Factors influencing the mental wellbeing of persons affected by leprosy in Sudurpashchim Pradesh, Nepal

Louise Pierneef – 2514658

On-site supervisor

Dr. Wim van Brakel & Anna van ‘t Noordende
Wibautstraat 137k
1097 DN Amsterdam
The Netherlands

VU supervisor

Dr. Mitzi Waltz
Vrije Universiteit
Faculteit der Bètawetenschappen, Athena Institute
De Boelelaan 1085
1081 HV Amsterdam

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Abbreviation list

CBR	Community-based rehabilitation
EHF	Eye, Hand, Foot
FGD	Focus group discussion
ICF	Informed consent form
MB	Multibacillary
MDT	Multidrug therapy
M. leprae	*Mycobacterium leprae*
NHRC	Nepal Health and Research Council
NLR	until No Leprosy Remains (Leprastichting)
NTD	Neglected tropical disease
PB	Paucibacillary
PHQ-9	Patient Health Questionnaire
PIF	Personal information form
SSI	Semi-structured interview
WEMWBS	Warwick-Edinburgh Mental Wellbeing Scale

Abstract

Background: Leprosy is a neglected tropical disease which often results in (permanent) physical disabilities. The disease is highly stigmatized and this, in turn can cause mental ill health of the individuals affected by leprosy. *Research objective:* The aim of this study was to investigate factors regarding personal, social/daily life and culture, influencing the mental wellbeing of leprosy-affected persons in Sudurpashchim Pradesh, Nepal, in order to develop interventions aimed at improving their mental wellbeing. *Methods:* A qualitative approach using semi-structured, in-depth interviews and focus group discussions (FGDs) was employed. 25 participants affected by leprosy and 12 controls were included in in-depth interviews. In addition, 13 leprosy-affected persons participated in FGDs. *Results:* We found that leprosy-affected persons with varying disability grades in Sudurpashchim Pradesh often experience mental distress and/or stigma. Participants reported physical weakness or pain, activity limitations, worries about their disease and its implications, feelings of shame, suicidal thoughts, and perceived and/or internalised stigma. Factors influencing mental wellbeing also included enacted stigma, social support, religion, participation (restrictions), the (in)ability to work, community attitudes, knowledge of leprosy and cultural beliefs around the disease. *Conclusions:* Many (social/daily life, cultural and personal) factors can affect the mental wellbeing of leprosy-affected persons. Further research including a larger, random sample and expansion of mental health services in Sudurpashchim Pradesh are needed. Counselling after diagnosis with leprosy and interventions aiming at increasing participation and leprosy awareness/knowledge in the community are essential in order to reduce the stigma surrounding leprosy.

1. Introduction

Leprosy is a neglected tropical disease (NTD) caused by *Mycobacterium leprae (M. leprae),* mainly affecting the skin and the nerves, resulting in (often permanent) physical disabilities (1). It is believed to be transmitted via the respiratory route, and is still endemic in many parts of the world, with over 200,000 newly diagnosed cases annually (1). The disease is strongly associated with poverty, and remains a public health problem in parts of Africa, South America and Asia (2-4). Nepal is one of the countries where the disease is still endemic, with more than 3,000 new cases diagnosed yearly (5). Although leprosy can be cured with multidrug therapy (MDT), permanent physical impairments often have already been incurred due to lack of timely diagnosis and treatment (6).

In addition to physical impairments, persons affected by leprosy often experience social stigma (7-9). Stigma is defined as “a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation which results from experiences, perception or reasonable anticipation of an adverse social judgment about a person or a group” (10). Stigma is especially prevalent in association with diseases showing evident physical signs (9), and for historical and cultural reasons, leprosy is one of the most stigmatized diseases worldwide (11).

The stigma associated with leprosy can affect many aspects of a person’s life, such as employment, marriage and social participation (11-14). In Nepal, leprosy-affected persons are often rejected and insulted (15). Various studies have found women to suffer more from leprosy-associated stigma in comparison to the other sex (8, 16-19). In South-East Nepal, women affected by leprosy were reported to face issues regarding their marital and sexual relationships, including negative attitudes, discrimination, violence and problems related to fear of the disease (11). The experience of stigma can also affect physical impairments, since people with leprosy often fear going to the doctor because of concern about how they may be treated or concern that their diagnosis may not be kept confidential, and therefore may not receive treatment in time (20).

Furthermore, stigma can lead to mental ill health of the persons affected by leprosy (14). Van Brakel et al. reported that in Indonesia, the main psychosocial problems found were shame, embarrassment, difficulties finding a marriage partner, and problems finding paid work (12). Feelings of shame or fear of the leprosy-affected individual can in turn result in anxiety and depression (8). Treatment of the disease often does not take away its psychosocial consequences (11). A recent literature review found that up to 50% of leprosy-affected people will experience mental health problems at some point in their lives (21).

1.1 Research aim and research question

The attention and distribution of resources to fight leprosy is of great importance in public health. Unfortunately, needs assessments of individuals who have already been affected by this often disabling condition are often lacking (9). Various studies show that leprosy, stigma and mental wellbeing are closely linked. To our knowledge, no specific data on mental wellbeing and stigma among persons affected by leprosy are available from the Sudurpashchim Pradesh province of Nepal and no studies describing the factors influencing mental wellbeing have been conducted here. The aim of this study was therefore to gain more insight into what (social/daily life, cultural and personal) factors influence the mental wellbeing of people affected by leprosy in this specific area of Nepal, in order to develop adequate interventions to improve their mental wellbeing. The following research question was thus addressed:

What (personal, social and cultural) factors influence the mental wellbeing of people affected by leprosy in the Sudurpashchim Pradesh province of Nepal?

2. Background

2.1 Contextual background

Sudurpashchim Pradesh

Sudurpashchim Pradesh, formerly known as Province 7, is located in the Western part of Nepal (see *Figure 1*) (22). The province covers an area of 19,539 square kilometres and has a population of 2,552,517. Prior to the renaming of urban and rural areas in Nepal, 58.9% of the population in Sudurpashchim Pradesh used to live in urban areas, whereas the other 41.1% lived in the more rural parts (23). Although recent data on this renaming are not available yet, Nepal has been reported to become more urbanised (24). The province is divided into nine districts: Achham, Baitadi, Bajhang, Bajura, Dadeldhura, Darchula, Doti, Kailali and Kanchanpur

Figure 1. Sudurpashchim Pradesh, Nepal.

(25). The main official language spoken is Nepali (30.2%) and the majority of the population is Hindu (97.2%) (25). Other religions are Buddhism and Christianity (26). The majority of women and men living in Sudurpashchim Pradesh work in agriculture, which accounts for 83.7% of the total number of employed women and 37.4% of the total number of employed men (23). In this area, it is also common for men to work in India and provide their families with income (27).

Human development

In 2018, more than half of the districts from Sudurpashchim Pradesh belonged to the country's ten least developed districts in human development, based on indicators such as poverty, food security, education, sanitation coverage, and health. All districts from Sudurpashchim Pradesh reported deficits in education, health and income as compared to national norms (25).

Leprosy and (mental) health care

Although the elimination of leprosy as a public health problem was declared by Nepal in 2010, more than 3,000 new leprosy cases are still being diagnosed yearly (28, 29). Over 83% of leprosy cases in Nepal reside in the Terai districts, which include Kailali and Kanchanpur districts of Sudurpashchim Pradesh (25, 30). In 2017, these districts accounted for the highest prevalence of leprosy in Sudurpashchim Pradesh, next to Achham (0.8 per 10,000 inhabitants of the population) (31). Leprosy care is provided at local health clinics. In 2016, 50.8% of 915 households were located 30-60 minutes away from the nearest government health facility in Sudurpashchim Pradesh (32). In the mental health sector (both public and private facilities), 0.22 psychiatrists were available per every 100,000 inhabitants in 2014 (29).

Stigma, attitudes and knowledge

Community perception influences the quality of life and (mental) wellbeing of persons affected by leprosy. A quantitative study carried out by Singh et al. evaluated the knowledge, attitudes and stigma surrounding leprosy amongst 423 community members from Southern Central Nepal (28). While half of the respondents had good knowledge, only a very small part had a positive attitude towards the disease, and myths about the cause of leprosy still existed. Key to favourable attitudes was knowledge of leprosy (28). In another study among 281 community members, individuals lacking information on leprosy reported higher stigma scores compared to individuals having information on the disease (33).

Marriage

According to Try, “it is undesirable to marry someone who has been or is affected by leprosy” in Nepali culture (34). Marriage is of great importance in Nepal (35). Although arranged marriages are slowly being replaced by love marriages (11), they are still widespread and occur at a relatively young age (average of 16.5 years for women born in the late 1970s) (36). In love marriages, family members still play a key role in the (dis)approval of potential life partners (11).

Literacy and gender

The Annual Household Survey 2016/2017 of Nepal reported a literacy rate of 66.8% for persons above 15 years (77.8% for males and 57.8% for females) (37). For Sudurpashchim Pradesh, no consistent data on literacy are available. A National Women’s Commission Report stated that women in Nepal have less access to education and health services. Although Nepal has made progress, gender inequality still remains (38). As described above, leprosy-affected women are considered to suffer more from leprosy-surrounded stigma than men, as in a male-dominated society such as Nepal, women have a low social status and are generally more dependent on others (18, 34).

2.2 Theoretical background

Leprosy is defined as “a complex disease caused by infection mainly of the skin, peripheral nerves, mucosa of the upper respiratory tract and eyes” and belongs to the group of so-called *NTDs* (39). NTDs are a diverse group of communicable diseases that occur in (sub)tropical conditions (40) and are called ‘neglected’, since the people who are most affected are often the poorest, who have a low public health priority status (41).

Many people with NTDs experience *stigma* (see *Section 1* for definition) (10). Three types of stigma can be recognized: *experienced/enacted stigma*, *perceived stigma* and *internalised stigma*. Experienced stigma is often named discrimination “enacted by the community or experienced by the person that is affected by the stigmatized disease” (42). Perceived stigma occurs when someone fears or expects negative attitudes and stigma. When negative attitudes, stereotypes or experiences are internalised and/or someone’s self-esteem or self-respect is affected, this is called internalised stigma (43). Experiencing stigma can lead to *social exclusion,* which “is characterised by unequal access to resources, capabilities and rights which leads to health inequalities” (44).

Stigma can be a consequence of *impairments,* which when paired with *activity limitations* and *participation restrictions* can become *disabilities.* An impairment is "a problem in body function or structure." For people with leprosy, an impairment in body function could be loss of sensation, whereas an impairment in body structure could be contractures and absorption (45). An activity limitation is "a difficulty encountered by an individual in executing a task or action," e.g. ploughing the field for a leprosy-affected farmer. A participation restriction is "a problem experienced by an individual in involvement in life situations," e.g. not being invited to community celebrations. Disability is complex, and results from both social and environmental difficulties that impact persons with impairments (46).

Impairment does not always result in disability. However, the term 'disability' is sometimes used interchangeably with the term 'impairment.' For example, in the case of leprosy, a *disability grade* is used to measure the level of impairment, and to monitor changes over time. Leprosy-related impairment is scored by the Eye, Hand, Foot (EHF) score, in which a maximum of 12 can be scored (2 for each eye, 2 for each hand and 2 for each foot). The eyes, hands and feet can be scored 0, 1 or 2, separately. Grade 0 is scored when there is normal sensation and no visible impairments. Grade 1 is given in case of impaired sensation, but no visible impairments. Grade 2 is given when visible impairments/deformity is present. Most often, the maximum EHF score is used to indicate impairment severity (45, 47).

The stigma faced by many people affected by NTDs appears to be a crucial mediator of mental illness (42). The WHO defines *mental health/wellbeing* as "a state of wellbeing in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (48). Depression is a common mental disorder with loss of interest in activities and persistent sadness (49). The WHO considers depression to be the main cause of illness and disability globally (50).

According to previous (unpublished) qualitative research carried out in Nepal on a similar topic, cultural factors, such as gender and local perspectives, influence the mental wellbeing of people affected by leprosy (51). A *culture* is described as "a system of shared ideas, systems of concepts and rules and meanings that underlie and are expressed in the way that humans live" (52). Cultural factors here also include religion, beliefs about leprosy, gender (roles), poverty, caste and marriage (53).

A *social environment* encompasses “the immediate physical surroundings, social relationships, and cultural milieus within which defined groups of people function and interact” (54). In this study, social factors include social networks such as family/home, work and the community where persons live in.

Personal factors here entail the personal feelings, emotions and experiences resulting from being affected by leprosy, which can either positively or negatively affect the mental wellbeing according to how being affected with this disease is perceived and dealt with.

3. Conceptual framework

This study uses a conceptual framework that was developed to show the relationship between NTDs, stigma and mental health, as shown in *Figure 2* (9).

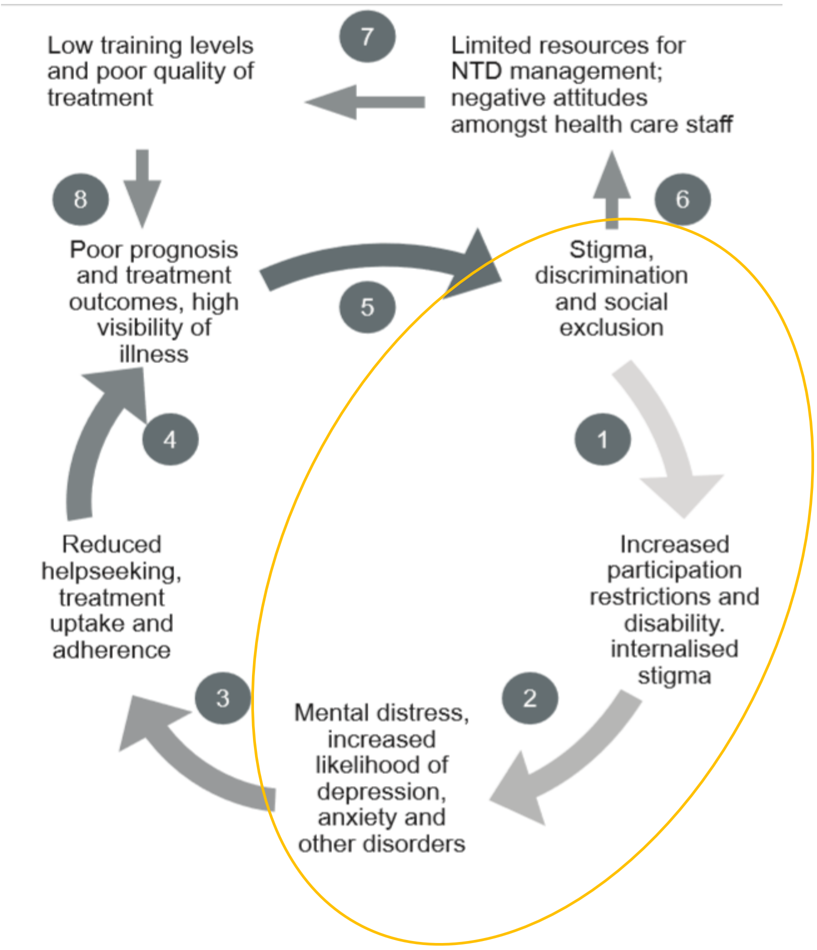

Figure 2. A framework on mental health, stigma and NTDs.

Figure 2 shows that stigma can result in many disadvantages that impact several aspects of life. Leprosy is an NTD that can result in severe impairments. People are often stigmatized, socially excluded and discriminated against (see numbers in *Figure 2*). They are excluded from social participation through the physical impact of NTD-related impairments, such as activity limitations and pain, and internalized stigma [1]. These factors may cause affected people to be at an increased risk of mental distress, including depression [2]. As a consequence, there may be reduced health-seeking behaviour and treatment uptake/adherence [3] (55, 56), which can lead to poor treatment outcomes and less favourable long-term prognosis [4]. Poor treatment outcomes reinforce stigma and discrimination [5] (57). Stigma and discrimination can negatively impact NTD management and quality of treatment, resulting in poor prognosis and less favourable treatment outcomes [6-8]. This study mainly focussed on steps 1 and 2 of the conceptual model, which include stigma, social exclusion, participation restrictions, disability and mental distress, as indicated by the yellow circle.

3.1 Qualitative study sub-questions

By using this framework to explore which factors influence the mental wellbeing of leprosy-affected persons in Sudurpashchim Pradesh, Nepal, the following sub-questions were addressed:

1. What personal feelings and experiences influence the mental wellbeing of people affected by leprosy in Sudurpashchim Pradesh, Nepal?
2. What social and daily life factors influence the mental wellbeing of people affected by leprosy in Sudurpashchim Pradesh, Nepal?
3. What cultural factors influence the mental wellbeing of people affected by leprosy in Sudurpashchim Pradesh, Nepal?
4. Do people affected by leprosy in Sudurpashchim Pradesh, Nepal experience perceived, experienced and/or internalised stigma, and if so, in what way?

4. Methods

4.1 Study design

This exploratory study employed a qualitative research design using in-depth, semi-structured interviews and focus group discussions (FGDs). Understanding leprosy-affected persons' perceptions, beliefs and experiences regarding factors influencing their mental wellbeing can best be explored through gathering in-depth data using qualitative methods (58). A qualitative research design fits this study very well, since qualitative research intends to find answers to ‘what’, ‘how’, or ‘why’ questions about social aspects of health, illness and health care and focuses on understanding, rather than measuring phenomena (58). The FGDs served as an addition to the interviews as this type of data collection allows to observe the interaction between participants (58, 59). Along with leprosy-affected persons, a control group was included in the in-depth interviews in order to compare between factors influencing the mental wellbeing of leprosy-affected persons and the general population. The qualitative study was complimented by a quantitative study conducted by a colleague researcher, the findings of which are described in another (unpublished) report. Most of the leprosy-affected participants in the qualitative sample were a subset of those in the quantitative sample.

4.2 Study site

This study was conducted in Kailali, Kanchanpur and Achham districts of the Sudurpashchim Pradesh province of Nepal. Those districts were included, since the greatest number of cases are reported to live here (31).

4.3 Study population

This study focused on two groups of people: people affected by leprosy and controls.

4.4 Eligibility criteria

Individuals affected by leprosy were included if they were above 18 years of age and resident in Sudurpashchim Pradesh of Nepal. Exclusion criteria for participants were people who were: not resident in Sudurpashchim Pradesh, unable to understand and/or speak Nepali, or additionally impaired or marginalized because of a comorbidity or disease other than leprosy (e.g. tuberculosis or lymphatic filariasis). Both persons who have completed their leprosy treatment as well as persons who still receive treatment were included in the study. Controls were included if they were above 18 years of age and resident in Sudurpashchim Pradesh. Exclusion criteria for participants were people who were: not resident in Sudurpashchim Pradesh, unable to understand and/or speak Nepali, or impaired because of leprosy or another disease.

4.5 Recruitment and sampling

Leprosy-affected individuals were found through collaboration with NLR Nepal, located in Kailali district. A gatekeeper from NLR introduced the researchers to multiple health coordinators in charge of health clinics in Kailali, Kanchanpur and Achham districts. Possessing specific information including contact details of leprosy-affected persons, health workers from these health clinics contacted persons affected by leprosy in order to recruit research participants. Sampling was mainly purposive, with maximum variation in order to capture within-population variations. Controls were recruited by the researchers going into the communities, striving to match characteristics - such as age, sex, living area and occupation - to the persons interviewed affected by leprosy. The participants varied in age, gender, religion, education, disability grade and mental wellbeing. We strived to include people with both poor and good mental wellbeing, which was ascertained by looking at the scores from the PHQ-9 (depression) (60) and the WEMWBS (mental wellbeing) questionnaires (61) administered by another researcher working on the project.

4.6 Data collection

Data were obtained by means of in-depth, semi-structured interviews and FGDs with people affected by leprosy and controls who were willing to participate in the study and sign for informed consent. The semi-structured nature of the interviews allowed the interviewer to adjust the questions to the specific context, and to explore the sensitive topics of leprosy and mental wellbeing (58). Data was collected between mid-April and the end of June 2019.

As not all leprosy-affected persons had told their families, friends or others about their diagnosis, they were invited to the health clinic for the interview. Control group interviews were mostly held at participant’s homes. The interviewer first filled out a Personal Information Form (PIF) asking the participant basic questions about personal characteristics, including gender, age, residence, religion, marital status, etc. (see *Appendix 1*). The impairments of participants were graded using the WHO’s eyes, hands and feet (EHF) scoring system (see also *Section 2.2*) (62). The highest EHF grade was used as the indicator.

Question themes of the in-depth, semi-structured interview guide for leprosy-affected persons were selected from the previously described conceptual framework (9) and from previous research on the connection between NTDs and mental wellbeing (12, 42, 51, 55). Topics included personal feelings and general experiences with leprosy, mental wellbeing, knowledge on leprosy, social life, community, culture and the future (see *Appendix 2.1*). The interview guide for controls included similar questions, leaving out specific questions on leprosy (see *Appendix 2.2*). Both interview guides were translated from English to Nepali by colleagues from NLR Nepal, translated back to English, and again translated into Nepali by a female Nepalese interpreter. As the process had an iterative character, questions were adjusted by pilot testing the interview guide with three leprosy-affected persons. Each interview lasted about 30 to 45 minutes. Interviews were conducted until data saturation was reached. For the purpose of minimizing inter-observer variation, all leprosy-affected individuals participating were interviewed by the same Nepalese female interpreter, who tried to build rapport by maintaining a listening, understanding and friendly posture towards participants. Before conducting the interviews, the interpreter was trained by the researcher in working with people affected by leprosy and qualitative data collection. Before the start of the interview, the study and its purpose were verbally explained, reassuring participants about their anonymity, and their right to refuse to answer or quit the interview at any time (see also *Section 4.8*). The interviews were conducted in Nepali and audio-recorded.

In addition to the individual interviews, two FGDs including leprosy-affected persons were conducted. An advantage of using FGDs is that individuals may be willing to tell more about their mental wellbeing if they are together with other individuals affected by leprosy, encouraging one another (59). One FGD included seven men and the other one included six women. Separate FGDs were held for men and women in order to allow the participants to speak freely. Each FGD lasted around two hours. The FGDs were led by the same Nepalese female interpreter in an environment as comfortable and easy to reach as possible for the participants. Prior to the FGDs, informed consent was obtained and confidentiality was ensured (also see *Section 4.8).*

A topic guide for the FGDs was developed beforehand (see *Appendix 2.2*). Data from the in-depth interviews contributed to deciding which concepts to explore further in the FGDs. During the FGDs, the interpreter summarized, listened and clarified in order to be able to build rapport with the participants (59). Both the researcher and a second Nepalese facilitator were present, they collected data about (non-verbal) interactions between the leprosy-affected persons. The questions posed in the FGDs were mostly open in order to stimulate conversation (59) about factors regarding personal, cultural and social life that influence the mental wellbeing of people with leprosy. Finally, the interpreter asked for further comments or questions, informed the participants about the use of the data, and thanked them for their participation.

4.7 Data analysis

The recordings in Nepali were transcribed and translated into English (verbatim transcription) by the interpreter. Data were kept in a secure database, and no names of leprosy-affected people were connected to the interview contents. Framework analysis was used, which allowed for structured analysis with predetermined themes giving clear direction (58). When new themes arose, these were also included to ensure room for participants to bring in new topics during the interview and to explore these further (59). This type of analysis thus also resembled some characteristics of the Grounded Theory Approach (58). In order to become acquainted with the data, transcripts were read multiple times before formal analysis. A coding scheme was developed based on Thematic Open Analysis. The qualitative analysis programme MAXQDA (Version 2018.1, VERBI Software GmbH) was used to assist in analysing the data. The coding scheme was applied to all the data, resulting in a chart that included data arranged according to the developed themes. Finally, a map was created identifying connections and interpretations based on the chart (58).

4.8 Ethical considerations

Prior to the research, ethical approval was sought and obtained from the Nepal Health and Research Council (Ref. No. 2925; see *Appendix 3*). Before conducting the interviews, all participants received an elaborate explanation of the nature and aims of the research. Participants' confidentiality was assured, and written informed consent was obtained on-site via signing the Informed Consent Form (ICF), which included a short description of the research, and assurance of confidentiality and the option to quit the interview at any time (see *Appendix 4*). Further permission was sought from the participants to audio-record the interview in order for the interpreter to transcribe and translate the data later on. When a person with leprosy was not able to give written informed consent, a thumbprint was obtained instead. For the purpose of confidentiality, data were kept in a secure database and no names of respondents were reported. A number was assigned to each interviewee and FGD participant, so that no names of participants were connected to the interview contents. A travel allowance was provided to each participant to ensure that no participant incurred costs related to taking part.

4.9 Quality criteria

Four criteria described by Devers (1999) were considered in order to maximize the rigor of qualitative research (63). Credibility of the study findings was ensured by triangulation: a fellow researcher checked the codes developed, and qualitative data were compared with the results of quantitative data collected by the fellow researcher as well as to existing research. Transferability of the research was increased by taking the study context into account, including the researcher's own position and influence on the results. Dependability was maximized by transparency throughout the whole process. The researcher kept journal notes on her personal experiences, perceptions and the possible implications of this throughout the research. She attempted to obtain a certain extent of confirmability by discussing findings from the data with her colleague researcher and supervisors, to ensure that the findings clearly derived from the data (58, 59).

5. Results

5.1 Characteristics of the study sample

In this study, a total of 50 participants, of whom 38 were affected by leprosy and 12 were controls, were included. Of this total number, 25 leprosy-affected persons as well as 12 controls participated in in-depth interviews. The remaining 13 leprosy-affected persons participated in FGDs. For the in-depth interviews, 12 men and 13 women affected by leprosy were included (see *Table 1*). Five men and seven women without leprosy were included as controls. The mean age was 51 years for the persons affected by leprosy (range: 23-73 years) and 48 for the control group (range: 22-76 years). Eleven leprosy-affected persons scored a disability grade of 0, five were graded as 1 and nine were graded as 2. Most of the leprosy-affected participants (n=23/25) and controls (n=10/12) were married. The majority of both groups were Hindu (n=20/25 for leprosy-affected; n=12/12 for controls) and lived in urban areas (n=19/25 for leprosy-affected; n=8/8 for controls). The most common occupations for both controls and leprosy-affected persons were farmer (n=9/25 for leprosy-affected; n=5/12 for controls) and housewife (n=11/25 for leprosy-affected; n=3/12 for controls). Two leprosy-affected participants were living in a leprosy village.

	Leprosy-affected (n=25)	Controls (n=12)
Mean age	51	48
Median age	53	46
Gender		
Female	13	7
Male	12	5
Area of residence		
Urban	19	8
Rural	6	4
Marital status		
Married	23	10
Widowed	1	2
Separated	1	-
Religion		
Hindu	20	12
Christian	5	-
Level of education		
Illiterate	12	3
Read and/or write only	7	6
Primary education	5	2
Secondary education	1	-
Higher education	-	1
Employment status		
Housewife	11	3
Farmer	6	5
Unemployed	5	1
Self-employed	2	2
Paid work	1	1
Level of family income		
No income	-	-
≤ 3000 Nepalese rupees/month	6	3
3001 – 5000 Nepalese rupees/month	5	-
5000 – 7000 Nepalese rupees/month	2	-
≥ 7000 Nepalese rupees/month	12	9
WHO EHF score		
0	11	-
1	5	-
2	9	-
District		
Kailali	12	5
Kanchanpur	8	5
Achham	5	2

Table 1: Background characteristics of leprosy-affected persons and controls in in-depth interviews

For the FGDs, six women and seven men affected by leprosy were included in separate group interviews (see *Table 2*). The mean age was 35 years for the women (range: 22-45 years) and 47 for the men (range: 25–76 years). All six female leprosy-affected persons scored a disability grade of 0. Of the leprosy-affected men, five were graded as 0 and two were graded as 1. Most of the FGD participants were married (n=5/6 for females; n=4/7 for males). One woman and one man were unmarried, whereas one woman and two men were widowed. The majority of both groups were Hindu (n=6/6 for females; n=6/7 for males). One man was Christian. All women (n=6/6) and almost all men (n=6/7) came from urban areas. Most of the women were housewives (n=5/6). Most of the men were either employed (n=3/7) or farmers (n=2/7).

	FGD female (n=6)	FGD male (n=7)
Mean age	35	47
Median age	36	40
Gender		
Female	6	-
Male	-	7
Area of residence		
Urban	6	6
Rural	-	1
Marital status		
Married	5	4
Widowed	-	2
Unmarried	1	1
Religion		
Hindu	6	6
Christian	-	1
Level of education		
Illiterate	1	-
Read and/or write only	4	3
Primary education	-	-
Secondary education	1	3
Higher education	-	1
Employment status		
Farmer	-	2
Housewife	5	-
Self-employed	-	1
Paid work	-	3
Unemployed	1	1
Level of family income		
No income	-	-
≤ 3000 Nepalese rupees/month	-	-
3001 – 5000 Nepalese rupees/month	1	-
5000 – 7000 Nepalese rupees/month	1	3
≥ 7000 Nepalese rupees/month	4	4
WHO score		
0	6	5
1	-	2
2	-	-
District		
Kailali	6	6
Kanchanpur	-	1

Table 2: Background characteristics of the leprosy-affected persons in FGDs

5.2 Personal feelings and experiences related to being affected by leprosy

While conducting interviews about mental wellbeing, it became apparent that many participants were not used to sharing their feelings with others. Nine of the 38 persons affected by leprosy and five out of 12 controls answered that they usually don't talk to anyone about their feelings. Moreover, sharing personal feelings did not necessarily include feelings on being affected by leprosy. Both controls and leprosy-affected persons indicated that sometimes they did talk to someone - either their husbands, family or other community members - when they are 'in a problem,' 'not feeling well,' or needing some form of help. Some participants kept their disease hidden from society. Although the majority of leprosy-affected participants (n=23/38) indicated that their families and others knew about their disease, one-third (n=12/38) indicated that only their family members knew and the remaining participants (n=3/38, all women) only shared it with their husbands. Reasons for keeping their disease hidden were the fear of reactions/opinions from others and discrimination after exposure, as well as the feeling that there is no advantage to or need for telling others.

5.2.1 Positive feelings

Personal feelings reported to positively affect the mental wellbeing of leprosy-affected persons included feelings of hope and trust in the future, not caring about other people's opinion, not thinking too much and feeling strong. Participants expressing some form of positive thinking often indicated that they did not worry about being affected by leprosy. For example:

"…I am very strong in this case. If I would have been thinking a lot I would not have survived…" (Woman affected by leprosy, age 38)

5.2.2 Negative feelings

Factors regarding personal feelings reported to have a negative effect on the mental wellbeing of persons affected by leprosy include fear of exposure to others than their close ones (n=10), fear of discrimination (n=11), and fearing/giving importance to someone else's opinion about them (n=10). The majority of leprosy-affected participants (n=27/38) were aware of the presence of stigma around leprosy and eight of them had experienced stigma in some way themselves. Furthermore, they felt bad about being affected by the disease in general, worried about disease transmission to others and progression of the disease/not being cured, such as leprosy reactions, the development of (visible) disabilities or death. Some even felt that they would be better off dead (n=5/38). Two examples of persons not wanting to disclose to others than their closest relations because they were afraid of being discriminated against are given below:

"…Because when I was very young I have seen leprosy-affected people who were forced to live in a cave or far away from their houses. That's why I didn't tell about my disease to anyone…" (Woman affected by leprosy, age 27)

"...My father-in-law and mother-in-law still discriminate around menstruation. If they knew about my disease, they would surely throw me out of my house…" (Woman affected by leprosy, age 32)

These feelings sometimes also resulted in internalised stigma, feeling ashamed, or embarrassed (n=14/38) or thinking that their condition might be the reason why their relatives were being treated in the wrong way (n=2). The latter is reflected in the following example:

"...My elder daughter doesn't have any problem in her married life, because she was brought up in a foreigner's place and she doesn't know much about us. But my younger daughter, she got married to a man nearby and recently they have been separated. I don't know what is the cause for that. It might be due to us [him and his wife, both affected by leprosy]…" (Man affected by leprosy living in a leprosy village, age 72)

Almost two in five of the persons affected by leprosy (n=14/38) said they sometimes experience feelings of shame or embarrassment. In addition, over one-third (n=14/38) reported that their self-esteem had reduced, mainly because they cannot do things as they once did. Feelings of shame were linked to physical appearance like visible patches on their skin or darkened skin colour from treatment, being affected by leprosy in general, and being unable to do the things they wanted to do. One man from the control group also felt ashamed about the latter, and two other controls felt ashamed speaking in a group. One leprosy-affected woman said:

"...I used to be very fair earlier, but now I have turned black [because of medicine]. My name is 'Dhauli', which means fair and people used to say that my name is 'Dhauli' and my complexion too… but nowadays I have turned black. People don't even recognize me and I feel ashamed of it…" (Woman affected by leprosy, age 35)

Two-thirds of the leprosy-affected participants (n=12/38) reported thinking about death, of whom five said they felt or had felt that it would be better to die than to live with leprosy, four were worried about death, one man felt that 'it would be good if he would die easily and go to Jesus.' One woman felt that it would not matter if she died and one woman said that she would commit suicide if her husband would tell anyone about her disease. Suffering from this disease seemed to be unbearable for some individuals, because of disability, difficulties in meeting responsibilities and pain. One man said:

"…If there is no disease in my body I feel good, but one year ago, there was an infection in my foot and I was unable to walk. At that time, I was very sad and I went to the river to commit suicide, because of the intolerable pain all day and night long. But some people of my village knew about it and they, together with my wife, turned me back and my wife said to me: "why are you doing this?" and I said: "it is better to die rather than tolerating this pain every day and night"…" (Man affected by leprosy, age 71)

5.3 Factors regarding social and daily life influencing the mental wellbeing of leprosy-affected persons

The majority of the leprosy-affected persons (n=23/38) considered their daily lives to be affected by living with this condition. This was mostly expressed as the inability to do the things in daily life as before. As most of the leprosy-affected persons were farmers and housewives, they mainly mentioned experiencing difficulty working in their fields or doing their house chores, like cooking or cutting wood for fuel. The most common cause for this was the feeling of weakness. One man felt that, due to leprosy, he had missed out on chances and said:

"…Yes, it has affected my life, because sometimes I used to think that if I wasn't affected so early [at the age of 14], I would have studied well, because my friends studying with me are in a good position or job and I wouldn't have had to leave my house…" (Man affected by leprosy living in a leprosy village, age 72)

5.3.1 Positive factors related to social and daily life

Social/daily life factors found to positively affect the mental wellbeing of leprosy-affected persons include support from family members or others, the ability to work, earn money and take care of family members or themselves, social participation, and a positive attitude from the community towards leprosy-affected persons, which was often linked to increased awareness of and knowledge about leprosy amongst community members.

Almost all of the leprosy-affected persons indicated that they get some form of support from either their family or friends, although two did not. Support came in various forms, from mental support (telling their family member or friend affected by leprosy not to worry since they could be cured, encouraging them to get treatment or helping them in obtaining their medicine) to taking over their work or household chores when they were unable to complete these. Most often, support came from the husband or wife. Most of the women and the majority of the men affected by leprosy mentioned this. One example is given below.

"…He never allows me to think negatively, always speaks positively, supports me and I feel good…" (Woman affected by leprosy, age 22)

Three men told us that they got married to their wives after receiving their diagnosis, and one woman also got married to her partner after finding out that she was affected by leprosy. One 25-year-old unmarried woman affected by leprosy said that she is now in a relationship, and her partner knows about her disease and has accepted her the way she is. A father of two children, who was relieved that his children were able to marry despite his condition, told us:

"…My daughter-in-law's parents allowed their daughter to marry my son. Many years ago it wasn't accepted to marry daughters to families in which there was a leprosy-affected person. Even my daughter got married and no one said that 'there is leprosy in your family'…" (Man affected by leprosy, age 71)

Another factor mentioned by leprosy-affected persons as positively influencing their mental wellbeing is that the attitude of the community towards leprosy has changed. Eleven leprosy-affected respondents mentioned the negative attitudes and discrimination of society towards persons affected by leprosy many years ago, as in the previous quote. Multiple participants told us that leprosy-affected persons used to be forced away from their villages, forced to live in huts or caves, but according to seven individuals this is now changing, as the new generation is more aware and has more knowledge about leprosy. One man described this as follows:

"…There is a difference in thinking between the old and new generations, because in the old days people were not so educated and they were bad. They treated leprosy-affected very badly, but now people are educated and they are good and they don't treat leprosy-affected in a bad way and they don't say anything in front of us and I feel good…" (Man affected by leprosy, age 76)

Among those seven participants, two were living in a leprosy village. Still, one man (grade 2 disability) from this village said that people are hesitant, two women (grade 0 and 1 disability) were afraid to tell about their disease to people other than their husband or family, and another man (grade 2 disability) said that people keep a little distance. Two of the persons who reported not experiencing any stigma or discrimination nowadays, had a disability grade of 0. The remaining woman had a disability grade of 1 and was living in a leprosy village.

5.3.2 Negative factors related to social and daily life

Social and daily life factors reported to have a negative effect on mental wellbeing include a negative attitude towards and discrimination against leprosy-affected persons by family members or others, separation from family, negative behaviour of the affected person's husband, lack of support, difficulties with work, responsibilities towards family, and participation restrictions. A negative attitude or bad behaviour from either the community or their own family members towards leprosy-affected persons was mentioned by over half of the participants (n=20/38). Participants mentioned that some community members dominate, discriminate, and keep their distance from leprosy-affected people. A negative attitude from in-laws was mentioned by five persons affected, spreading unwanted rumours about their disease or treating them badly. One woman said, crying:

"…My sister-in-law treated me very badly. I looked after her children, cared for them, reared them, but for the last six months, since I was diagnosed with leprosy, she doesn't send her children to my house. She might be scared, but my daughter went to her and asked why she doesn't send her children to me, because the doctor has already said that now this disease is not transmitted to anyone, because I have started taking medicine and she didn't say a word and I feel very bad about it…" (Woman affected by leprosy, age 36)

Another woman told us about what happened to her many years ago, when her father-in-law came to her father's house and told him that he would have a new daughter-in-law, because the woman was affected by leprosy. Feeling ashamed, she left her house, eventually ended up in a leprosy village and has been separated from her husband ever since. Separation from family members – because of marriage or death - was also found to negatively influence the mental wellbeing of participants from the control group. One man from the control group said:

"…Nowadays I am separated from my family. Because of that reason, I can't sleep well…" (Man from control group, age 29)

One-third of the leprosy-affected women (n=7/19) mentioned negative behaviour from their husbands. This included a drinking husband (n=3), having a fight with the husband (n=2) and an unsupportive husband (n=2). The drinking of the husband was also mentioned by one woman from the control group. A woman affected by leprosy said:

"…He lives in India and he is a drunkard. He enjoys his life and he hasn't come home for very long. (…) He came home a few months ago and I explained him about my disease and he left after a few days without saying anything…" (Woman affected by leprosy, age 50)

Lack of support caused worries about the future for some persons affected by leprosy, being concerned about who will be there to take care of them. One man from the control group expressed similar worries and said:

"…I just think about what me and my wife will do, because she can't see and she's unable to work also. How will my daughters-in-law treat us in the future when we can't do anything..." (Man from control group, age 65)

Current difficulties with work were mentioned by almost all leprosy-affected participants (n=32/38) and two-thirds of the controls (n=8/12). Although two-thirds considered this to be due to leprosy, some also believed it was due to their age (n=5/38). For the controls, difficulties with work were mostly linked to age (n=5/8). When asked about their thoughts about the future, multiple leprosy-affected participants answered that they wish the best for their children and want to provide them a good future. These responsibilities towards others, however, sometimes led to mental distress, when not being able to fulfil their desires because of difficulties with work and earning money. Troubled about his responsibilities towards his children and wife, one man said:

"…I have to do everything for my family, like earning. I can't tell anyone to look after my family, because they are my responsibility and I have to do it whether I can or I can't. I collect pebbles and sell them. That is my source of income, but sometimes I can't sell even a bag of pebbles even for six months. (…) I was unable to buy books and notebooks for my sons and they had to drop out from school and my wife also has to suffer a lot. It was better if I would have hanged myself at that time rather than having all of these problems…" (Man affected by leprosy, age 52)

Except for one of the leprosy-affected persons, all of the others said they were invited to wedding ceremonies and celebrations in their community (n=37/38). However, two of them noted that they were not invited as often as before. All of the controls said they were invited, and most of them also used to attend. Of the leprosy-affected persons, five indicated that nowadays they do not attend. Participation restrictions either resulted from impairment or disability, physical weakness or pain, internalised stigma or reactions from the community. Illustrating this, one woman said:

"…After having this disease, I usually don't visit my friends and they don't either. I used to wear a mask and when people asked about that I said: 'the doctor has referred me to stay away from dust and smoke…' Because this disease transmits through the respiratory route. (…) I'm aware about it and I myself maintain a distance with them…" (Woman affected by leprosy, age 35)

5.4 Cultural factors affecting the mental wellbeing of leprosy-affected persons

Next to questions about their personal feelings and social life, some general questions were asked regarding their knowledge and ideas about their condition. Out of 38 leprosy-affected participants, 22 participants knew that leprosy is a communicable disease and four persons knew that the disease is transmitted via the respiratory route. Four participants mentioned that no one at the health clinic explained anything to them about leprosy and eight said that they did not ask anyone either, making room for many beliefs surrounding the disease. These beliefs included the perceptions that leprosy is non-communicable (n=8), genetic (n=5), caused by poor hygiene (n=3) or blood contamination/infection (n=5), transmitted sexually (n=1), through water (n=1) or by sharing your food or clothes with leprosy-affected persons (n=7). One additional belief is illustrated below.

"…Leprosy is of seven types. (…) One is which degrades bone. Two is which degrades muscle. Three is which causes disability. Four is in which the microorganism of leprosy enters your head and you only have severe headache. Five is in which you cannot use blades or sharps. Six is in which you cannot use nail cutters. Seven is if you are injured by thorns and there might be a wound which further develops into leprosy…" (Man affected by leprosy, age 52)

A few persons affected by leprosy (n=4/38) thought that leprosy was their fate or bad luck. Persons (n=13/38) also mentioned that others believed leprosy was 'God's curse,' caused by an evil spirit, a curse from previous life, sins from the past or sins from their ancestors. Some people in the community did not believe that persons were affected by leprosy. The following quote is an example of others' beliefs when the interviewer asked them about the existence of local beliefs around leprosy:

"…Once my husband said to me that this disease affects the people who have done bad things. I don't know where he heard this from. May God know whether I did anything bad…" (Woman affected by leprosy, age 44)

5.4.1 Positive cultural factors

Cultural factors reported to have a positive influence on mental wellbeing are finding comfort in religion, having adequate knowledge about leprosy, rejecting traditional beliefs around leprosy, and the relief of/believing in treatment. When the interviewer asked about local beliefs around leprosy in the community and their own feelings about these, one man answered:

"…I don't believe in such things. If it was a curse, then why was I cured after taking medicine? Because my family didn't sacrifice any goats, hens and didn't worship for me…" (Man affected by leprosy, age 34)

One woman said:

"…Now I feel good. There was a time when I used to think that I would die, but nowadays I think I will be cured…" (Woman affected by leprosy, age 35)

Religion was a helpful tool in relieving mental distress around the disease. In the leprosy village, many of the leprosy-affected persons living there had adopted Christianity in the belief that it might cure them. Almost three quarters of the leprosy-affected people who participated in in-depth interviews (n=18/25), considered praying to be important and most of them expressed positive feelings regarding religion, making them feel strong or relaxed. One man said:

"…I visited many religious places, worshipped God and even built a temple, praying that this disease might not affect my offspring. (…) If I am sad, I just worship and feel relaxed…" (Man affected by leprosy, age 76)

5.4.2 Negative cultural factors

Several cultural factors were found to have a negative impact on mental wellbeing. These factors included traditional/cultural beliefs that were often related to poor knowledge about leprosy, from both the persons affected themselves as well as others. Leprosy-affected persons' own beliefs, in addition to the local beliefs, influenced mental distress, causing individuals to wonder whether they might actually have committed a sin. One woman said:

"…I feel very bad and I think I haven't done anything wrong. Sometimes I think that my father married me off before I started menstruating and it may be because of that sin that I am having this disease. Otherwise, I haven't done anything wrong…" (Woman affected by leprosy, age 36)

And one man said:

"…People in my community say that I am affected by leprosy, because I have done some evil things. Like, I do slaughtering of animals. They say that I am cursed because of it. I do it to look after my family and I do good things, not bad…" (Man affected by leprosy, age 62)

As reflected in the last quote, some persons affected by leprosy were left baffled, not understanding why it was them who were affected by a disease that is considered to be God's curse or caused by an evil spirit, while they feel like they haven't done anything wrong. Other people saying such things made them feel bad. One woman said:

"…We did good to everyone, but I don't know what happened to us…" (Woman affected by leprosy, age 25)

6. Discussion and conclusion

We found that many persons affected by leprosy with varying disability grades experienced mental distress and/or discrimination. Personal factors that caused mental distress often resulted from physical weakness or pain, activity limitations, perceived and/or internalised stigma. In addition, leprosy-affected persons experienced stigma enacted by family or community members in the form of discrimination. Support from family members – the husband or wife in particular - and religion were considered to be very important in coping with the disease. Other social and daily life factors influencing the mental wellbeing of leprosy-affected persons were social participation (restrictions), the (in)ability to work and the community attitudes towards leprosy. Many cultural beliefs around leprosy existed and were often causes for discrimination.

6.1.1 Personal feelings

Numerous studies – both clinical and epidemiological - in various countries have measured the prevalence of psychosocial problems among leprosy-affected persons (64-67). Many of these individuals were found to suffer from mental health problems, among which depression was most common (17). In the current study, multiple persons affected reported negative effects, such as worry about their disease and its implications, feeling ashamed or embarrassed, and suicidal thoughts. As reported by Singh, psychological care of people affected by leprosy is insufficient (17) and this also holds true for the province of Sudurpashchim Pradesh. A study by Shen et al. found suicide to be the major cause of death among active leprosy patients in China (68) and Philip reported that suicidal thoughts were more apparent when deformity had developed (69). Similarly in our study, four out of five participants who felt they would be better off dead had a disability grade of 2. For the remaining man, body aches were unbearable.

Some of the participants affected by leprosy kept their disease hidden from society or only shared it with their close ones. In line with our study, a mixed-methods study from Adhikari in Western Nepal reported disease concealment was due to the fear of discrimination (70). In our study, about one-third of the participants also reported internalised stigma, feeling ashamed about their disease or physical appearance. Similarly, a literature review from Rafferty described that people with leprosy might feel ashamed due to community attitudes and deformities (8). Poor knowledge and cultural beliefs might have affected their feelings about themselves, questioning whether they might have done something that resulted in them being affected by leprosy. Multiple participants mentioned their darkened skin colour, a side effect from leprosy treatment as a reason for shame. In some Asian and South American countries, fair skin is preferred (71). Skin colour can also be indicative of caste. Therefore, although not witnessed here, changing skin colour might also cause problems in treatment adherence (72).

6.1.2 Social and daily life factors

Some of the participants indicated they were participating less in the community because of fear of reactions to their condition from others. In agreement with this, Adhikiri et al. described that feelings of shame can result in anxiety and depression, which in turn may cause social participation restrictions (70). Our respondents indicated that restricted participation may also result from physical weakness, impairments or disability. Difficulties in everyday house chores, like cooking or cutting wood for fuel were mentioned. Some individuals were also unable to work and earn enough money to meet the responsibilities they have towards their family and this resulted in mental distress. These findings are supported by a study by van Brakel et al., who stated that among persons affected by leprosy in Indonesia, the main problems related to participation restrictions and stigma were shame, difficulties in employment and marriage-related problems (12). In our study, however, difficulties with work were sometimes also related to increasing age and its associated reduced physical functioning for both affected and unaffected persons.

Whereas other studies found problems with marriage, such as divorce (73, 74) or problems for leprosy-affected persons or their children to find a marriage partner (12), most of the participants in our study indicated not to experience such types of problems. Only one woman got separated from her husband due to her leprosy, many years ago. Three men and one woman got married after their partners knew about their disease and one woman had disclosed her disease and was about to get married. Possible explanations for this finding could be that one of the men (disability grade 2) married a woman who was also affected by leprosy, two others had no visible signs and adequate knowledge on the disease (about treatment and cause) among partners was also linked to positive attitudes. Still, problems within married life existed. The leprosy-affected persons who expressed negative behaviour from their life partners – drinking (too much) alcohol, having a fight or being unsupportive - were all women. The drinking of the husband was also mentioned by one woman from the control group. Similar behaviour was described in a study among married women in Eastern Nepal (11). Many studies found leprosy and it’s stigma to have a worse impact on women than men, as in Nepal, women generally have a lower social status and when affected by leprosy, the risk of being discriminated against is higher (8, 16, 17, 75). The quantitative part of this project found both affected and unaffected women to have a poorer mental wellbeing than men.

Another interesting finding was the fact that some of the leprosy-affected persons in this study said there was less stigma now compared to before. This was believed to be due to greater awareness and education about leprosy of the current generation, which was recently also described by Marahatta et al (76). These authors found that leprosy awareness among community members in Lalitpur district of Nepal had increased and discrimination was believed to belong to the past. Singh et al. found a significant link between adequate knowledge and positive attitudes towards leprosy (28). Nonetheless, in our study, negative attitudes towards leprosy were still mentioned by 20 out of the 38 participants affected by leprosy, indicating that the stigma surrounding leprosy is still a problem. Little to no information about leprosy was provided by the health clinics and many local beliefs existed.

Social support from life partners, family or other people from the community was considered very important by the leprosy-affected persons and was often linked to positive feelings. As already suggested by other studies, future interventions directed at improving the mental wellbeing of leprosy-affected individuals and decreasing stigma should thus include families and communities (8, 18, 77).

6.1.3 Cultural factors

Knowledge about leprosy was found to be poor among leprosy-affected persons as well as the community members of Sudurpashchim Pradesh. Many cultural beliefs around leprosy were found and these often caused mental distress among the persons affected. For example, it made them wonder whether they actually had committed a sin. Singh et al. found similar cultural beliefs amongst community members in Southern Central Nepal, including the perceptions that leprosy comes from bad blood, a curse or having committed a sin (28). According to Raju, inadequate knowledge, understanding and mistaken beliefs regarding leprosy keep the stigma going (78) and this is likely also the case in Sudurpashchim Pradesh.

A cultural factor that helped people find peace of mind was religion and praying in particular. Remarkable was that in the leprosy village, most of the leprosy-affected persons had converted to Christianity, as this was the religion adopted by doctors who had provided them treatment and relief of their problems. They believed that being a Christian might positively affect their condition or even cure them. Religion often functions as a source of resilience in mental health and illness (79, 80). However, religious beliefs can also be problematic as believing that religion might cure you could lead to treatment avoidance and this should be taken into account when religious leaders are included in interventions (81).

6.2 Strengths and limitations

A limitation of the study is the small sample size, specific area and purposive method of sampling, which limits the generalizability of our findings to the entire study population. As mental wellbeing is a sensitive topic and some leprosy-affected individuals were afraid of exposure, we were not able to visit them at their homes. Especially in Kanchanpur district, individuals did not want to participate. Some people went to the clinics in other districts to obtain their medicine, so that they would not be seen by others. This might have biased the results, since people experiencing high stigma, more severe mental distress or fear of exposure might thus have been excluded, causing us to underestimate the severity of stigma and mental distress. Another limitation was the need to use a Nepalese interpreter, since mistakes or misinterpretations might have been made during transcription and/or translation of the interviews into English. During the interviews, interpretation might also have influenced the findings, since not all participants understood or spoke Nepali very well and questions required more explanation. Furthermore, feelings appeared to be a difficult concept which participants were not used to talk about. Nepal tends to have a culture where mental distress is experienced as physical distress, also known as ‘somatization’ (82, 83). We might have missed out on certain information as the vocabulary for discussing feelings might have been limited. However, we strived to minimise bias by repeatedly giving the Nepalese interpreter feedback on interviewing skills and thoroughly discussing interview data and translation with both her and other Nepalese colleagues. Furthermore, we tried to ensure that interview surroundings were as comfortable as possible for the participant and when individuals seemed to be hesitant in answering questions during interviews, the presence of the (Dutch) researcher was re-evaluated. A strength of the study is the fact that all of the interviews were conducted by the same female Nepalese interpreter, who was experienced in conducting qualitative research and had adequate knowledge on leprosy and how to behave around persons affected by this disease.

6.3 Conclusion

This study found that in Sudurpashchim Pradesh:

1) Many (social/daily life, cultural and personal) factors – such as social support, participation (restrictions), activity (limitations), stigma, religion, cultural beliefs, knowledge and community attitudes - can influence the mental wellbeing of leprosy-affected persons. Mental distress was reported by many participants, including shame, worries and suicidal thoughts.
2) Stigma around leprosy still exists in different forms (perceived, enacted and internalised stigma).
3) Both stigma and physical impairments can lead to participation restrictions and difficulties with work.
4) Knowledge about the disease - of both leprosy-affected persons themselves as well as others - can positively influence attitudes towards the disease and likely, the mental wellbeing of leprosy-affected individuals.

6.4 Further research and recommendations for future practice

Further research including a larger, random sample is required in order to be able to evaluate the situation around leprosy-affected persons and their mental wellbeing on a wider scale. As for future practice in Sudurpashchim Pradesh, expansion of mental health services is urgently needed as, to date, very limited psychological care is available in this region according to our experiences. In addition, counselling after diagnosis of leprosy is essential and ideally, life partners, spouse and/or other close ones should be included in this since social support is crucial. Firstly, counselling should focus on explaining about the aetiology of leprosy, the way it is transmitted and the benefits of treatment, and thereby aim to reduce the effects of cultural beliefs and stigma around the disease. Secondly, counselling should strive to prevent and take care of the mental problems – such as worries, shame and suicidal thoughts - experienced by leprosy-affected individuals. Mental health counselling could possibly be provided in groups, as this was found to be effective in decreasing stigma-related effects in Indonesia (84). Especially for women, this could be fruitful, as in our FGDs, women seemed to feel supported by one another and encouraged each other to open up about their feelings and experiences with being affected by leprosy. Moreover, interventions should adopt a gender-based approach. Finally, advocacy programs using local media to make the community more aware of leprosy, and interventions to increase employment options and social participation for affected persons should be developed. Programmes or workshops using technical tools to help with household or farm chores could potentially lessen the burden of leprosy-related activity limitations.

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Appendix 1. Personal Information Form (PIF)

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

	O Hearing O Physical (upper limb/lower limb/other body parts) O Mental O Several problems
Severity of difficulty in vision	O No difficulty O Some difficulty O A lot of difficulty O Cannot do at all / Unable to do O Don’t know
Severity of difficulty in hearing	O No difficulty O Some difficulty O A lot of difficulty O Cannot do at all / Unable to do O Don’t know
Severity of difficulty in upper body	O No difficulty O Some difficulty O A lot of difficulty O Cannot do at all / Unable to do O Don’t know
Severity of difficulty in mobility	O No difficulty O Some difficulty O A lot of difficulty O Cannot do at all / Unable to do O Don’t know
Severity of difficulty in self-care	O No difficulty O Some difficulty O A lot of difficulty O Cannot do at all / Unable to do O 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)	Yes / No
MB/PB leprosy	MB / PB
Do others know you have this condition	Yes / No
Time since onset of disease	...... (years/months)

Time since onset of disability	….. (years/months)
Time since diagnosis*	...... (years/months)
Participates/d in CBR program	Yes / No / Don’t know

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

Appendix 2.1. Interview guide for leprosy-affected persons: in-depth, semi-structured interviews

A. Steps of the SSI
   1. Introduce ourselves
   2. Introduce study and aim of today
   3. Ask informed consent, and fill in Informed Consent Form
   4. Fill in respondent's information (PIF)
   5. Follow the rest of the SSI guide below
   6. Thank and close

B. **SSI.1**: Interview guide in-depth semi-structured interviews

Welcome, introduction

This interview covers several topics. We will ask some questions about your daily life, your culture and your social life. We will also ask some questions about your experiences with having to live with leprosy and how this makes you feel.

Concept	**Indicator**	**Questions**
Knowledge on leprosy	Perceptions/beliefs	1. I understand you have a disease related-condition, can you tell me what you know about your condition? 2. What do you think causes leprosy? 3. How do you think leprosy is transmitted? 4. Do you think that contact with you might have any good or bad effects on others around you? *Probing:* Why/why not?
Social life	Family/home	5. Can you tell me something about where and with who you live? 6. What is your role in the household? 7. What obligations do you have towards your husband/wife? Probing: cooking, providing money, taking care of the children 8. What obligations does your husband/wife have towards you? 9. Are there any factors that have a good or bad influence on your marriage? Which ones (probing for good and bad)? 10. Do you feel that your condition has caused problems in your marriage or do you feel that your condition might make it difficult for you to marry? *Probing: what kind of problems? Explain?*

	Experienced/perceived stigma	11. Who did you tell you have leprosy? *Probing: family members, husband/wife, children, neighbours, friends, everyone.* If no: a. Why did you not tell them? If yes: b. What did you say to them? c. How did your friends/family/others react when you told them about your condition? d. How does/did this make you feel? e. Do you feel that your condition might have a social impact for your children? *Probing:* Why? What kind of problems? How does this make you feel? f. Do you feel that your condition might have a social impact for other family members? *Probing:* Why? What kind of problems? How does this make you feel?
	Friends	12. How many close friends do you have? If no friends: skip to question 13. 13. What do you usually do with your friends? Probing: drinking tea together, having conversation 14. Do your friends know you have leprosy? If no: a. Have you told them? Why not? If yes: b. Do you still do the same things now that they know you have leprosy? 15. Do you still have the same friends? *Probing:* Why not?
	Work	16. Do you work? If yes: a. What kind of work do you do? b. What do you like about your work? Is there anything you don't like? c. What is the relationship with your colleagues? Do you have any friends at work? d. Do you experience any difficulties at your work? *Probing:* Could you please explain? Example?

		<u>If no:</u> e. Why not? f. Did you work before you had leprosy? g. Why did you stop? h. Was it your own choice to stop working? i. How does it make you feel that you are unable to work? 17. Do you go to school? (*only if correct age*) <u>If yes:</u> a. Do you experience any difficulties at your school? *Probing:* Could you please explain? <u>If no:</u> b. Why not? c. Was it your own choice to not go to school? d. How does it make you feel that you are unable to go to school?
	Participation	18. Are people affected by leprosy invited to marriage events and celebrations in your community? *Probing:* If no, why not? 19. Are you invited? *Probing:* If no, why not? 20. Were you invited to celebrations in your community before you had leprosy? 21. Are you able to sit and eat with your family, neighbours, or other community members? *Probing:* With who? 22. Do people visit you at your home? *Probing:* If no, why not?
	Internalized stigma	23. How does/did this make you feel? 24. Do you hide your conditions from society? *Probing:* Why?
Community/culture	Personal feelings	25. With who do you talk about your feelings? 26. Is it normal to talk about your feelings in your community? 27. Do you also talk to them when you are not feeling well / difficult times? *Probing:* If no, why not? Probing: can you give an example of things you discuss during difficult times? 28. Is your community important to you? Why? 29. Do you feel that it is important what community members think about you? Why? Probing: How do they treat you?
	Community attitudes	30. Are people in your community aware about leprosy? 31. What are the attitudes of people in your community towards people affected by leprosy? 32. Do community members respect you? Do your community members respect your family? *Probing:* can you give an example? How do you know you are (not) respected? 33. How does that make you feel?

		34. Are there any local beliefs around leprosy or the cause of leprosy in your community? Example?
	Participation/barriers	35. What daily activities do people in your community normally do? 36. Does a person affected by leprosy also do all those things? Of these things, is there anything you cannot do? If not, can you please explain?
Experiences with and feelings about leprosy	Feelings about leprosy	37. Can you tell me something about how living with this condition affects your daily life? *Probing:* Is there anything you can't do because of your condition? Example? How does that make you feel? If woman: Could you describe your feelings about being a woman with leprosy?
Mental wellbeing	Feelings related to mental wellbeing	38. Do you sleep well? *Probing:* Do you ever have trouble falling asleep, staying asleep, or sleeping too much? Why? 39. Do you feel that you have enough energy? *Probing:* Do you ever feel tired? Why? 40. Do you eat well? *Probing:* Do you ever lose your appetite or overeat? Why? 41. Can you concentrate well on things? *Probing:* Why not? 42. Do you ever feel sad, afraid or worried? Example? 43. Do you ever feel ashamed or embarrassed? Example? 44. What makes you feel good/bad? Example?
	Feelings about self	45. Could you describe how you feel about yourself? Explain? 46. Has leprosy influenced your self-esteem or self-respect? Explain?
	Emotional/social support	47. Do you get support from family/friends when you are not feeling well? *Probing:* How do they help you? What do you do when you are not feeling well? Example? 48. Do you ever pray? *Probing:* How does it make you feel?
Future		49. What do you think about your future? *Probing:* Could you describe your feelings?

Final question

Do you have any questions about the interview?

Appendix 2.2. Interview guide for controls: in-depth, semi-structured interviews

A. Steps of the SSI
   7. Introduce ourselves
   8. Introduce study and aim of today
   9. Ask informed consent, and fill in Informed Consent Form
   10. Fill in respondent's information (PIF)
   11. Follow the rest of the SSI guide below
   12. Thank and close

B. **SSI.2**: Interview guide in-depth, semi-structured interviews for controls

Welcome, introduction

This interview covers several topics. We will ask some questions about your daily life, your culture and your social life and how these factors influence your mental wellbeing.

Concept	**Indicator**	**Questions**
Social life	Home/contacts	1. Can you tell me something about where and with who you live? 2. What is your role in the household? 3. What obligations do you have towards your husband/wife? Probing: cooking, providing money, taking care of the children) 4. What obligations does your husband/wife have towards you? 5. Are there any factors that have a good or bad influence on your marriage? Which ones (probing for good and bad)? 6. Are there any problems in your marriage? *Probing:* what kind of problems? Can you explain?
	Friends	7. How many close friends do you have? 8. What do you usually do with your friends? Probing: drinking tea together, having conversation
	Work	9. Do you work? If yes: a. What kind of work do you do? b. What do you like about your work? Is there anything you don't like? c. What is the relationship with your colleagues? Do you have any friends at work? d. Do you experience any difficulties at your work? *Probing:* Could you please explain? If no: e. Why not?

		f. Did you work before? If so, what kind of work did you do? g. Why did you stop? h. Was it your own choice to stop working? i. How does it make you feel that you are unable to work? 10. Do you go to school? (*only if correct age*) <u>If yes:</u> a. Do you experience any difficulties at your school? *Probing:* Could you please explain? <u>If no:</u> b. Why not? c. Was it your own choice to not go to school? d. How does it make you feel that you are unable to go to school?
	Participation	11. Do you attend marriage events and celebrations in your community? *Probing:* If no, why not? 12. Are you invited? *Probing:* If no, why not? 13. Do people visit you at your home? *Probing:* If no, why not?
Community/culture	Personal feelings	14. Is it normal to talk about your feelings in your community? 15. With who do you talk about your feelings? 16. Do you also talk to them when you are not feeling well / difficult times? *Probing:* If no, why not? Probing: can you give an example of things you discuss during difficult times? 17. Is your community important to you? 18. Is it important to you how community members think about you? Probing: How do they treat you?
	Meaning to community	19. Do community members respect you? Do your community members respect your family? *Probing:* can you give an example? How do you know you are (not) respected? 20. How does that make you feel?
	Barriers	21. What daily activities do people in your community normally do? Probing: working on the land, groceries, cooking 22. Can you do all those things? Of these things, is there anything you cannot do? If not, can you please explain?
Mental wellbeing	Feelings about self	23. Could you describe how you feel about yourself? 24. Is there anything in your life that has influenced your self-respect or self-esteem?
	Feelings related to mental wellbeing	25. Do you ever feel sad, afraid or worried? *Probing:* What makes you feel that way? 26. Do you ever feel ashamed or embarrassed? *Probing:* What makes you feel that way? 27. What makes you feel good/bad?

		28. Do you sleep well? *Probing:* Do you ever have trouble falling asleep, staying asleep, or sleeping too much? Why? 29. Do you feel that you have enough energy? *Probing:* Do you ever feel tired? Why? 30. Do you eat well? *Probing:* Do you ever lose your appetite or overeat? Why? 31. Can you concentrate well on things? Why not?
	Emotional/social support	32. Do you get support from family/friends when you are not feeling well? *Probing:* How do they help you? What do you do when you are not feeling well? 33. Do you ever pray? *Probing:* How do you feel after praying?
Future		34. What do you think about your future? *Probing:* Could you describe your feelings?

Final question

Do you have any questions about the interview?

Appendix 2.3. Interview guide for leprosy-affected persons: FGDs

A. Steps of the FGD

1. Introduce ourselves
2. Introduce study and aim of today
3. Ask informed consent, and fill in Informed Consent Form
4. Fill in respondent's information (PIF)
5. Audio-recording on
6. Icebreaker (introducing round: name and residence)
7. Follow the rest of the FGD guide below
8. Thank and close

C. **FGD**: Interview guide FGDs for leprosy-affected persons

Welcome, introduction

This focus group discussion covers several topics. We will ask some questions about your daily life, your culture and your social life. We will also ask some questions about your experiences with having to live with leprosy.

Knowledge on leprosy

1. I understand you have a disease related-condition, can you tell me what you know about your condition? Probing for cause and transmission
2. Do you think that contact with you might have any good or bad effects on others around you? *Probing:* Why/why not? What kind?

Social life

3. What obligations do you have towards your husband/wife? Probing: cooking, providing money, taking care of the children
4. What obligations does your husband/wife have towards you?
5. Do you feel that your condition has had any good or bad effects on your marriage? Can you explain?

Stigma/participation

6. Who did you tell you have leprosy? *Probing: family members, husband/wife, children, neighbours, friends, everyone.*

- How did they react?
- How do they treat you?
- How does that make you feel?

- Why did you not tell others?

7. Are people affected by leprosy invited to marriage events and celebrations? Why/why not?
8. Are you invited?
9. How does that make you feel?

Community

10. What are the attitudes of people in your community towards people affected by leprosy?
11. Are there any local beliefs around leprosy or the cause of leprosy in your community? Example?
12. How do they treat you?
13. How does that make you feel?

Experiences with and feelings about leprosy

14. Can you tell me something about how living with this condition affects your daily life?
15. Is there anything you can’t do because of your condition? Example?
16. How does that make you feel?

Personal feelings

17. With whom do you talk about your feelings?
18. Do you also talk to them when you are not feeling well / difficult times? *Probing:* If no, why not? Can you give an example of things you discuss during difficult times?

Mental wellbeing

19. Do you ever feel sad, afraid or worried? Why?
20. What makes you feel good? Example?
21. What makes you feel bad? Example?
22. Could you describe how you feel about yourself? Explain?
23. Do you ever feel ashamed or embarrassed? Example?
24. Has leprosy influenced your self-esteem or self-respect? Explain?

Support

25. Do you get support from family/friends when you are not feeling well?
26. How do they help you?
27. How does that make you feel?

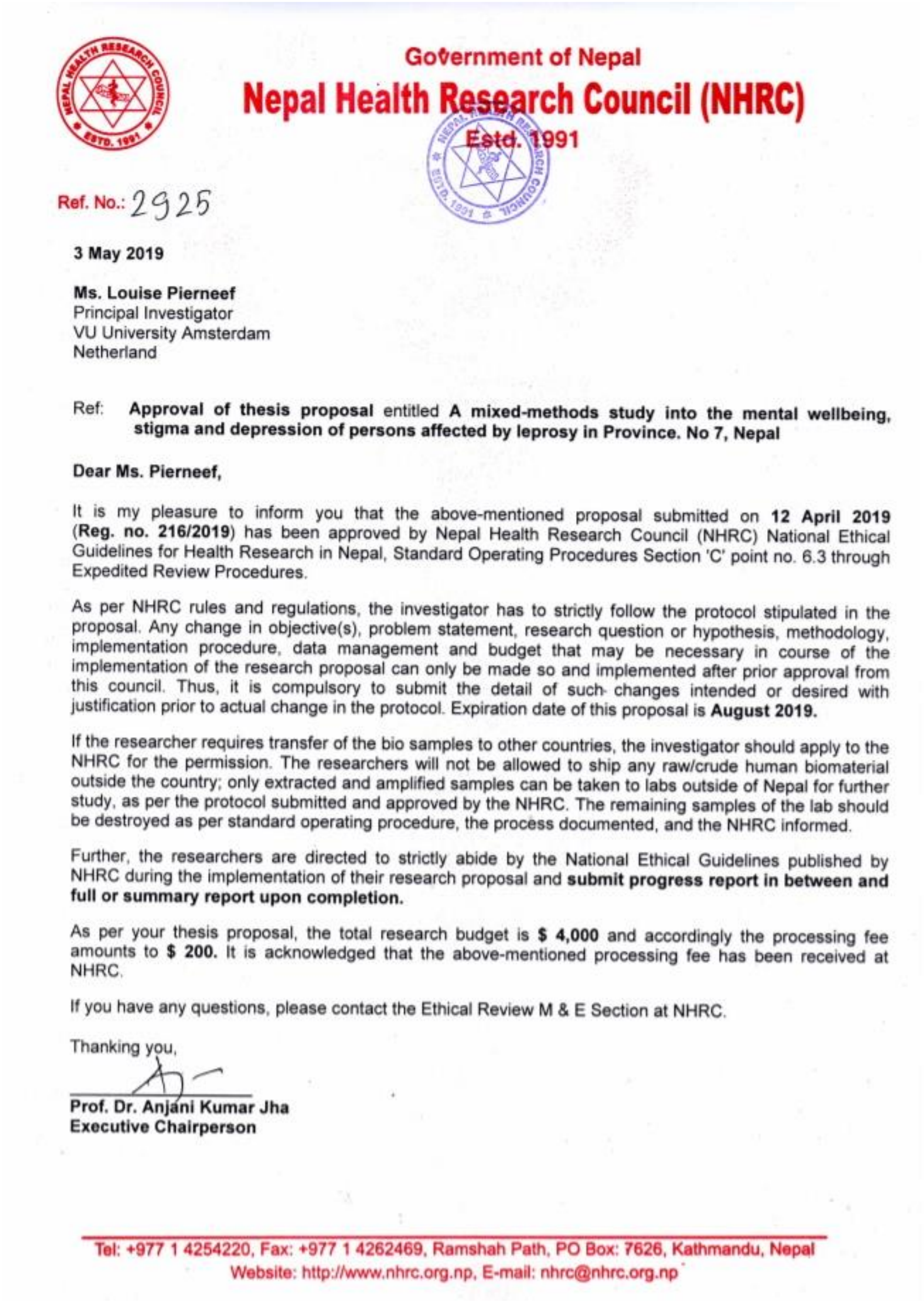
Future

28. What do you think about your future? *Probing:* Could you describe your feelings?

Final question

Do you have any questions about the interview?

Appendix 3. NHRC Approval Letter



Government of Nepal
Nepal Health Research Council (NHRC)
Estd. 1991

Ref. No.: 2925

3 May 2019

Ms. Louise Pierneef
Principal Investigator
VU University Amsterdam
Netherland

Ref: **Approval of thesis proposal** entitled **A mixed-methods study into the mental wellbeing, stigma and depression of persons affected by leprosy in Province. No 7, Nepal**

Dear Ms. Pierneef,

It is my pleasure to inform you that the above-mentioned proposal submitted on **12 April 2019** (**Reg. no. 216/2019**) has been approved by Nepal Health Research Council (NHRC) National Ethical Guidelines for Health Research in Nepal, Standard Operating Procedures Section 'C' point no. 6.3 through Expedited Review Procedures.

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol. Expiration date of this proposal is **August 2019.**

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission. The researchers will not be allowed to ship any raw/crude human biomaterial outside the country; only extracted and amplified samples can be taken to labs outside of Nepal for further study, as per the protocol submitted and approved by the NHRC. The remaining samples of the lab should be destroyed as per standard operating procedure, the process documented, and the NHRC informed.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and **submit progress report in between and full or summary report upon completion.**

As per your thesis proposal, the total research budget is **$ 4,000** and accordingly the processing fee amounts to **$ 200.** It is acknowledged that the above-mentioned processing fee has been received at NHRC.

If you have any questions, please contact the Ethical Review M & E Section at NHRC.

Thanking you,

Prof. Dr. Anjani Kumar Jha
Executive Chairperson

Tel: +977 1 4254220, Fax: +977 1 4262469, Ramshah Path, PO Box: 7626, Kathmandu, Nepal
Website: http://www.nhrc.org.np, E-mail: nhrc@nhrc.org.np

Appendix 4. Informed Consent Form (ICF)

Mode of administration	Verbal
Organization	Netherlands Leprosy Relief (NLR)
Address	NLR Nepal field office, Dhangadhi - P.O. Box-35, Dhangadhi Sub-Metropolitan City, Ward No. 5
Contact no.	091-522499
Nepali contact no.	+9779852033377
Title of study	A mixed-methods study into the mental wellbeing, stigma and depression among persons affected by leprosy in Sudurpashchim Pradesh of Nepal

Introduction
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 one hour. Do you have any questions so far? I would like to record this conversation to make sure I remember correctly what you have said, would that be ok with you?

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: __ / __ / __