

**A Quantitative Study into the Mental Wellbeing of Persons
Affected by Leprosy in Province No. 7, Nepal**



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08-23-2019

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Internship report details

Number of ECTS	27 ECTS
Word count	10.424 (minus references, appendices and tables and figures)
Date of submission	08-23-2019

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Abstract

Introduction:

Despite effective treatment for leprosy, the disease is still endemic in Nepal. Studies show that leprosy-affected persons experience stronger stigma than individuals who are affected by other (dermatological) diseases. This experience of stigma can have social and psychological consequences, which increase the risk of mental disorders.

Research objective:

To measure the mental wellbeing status and severity of depression among persons with leprosy in Province no.7, and to which extent they experience stigma, compared with community members who do not have leprosy .

Methods:

This study used a cross-sectional stratified survey design to gather data about case and control groups. For each person, three questionnaires were used: The Warwick Edinburgh Mental Wellbeing Scale (WEMWBS), the Patients Health Questionnaire (PHQ-9) and the Explanatory Model Interview Catalogue Stigma Scale for affected persons (EMIC-AP) or controls (EMIC-CS).

Results:

The median WEMWBS total score of the leprosy-affected group was 53.0 (IRQ 45.0 -46.0). The median PHQ-9 total score was .5 (IRQ 0.00 – 6.8). Within this group, mild to severe depression was indicated in 37%. The median total EMIC-AP score, which measures perceived stigma, was 6 (IRQ 0.0 -11.3). The median WEMWBS total score of the control group was 59.5 (IRQ 55.0-65.3). The median PHQ-9 total score was 0 (IRQ 0.0 – 1.0). Within the control group, 7.6% had scores that indicated mild to severe depression. The percentage of community members who perceived negative attitudes and behavior towards people affected by leprosy was 45.5%. The median EMIC-CS score for leprosy was 6.0 (IRQ 2.0 – 16.0).

Conclusion:

Leprosy-affected people had a better mental wellbeing and a less severe depression than expected. However it is likely that these results are underestimated due to selection bias within the leprosy-affected group. Also 26% of the leprosy-affected persons recently thought of suicide and/or self-harm. Besides, the prevalence of depression among leprosy-affected persons was almost 5 times higher than among community members. This difference does might be caused by leprosy, but could also be caused by other variables. This study showed that public stigma towards leprosy-affected persons in Province no.7 is still high.

Introduction and background

Leprosy, or Hansen's disease, is a neglected tropical disease (NTD) that causes serious health problems in many parts of the world. The disease is caused by *Mycobacterium leprae* (*M. Leprae*). In humans, the bacteria produce a chronic infection that affects mainly peripheral nerves and skin. Furthermore, the bacteria can also affect structures such as the eyes, mucous membranes, bones and testes (White and Franco-Paredes, 2015). The disease may lead to impairments and limitations in activity, and because it is highly stigmatised, community beliefs about leprosy can lead to participation restrictions and marginalization (Pryce et al., 2018).

The World Health Organization (WHO) classifies leprosy-related impairments according to the WHO disability grading system. Each hand, foot and eye (left and right) is graded on its own, whereby a grade of 0 indicates 'no impairment,' grade 1 indicates 'loss of sensation in the hand, eyes or foot', and grade 2 indicates 'visible impairment' (De Souza et al., 2016). Either the highest grade (WHO disability grade) or the sum of the six grades, the Eyes Hand Feet (EHF) score, is used to indicate the severity of the impairment (World Health Organization, 1988).

Fortunately, the long-term health outcomes for individuals affected with leprosy have improved with the discovery of multidrug therapy (MDT) and the use of anti-inflammatory therapies (White and Franco-Paredes, 2015). Despite the existence of effective treatment for leprosy, the disease is still endemic in many parts of the world. With more than 3,000 new leprosy cases annually, Nepal is one of the 13 most highly endemic countries in the world (Toh et al., 2018). Also, a large number of people who have been treated with MDT and are therefore cured from leprosy, still suffer from long-term complications of leprosy such as disability, disfigurement and social stigma (White and Franco-Paredes, 2015). The experience of stigma by leprosy-affected individuals can lead to many negative social and psychological consequences, which may increase the risk of mental disorders (Van Brakel et al., 2012).

Contextual background

Since 2015, Nepal has been divided into seven Provinces. This study focuses on Province no. 7, also known as Sudurpashchim Pradesh. This province is in the south west of Nepal and borders with India and Tibet. The province has 9.6% of the total population of Nepal, and most of people in Province no. 7 live in urban areas (58.9%) (Ministry of Health and Population (MOHP) [Nepal], New ERA, ICF International, 2012). However, recently the government of Nepal made a new distinction between urban and rural areas. Unfortunately, to our knowledge, there are no new data available yet on the percentage of the people living in urban and rural areas under this new definition. Nevertheless, it is known that Nepal is facing urbanisation (Desa, 2014).

Within Province no. 7, 97.2% of the population is Hindu and 30.2% speaks the Nepali language (Nepali, Ghale and Hachethu, 2018). To our knowledge, there have been no recent gender and age distribution data published specifically for Province no.7. This study uses the population distribution for Nepal from 2016 (*figure 1*). This figure shows that Nepal has a young population with slightly more females than males. The median age range of the general population of Nepal is 30-34 years (Ministry of Health and Population (MOHP) [Nepal], New ERA, ICF International, 2017).

In Nepal primary healthcare is organised by district and consists of preventive, promotive and curative services. In urban areas these services are delivered by hospitals, while rural areas rely on primary health care centers, health posts and sub health posts (Angdembe, Kohrt, Jordans, Rimal and Luitel, 2017; Luitel, Baron, Kohrt, Komproe and Jordans, 2018). Patients first go to sub-health post, who provide basic health services in the community. If they can not help patients, then they will be redirected to health post or health care centers (Luitel, Baron, Kohrt, Komproe and Jordans, 2018). Leprosy care is mostly integrated into general health services. In addition, in some districts there are clinics specialized in leprosy that provide free treatment.

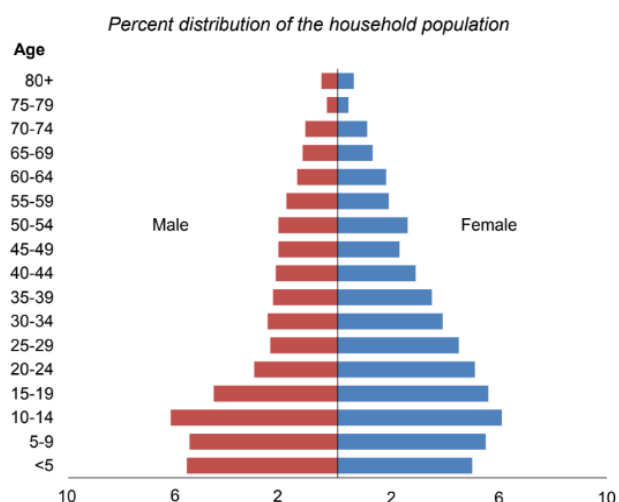


Figure 1 population pyramid of Nepal (Ministry of Health and Population (MOHP) [Nepal], New ERA, ICF International, 2017).

Nepal, and therefore Province no. 7, still has a lack of proper mental healthcare. Mental healthcare is centralized in a few hospitals in large cities. These can only be visited by people who can afford this type of care. There is also a shortage of psychiatrists, not only nation-wide but also within the large cities. For example, in large cities there are 0.22 psychiatrists and 0.66 psychologists per 100,000 people (Jha, 2007; Luitel et al., 2018). Some NGOs provide general counseling by trained para-professional counselors, but these services tend to be focused on specific population groups, such as people affected by conflict, survivors of human trafficking, victims of domestic and gender-based violence, and refugees (Luitel et al., 2015).

In addition to the lack of proper mental health care, there is also a lack of awareness of mental illnesses among the general population, and stigma is often attached to having a mental disability. Attitudes towards (mental) health and illness are often grounded in religious and superstitious beliefs, which means that the population of Nepal often seeks help from traditional healers. While help-seeking is shifting towards biomedical sources, traditional healers do still have a lot of power, and can be a barrier to further improving mental healthcare. On the other hand, traditional healers are trusted and respected figures in the Nepali society, therefore they could also help with raising awareness and reducing stigma around mental illnesses (Brenman, Luitel, Mall and Jordans, 2014).

Conceptual framework

Mental wellbeing

According to the World Health Organization (2010), mental health is ‘a state of wellbeing 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’. When persons are unable to meet these criteria, it may be due to a psychiatric disorder.

In comparison with the general population, individuals who are affected by leprosy are more likely to have a psychiatric disorder and a poor mental wellbeing (Litt, Baker and Molyneux, 2012). However, due to the medical focus on eliminating leprosy and other NTDs, the psychological impact of leprosy has only recently been acknowledged. To eliminate leprosy as ‘a public health problem’, the focus must also include reducing the psychological impact of leprosy (Bailey et al., 2018).

Depression

Depression has a high prevalence among individuals who are affected by leprosy (Singh, 2012; Tsutsumi et al., 2007). Depression is characterized by a ‘depressed mood, diminished interest, impaired cognitive function and vegetative symptoms’ (Otte et al., 2016).

A large proportion of the affected individuals feels desperate and has suicidal thoughts. Some of them actually attempt suicide (Tsutsumi et al., 2007). A study in South Africa showed that one-third of the black patients committed suicide after they were diagnosed with leprosy (Rafferty, 2005), demonstrating the urgency of reducing stigma and improving the mental wellbeing of individuals who are affected by leprosy.

Stigma

Individuals who are affected by leprosy often experience stigma (Pryce et al., 2018; Rafferty, 2005). Stigma was defined by Weiss, Ramakrishna, and Somma (2006) as ‘a social process, experienced or anticipated characterized by exclusion, rejection, blame, or devaluation that results from experiences, perception or reasonable anticipation of an adverse social judgment about a person or a group’.

Studies show that individuals who are affected by leprosy experience stronger stigma than individuals who are affected by other stigmatized diseases (Tsutsumi et al., 2007). Individuals who are affected by leprosy are often stigmatized by their community, some of whom may believe that the affected individual committed a sin. For this, they have to pay by being affected with leprosy (Yamaguchi, Poudel and Jimba, 2013). Other reasons to stigmatize affected individuals are the fear of contagion or the association with (visible) disability (Stevelink, Van Brakel and Augustine, 2011). In Nepal, and in other parts of the world, visible disfigurement is commonly associated with the experience of stigma by leprosy-affected individuals (Marahatta et al., 2018).

Leprosy-affected persons in Nepal are often rejected and insulted, and experience an unsympathetic reaction from their community (Brouwers, Van Brakel and Cornielje, 2011). In the Nepali culture, belonging to a family and a community is really important. When people with leprosy are socially rejected, they lose a part of their identity. This experience of stigma could also affect life areas such as people’s dignity, social status, employment opportunities or job security, marriage and relationships (Van Brakel, 2003).

Not only are individuals affected by leprosy stigmatized by the community, they could also experience self- stigma. Self-stigma refers to negative feelings about oneself, including the fear of being stigmatized by the community (and even believing that one deserves to be excluded), and is common among conditions that can be concealed. This fear could lead to emotional stress and anxiety, depression, (thoughts of) suicide, isolation, and problems in relationships with family and friends (Rafferty, 2005; Van Brakel, 2003).

Theoretical framework

Factors that can influence experienced stigma for individuals affected by leprosy are negative beliefs, type of impairment, ability to participate, gender, ethnicity and socio-economic status (Rohwerder, 2018). This experience of stigma can have social and psychological consequences, which also increase the risk of mental disorders (Van Brakel et al., 2012). In addition, due to the experience of stigma, leprosy-affected persons may be afraid to go to a doctor or do not adhere to their treatment plan. This can result in poor prognosis and treatment outcomes, including a higher risk of impairments (Brouwers, Van Brakel, and Cornielje, 2011; Heijnders, 2004; Rensen, Bandyopadhyay, Gopal, and Van Brakel, 2011).

Mental wellbeing of affected individuals can also be influenced by stigma, impairment level, educational opportunities and gender, with female leprosy patients often having a lower mental wellbeing status than men (Litt et al., 2012; Rensen, Bandyopadhyay, Gopal, and Van Brakel, 2011; Tsutsumi et al., 2007).

Within this study, the mental wellbeing status and the level of stigma attached to leprosy-affected individuals were measured. In addition, the effect of demographic factors on mental wellbeing, status and stigma were investigated. The conceptual model shown in *Figure 2* describes the relationship between the stigma attached to NTDs, such as leprosy, and the mental wellbeing of affected individuals. This model is an adapted version of the model developed by Eaton (2017), which predicts that stigma, discrimination and social exclusion increase participation restrictions and self-stigma. Affected individuals experience mental distress and have an increased likelihood of depression, anxiety and other mental health disorders. This added health burden is likely to lead to less favourable prognosis and treatment outcomes, and high visibility of impairments caused by leprosy. This effect can increase the experienced stigma, discrimination and social exclusion (Eaton, 2017). We expected that demographic variables could influence the experience of stigma, discrimination and social exclusion. Therefore, the effect of demographic factors on the experience of stigma, discrimination and social exclusion is also included in the adapted version of the model.

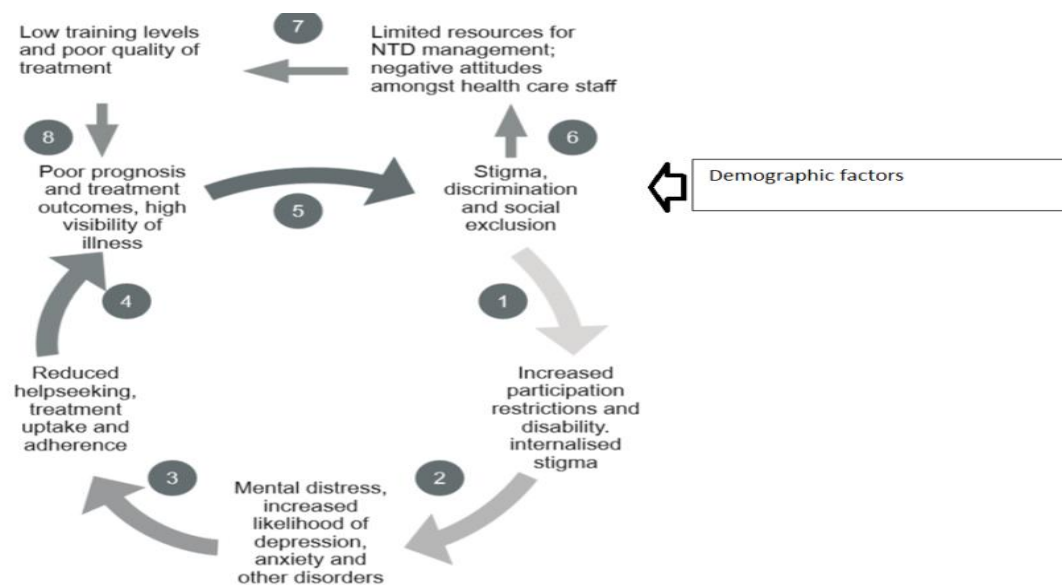


Figure 2: Model of mental health, stigma and Neglected Tropical Diseases: links between factors relevant to people affected by NTDs (adapted from Eaton, 2017)

In conclusion, leprosy is still endemic in Nepal. The stigma around this disease can lead to poor mental wellbeing, which in turn can cause delay in diagnosis and poor treatment adherence. In order to deliver effective treatment, and therefore to help eliminate leprosy, it is necessary to consider the effects and amount of perceived stigma, and the physical and psychological barriers of being affected by leprosy (Bailey et al., 2018; Groce and Trani, 2009; Rafferty, 2005; Rao, Raju, Barkataki, Nanda and Kumar, 2008). It is therefore important to know the mental wellbeing status and severity of depression of leprosy-affected persons, and the extent to which they experience stigma. To get more insight into the level of stigma towards affected by leprosy within Province no. 7 of Nepal, the perceived community stigma towards leprosy-affected persons was measured. To our knowledge, this is the first study to examine this in Province no. 7 of Nepal.

Methods

Study design

This study used a cross-sectional stratified survey design.

Study Population

In this research, the study population consisted of leprosy-affected persons in Province no. 7 of Nepal. To be eligible for the case group of this study, people needed to be affected by leprosy, 18 years old or above, and be resident in Province no. 7. They were excluded if they had another major comorbidity or long-term disability unrelated to leprosy. The community members had the same inclusion and exclusion criteria, except that they were not affected by leprosy.

Sample Size and Sampling Method

Three districts of Province no. 7 were selected as the study area. These areas had a relatively high prevalence of leprosy. The selected areas were Achham, Kaiali and Kanchanpur districts.

Risal, Manandhar, Linde, Steiner and Holen (2016) found a prevalence of depression and anxiety of 10.1% among the general population of Nepal. To warrant specific action, we decided that the prevalence of depression among people affected by leprosy should be at least 15 percent higher than among the general population. Using EpiCalc2000, we calculated that at least 100 participants would be needed in each group to find a minimum statistical relevance. A total of 100 leprosy affected persons and 158 controls were selected through a mix of convenience and purposive sampling. The villages and the health post or hospital where the leprosy-affected participants were patients were randomly chosen by the researchers. To ensure that the community members would be representative of the population of Nepal, we used frequency matching on age and sex.

Data collection

For each person in the case or community members group, three different questionnaires were used: The Warwick Edinburgh Mental Wellbeing Scale (WEMWBS), the Patients Health Questionnaire (PHQ-9) and the Explanatory Model Interview Catalogue Stigma Scale for affected persons or community (EMIC-AP or EMIC-CS). All of the questionnaires were verbally administered by a trained interviewer between 22 April and 30 June 2019.

Warwick Edinburgh Mental Wellbeing Scale (WEMWBS)

The WEMWBS scale contains 14 positively phrased items that are answered on an ordinal 5-point Likert scale (Stewart-Brown et al., 2009). The scale aims to capture a wide conception of wellbeing.

Therefore the WEMWBS includes eudaimonic and hedonic perspectives (Fat, Scholes, Boniface, Mindell, & Stewart-Brown, 2017). An eudaimonic perspective focuses on meaning and self-realization, and defines wellbeing in terms of the degree to which a person is fully functioning, while a hedonic perspective focuses on happiness, and defines wellbeing in terms of pleasure and pain avoidance (Ryan & Deci, 2001).

The WEMWBS has good face and content validity. The questionnaire is suitable for use in population-level surveys, since it is short and has performed well against accepted criteria at a population level. In a population survey in the United Kingdom, the Cronbach's alpha was 0.91, which means that WEMWBS has a good internal consistency (Tennant et al., 2007). The WEMWBS has been culturally validated in several countries, such as Spain (Castellví et al., 2014), Brazil (Santos et al., 2015) and Italy (Gremigni & Stewart-Brown, 2011). Recently it has also been validated in Nepal. This study showed that the Nepali version of the WEMWBS has adequate psychometric properties, with an internal consistency of $\alpha=0.85$ (Dijkstra, Van Brakel, Van Elteren, Banstola and Shakya, 2018).

The Patients Health Questionnaire (PHQ-9)

The PHQ-9 is a questionnaire that measures depression. It is based on the DSM-IV criteria for depression, and assesses whether the respondent experienced any of nine depressive symptoms in the previous two weeks. The questionnaire consists of nine items that can be scored from 0 to 3; with 'not at all' indicating a score of 0, 'several days' indicating a score of 1, 'more than half of the days' indicating a score of 2 and 'nearly every day' a score of 3. A tenth item measured how difficult these problems are for the participant in doing their work, taking care of things at home, or getting along with other people. This item was not scored, but could be answered with 'not difficult at all,' 'somewhat difficult,' 'very difficult' or 'extremely difficult' (Kroenke, Spitzer, & Williams, 2001). Therefore the PHQ-9 score can range from 0 to 27, and combined responses can be subdivided into five severity categories of depression: minimal (0-4), mild (5-9), moderate (10-14), moderately severe (15-19) and severe (20-27) (Kroenke et al., 2001; Monahan et al., 2009).

The questionnaire has been validated in the general population of Germany (Martin, Rief, Klaiberg, & Braehler, 2006) and the PHQ-9 has been culturally validated in Nepal (Dijkstra et al. 2018; Kohrt, Luitel, Acharya, & Jordans, 2016). Dijkstra et al. (2018) showed a good internal consistency ($\alpha=0.76$) and concluded that the PHQ-9 is a sufficient tool to measure depression among leprosy-affected persons in Nepal.

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

The EMIC-AP is a scale which measured the experience and fear of discrimination, and the level of anticipated stigma. This means that the EMIC-AP measures the awareness of negative attitudes regarding their condition as experienced by illness-affected people (De Korte, Pongtiku, Rantetampang, & Van Brakel, 2018). The version of the EMIC-AP that was used in this study contained 15 items, each in the form of a question. The answers were scored from 3 to 0, with 'yes' indicating a score of 3, 'possibly' indicating a score of 2, 'no' indicating a score of 1, and 'don't know' indicating a score of 0. The sum of the items indicates the overall level of perceived and experienced stigma. The higher the score on the EMIC-AP, the higher the level of perceived and experienced stigma. The EMIC-AP in the Nepali language has been used before in Western Nepal. Although the questionnaire was useful to measure perceived stigma, it does not give a complete picture of the stigma towards leprosy-affected people (Adhikari, Kaehler, Chapman, Raut, & Roche, 2014).

The Explanatory Model Interview Catalogue Community Scale (EMIC-CS)

The EMIC-CS scale is designed to measure illness-related perceptions, beliefs and practices. The EMIC-CS consists of 15 items related to perception of stigma towards leprosy affected persons. Each item can be answered with 'Yes,' 'Possibly,' 'No,' 'Don't know.' These answers are scored from 3 to 0; with 'Yes' indicating a score of 2, 'Possibly' indicating a score of 1, 'No' and 'Don't know' indicating a score of 0. The International Federation of Anti-Leprosy Associations (ILEP) recommends using the EMIC-CS to measure perceived stigma in the community. The scale is available in Nepali, and was used before in Western Nepal (Adhikari, Shrestha, Kaehler, Raut, & Chapman, 2013). In the present study, a cut-off point for perceived stigma of 8 was used. This relatively high score increases the specificity of the cut-off point, lowering the risk of false positive classification of perceived stigma (Sermittirong, Van Brakel, Kraipui, Traithip and Bunders, 2015).

Data analysis

All scores were entered in Epi Info (v. 7.2) and analysed in SPSS (IBM SPSS Statistics 25). The main outcomes were the prevalence of perceived stigma and depression, expressed as percentages with 95% confidence intervals and as a mean wellbeing score with a 95% CI. Descriptive statistics were derived to give an overview of the demographic characteristics. To examine differences in characteristics between the case and control group, a t-test was performed for numeric variables. To analyse associations between categorical data, a Chi-square test or Fisher's exact test was used.

To examine associations between an outcome and two or more explanatory (independent) variables, such as the association between depression and being affected by leprosy, stigma and age, (multivariate) linear regression analyses was performed. In addition, the influence of covariates such as the disability grade,

religion, age, level of education, occupation and marital status will be examined by performing multivariate linear regression analysis. If outcome variables were not normally distributed, a bootstrap multivariate analysis was performed. In our dataset, the sum scores of all of the questionnaires were not normally distributed, which is why we reported medians rather than means to represent the average scores. When other studies report a mean, it is assumed that their dataset was normally distributed, and the mean and median are the same or close together, and also represent the average score. This allows the both averages to be compared.

Ethical considerations

Ethical approval was given by the Nepal Health Research Council (NHRC). Participants were asked to give written informed consent in advance before participating in this study, the informed consent form can be found in Appendix 1 (English version). If participants were not able to read and write, the form was read to them and a thumbprint was used to give informed consent. All the information was handled confidentially. This means that data was not shared with others, and personal identifying information was separated from the data. Participants were able to withdraw from the study at any time during the study, without any negative consequences. No incentives were offered.

	Leprosy-affected n	Reference n (%)
Number of people	100	158
Mean age	50.97	34.78
Sex		
- Female	62	81 (51.3)
- Male	38	77 (48.7)
Marital Status		
- Married	77	123 (77.8)
- Never married	4	26 (16.5)
- Windowed	19	8 (5.1)
- Separated	0	1 (0.6)
Religion		
- Hindu	88	155 (98.1)
- Christian	11	2 (1.3)
- Muslim	1	1 (0.6)
Residency		
- Urban	78	145 (91.8)
- Rural	22	13 (8.2)
District		
- Kanchanpur	41	68 (43.0)
- Kaiali	39	70 (44.3)
- Achham	20	20 (12.7)
Level of education		
- Illiterate	38	15 (9.5)
- Read and write only	20	20 (12.7)
- Primary education	19	24 (15.2)
- Secondary education	21	76 (48.1)
- University	2	23 (14.6)
Employment status		
- Housewife	49	46 (29.1)
- Employed in business/government	15	39 (24.7)
- Farmer	16	12 (7.6)
- Self-employed	6	41 (25.9)
- Student	2	13 (8.2)
- Unemployed / Non-paid work	12	7 (4.4)
Level of family income		
- More than 7000 Rupees per month	48	112 (70.9)
- 5001-7000 Rupees per month	20	29 (18.4)
- 3001-5000 Rupees per month	13	12 (7.6)
- No income – 3000 rupees per month	9	4 (2.5)
- No income	10	1 (0.6)

Table 1: Demographic characteristics in number and percentages for leprosy affected (n=100) and control group (n=158)

Results

In total, 100 leprosy-affected individuals were included in this study, of whom 62% were female. The mean age of this leprosy-affected group was 51.0. For the community members group, 158 non-affected people were included in this study, of whom 51.3% were female. The community members had a mean age of 34.8. The two groups differ significantly in mean age ($p = 0.00$), residency ($p = 0.00$), religion ($p = 0.00$), level of education ($p = 0.00$), employment status ($p = 0.00$) and level of income ($p = 0.00$).

In both groups the majority were Hindu, married, lived in urban areas and had an income of more than 7000 rupees per month. Most of the female participants were housewives. Among the leprosy-affected participants, most of the males were farmers, while most males in the reference group were self-employed. *Table 1* shows the demographic characteristics of both groups.

Leprosy-affected participants

On average, the leprosy-affected participants started to experience symptoms 116 months (9.6 years) ago. The mean time since diagnosis was 98 months (8.1 years). While 21% of the leprosy-affected participants had a WHO score of 2, which indicates a visible disfigurement, the majority of the leprosy-affected participants (52%) had a WHO score of 0, which indicates no deformity or sensory loss. If the participants had a leprosy-related disability, it had a mean onset of 198 months (16.6 years) previously. Usually, persons in the living environment of the leprosy-affected participant know about their (former) leprosy status (69% of the time), while 31% tried to hide their disease from family and friends.

Scale	R ²	Variables	β	Significance
WEMWBS	0.68	Age	-0,175	0,01
		Sex		
		- Male	+ 5.638	0.01
		- Female ^{REF}		
		EHF score	-1.323	0.01
		Total EMIC score	-0.242	0.02
		Family income		
		-Up to 5000 rupees per month	-4.689	0.00
		- More than 7000 rupees per month ^{REF}		
		Severity of difficulty in mobility	-3.451	0.04
PHQ-9	0.32	WHO disability score		
		- WHO score 0 ^{REF}		
		- WHO score 1	+1.042	0.22
		- WHO score 2	+5.202	0.00
		Education level	+ 0.061	0.02
		- Illiterate ^{REF}		
		- Read and write only	-2.704	0.02
		- Primary education	-2.564	0.02
EMIC-AP	0.21	- Higher education	-2.864	0.00
		Gender	-2.73	0.02
		Others know about leprosy	-4.425	0.00
		Education level		
		- Illiterate ^{REF}		
		- Higher Education	-2.979	0.01
		EHF score	+ 0.581	0.08

Table 2: Variables that influence the mean total WEMWBS (mental wellbeing), PHQ-9 (depression) and EMIC-AP (perceived stigma) among leprosy affected participants (N=100), with a predetermined cut-off point of $p=0.05$. REF= reference selected category.

The mental wellbeing of leprosy-affected participants

The median WEMWBS score of persons in the leprosy-affected group was 53.0 (IRQ 45.0 -46.0), and individual scores ranged from 14 to 70. A highly negative correlation between the total WEMWBS score, which measures mental wellbeing, and the PHQ-9 score, which measures depression, was found ($r = 0.701$, $p = 0.00$). Higher scores on the WEMWBS correlated with lower scores on the PHQ-9. Because they measure similar phenomena PHQ-9 and WEMWBS will not be included in the respective models examining factors that contribute to depression and mental wellbeing.

A multivariate linear regression analysis with bootstrapping was run to predict the total mean WEMWBS score. *Table 2* shows the significant results of this multivariate linear regression analysis. Age, gender, EHF score, total EMIC score, level of family income and severity of difficulty in mobility significantly affect the mean WEMWBS score, and therefore affect mental wellbeing.

The older the participants, the lower their mean WEMWBS score, and therefore the poorer their mental wellbeing ($\beta = -0.175$, $p = 0.01$). Gender had a significant effect as well, whereby males scored on average 5.6 points higher than females on the WEMWBS scale ($p = 0.01$). The results also showed that with every point increase on the EHF scale, the mean WEMWBS decreased by 1.3 points ($p = 0.01$).

Therefore participants with a more severe disability had on average a poorer mental wellbeing.

Perceived stigma also significantly influenced the mean WEMWBS scores of leprosy-affected participants. For every point the leprosy-affected participant scored on the EMIC-AP, their mental wellbeing decreased with 0.2 points ($p = 0.02$).

Moreover, when the participant's family had an income of up to 5000 rupees per month ($\beta = -4.689$, $p = 0.00$), their mean WEMWBS score would be significantly lower as compared to participants who had a family income of more than 7000 rupees. A family income of 5000–7000 rupees per month had no significant effect on the mental wellbeing of the control group.

Furthermore, the severity of difficulty in mobility had also a significant effect on the mental wellbeing of leprosy-affected participants. The more difficulty the participant had with mobility, the lower their mean WEMWBS score was ($\beta = -3.451$, $p = 0.04$). Together age, sex, WHO disability score, level of family income and severity of difficulty in mobility explained 68% in the variance seen in WEMWBS scores ($R^2 = 0.68$), and therefore the mental wellbeing of leprosy-affected participants.

The WEMWBS score was not significantly affected by marital status, religion, area of residence, district, education level, employment status, time since diagnosis, time since onset of disease, time since leprosy-related impairment, occurrence of visible signs of impairment, whether others know about their leprosy, and severity of difficulty in vision, hearing, upper body and self-care.

Depression in leprosy-affected cohort

The median PHQ-9 total score, which is a measure for severity of depression, was 2.5 (IRQ 0.00 – 6.8). Within this leprosy-affected group, depression was indicated in 37%, which means that 37% had a total PHQ-9 score of 5 or above. The majority of the participants affected by leprosy had a minimal indication for depression. Of the participants whose scores indicated depression, most had a mild indication (29%). Only 3% had an indication for moderate depression, 4% for moderately severe depression and 1% for severe depression. However, 26% of the participants affected with leprosy said that they have thought of suicide or self-harm within the past two weeks.

Table 2 shows the results of the multivariate linear regression analysis with bootstrapping for the total PHQ-9 score in people affected by leprosy. This analysis shows the variables that significantly influenced the mean total PHQ-9 score, and therefore the severity of depression.

Participants who had a WHO disability score of 2, which indicates a leprosy-related impairment, scored on average 5.2 points more on the PHQ-9 scale than participants with a WHO score of 0, which indicates no impairment. Also, the education level of leprosy-affected participants significantly influenced the severity of depression. If participants could read and write ($\beta = -2.704$, $p = 0.02$), completed primary school ($\beta = -2.564$, $p = 0.02$) or had any higher education (secondary school or university) ($\beta = -2.865$, $p = 0.00$) the mean PHQ-9 score was lower compared to leprosy-affected participants who were illiterate. Together, WHO disability score and education level explained 32% of the variance amongst the PHQ-9 score ($R^2 = 0.32$), and therefore the severity of depression.

The PHQ-9 score was not significantly affected by age, gender, marital status, religion, area of residence, district, level of family income, employment status, time since diagnosis, time since onset of disease, time since leprosy-related impairment, occurrence of visible signs of impairment, if others know about their leprosy, or severity of difficulty in vision, hearing, upper body, mobility and self-care.

Stigma among leprosy-affected participants

The median total EMIC-AP score, which measures perceived stigma, was 6 (IRQ 0.0 -11.3). According to the EMIC-AP, stigma was perceived primarily in the areas of shame and embarrassment due to leprosy, loss of self-esteem, disclosure concern and concealment of leprosy (*Figure 3*). Among the leprosy-affected participants, 53% felt shame or embarrassment due to leprosy, 46% said they thought less of themselves because of their leprosy, 32% didn't discuss their leprosy with persons who are close to them, and 32% tried to keep others from knowing about their disease.

In addition, 15% of the participants said they experienced less respect from others because of their leprosy and 11% thought that contact with them, a leprosy-affected person, could have a bad effect on others. 11% felt that others might refuse to visit their homes because they are affected by leprosy, while only 2% had actually be asked to stay away from work or social groups. Only one person said that they had decided on their own to stay away from work or social groups. According to the participants, their family felt almost no stigma, only 2% thought that their leprosy could cause social problems for their children.

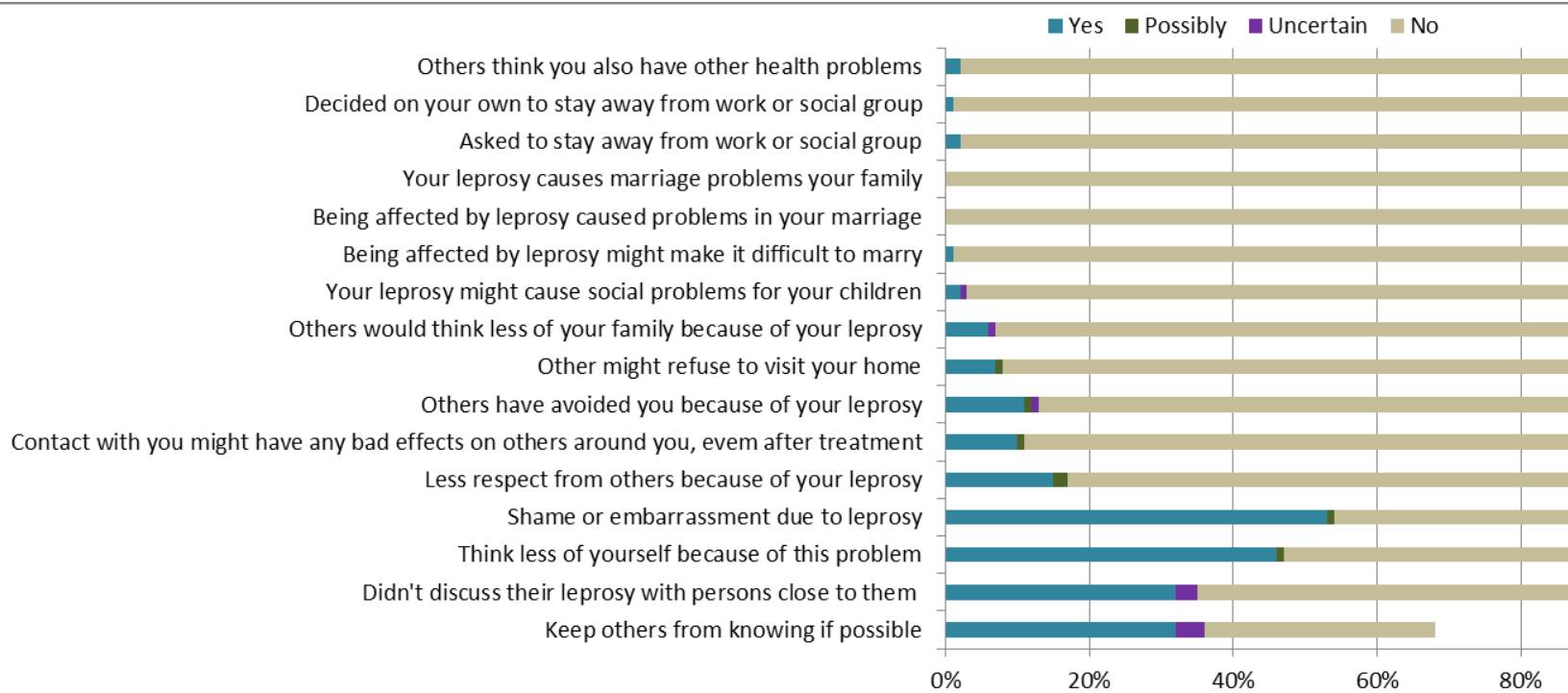


Figure 3 Distribution of answers given on EMIC-AP by leprosy-affected participants

Table 2 shows the results of the multivariate linear regression analysis with bootstrapping for the EMIC-AP score for leprosy-affected participants. This analysis shows variables that significantly influenced the mean EMIC-AP score, and therefore influenced the perceived stigma. When the leprosy affected participants told people in their environment about their leprosy, it decreased the mean EMIC-AP score with 4.4 points, ($p = 0.00$). In addition, when leprosy-affected participants completed higher education (secondary education and university), their mean EMIC-AP score decreased with 3.0 points ($p = 0.01$). Although the EHF score did not have a significant independent effect, it did influence the model fit and was thus retained in the model. On average, participants with a higher EHF score perceived more stigma ($\beta = +0.581$, $p = 0.08$). Gender, others knowing about their leprosy status, education level and EHF score

explained 21% of the variance among the EMIC-AP scores ($R^2 = 0.21$), and therefore the level of perceived and experienced stigma.

The EMIC-AP score was not significantly affected by age, gender, marital status, religion, area of residence, district, education level, employment status, level of family income, time since onset of disease, time since diagnosis, time since disability, WHO disability score, EHF score, occurrence of visible signs of disability and severity of difficulty in vision, hearing, upper body, mobility and self-care.

Community members of Province no. 7

Mental wellbeing of community members of Province no. 7

The median WEMWBS total score of the community members was 59.5 (IRQ 55.0-65.3) and ranged from 14 to 70. A multiple regression analysis was run to predict the mean WEMWBS score from gender, age, marital status, religion, residency, education level, employment status, income level, current disorder and severity in difficulty in vision, hearing, upper body, and mobility.

Table 3 shows the significant results of this multivariate linear regression analysis with bootstrapping.

Age, gender and family income have a significantly independent effect on the mean WEMWBS score, and therefore on mental wellbeing. The older the participants are, the lower their mean WEMWBS will be ($\beta = -0.177$, $p = 0.00$). The result shows that males scored 4.1 point higher females, and therefore on average, they report a better mental wellbeing than females.

Moreover, a family income up to 5000 rupees per month affects the mean WEMWBS score as well ($\beta = -2.9$, $p=0.03$). A family income of 5000–7000 rupees per month had no significant effect on the mental wellbeing of the control group. Together age, sex and family income explain 28% in the variance of the total WEMWBS score ($R^2=0.28$) of the control group.

Depression community members

The median PHQ-9 total score, which is a measure of severity of depression, was 0 (IRQ 0.0 – 1.0).

Within the control group 7.6% had scores that indicated a mild to severe depression, which means that 12 participants scored a total PHQ-9 score of 5 or above. The majority of the community members had a minimal indication for depression. Most of the participants, whose scores indicated depression, had a mild indication (7%). Only 1 participant had a severe depression. In addition, 4% ($n=7$) of the community members said that they have thought of suicide and/or self-harm in the last two weeks. Since there was almost no depression among community members of province no. 7, no regression analysis was performed.

Community stigma towards leprosy affected persons

The percentage of community members who perceived negative attitudes and behavior towards people affected by leprosy was 45.5%. The median EMIC- CS score for leprosy was 6.0 (IRQ 2.0 – 16.0). *Figure 4* shows the beliefs and attitudes of the community members towards leprosy-affected persons in the community. 44% of the community members thought that leprosy-affected persons would keep others from knowing about their condition.

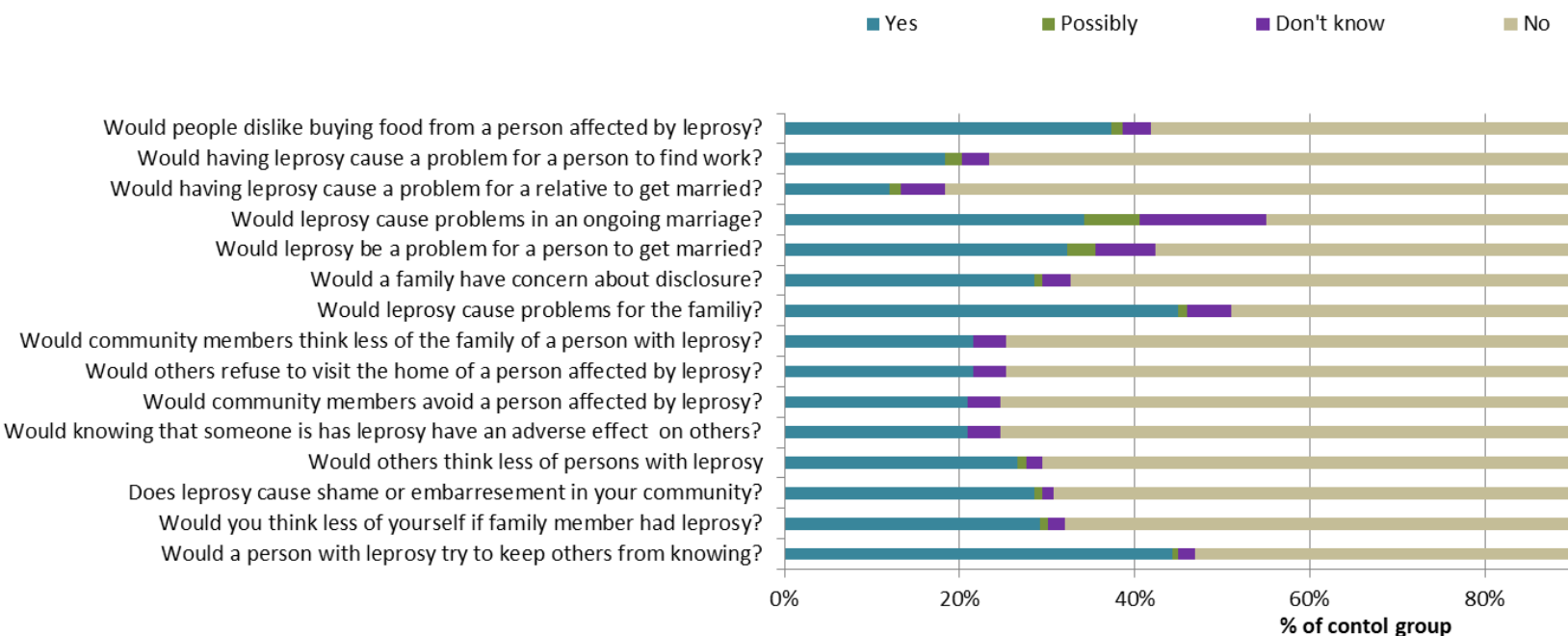


Figure 4: Distribution of answers given to EMIC-CS questions by community members

Among respondents, 28% believed that people affected by leprosy cause shame in the community and would think less of themselves if a family member had leprosy. The community members (28%) also thought that others think less of leprosy-affected persons. Forty-five percent believed that leprosy will cause problems for the family, and 28% thought that a family will have concerns about disclosure of the affected person's condition. However, 22% said that community members would think less of the family of an affected person, and just 18% believe that relatives of an affected person will have difficulty in getting married.

Leprosy is thought to cause a problem in an ongoing marriage, according to 34% of the community members, and 32% said that it would be a problem for those who wish to get married. Only 12% thought that leprosy would cause difficulties in finding work. Furthermore, 37% of the community members did not like to buy food from an affected person.

Table 3 shows the results of the multivariate regression analysis with bootstrapping for the EMIC-CS score for participants affected by leprosy. On average, the older the community members, the higher their EMIC-CS score ($\beta = +0.09$, $p=0.102$). However, this association did not reach significance at a 5% level. Community members from Kanchanpur district have a significantly higher mean EMIC-CS score than community members from Kaiali district. In addition, education level had also a significant independent effect on the EMIC-CS score. If the community member could only read and write, they scored on average 4.3 points more on the EMIC-CS compared to community members who finished any education beyond primary school, such as secondary school or university ($p = 0.05$). Together, age, district and education level explain 12% ($R^2=0.12$) of the variance in perceived community stigma.

The EMIC-CS score was not significantly affected by gender, marital status, religion, area of residency, education level, employment status, level of family income and by severity of difficulty in vision, hearing, upper body, mobility and self- care.

Scale	R ²	Variables		Significance
WEMWBS	0.28	Age	-0,177	0.00
		Sex		
		- Female ^{REF}		
		- Male	+ 4.074	0.00
		Family income		
		- Up to 5000 rupees per month	-3.505	0.00
EMIC-CS	0.12	- More than 7000 rupees per month ^{REF}		
		Age	+0.09	0.102
		District		
		- Kaiali ^{REF}		
		- Kanchanpur	+3.482	0.00
		Education		
		- Higher education ^{REF}		
		- Read and write only	+4.320	0.05

Table 3: Variables that influence the mean total WEMWBS (mental wellbeing), PHQ-9 (depression) and EMIC-CS (community perceived stigma) among the control group (N=158). REF= reference selected category

Discussion

In the present study a baseline measurement of the mental wellbeing, severity of depression and perceived stigma among leprosy-affected persons was performed. To get a good overview of stigma towards leprosy-affected persons in Province no. 7, perceived community stigma was also measured.

Factors that could influence these baseline measurements and the perceived community stigma were examined. The majority of people in both sample, the leprosy-affected and community members, were female, Hindu, married, lived in urban areas and had an income of more than 7000 rupees per month.

Overall, the scores of the mean WEMWBS, PHQ-9 of leprosy-affected persons and the EMIC-AP were lower than we expected. Healthcare workers in Province no. 7 reported that leprosy-affected persons experienced high levels of stigma, and most of the affected persons try to keep others from knowing about their disease. As a consequence, persons affected by leprosy refused to participate because they were scared that participating in this study would reveal their secret. It is therefore possible that this study only includes participants who anticipate or experience less stigma. As explained in the theoretical framework, stigma influences mental wellbeing and the severity of depression. If a significant number of the persons who declined to participate were very different from those who did participate, it is likely that our study overestimated the mental wellbeing and underestimated the severity of depression among leprosy-affected participants.

Mental wellbeing, severity of depression and perceived stigma of leprosy affected participants

In our study most of the leprosy-affected participants had a WHO disability score of 0, which indicates no deformity or sensory loss. Only 21% had a WHO disability score of 2, which indicates a visible disfigurement. These findings are inconsistent with previous leprosy studies in Nepal and in other parts of the world. In these studies the majority of the participants had a WHO disability score of 1 or 2 (Adhikari et al., 2014; Jindal, Singh, Mohan and Mahajan, 2013; Van Dorst, 2018). However, according to the NLR office in Dhangadhi, Province no. 7, Nepal, the WHO disability percentages from the present study are representative for the province. According to them, due to their programs, most leprosy-affected people are now detected early and therefore fewer people will develop a leprosy related disability.

The results show that the median WEMWBS score, which measures the mental wellbeing, of leprosy-affected participants was 53.0. This finding was consistent with Van Dorst (2018), who found a mean WEMWBS score of 49.0 among persons affected by leprosy in South-Nepal.

The total WEMWBS score and the total PHQ-9 scores, which measure severity of depression, were highly negatively correlated ($p = 0.00$). This means that the poorer the mental wellbeing, the more depressed were the participant. Our study found a prevalence of mild to severe depression of 37.0% and a prevalence of moderate to severe depression of only 1%. These results are not in line with previous research on the prevalence of depression among persons affected by leprosy. In South-Nepal a prevalence of a moderate to severe depression of 24.6% was found among leprosy-affected persons (Van Dorst, 2018). In addition, among leprosy-affected persons in Taiwan, India and Ethiopia a higher prevalence of depression was also found, respectively 25%, 15%, and 85% (Haroun et al., 2012; Jindal et al., 2013; Su, Wu and Lin, 2012). This difference in prevalence might be caused by difference in culture and sample group characteristics. But is more likely that this difference is due to the selection bias in the present study). Twenty-six percent of the leprosy-affected persons thought of suicide and/or self-harm within the past two weeks, which indicates that the prevalence of depression may well be much higher. This high percentage suggests that the used questionnaire did not adequately measure the prevalence of depression in Province no. 7. A reason for this could be that people in Nepal tend to somaticize mental health problems, while the PHQ-9 focused on mental-health related problems and not on physical health problems.

The median total EMIC-AP score, which measures perceived stigma among leprosy-affected persons, was 6.0. The areas of perceived stigma most frequently mentioned were shame and embarrassment, self-esteem, disclosure concern and concealment of leprosy. This is consistent with previous research in (western) Nepal (Adhikari et al., 2014; Engelbrektsson and Subedi, 2018). Pierneef (2019) found that people affected by leprosy in Province no. 7 had a reduced self-esteem and feelings of shame and embarrassment, whereby reduced self-esteem was a result of feeling that they could not do anything as they had done before. Physical appearance, such as skin patches and altered skin color, and being unable to do the thing they wanted to do cause feelings of shame among leprosy-affected persons. Disclosure concern and concealment of leprosy fits within the Nepali context. As mentioned in the conceptual framework, people affected by leprosy in Nepal are likely to face a loss of dignity, discrimination and social hesitation. To prevent that, people who are diagnosed with leprosy are likely to conceal their condition (Engelbrektsson and Subedi, 2018). However, concealment of their condition could lead to psychological challenges and therefore affect the mental wellbeing (Pachankis, 2007).

Mental wellbeing, severity of depression and perceived community stigma of the community members of Province no. 7

The characteristics of the community members corresponds with the general population in terms of age and gender (Ministry of Health and Population [MOHP Nepal]. et al., 2017).

The community members had a median WEMWBS score of 59.5. This is a higher mean WEMWBS score than found in previous studies. Van Dorst (2018) found a mean WEMWBS score of 58.3 in South-Nepal and among the general population of the United Kingdom the mean WEMWBS score was around 50, according to several studies (Lloyd and Devine, 2012; Tennant et al., 2007). Another study in Pakistan reported a mean WEMWBS score of 48.1 among health care providers (Waqas et al., 2015). This difference in mean WEMWBS score could be caused by difference in culture and sample group. For example this study spook to community members with a high social economic status, while in reality most of the general population of Nepal have a low social economic status (Tiwari 2017, Ministry of Health and Population [MOHP Nepal]. et al., 2017). This difference could influence the mental wellbeing of community members,

In the community group 7.6% had symptoms of mild depression, and none of these participants had an indication for a moderate to severe depression. However, 4% of the community members said that they had thought of suicide and/or self-harm. Other studies in Nepal reported a higher prevalence of moderate to severe depression among the general population, namely around 11% (Luitel, Jordans, Kohrt, Rathod, & Komproe, 2017; Risal, Manandhar, Linde, Steiner and Holen, 2016).

Although the prevalence of depression among leprosy-affected persons was much higher than the prevalence of depression among community members, this effect does not have to be due to leprosy since both groups significantly differ from each other. It is likely that this effect is caused by multiple variables such as having leprosy, gender and social economic status.

The percentage of community members who perceived negative attitudes and behavior towards leprosy-affected people was 45.5%. This is high, but is less than was found in India and Thailand, where 94% and 75.4% of community members said they perceived negative attitudes and behavior towards people affected by leprosy (Ballering, 2011; Sermrittirong, Van Brakel, Kraipui, Traithip and Bunders-Aelen, 2015). The most important areas of perceived stigma, according to the community members of Province no. 7, were concealment, problems for the family and marriage problems. In addition, community members did not like to buy food from a person affected by leprosy. Other research on perceived community stigma in Western Nepal, India and Thailand found also that according to the community members concealment of leprosy and marital problems are still a major concern for leprosy-affected

persons (Adhikari et al., 2014; Ballering, 2011; Sermrittirong, Van Brakel, Kraipui, Traithip and Bunders-Aelen, 2015).. Ballering (2011) found that 58.8% of the community members of Chandauli district, India, thought that leprosy would cause problems for the family. This was similar to the results of the present study, whereby 45% thought that leprosy would cause problems for the family.

The percentage of community members in Province no. 7 who said they disliked to buy food from leprosy-affected persons was lower than was found in the study of Adhikari et al. (2013) in Western Nepal (37% vs 47% respectively). The lower percentage of stigma towards leprosy-affected persons could be caused by the fact that almost no community members in the present research said they knew someone with leprosy. Also, due to the lower WHO disability grade of leprosy-affected people in Province no. 7, leprosy might be less visible in the community, which could affect attitudes and behaviors towards leprosy-affected persons. In addition these differences could also be caused by regional cultural differences (Michgelsen, Peters, Van Brakel and Irwanto, 2018).

Factors that influence mental wellbeing of leprosy-affected participants and community members

Factors that together explained 68% of the variance in level of mental wellbeing among leprosy-affected participants and 28% of the variance among community members were age, gender, impairment severity score, level of family income, perceived stigma and severity of difficulty in mobility. Below, these factors will be discussed.

Age and mental wellbeing

The present study found that older participants experienced poorer mental wellbeing as compared to younger participants. This is in line with our expectations and previous research. Studies in the high-income countries found also that older people experience a slightly lower psychological well-being. Older people may experience less personal growth and purpose in life, which can affect their mental wellbeing. In addition, older people are likely to feel less social coherence and social contribution (Pinquart, 2002; Read, Westerhof and Dittmann-Kohli, 2005; Westerhof and Keyes, 2010). The effect of age could be explained by age-related differences in life contexts. For example, older people are more likely to experience adverse life events, such as having a chronic disease and/or disability, to live with pain, and to experience activity limitations (Sinha, Shrivastava and Ramasamy, 2013; Westerhof and Keyes, 2010).

Gender and mental wellbeing

The present study found that gender had a significant influence on mental wellbeing, with women having a poorer mental wellbeing than men. This is in line with our expectations and with previous research (Van Dorst, 2018). The WHO states that gender is a critical determinant of mental health and mental illness, such as depression, and that women have a higher risk of poorer mental health than men. According to the WHO, this difference may be caused by gender-based violence, socioeconomic disadvantages, low

income and income inequality, low or subordinate social status and rank, and a high responsibility for the care of others (WHO, 2019). Also, a study in India (Patel et al., 2006) was found that gender disadvantages could cause a greater risk for females to suffer from common mental disorders.

Nepal has a male-dominant culture, where females have unequal power and lack autonomy compared to males (Van 't Noordende, Van Brakel, Banstola and Dhakal, 2016). Domestic violence against females is also common in Nepal (Paudel, 2007). Taking this into account, gender inequality could explain why females in our study, in both groups, had poorer mental wellbeing scores. However, the effect of gender in the community group was smaller compared to the effect of gender in the leprosy-affected. This could be explained by the double burden faced by women affected by leprosy. Besides the fact that women experience gender inequality, affected women also need to deal with the (social) consequences of leprosy. In general, women affected by leprosy are worse off than men. For example, women experience more negative reactions to their leprosy status compared to men (Peters et al., 2014). This could lead to a poorer mental wellbeing and more severe depression among leprosy-affected women.

Level of family income and mental wellbeing

Several studies found also a positive association between income and mental wellbeing (Gardner and Oswald, 2007; Gresenz, Sturm and Tang, 2001; Sareen, Afifi, McMillan and Asmundson, 2011). In addition, Tsutsumi et al. (2007) found in Bangladesh that a lower annual income lead on average to a poorer quality of life. The association between income and mental wellbeing could be explained by the social causation theory, which argues that a low income, the related stress and reduced capacity to cope, lead to an increased risk of mental illness (Sareen et al., 2011). Therefore people with a low family income were expected to have a poorer mental wellbeing than people with a higher family income.

Perceived stigma and mental wellbeing

The present study found that perceived stigma could lead to poorer mental wellbeing. This is in line with our expectations and previous research (Litt et al., 2012; Van Brakel, 2006; Van Dorst, 2018). As mentioned in the theoretical framework, perceived stigma, discrimination and social exclusion increase participation restrictions and self-stigma. This could cause mental distress in leprosy-affected individuals and increase the risk of mental disorders (Van Brakel et al., 2012).

Disability and mental wellbeing

The present study found that having an impairment related to leprosy, and therefore having a higher EHF or WHO disability score, could cause poorer mental wellbeing. Having difficulty with mobility also tended to cause a poorer mental wellbeing. This is consistent with our expectations and previous research (Kaur and Van Brakel, 2002; Singh, 2012; Van Dorst, 2018). Tsutsumi et al. (2007) showed that leprosy-affected people with an impairment had a lower quality of life and worse general mental health compared

to affected persons without a disability.

The association between disability and mental wellbeing could be explained by the higher participation restrictions people with a (visible) impairment face. Due to their impairment, they are less able to participate, or their participation could be obstructed by stigma or discrimination. This could mean that leprosy-affected people with a disability experience stigma and are therefore excluded, or that they perceive stigma and therefore voluntarily withdraw to participate. Experience of participation restriction and stigma could in turn affect the mental wellbeing and lead to more severe depression (Adhikari et al., 2014; Kaur and Van Brakel, 2002; Nicholls et al., 2005).

Factors that influence depression in leprosy-affected participants

Factors that significantly influenced the severity of depression in leprosy-affected persons in the current study were WHO disability score and education level. Together they explained 32% of the variance in depression severity. As stated in the results, mental wellbeing and depression are highly correlated. Therefore, it is expected that the explanation for the effect of disability is the same for depression as for mental wellbeing

Education level and severity of depression

The results showed that education level had a significant influence on severity of depression in leprosy-affected participants. Illiterate participants were more likely to have severe depression compared to participants who followed or completed any education level. In line with the present study, previous research found that education was an important factor in explaining the variance of depression (Akhtar-Danesh and Landeen, 2007). Research reported that people with the lowest education level had a higher prevalence of psychiatric morbidity. People with a low education level often have a low socioeconomic status. Several research found that people with a low SES, and therefore people who are illiterate, are twice as likely to suffer from a depression than people with a high SES (Akhtar-Danesh and Landeen, 2007; Lorant et al., 2003). This effect could be explained by risk factors associated with low SES, such as poorer coping styles, ongoing life events, stress exposure, weaker social support and disability (Lorant et al., 2003).

Factors of leprosy-affected participants that influence perceived stigma

Within the leprosy-affected group, perceived stigma was influenced by gender, if others know about their leprosy, education level and EHF score.

Sex and perceived stigma

Besides mental wellbeing, gender has also a significant effect on perceived stigma. Whereby females perceive more stigma compared to males. This is in line with our expectations and previous research (Rohwerder, 2018; Try, 2006; Varkevisser et al., 2009; Zodpey, Tiwari and Salodkar, 2000). As mentioned before, females in Nepal experience gender inequality. This gender inequality could lead to more self-stigmatization, more concealment, treatment delay, difficulties in marriage and more social rejection from family and community members compared to males (van Dorst, 2018). This finding is supported by other research performed in Nepal (Pierneef, 2019; Try, 2006; van 't Noordende, et al., 2016).

Concealment of leprosy and perceived stigma

When others knew about a person's leprosy, it led to a lower level of perceived stigma. This suggests a low community stigma in Province no. 7, but this is not in line with the current results of community stigma in Province no.7. A possible explanation could be that leprosy-affected participants told only those closest to them about their disease, and still concealed it from others. In this way they experience less stigma in the larger community, but do experience relief from feeling that they must hide their condition even at home and with close friends. Those who are open about their diagnosis receive a lower score on the EMIC-AP compared to people who did not even tell close contacts about their disease. Participants who took this step are likely to score fewer points on the second question of the EMIC-AP, which is about telling people close to you about your leprosy. Due to this question, participants who concealed their disease are unable to score 0 points, while participants who did tell can score 0 points on the EMIC-AP. Another explanation could be that the ones who know about the disease do not believe it is leprosy, and think the affected persons suffer from another disease. Leprosy-affected persons could experience less stigma if so.

Impairment and perceived stigma

If participants had a leprosy-related impairment, they perceived more stigma. This is in line with previous research and our expectations. As mentioned in the theoretical framework, impairment is associated with more stigma (Bailey et al., 2018; Eaton, 2017; Rafferty, 2005; Tsutsumi et al., 2007; van Brakel et al., 2012). This could be explained by the same explanation that explains the association between mental wellbeing and disability.

Education level and perceived stigma

Adhikari et al. (2014) researched perceived stigma among leprosy-affected persons in Nepal, and also found that education level was also an influence. They found that on average leprosy-affected participants who did not complete primary education experienced more perceived stigma than leprosy-affected persons who completed higher education levels (Adhikari et al., 2014). This association between education level and perceived stigma was also found in India (Rao et al., 2008). The effect of education level and perceived stigma by leprosy-affected participants could be due to improved knowledge of leprosy among leprosy-affected participants. It is likely that the more a person is educated, the more he knows and learned about leprosy. Knowledge about their disease empowers leprosy-affected persons to follow the treatment, to have confidence, and be able to better cope with (negative) reactions to their condition from others. This could lead to better acceptance of their disease, and decrease self-hate (Rafferty, 2005)

Among the community members in our study, education levels also influenced the community stigma towards leprosy. A study in Nepal, India and Thailand also found that perceived stigma correlates with the level of education: those with lower levels of education had a higher level of perceived stigma (Adhikari et al., 2013; Kaehler, Adhikari, Raut, Marahatta and Chapman, 2015; Rao et al., 2008). Possibly, community members with a higher level of education have in general more knowledge about leprosy and are more able to resist the negative stereotypes of leprosy (Adhikari et al., 2013; Kaehler et al., 2015).

Other factors of community members that significantly influenced perceived stigma

Community stigma towards leprosy-affected participants was also significantly influenced by district. Community members who lived in the Kanchanpur district were more likely to perceive negative attitudes and behavior towards people affected by leprosy, compared to community members from the Kaiali district. It could be that the participants in Kanchanpur came from higher caste than participants from Kaiali districts. Higher castes are more strictly in their religious rituals, which are associated with stigma towards leprosy affected persons (Adhikari et al. 2013).

Strength and limitations

This study had some strengths and limitations. The first limitation was the sampling method. As a result of the stigma, random sampling was not an option. The researchers believe that participants who anticipated or experienced less stigma were more likely to want to participate. Additionally, the method used to sample the community members could lead to sampling bias and to a less representative sample of the community members. Although the community members were matched on gender and age with the general population of Nepal, other demographic variables, like family income or education level, could still influence the data.

Second, some of the participants found it hard to answer the questions directly; and therefore needed the interpreter to interpret the answers. This could lead to loss of nuances in the data. Also, not all of the participants were native Nepali speakers, which could lead to misunderstanding of the questions and/or answers. To reduce the likelihood of interview bias, the interpreter chosen had knowledge about leprosy and had experience with conducting interpreter-mediated interviews. In addition, the interpreter was familiar with the culture and with several other languages that were spoken in this district.

Third, although the WEMWBS and PHQ-9 were validated by Dijkstra et al. (2018), the EMIC-AP and the EMIC-CS had not yet been culturally validated in Province no. 7. Both of the questionnaires had been used before in Western Nepal, but the Nepali version of the EMIC-AP did not seem to be suitable for this study. It is likely that some of the questions were not completely understood by the participants. The questions are about perceived stigma, while participants might have understood them as a question about experienced stigma. This is based on the fact that some participants said they were convinced that they would certainly have experienced higher levels of stigma had they not concealed their condition. If this indeed is the case, it is likely that the perceived stigma is underestimated, since almost 1/3 of the participants had concealed their disease

An important strength of this study was that it covered a diverse and large area of Province no.7. Three districts were included, and within each district, many hospitals and health posts were visited. This led to results that were more representative of the leprosy-affected and general population of Province no. 7, Nepal.

Another strength was that although the WEMWBS and PHQ-9 were only recently culturally validated, they, as well as the EMIC-AP and EMIC-CS, were checked for translation and adapted by our trained interpreter as needed.

Furthermore, this study is part of a mixed methods study. There was close collaboration between the two different researchers, and the qualitative part of the mixed methods study found similar results, which makes our findings more reliable.

Conclusion

On average, people affected by leprosy had a better mental wellbeing and a less severe depression than expected. However, 26% of the leprosy-affected persons thought of suicide and/or self-harm within the past two weeks, indicating that the prevalence of depression may well be much higher. Also was the prevalence of depression among community members almost five times lower than the prevalence of depression among affected persons. But this effect does not have to be caused by leprosy, but this could also be caused by several variables. In our sample, 68% of the variance in mental wellbeing was explained by age, gender, EHF-score, EMIC-AP score, family income and severity of difficulty in mobility. Gender

had a major effect on mental wellbeing: on average males had a better mental wellbeing than females. Depression could be largely explained by WHO disability scores and education levels. In general, leprosy-affected persons with a (visible) disability were more likely to have poor mental wellbeing and a more severe depression.

This study also showed that stigma towards leprosy-affected persons in Province no. 7 is still present. Perceived stigma among leprosy-affected persons was positively affected when others knew about their condition, and the most affected areas were shame and embarrassment, self-esteem, disclosure concern and concealment of leprosy. Among the community members of Province no. 7, 45% perceived negative attitudes and behavior towards people affected by leprosy. The most affected areas of perceived stigma, according to the community members of Province no. 7, were concealment, problems for the family and marital problems as well as community members not liking to buy food from a person affected by leprosy. Leprosy-affected persons reported perceived stigma in similar areas, however, leprosy-affected persons do not report marital problems.

Recommendations

For further studies it is recommended to do another baseline measurement of mental wellbeing, depression and perceived stigma among leprosy-affected persons. Participants should be randomly selected, and selection bias must be avoided. Therefore it is advised to take more time for data collection, and to collaborate closely with the patients' healthcare workers in order to gain their trust and make leprosy patients willing to participate. Therefore the healthcare workers need to understand the aim and the importance of the research

Also, further research should validate a questionnaire that measures perceived and anticipated stigma among leprosy-affected persons in Province no.7. Additionally, it is recommended to set up a communication and information program that further educates community members on leprosy and by doing so, reduce stigma towards leprosy-affected persons in Province no. 7.

Although this study did not find an extremely high prevalence of poor mental wellbeing and depression, it is still recommended to improve mental healthcare in Province no. 7. To our knowledge, there currently is no mental healthcare center in Province no. 7 that could treat people with a mental disorder such as depression. Mental wellbeing programs for leprosy-affected persons should focus especially on women and those with a higher EHF score, difficulty in mobility, and income under 5000 rupees per month.

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Appendices

Appendix 1: Informed consent English version

Hello, Mr./Mrs. [name], thank you for taking the time to talk with us. My name is [name] and this is Manon Scheltema and Louise Pierneef, two students from the Netherlands, who will observe this interview. We work together with Netherlands Leprosy Relief. The purpose of this study is to learn more about the mental status of leprosy-affected persons.

We will use the results to help improving the leprosy health services in Nepal in future. Today I would like to ask you some questions about your experience with leprosy, and about your life and how you feel about yourself. If you feel that a question is too personal, or if you are unhappy to answer for any reason, please tell us, and we will skip this question. You are free to stop the interview at any moment. This will not make any difference to the treatment you will receive in future. The interview will take about half an hour. Do you have any questions so far? Consent of participants

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

Name of participant:

Signature of participant:

Date: __ / __ / __

Name of interviewer:

Signature of interviewer:

Date: / __ / __

Appendix 2: Personal Information form English version

Date of interview/...../..... (day / month / year)
Respondent number
Medical file/dossier number* / Not applicable
Sex	Male / Female
Age years
Marital status (Tick only one)	<input type="radio"/> Married <input type="radio"/> Remarried <input type="radio"/> Widowed <input type="radio"/> Separated <input type="radio"/> Never married
Religion	<input type="radio"/> Hindu <input type="radio"/> Buddhist <input type="radio"/> Christian <input type="radio"/> Muslim <input type="radio"/> Other:
Residency	Urban / Rural
Area of residency
Level of education (Tick highest ever completed)	<input type="radio"/> Illiterate <input type="radio"/> Read and/or write only <input type="radio"/> Primary education <input type="radio"/> Secondary education <input type="radio"/> University <input type="radio"/> Other:
Employment status	<input type="radio"/> Farmer <input type="radio"/> Teacher <input type="radio"/> Officials (employed in government) <input type="radio"/> Officials (employed in private sector) <input type="radio"/> Public enterprise <input type="radio"/> Owner of private business / shop / restaurant, etc. ^[L] _{SEP} <input type="radio"/> Employed in business <input type="radio"/> Non-paid work, such as volunteer or contributing to family income <input type="radio"/> Student <input type="radio"/> Housewife <input type="radio"/> Retired <input type="radio"/> Unemployed <input type="radio"/> Other, specified:
Level of family income	<input type="radio"/> No income <input type="radio"/> ≤ 3000 Rupees per month <input type="radio"/> 3001 – 5000 Rupees per month <input type="radio"/> 5001 – 7000 Rupees per month <input type="radio"/> More than 7000 Rupees per month
Caste	<input type="radio"/> Low <input type="radio"/> Middle <input type="radio"/> High

Current disorder	Related to: <input type="radio"/> Speech <input type="radio"/> Vision <input type="radio"/> Hearing <input type="radio"/> Physical (upper limb/lower limb/other body parts) <input type="radio"/> Mental <input type="radio"/> Several problems <input type="radio"/> None
Severity of difficulty in vision	<input type="radio"/> No difficulty <input type="radio"/> Some difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> Cannot do at all / Unable to do <input type="radio"/> Don't know
Severity of difficulty in hearing	<input type="radio"/> No difficulty <input type="radio"/> Some difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> Cannot do at all / Unable to do <input type="radio"/> Don't know
Severity of difficulty in upper body	<input type="radio"/> No difficulty <input type="radio"/> Some difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> Cannot do at all / Unable to do <input type="radio"/> Don't know
Severity of difficulty in mobility	<input type="radio"/> No difficulty <input type="radio"/> Some difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> Cannot do at all / Unable to do <input type="radio"/> Don't know
Severity of difficulty in self-care	<input type="radio"/> No difficulty <input type="radio"/> Some difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> Cannot do at all / Unable to do <input type="radio"/> Don't know
Eyes Hand Feet Score (Leprosy-affected people only)*	1. Right eye 0 – 1 - 2 2. Left eye 0 – 1 - 2 3. Right hand 0 – 1 - 2 4. Left hand 0 – 1 - 2 5. Right foot 0 – 1 – 2 6. Left foot 0 – 1 – 2
WHO Eyes, Hands and Feet impairment score: (Leprosy-affected people only)*
Occurrence of visible signs of disability (Observation) (Leprosy-affected people	Yes / No

only)*	
MB/PB leprosy (Leprosy-affected people only)*	MB / PB
Do others know you have this condition (Leprosy-affected people only)*	Yes / No
Time since onset of disease (Leprosy-affected people only)* (years/months)
Time since onset of disability (Leprosy-affected people only)* (years/months)
Time since diagnosis* (Leprosy-affected people only)* (years/months)

Appendix 3: Warwick-Edinburgh Mental Wellbeing Scale (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

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Appendix 4: The Patient Health Questionnaire (PHQ-9)

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

Column Totals _____ + _____ + _____

Add Totals Together _____

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

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

Appendix 5: Explanatory Model Interview Catalogue Stigma Scale (EMIC-AP)

No.	Question	Yes (3)	Possibly (2)	Uncertain (1)	No (0)
1	If possible, would you prefer to keep people from knowing about your leprosy ?				
2.	Have you discussed your leprosy with the persons you consider closest to you, the one whom you usually feel you can talk to most easily? (reversed score)				
3.	Do you think less of yourself because of your leprosy? Has it reduced your pride or self-respect?				
4.	Have you ever been made to feel ashamed or embarrassed because of your leprosy				
5.	Do your neighbors, colleagues or others in your community have less respect for you because of you leprosy?				
6.	Do you think that contact with you might have any bad effects on others around you even after				

	you have been treated				
7.	Do you feel others have avoided you because of your leprosy?				
8.	Would some people refuse to visit your home because of this condition even after you have been treated				
9.	If they knew about it would your neighbors , colleagues or others in your community think less of your family because of your leprosy?				
10.	Do you feel that leprosy might cause social problems for your children in the community?				
11 A (unmarried)	Do you feel that this disease might make it difficult for you to marry?				
11 B (married)	Do you feel that this disease caused problems in your marriage?				
12	Do you feel that your leprosy makes it difficult for someone else in your family to marry?				
13.	Have you been				

	asked to stay away from work or social groups?				
14.	Have you decided on your own to stay away from work or social groups?				
15.	Because of your leprosy, do people think you also have other health problems?				

Appendix 6: The Explanatory Model Interview Catalogue Community Scale (EMIC-CS)

1. Do you have a close relationship, family or non-family, with someone diagnosed with leprosy? If No go to question 5	Yes / No			
2. Who is affected by leprosy?	<input type="radio"/> Father <input type="radio"/> Mother <input type="radio"/> Wife / Husband <input type="radio"/> Child <input type="radio"/> Other _____			
3. Type of impairment of affected person	Related to: <input type="radio"/> Speech <input type="radio"/> Vision <input type="radio"/> Hearing <input type="radio"/> Physical (upper limb/lower limb/other body parts) <input type="radio"/> Mental <input type="radio"/> Several problems <input type="radio"/> None			
4. Does the affected person have visible signs of his/her impairment?	Yes / No			
	Yes	Possibly	Uncertain	No
5. Do you think this person should not disclose his/her condition beyond his/her closest family members, friends				
6. Do you think this person think less of himself / herself because of this problem?				
7. Do you think most people might make this person feel ashamed or embarrassed because of this problem?				
8. If you think about it, would this person's neighbours, colleagues or most other				

people, in his / her community think less of him / her because of this problem?	
9. Do you think his / her condition would have bad effects on others (might this person be dangerous, dirty or polluting)	
10. Can contact with a person like this hurt someone either physically or in some other way?	
11. Would most people feel pity with disgust for this person because of his/her condition?	
12. Would some people refuse to visit this person's home because of his/her condition?	
13. If they knew about it, would colleagues or most other people in the community think less of the person's family because of the problem?	
14. If people knew about it, might this problem make it more difficult to marry?	
15. If this person were married, might this condition cause problems in his/her marital life?	
16. Could this problem make it more difficult for someone in this person's family to marry?	

