental wellbeing, in people affected with leprosy. This analysis shows what variables significantly influence the mean total WEMWBS score and therefore the mental wellbeing of people affected with leprosy.

Table 3 shows that the level of perceived stigma, measured by the mean total 5-QSI-AP score, appears to significantly affect the mean total WEMWBS score. For every extra point on the 5-QSI-AP scale, the mean total WEMWBS score lowers with more than 1.5 points (p = 0.012). Furthermore, the results show that women have on average a 10.8 point lower wellbeing score than men (p = 0.000). Caste also had an independent effect on the mental wellbeing status. The wellbeing score was on average 9.89 points lower (p = 0.008) for people from a middle caste compared to people from a low caste. People from a high caste have a significantly higher WEMWBS score (5.80 points, p = 0.053) than people from a low caste.

Variables		**B**	**Significance**
Mean total 5-QSI-AP score		.787	0.000
Gender			
	Male^{REF}	-	-
	Female	2.73	0.004
Disability grade			
	Disability grade 0 + 1^{REF}	-	-
	Disability grade 2	3.11	0.007
Religion			
	Hinduïsm^{REF}	-	-

Table 2: *Variables that influence the mean total PHQ-9 score (depression) in people affected with leprosy (n = 86) with a predetermined cut-off point of p = 0.05. REF = the selected reference category.*

Thus leprosy-affected people from a low caste have a poorer mental wellbeing than people from a high caste but a better mental wellbeing than people from a middle caste. Moreover, the results show that people with a disability grade of 2 have a significantly lower total mean WEMWBS score than people with a disability grade of 0 or 1 (5.58 points, *p* = 0.033). Finally, it appears that Muslims score on average 12.2 point lower than Hindus (*p* = 0.012). The mean total WEMWBS score was not significantly affected by age, area of residence, level of education, occupation, marital status and district.

Relationship between stigma and depression, mental wellbeing

Table 2 and *Table 3* show that the mean total 5-QSI-AP score, an indicator for the level of perceived stigma, appears to highly affect a person's level of depression and mental wellbeing status. *Figure 7* shows the correlation between the mean total 5-QSI-AP score (x-axis) and the mean total PHQ-9 (y-axis in *Figure 7a*) and mean total WEMWBS score (y-axis in *Figure 7b*).

Variables		B	Significance
Mean total 5-QSI-AP score		-1.52	0.012
Gender			
	Male^{REF}	-	-
	Female	-10.8	0.000
Caste			
	Low^{REF}	-	-
	Middle	-9.89	0.008
	High	5.80	0.053
Disability grade			
	Disability grade 0+1^{REF}	-	-
	Disability grade 2	-5.58	0.033
Religion			
	Hinduïsm^{REF}	-	-
	Islam	-12.2	0.012

Table 3: *Variables that affect the mean total WEMWBS (mental wellbeing) in people affected with leprosy (n = 86) with a predetermined cut-off point of p = 0.05. REF = the selected reference*

Figure 7a shows that there is a positive correlation between the total mean 5-QSI-AP score and the total mean PHQ-9 score. Thus, the higher the level of perceived stigma, the higher the chance of depression. *Figure 7b* shows that there is a negative correlation between the mean total 5-QSI-AP score and the mean total WEMWBS score. The higher the level of stigma, the lower the WEMWBS score, and thus a poorer mental wellbeing. Further analysis shows that the coefficients of both relationships are highly significant.

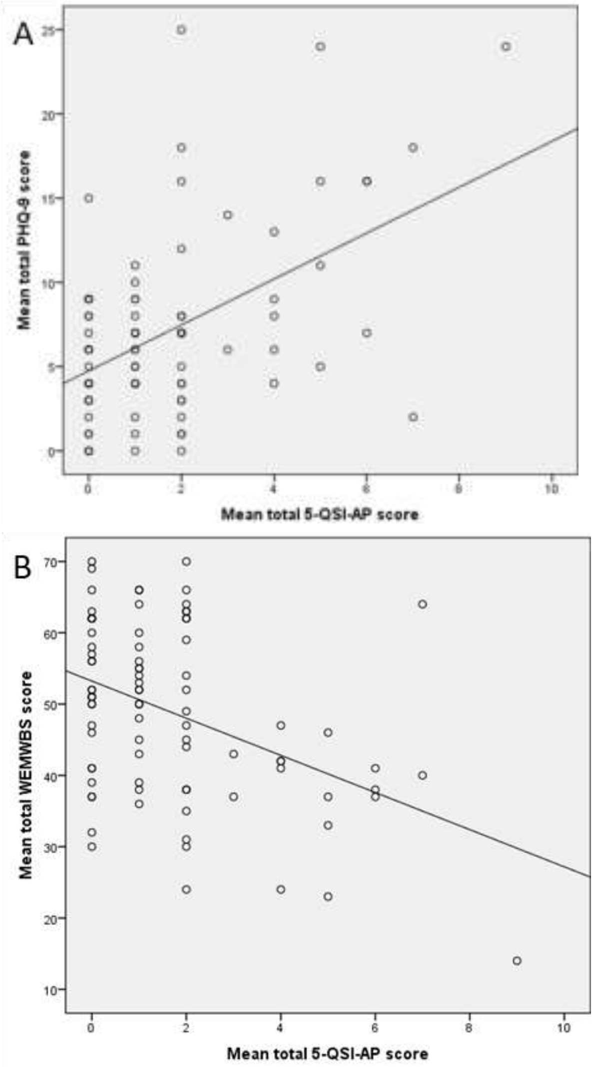

Figure 7: *correlation between the mean total 5-QSI-AP score and* ***A.*** *the mean total PHQ-9 score and* ***B.*** *the mean total WEMWBS score in people affected with leprosy (n = 86)*

Validation stigma scale

Table 7 shows that the mean total 5-QSI-AP score is correlated with the mean total PHQ-9 score and WEMWBS score and therefore is associated with both depression and mental wellbeing. Additional validation analysis was performed in order to examine the validity of the 5-QSI-AP scale. The results show that this questionnaire had a Cronbach's alpha of 0.74, which indicates a good internal consistency for a short scale. Furthermore, the results show that none of the questions had missing values except for the fourth question, which is '4. Would leprosy cause a problem for a person to get married or in an existing marriage?'. Almost 25% of the people did not answer this question. Finally, more than 15% of the sample score the minimum score of zero, which indicates a floor effect. A minimum score of zero means that there is that person experiences no perceived stigma so no further interventions are needed.

Discussion

The two aims of this study were: to determine the baseline level of depression and mental wellbeing status; and to examine what factors affect depression and mental wellbeing, in people affected by leprosy in southern Nepal. The majority of participants, in both the leprosy-affected and the reference group, lived in a rural area, were illiterate, did household work, were Hindu, were currently married and belonged to a low caste. The characteristics of our sample population corresponded with the characteristics of the participants affected with leprosy of another study conducted in the LLSC catchment area (Pryce et al., 2018). This confirms that our sample population is representative for people affected with leprosy who participate in SHGs in the catchment area of LLSC in southern Nepal.

Level of depression and mental wellbeing status

The results showed that the mean depression score was significantly higher in leprosy-affected people group than in people from the reference group (7.54 vs 3.61, *p* = 0.000). These results are in line with the study of Tsutsumi, which reported a higher mean depression scores in people affected with leprosy compared to the general public (2004). Furthermore, higher mean depression scores were also found for other NTDs, including podoconiosis (nonfilarial elephantiasis) and lymphatic filariasis (Mousley et al., 2014; Ton, Mackenzie, & Molyneux, 2015).

The prevalence of depression among people affected with leprosy was also significantly higher than in the reference group (24.6% vs 0.0%). This corresponds with a 50-fold increased risk of depression for people affected by leprosy (OR = 52.6, *p* = 0.000). Several studies found strongly varying prevalence rates of depression (9.9% - 76%) in people affected with leprosy, which included the prevalence rate of 24.6% found in our study (Bhatia, Chandra, Bhattacharya, & Imran, 2006; Kumar & Verghese, 1980b; Senturk & Sagduyu, 2004; Singh, 2012; Verma & Gautam, 1994; M. G. Weiss et al., 1992). This variation in prevalences is most likely due to the differences in sample characteristics. Verma et al. found a prevalence much higher prevalence of 76%, but the leprosy-affected people in this study were displaced because of leprosy, which might greatly impact their mental health (1994). The study of Kumar et al. reported a lower much prevalence (9.9%), but their study population included more than twice as much men than women in contrast to our study were the gender distribution was roughly equal (1980a). Our study revealed that gender significantly affect the level of depression and therefore this difference in gender distribution may explain the dissimilar prevalences found.

A prevalence of depression of zero in the reference group was not in line with our expectations and the literature (Risal, Manandhar, Linde, Steiner, & Holen, 2016). The study of Risal et al. reported an age- and gender-adjusted prevalence of depression of 4.2% in a representative sample of Nepalese adults (2016). This difference in prevalence in non-affected people might be due to the usage of a non-fitting cut-off point in our study. The cut-off point used in our study was established in a western population and indicates specifically a major depressive disorder instead of depression in general. Therefore the cut-off point could have been too high and thus missed cases of depression in both the reference and sample population. The difference might also be due to the fact that this instrument was not a suitable for measuring depression in the reference group. It could be that people participating in SHGs were familiar with these types of issues, while people from the general population were not. Therefore, this instrument might have captured good data from leprosy-affected people, but not from people of the general population. For further use of this instrument it would be valuable to determine a cut-off point suitable for this context and to validate this instrument in the general population.

Furthermore, our study revealed that the prevalence of thoughts about suicide or self-harm was also significantly higher (p=0.000) in people affected with leprosy (50.0%) compared to the reference group (20.4%). Although the prevalence we found is much higher, the difference is in line with the study of Leekassa et al. who reported more suicidal ideation in people affected with leprosy (18.5%) in comparison to people with other skin conditions (6.3%) (2004). The higher prevalence found in our study might be caused by the inclusion of both thoughts of self-harm and suicide in our study, compared to only suicidal ideations in the study of Leekassa et al.. In addition, we observed that suicidal thoughts are common in the Maithili culture and people talk openly about this subject, which may be different in other cultures.

Next, we found that the mean mental wellbeing score was significantly lower (*p*=0.000) in the leprosy-affected group (49.0) than in the reference group (58.3), which indicates that leprosy-affected people experience poorer mental wellbeing. Several studies in the United Kingdom reported mean total WEMWBS scores of around 50 (Lloyd & Devine, 2012; Public Health England, 2012; Tennant et al., 2007). To our knowledge, only one study has been conducted in a southern study population, amongst Pakistani health care providers. This study reported a mean wellbeing score of 48.1, which is lower than the mean score in the reference population in Nepal (Waqas et al., 2015). The difference in score might be explained by the high levels of stress experienced by health care providers or the difference in culture and context. Additional research in leprosy endemic populations will be needed to compare and interpret the mean wellbeing score found in our study and to establish whether the lower mental wellbeing among persons affected by leprosy is a more universal phenomenon.

In addition, the results showed that the prevalence of poor mental wellbeing scores was significantly higher in people affected by leprosy than in the reference group (38.0% vs 9.30%, *p*= 0.000). People affected with leprosy had a six-fold increased risk of having poor mental wellbeing (OR = 6.0, *p* = 0.000). These findings are very similar to the findings of Leekassa et al, who reported a higher level of mental distress, which is a lack of psychological wellbeing, amongst leprosy-affected people. In their study, the prevalence of mental distress was 52% amongst people affected with leprosy in comparison to 7.9% in people with other skin conditions. Leekassa et al. concluded that people affected with leprosy have a seven-fold increased risk of mental distress (OR = 7.1) compared to people with other skin conditions (2004).

Finally, the validity of the above findings was strengthened by the significant inverse relationship between the wellbeing score and the depression score. Thus, the poorer the mental wellbeing the higher the level of depression. This is in line with our expectations and the literature, which reports that mental illness and mental wellbeing are highly related (Ryan & Deci, 2001; Taggart et al. 2015). Since it was already known that the mean depression scores and the mean wellbeing scores were highly related, these variables were not included in the respective models examining factors that contribute to depression and poor mental wellbeing.

Factors in depression and mental wellbeing

Multivariate analysis showed that the factors that significantly influence both the level of depression and the wellbeing status were the level of perceived stigma , gender, religion and disability grade. Additionally, the mental wellbeing status was also affected by the caste. These factors are more extensively discussed below.

Stigma

The results showed that the level of perceived stigma significantly affect the level of depression and mental wellbeing status. Further analysis shows that the level of perceived stigma is positively correlated with depression and negatively correlated with mental wellbeing. Thus the higher the level of perceived stigma, the higher the level of depression and the poorer the mental wellbeing. These results are supported by the study of Tsutsumi et al., which reports that depression scores were higher in people with high level of self-perceived stigma compared to people with low levels of self-perceived stigma (2004). Furthermore, the results are in line with the review of van Brakel, which states that stigma affects people psychologically: it can cause or aggravate psychiatric morbidity and contributes to lower self-esteem (2006). Finally, another study by Tsutsumi et al. revealed that perceived stigma significantly affected all aspects of quality of life, included the psychological subdomain (2007).

Gender

The finding that on average women had a higher level of depression and poorer mental wellbeing is in line with our expectations and observations. Gender inequalities in combination with leprosy are also described in literature by Le Grand (1997) and Morrison (2000). These reviews describe women with leprosy as facing “double jeopardy.” This double jeopardy is caused by a combination of biological factors and culturally defined bias, which results in more stigma and isolation for women. Furthermore the review of Dijkstra et al. shows that women experience more stigma, have a lower life score and a higher mental burden. Moreover, this review reveals that the inferior position of women results in more self-stigmatisation, more concealment and treatment delay, more difficulties with marriage, more social rejection from family and community (2017) . Finally, the study of van Netten reveals that women in southern Nepal are dependent on their husbands or family in law in case of being widowed. If these husbands or family in law are unreliable or hostile because of leprosy-related stigma, women are left in an especially vulnerable position (2018). All in all, both biological and cultural factors might explain our finding that women had a higher level of depression and poorer mental wellbeing.

Caste

Although the caste system has been illegal in Nepal since 2005, it continues to affect the lives of people in Nepal. The results of this study showed that people from a middle caste had the poorest mental wellbeing, people from a low caste had a moderate mental wellbeing and people from a high caste had the best mental wellbeing. These results are not in line with our expectations and literature, which reports the poorest mental wellbeing in people from a lower caste (Tsutsumi et al., 2007; Verma & Gautam, 1994).

These findings could be explained by the different initial expectations patterns of people from different castes. It would be possible that low-caste people have less expectations and are therefore more easily satisfied with life compared to those in of higher castes, who might have the expectation to move up in life. This may result in lower mental wellbeing scores for middle and higher caste people when they get affected by leprosy.

Our findings might also be explained by the fact that leprosy is often perceived as a disease of the poor, since leprosy is most common in impoverished communities. This association between leprosy and poverty may have a greater effect on the status and marriage prospects for people from a middle or high caste in comparison to people from the lowest caste. This loss of status caused by stigmatized diseases was also described by Phelan et al. (2014). Moreover this is in line with the study of Vyas et al. which revealed that leprosy-related stigma has more impact on educated women belonging to a higher socioeconomic group than women with a low socioeconomic background (1982).

The difference between the scores for people from middle and higher castes might be that explained by the fact leprosy also negatively affect work and income generation (Tsutsumi et al, 2007) . The decrease in income, might be a bigger problem for people from a middle caste than for people from a higher caste and it might greatly impact mental wellbeing. Thus the poorest mental wellbeing in people from a middle class might be explained by financial and status-related consequences leprosy has for these people.

Disability grade

The results showed that people with a higher disability grade and thus greater visible deformities had a higher level of depression and poorer mental wellbeing. People with a higher disability grade are more likely to have participation restrictions and to be affected by stigma These restrictions might also influence social life and can seriously affect mental wellbeing (Adhikari et al., 2014; Cross & Choudhary, 2005). The results are in line with our expectations and with previous literature (Behere, 1981; Kaur & Ramesh, 1994; Kaur & Van Brakel, 2002; Kisivuli et al., 2005; Kumar & Verghese, 1980a; Mhasawade, 1983; Singh, 2012). Our results confirm the findings of Leekassa et al. which showed that a high disability score (EHF score) was significantly associated with mental distress (OR = 3.96) (2004). Furthermore, the study of Tsutsumi et al. 2007 also reported that the quality of life and general mental health of leprosy people tend to be worse for people with deformities than for those without. (2007). Thus it is of great importance for the both physical and mental wellbeing to prevent or minimize impairment in people affected by leprosy.

Religion

The results show that Muslims have a poorer mental wellbeing and a higher level of depression. This was not in line with our expectations and literature (M. G. Weiss et al., 1992). The study of Weiss et al. revealed that the reference to karma, which is an important element of Hinduism and does not exist in the Islam, as an explanation for their disease was significantly associated with the diagnoses of depression (1992). A possible explanation for our findings could be that having leprosy has different consequences in different religions. Van Netten reported that leprosy-affected Muslim women can easily be replaced by another woman, since polygamy is allowed in the Islam (2018). In Hinduism and Buddhism polygamy is not common and therefore replacement might be less of a threat. The results might also be explained by the fact that the Islam is a minority in Nepal and Muslims have an lower social status in the Terai region compared to Hindus. This inferior position causes lower economic status and restricted access to education (Dastider, 2000; Siddique, 2001). To determine in what ways religion actually affect depression and mental wellbeing in people affected by leprosy, more research should be done.

Stigma scale

Initially, this study included the Explanatory Model Interview Catalogue (EMIC) stigma scale instead of the 5-QSI-AP to measure the level of perceived stigma. However during the pilot study it became clear that this scale was not comprehensible for the sample population for several reasons. First of all, the scale used complicated concepts like ‘self-respect’ and ‘dignity.’ Second, the scale contained some dual questions. Finally, several types of questioning, like ‘imagine that…’ questions, were not common in the Maithili culture and therefore poorly understood. Therefore an extensive validation study for the EMIC stigma scale is needed in order to use this scale in a sample populations with a low literacy and limited vocabulary.

Therefore, it was decided to use another stigma scale, the 5-Question Stigma Indicator – community stigma (5-QSI-CS). This questionnaire only contained 5 questions and used simpler language. During the pilot study with this questionnaire, it became clear that people from the sample population could easily understand the questions and were able to answer them correctly. The results show that this questionnaire has a good internal validity (Cronbach’s $\alpha = 0.74$) and that there were no missing values expect for question 4. Question 4 is about whether leprosy would cause a problem for a person to get married on in an existing marriage. However, a substantial part of the people in SHGs are widowed and therefore not able to answer this question. Thus, this missing value was not related to incomprehension but was related to the characteristics of this sample population. Finally, the results show that more than 15% of the people score a minimum score of zero, which indicates a floor effect. However, a high sensitivity around zero is not needed for this scale, since a low score means that people do not experience perceived stigma and thus no interventions are needed for these people. All in all, our observations and the results indicate that the 5-QSI-CS could be a reliable and valuable tool for the assessment of the level of perceived stigma in leprosy affected people. However, it would be valuable to do a full validation study and replace the fourth question by another family-related question to prevent missing values.

Strengths and limitations

This study had both strengths and limitations. One of the limitations of this study is that the participants affected by leprosy participated in SHGs. It would be possible that this programme positively influence the mental health and wellbeing and that participant therefore have lower levels of depression and a better mental wellbeing. In this case, the results of this study might be and underestimation of these levels in people affected by leprosy who do not participate in SHGs. On the other hand, participants of SHGs might also score poorer on mental health and wellbeing because they are more used to think and talk about these issues. This effect of SHGs was also reported by Dijkstra (2018). This would lead to an overestimation of the levels of depression and poor mental wellbeing in people affected by leprosy who do not participate in SHGs. Another limitation of this study is that there are great differences in setting, culture, ethnicity, local language and environment among districts in Nepal. Therefore the subjects of this study are not necessarily representative of the whole of Nepal. Finally, the sample population was rather homogenous in terms of their social and demographic characteristics. Therefore, some variables could not be included in the multivariate linear regression analysis or had to be grouped in order to have a sufficient number participants per category.

Despite these limitations, this study had a number of important strengths which adds weight to the conclusions drawn. The major strength of this study is that it provides quantitative evidence for the associations between various factors and depression and mental wellbeing described in earlier qualitative studies by using three different instruments. The use of three different questionnaires in one study (PHQ-9, WEMWBS and 5-QSI-AF) to quantitatively measure perceived stigma, depression and mental wellbeing makes this study highly valuable. Furthermore, the results of this study are statistically reliable because of the big sample size, a sample of 146 persons affected with leprosy and more than 50 people from the general population. Finally, this study was part of a mixed-model study thus there was close collaboration between the different researchers. Moreover, there was also good collaboration with the local experts and researchers. Therefore, the findings of this study were constantly discussed and reflection took place, which makes the results more reliable.

Implications

This study shows that the psychosocial aspects of leprosy are as important as the physical ones. The findings suggest that mental health interventions are needed for many Nepali (former) leprosy patients.

These interventions should be developed at different levels. First of all, health care providers should be trained in recognizing depression and other mental health problems, to improve detection of people who need mental health care. These professionals should also be trained to respond to the emotional burden of leprosy, in order to improve the treatment of mental health problem.

Second, more collaboration and better coordination is needed between different health care partners, such as mental health services and the leprosy control programme executed by the basic health services. Good collaboration between the government leprosy services and NGOs and DPOs working in the field of leprosy is also important. This improved collaboration and coordination may result in more rapid and more appropriate care for people struggling with mental health problems.

Third, it might be helpful to add a psychotherapeutic aspect to the SHGs, such as psychological education. It might be valuable to train one or members of each SHGS as a peer counsellor to provide psychological support in the SHGs. This study reveals that people affected with leprosy often need psychological assistance as well as financial and social support, which are already provided by these SHGs.

Fourth, individual interventions may be needed for those whose mental health is most severely affected. Preventive education should be given to those at risk. With the help of the factors identified in this study, these individuals might be easier to identify. Since there are limited resources for mental health care in developing countries, it is highly important to correctly identify the people that really need additional psychiatric support.

Finally, the results of this study highlight that proposed interventions should take gender bias and the cultural background of patients into consideration in order to succeed. Further research should be directed towards investigating specific and practical interventions to decrease the level of depression and improve the mental wellbeing status of people affected with leprosy.

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Appendices

Appendix 1: Personal information sheet

Personal details

First name :

Last name :

Age :

Gender : Male/ Female

Address :

Area of residence: Rural/ Urban

District: Dhanusha/ Mahottari/ Sindhuli/ Sarlahi

Highest education completed: Illiterate/ can read, write / primary/ secondary/ higher education

Work status: Employed /self-employed/ unemployed/student/ housewife/ agricultural

Religion: Hinduism/ Buddhism/ Christianity/ Islam /other

Marital status: Never married / living together/ currently married/ divorced/widowed

Caste: High/ middle/ low

For how low are you diagnosed with leprosy?

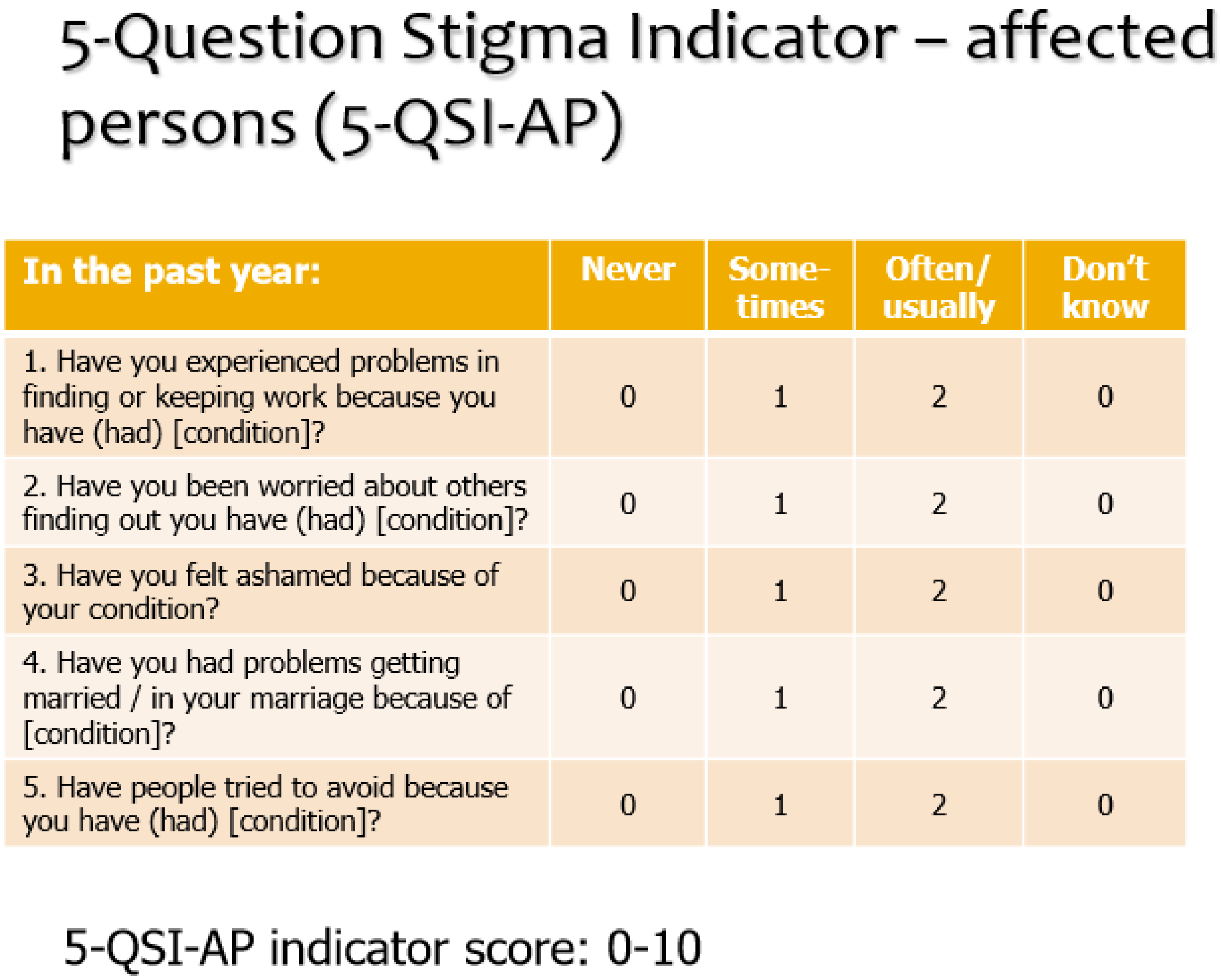
………………months/years

Disability grade 0/1/2

Do you have a close relationship, family or non-family, with someone diagnosed with leprosy? yes / no

Notes:

Appendix 2: English version 5-QSI-AP

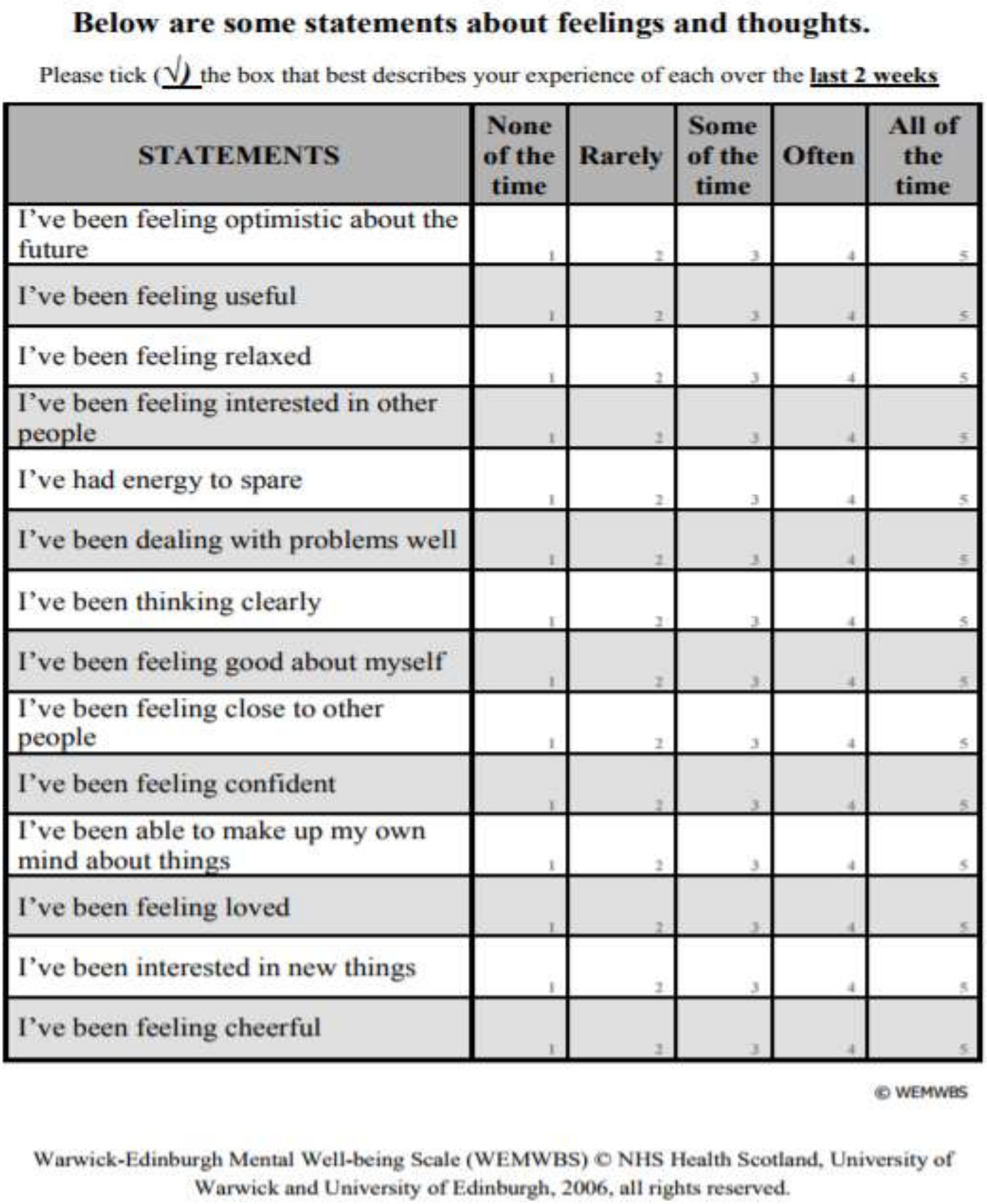


5-Question Stigma Indicator – affected persons (5-QSI-AP)

In the past year:	Never	Some-times	Often/ usually	Don't know
1. Have you experienced problems in finding or keeping work because you have (had) [condition]?	0	1	2	0
2. Have you been worried about others finding out you have (had) [condition]?	0	1	2	0
3. Have you felt ashamed because of your condition?	0	1	2	0
4. Have you had problems getting married / in your marriage because of [condition]?	0	1	2	0
5. Have people tried to avoid because you have (had) [condition]?	0	1	2	0

5-QSI-AP indicator score: 0-10

Appendix 3: English version WEMWBS

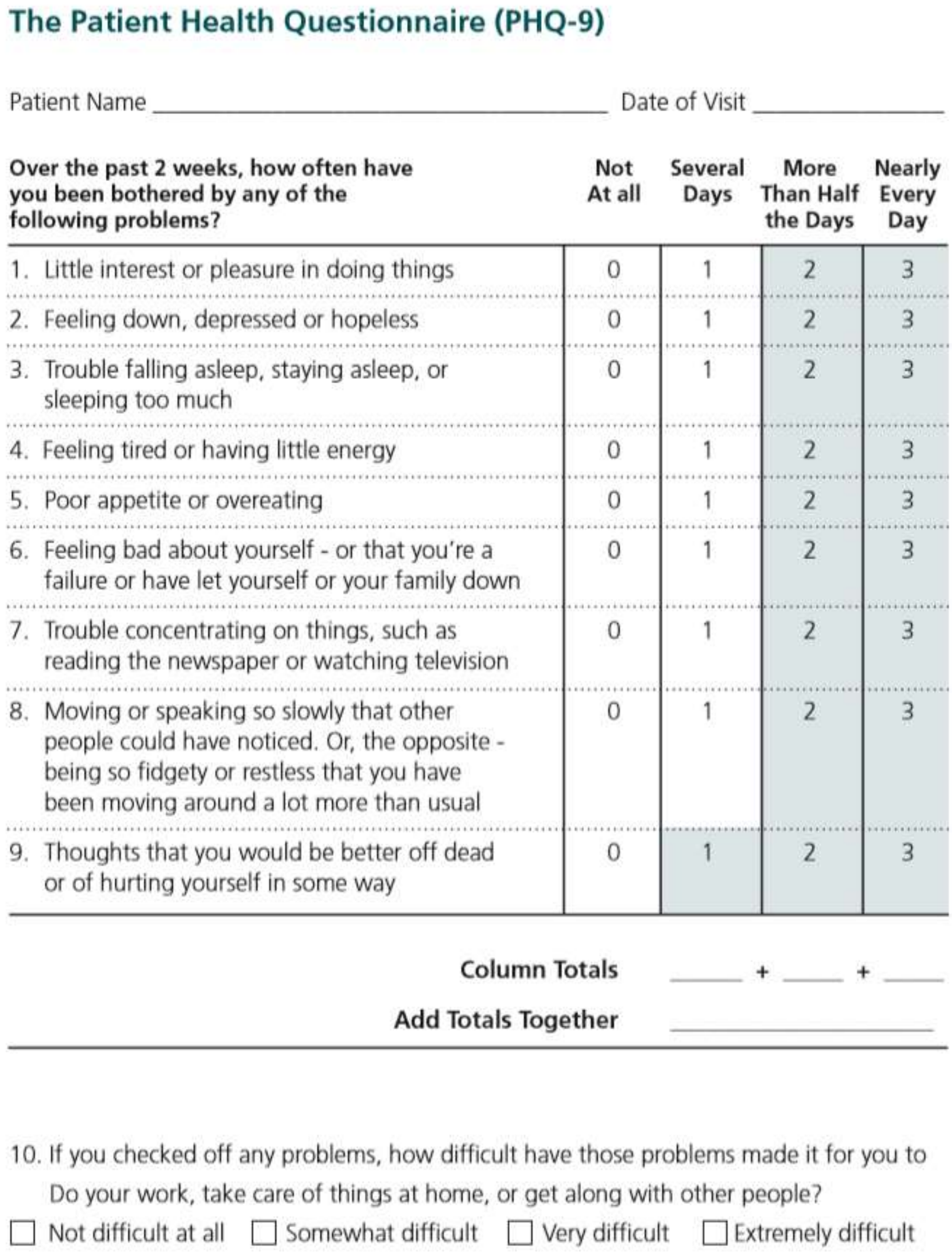


Below are some statements about feelings and thoughts.

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

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

Appendix 4: English version PHQ-9



The Patient Health Questionnaire (PHQ-9)

Patient Name ______________________________ Date of Visit ____________

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

Column Totals _____ + _____ + _____

Add Totals Together ________________

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

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

Appendix 5: English version informed consent sheet

Informed Consent Form

Co-investigator: Marloes van Dorst and Wiebrich van Netten
Organization: Netherlands Leprosy Relief
Title of the study: Depression, mental wellbeing and stigma among people affected by leprosy and lymphatic filariasis at the Lalgadh Leprosy Hospital & Services Centre in Dhanusha District, Nepal.

Collaborations: The VU University Amsterdam and the Netherlands Leprosy Relief NLR with be scientific partners in this study.

Introduction: The aim of the study is to get more insight into the mental health and stigma among patients with leprosy or lymphatic filariasis. The results of the study will help the health services in Nepal to help people with disabilities due to diseases like yours better in future. We will ask you about your experiences and thoughts related to leprosy or lymphatic filariasis. If you feel that the questions are too personal, please tell us, and we will skip this question.

Voluntary participation: Your participation in this research is voluntary, which means that you can decide to stop at any time. If you decide to participate or to not participate, your treatment and the services you use from the hospital will not change. You will not receive any money or other resources for your participation in this study.

Procedures and confidentiality: The interview related to the questionnaires will be approximately 15 minutes. We will fill in your answers on the questionnaire form. In case you participate in the in-depth interview this will take approximately 45/60 minutes extra. This interview will be audio recorded in order to be transcribed later. To protect your privacy, we will not share your information with anyone outside the research team. The information will be stored in a safe place.

Contact: Do you have any questions? For questions and more information please contact us.
Department Lalgadh Leprosy Service Centre. Lalgadh Leprosy Services Centre. Lalgadh Bengadawar VDC - 9, Dhanusha District, Janakpur. Phone (at LLSC): +977-41-620182

Consent: I have understood the information, and the researcher has answered my questions. I know I am able to refuse to participate in this study. I am a voluntarily participant in this study

Date: ____________________________

Signature participant Signature Researcher

____________________________ ____________________________

Thank you very much for participating in this study.

Appendix 6: English version Explanatory Model Interview Catalogue (EMIC scale)

No.							
		Always	Often	Sometimes	Rarely	Never	Score
		4	3	2	1	0	
1	If possible, would you prefer to keep people from knowing about leprosy?						
2	Have you discussed this problem with the person you consider closest to you, the one whom you usually feel you can talk to most easily?						
3	Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?						
4	Have you ever been made to feel ashamed or embarrassed because of this problem?						
5	Do your neighbors, colleagues or others in your community have less respect for you because of this problem?						
6.	Do you think that contact with you might have any bad effects on others around you even after you have been treated?						
7	Do you feel others have avoided you because of this problem?						
8.	Would some people refuse to visit your home because of this condition even after you have been treated?						
9	If they knew about it would your neighbors, colleagues or others in your community think less of your family because of this problem?						
10	Do you feel that your problem might cause social problems for your children in the community?						
11 A Unmarried	Do you feel that your experience of leprosy might make it difficult for you to marry?						
11 B Married	Do you feel that your experience of leprosy has caused problems in your marriage?						
12	Do you feel that your experience of leprosy makes it difficult for someone else in your family to marry?						
13	Have you been asked to stay away from work or social groups?						
14	Have you decided on your own to stay away from work or any social group?						
15.	Because of leprosy people think you also have other health problems?						