

## Factors influencing the mental wellbeing of persons affected by leprosy in Far-Western Nepal

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### Summary

**Objective** To investigate factors that influence the mental wellbeing of persons affected by leprosy in Far-Western Nepal.

**Methods** The study used a cross-sectional design with a qualitative approach. Semi-structured, in-depth interviews and focus group discussions covering topics such as feelings towards and experiences with leprosy, mental wellbeing, knowledge about leprosy, social life, community, culture and future outlook were employed. The data were analysed using Framework Analysis and Thematic Open Analysis.

**Results** A total of 25 persons affected by leprosy were included in the in-depth interviews and 13 persons participated in focus group discussions. We found that participants often experienced stigma and/or mental distress. 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 included discrimination, social support, religion, participation (restrictions), (in)ability to work, community attitudes, knowledge of leprosy and cultural beliefs about the disease.

**Conclusions** This study revealed that the majority of participants faced leprosy-related stigma, physical discomfort, restrictions in social participation and mental distress. We recommend the development of interventions such as counselling after diagnosis with leprosy, increasing leprosy awareness and knowledge, addressing negative attitudes and beliefs in the community and stimulating social participation.

**Keywords:** Leprosy, mental wellbeing, stigma, culture, community, participation, social life

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## Introduction

Leprosy is a neglected tropical disease (NTD), caused by *Mycobacterium leprae*. Leprosy is still endemic in many parts of the world, with over 200,000 new patients diagnosed annually.<sup>1</sup> The disease is believed to be transmitted predominantly via the respiratory route and mainly affects the skin and peripheral nerves. Nerve damage may result in (often permanent) physical impairments, including visible disfigurements.<sup>2,3</sup> Although leprosy can be cured with multidrug therapy (MDT), permanent physical impairments have often already been incurred due to lack of timely diagnosis and treatment.<sup>4</sup>

In addition to physical impairments, persons affected by leprosy often experience social stigma.<sup>5-7</sup> The stigma associated with leprosy can affect various aspects of a person's life, such as employment, marriage and social participation.<sup>8-11</sup> Many persons affected by leprosy also report being socially rejected and insulted,<sup>12-14</sup> which may result in mental ill health.<sup>15</sup> This is reflected by the fact that psychiatric disorders and psychosocial problems including depression, anxiety disorders and suicide (attempts) are common among persons affected.<sup>16-21</sup>

In Nepal, more than 3,000 new leprosy cases are still diagnosed each year.<sup>1</sup> Over 83% of leprosy cases in Nepal are among persons who reside in the Terai districts, which include Kailali and Kanchanpur districts of Sudurpashchim Pradesh.<sup>22</sup> In 2017, these districts accounted for the highest prevalence of leprosy in Sudurpashchim Pradesh, in addition to Achham (0.8 per 10,000 inhabitants of the population).<sup>23</sup>

Multiple studies have reported on leprosy-related stigma in Nepal.<sup>5-7</sup> A study in South-East Nepal found that women affected by leprosy experienced problems in their marital and sexual relationships because of their condition. These included negative attitudes, discrimination, violence, and problems related to fear of the disease.<sup>8</sup> Moreover, it has been reported that in Nepal, persons affected by leprosy have a significantly lower level of mental wellbeing in comparison to the general population. Depression was more common in affected persons, and severity of depression was associated with the individuals' disability grade.<sup>20</sup>

Attention to leprosy and distribution of resources to fight leprosy are of great importance in public health. Unfortunately, needs assessments of individuals who have already been affected by this often disabling condition are lacking.<sup>24</sup> As described above, various studies show that leprosy, disability, stigma, and mental wellbeing are closely linked.<sup>11,12,25</sup> In this study, we use mental wellbeing as synonymous with mental health, defined as "a state in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community".<sup>26</sup>

Given the lack of specific data on mental wellbeing and stigma among persons affected by leprosy in Western Nepal and in-depth studies describing the factors influencing this, the aim of this study was to increase knowledge regarding the (personal, social/daily life, and cultural) factors that influence mental wellbeing of persons affected, in this region. These data could then be used in the development of interventions aimed at improving their mental wellbeing.

## Material and methods

### STUDY DESIGN

The study used a cross-sectional design with a qualitative approach. In-depth, semi-structured interviews and focus group discussions (FGDs) were conducted. The FGDs served as an addition to the interviews, as this type of data collection allows observation of the interaction between participants and an assessment of what are majority views or experiences versus individual opinions or experiences.<sup>27,28</sup>

## STUDY SITES

This study was conducted in Kailali, Kanchanpur and Achham districts of the Sudurpashchim Pradesh province of (Western) Nepal. 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.<sup>29</sup>

## STUDY POPULATION AND SAMPLE

This study focused on persons affected by leprosy. Individuals were included if they were above 18 years of age and resident in the Sudurpashchim Pradesh province (Far-West Province) of Nepal. Exclusion criteria were: unable or unwilling to give informed consent, 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) as we were interested in factors that influenced the mental wellbeing of individuals affected by leprosy, specifically. Persons who had completed their leprosy treatment as well as those who still received treatment were included in the study to capture a complete overview of persons affected. Participants were recruited by staff of NLR Nepal who introduced the researchers to health coordinators in charge of health clinics in Kailali, Kanchanpur and Achham districts. They in turn contacted persons affected by leprosy and asked consent of potentially eligible participants. Sampling was purposive, with maximum variation in order to capture within-population variations. We aimed to include people with a range of levels of mental wellbeing, which was assessed with the WEMWBS, which measures mental wellbeing<sup>30</sup> and the PHQ-9,<sup>31</sup> which is used to assess depression severity. These questionnaires were administered by another researcher working on the quantitative part of this project (manuscript in preparation). We aimed to include participants who varied in age, gender, religion, education, and disability grade.

## DATA COLLECTION

Leprosy-related impairment was scored using the WHO maximum grade.<sup>32</sup> Hands, feet and eyes can be scored 0, 1 or 2, indicating no loss of sensation, no visible deformity and no eye problems due to leprosy (grade 0), loss of sensation or eye problems due to leprosy but no visible deformity (grade 1), and visible deformity or severe visual impairment (grade 2).

Data were obtained by means of in-depth, semi-structured interviews and FGDs. 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.<sup>27</sup> As not all persons affected by leprosy had told their family members, friends and/or others about their diagnosis, they were invited to the health clinic so they could participate in the interview without disclosing their condition. All participants were interviewed by the same female Nepalese interpreter, who was experienced in working with persons affected by leprosy and in qualitative data collection methods. The interpreter received additional training from the authors.

For both in-depth interviews (IDIs) and FGDs, interview guide topics included feelings towards and experiences with leprosy, mental wellbeing, knowledge about leprosy, social life, community, culture and future outlook. For each topic, we attempted to explore the feelings involved on an in-depth level and understand how these related to participant's

mental wellbeing. These topics were based on a conceptual framework developed to show the relationship between NTDs, stigma and mental health.<sup>24</sup> This study mainly focused on steps 1 and 2 of the conceptual model, which include stigma, social exclusion, participation restrictions, disability and mental distress.

The interview guides of the IDIs and FGDs were translated from English to Nepali by persons familiar with the leprosy field and experienced in translating. Next, interview guides were translated back to English, and again translated into Nepali by a different translator.

Each IDI lasted about 30–45 min. Questions were adjusted by pilot-testing the interview guide with three participants; these data were also included in the dataset.

Two separate FGDs were held; one for men and one for women, to allow the participants to speak freely. The FGDs were led by the interpreter (MB) who also conducted the IDIs in an environment as comfortable and easy to reach as possible for the participants, such as a private room in a health clinic. Both the first author (LP) and a second female Nepalese facilitator (US) were present to collect data about (non-verbal) interactions between participants. Questions posed in the FGDs were mostly open in order to stimulate conversation.<sup>28</sup> Each FGD lasted approximately two hours.

All interviews were conducted in Nepali and audio-recorded. Interviews were conducted until no new information to address the research question was generated. After each interview, the researchers discussed whether data saturation was reached. Data was collected between mid-April and the end of June 2019.

#### DATA ANALYSIS

The recordings of the interviews were transcribed verbatim in Nepali and translated into English by the interpreter. Data were kept in a secure database, and no names or addresses of participants were connected to the data. Framework analysis was used, with predetermined themes based on the framework developed by Eaton mentioned earlier, giving clear direction.<sup>24,27</sup> When new themes arose, these were also included.<sup>28</sup> Transcripts were read multiple times before formal analysis. To place issues into context, interviews and analyses were discussed among the Nepali and Dutch researchers involved in the study. A coding scheme was developed based on Thematic Open Analysis. All information in the transcripts was coded by the lead author (LP). The qualitative analysis programme MAXQDA 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.<sup>27</sup>

#### ETHICAL CONSIDERATIONS

Before each interview and FGD, written informed consent was obtained, and 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. The study received ethical approval from the Nepal Health and Research Council (NHRC) under Ref. No. 2925.

## Results

#### CHARACTERISTICS OF THE STUDY SAMPLE

A total of 38 persons affected by leprosy were included in the study: 25 persons participated in IDIs and 13 participated in FGDs (see Table 1). In the IDIs, 12 men and 13 women were included. The mean age was 51 (range: 23–73 years). In the FGDs, six women and seven men

**Table 1.** Background characteristics of the study participants

	<b>In-depth interviews (<i>n</i> = 25)</b>	<b>Focus group discussions (<i>n</i> = 13)</b>
<b>Mean age</b>	51	41
<b>Median age</b>	53	36
<b>Gender</b>		
Female	13	6
Male	12	7
<b>Area of residence</b>		
Urban	19	12
Rural	6	1
<b>Marital status</b>		
Married	23	9
Widowed	1	2
Separated	1	2
<b>Religion</b>		
Hindu	20	12
Christian	5	1
<b>Level of education</b>		
Illiterate	12	1
Read and/or write only	7	7
Primary education	5	—
Secondary education	1	4
Higher education	—	1
<b>Employment status</b>		
Housewife	11	2
Farmer	6	5
Unemployed	5	1
Self-employed	2	3
Paid work	1	2
<b>Level of family income</b>		
No income	—	—
≤3000 Nepalese rupees/month	6	—
3001–5000 Nepalese rupees/month	5	1
5000–7000 Nepalese rupees/month	2	4
≥7000 Nepalese rupees/month	12	8
<b>WHO maximum grade</b>		
0	11	11
1	5	2
2	9	—
<b>District</b>		
Kailali	12	12
Kanchanpur	8	1
Achham	5	—

were included in separate group interviews. The mean age was 36 (range: 22–76 years). Most participants were married ( $n = 23/25$  for IDIs and  $n = 9/13$  for FGDs) and the majority of the participants in both groups were Hindu ( $n = 20/25$  for IDIs and  $n = 12/13$  for FGDs). Except for two IDI participants living in a leprosy village, all participants lived in urban areas. For IDIs, 11 persons had a disability grade of 0, five were graded as 1 and nine were graded as 2. In the focus groups, 11 participants had a disability grade of 0 and two were graded as 1.

PERSONAL FEELINGS AND EXPERIENCES RELATED TO BEING AFFECTED BY LEPROSY

Although the majority of the IDI participants ( $n = 16/25$ ) indicated that their families and others knew about their disease, some indicated that only their family members knew, and two women had only told their husbands. Reasons for not disclosing their disease status were fear of (negative) reactions from others and discrimination, as well as the feeling that there would be no advantage or need to tell others. One woman told her husband that she would commit suicide if he told anyone about her disease.

*Positive feelings*

Personal feelings reported to positively affect the mental wellbeing of persons affected by leprosy included feelings of hope and trust in the future, not caring about other people's opinion, not thinking/worrying too much, and feeling strong. One participant explained:

*"...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)

And one man in the FGD asked another participant:

*"...Why are you worried? Because everyone might have some disease, even God has some diseases. I don't worry at all ..."* (Man affected by leprosy, age 76)

*Negative feelings*

Most participants were aware of the presence of stigma around leprosy, and some of them had experienced stigma in some way themselves. This is illustrated by the following quote:

*"...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)

A number of participants in the IDIs and FGDs ( $n = 13/38$ ) reported that their self-esteem had reduced, mainly because they could not do things as they once did. In addition, many experienced feelings of shame. Participants explained that they felt ashamed about their physical appearance (e.g. patches on the skin or darkened skin colour from treatment), about being affected by leprosy in general, and about being unable to do the things they wanted to do. These feelings sometimes led to persons thinking that their disease reflected badly on family members.

*"...My eldest 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 the cause of that is. It might be due to us [the participant and his wife, both affected by leprosy] ..."* (Man affected by leprosy living in a leprosy village, age 72)

Participants also indicated that they worried about transmitting the disease to others and about not being cured. Quite a few participants said they thought about dying ( $n = 11/25$ ). Whereas a few were worried about death, others said they felt or had felt that it would be better to die than to live with leprosy. Most of the individuals reporting the latter had a grade 2 disability ( $n = 4/5$ ). One woman felt that it would not matter if she died. Some participants explained that being affected by leprosy was unbearable, because of disability, difficulties in meeting responsibilities and pain. One woman said:

*"...I am very sad, because I have a disability in my lower limbs. I think it is better to die rather than living with such a condition ..."* (Woman affected by leprosy, age 50)

## FACTORS REGARDING SOCIAL AND DAILY LIFE INFLUENCING THE MENTAL WELLBEING OF PERSONS AFFECTED BY LEPROSY

Over half of the participants mentioned the inability to do day-to-day activities as before, like cooking, farming or cutting wood. Most participants explained that this was caused by feelings of physical weakness ( $n = 17/38$ ).

*Positive factors*

Almost all participants indicated that they receive some form of support from family or others ( $n = 24/25$ ). Support came in various forms, from mental support to others taking over work. Most often, support came from the participant's spouse.

A few participants from IDIs and FGDs ( $n = 4/38$ ) told us that they got married to their partners after receiving their diagnosis. One woman had disclosed her disease and was about to get married. 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: "there is leprosy in your family" ..."* (Man affected by leprosy, age 71)

Several participants told us that persons affected by leprosy used to face discrimination and be forced away from their villages in the past, but the majority said that community members treat persons affected well right now. According to some individuals ( $n = 5/38$ ), there is more awareness, more knowledge, and a more positive attitude towards leprosy among the new generation. One man said:

*"...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)

*Negative factors*

Some participants mentioned that community members still discriminate and/or keep their distance from persons affected by leprosy. A negative attitude from in-laws was mentioned by a few women from IDIs ( $n = 3/25$ ) and the FGD ( $n = 3/13$ ), spreading unwanted rumours about them regarding 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)

A number of women ( $n = 7/19$ ) mentioned negative behaviour from their husbands, such as drinking, having fights or being unsupportive. This lack of support caused worries about the future for some participants, who were concerned that there would be nobody to take care of them. For some participants, the inability to work and provide for their family led to mental distress. One man explained:

*"...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)*

Although all but one of the participants said they were invited to wedding ceremonies and celebrations in their community, a few participants noted that they were not invited as often as before and some indicated that nowadays they do not attend. Participation restrictions were said to result from impairment or disability, feeling weak or having pain, and negative attitudes from the community. Being self-aware about their condition, some individuals restricted themselves. Illustrating this, one woman said:

*“...After having this disease, I usually don't visit my friends and they don't [visit me] 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)*

#### CULTURAL AND RELIGIOUS FACTORS AFFECTING THE MENTAL WELLBEING OF PERSONS AFFECTED BY LEPROSY

There were many beliefs about leprosy in the study area, such as the perceptions that leprosy is non-communicable, a genetic disease, caused by poor hygiene, transmitted through sexual contact, through water or by sharing food or clothes with persons affected. A few persons ( $n = 7/38$ ) thought that leprosy was their fate or bad luck. Some persons also mentioned that others in their community believed leprosy was a curse from God, caused by an evil spirit, or a curse or sins from their previous life. This was also mentioned in the FGD.

#### *Positive factors*

Cultural and religious factors reported to have a positive influence on mental wellbeing are finding comfort in religion and rejection of traditional beliefs around leprosy. When the interviewer asked the participants about their feelings towards local beliefs about leprosy, 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)*

Religion was reported to be helpful in relieving mental distress around the disease. Many participants said religion made them feel strong, relaxed and gave them a sense of control. 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)*

#### *Negative factors*

Traditional religious beliefs—especially the belief that leprosy is a sin or curse—had a negative impact on mental wellbeing. These beliefs were often related to incorrect knowledge about leprosy. Beliefs caused participants to question themselves and caused mental distress. The belief that leprosy is caused by sins, for example, made participants wonder whether they

might have actually committed a sin. Some persons did not understand why they were affected by a disease that is considered to be God's curse. 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 two others 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)

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

## Discussion

In the current study, many persons affected by leprosy experienced mental distress, such as worry about their disease and its implications, feeling ashamed or embarrassed, and suicidal thoughts. Numerous studies in various countries have measured the prevalence of psychosocial problems among persons affected by leprosy,<sup>17–19,33</sup> among which depression was found to be most common.<sup>21</sup> Singh reported that psychological care of persons affected by leprosy was insufficient up to 2012,<sup>16</sup> and this still holds true for Far-Western Nepal. A study in China found suicide to be the major cause of death among leprosy patients.<sup>34</sup> Another study reported that suicidal thoughts were more apparent among persons with visible impairments.<sup>35</sup> This could explain the findings in our study, where four out of the five participants who felt they would be better off dead had a grade 2 disability.

Some participants in our study kept their disease hidden from society and only shared it with those closest to them as they were aware of and/or feared the stigma surrounding leprosy, which was also found in a similar mixed-methods study in Western Nepal.<sup>7</sup> Furthermore, participants in our study reported signs of internalised stigma, such as feeling ashamed about their disease or physical appearance. Similarly, previous literature describes that people with leprosy might feel ashamed due to community attitudes and deformities.<sup>12,21,36</sup> Several participants mentioned that darkening of the skin, a side effect of leprosy treatment, was a reason for shame. This was found in another study as well.<sup>37</sup> In some Asian and South American countries, fair skin is preferred.<sup>38</sup>

Participants also indicated that they participated less in the community because of fear of negative reactions to their condition from others. This was supported by another study in Nepal by Adhikari and colleagues.<sup>7</sup> In the present study, participation restrictions seemed to result mostly from physical weakness, impairments or disability. Some individuals were unable to work and earn enough money to provide for their families and this resulted in mental distress. A study in Indonesia, also described that the main problems in the area of participation restrictions and stigma among persons affected by leprosy were shame, difficulties in employment and marriage-related problems.<sup>9</sup> Self help groups<sup>39</sup> could potentially be helpful as these have been found to improve mental wellbeing and reduce stigma, by improving a person's self-esteem, dignity and social status in the community.<sup>20,40–42</sup>

Whereas other studies found problems with marriage, such as divorce<sup>43,44</sup> or problems for persons affected by leprosy or their children to find a marriage partner,<sup>9</sup> most individuals in our study indicated that they did not experience such problems. Only one woman was separated

from her husband due to her leprosy, many years ago. Another man was worried about his eldest daughter not being able to find a marriage partner due to his and his wife's leprosy status. However, this was not reported more often. On the contrary, a few men and one woman got married after their partners heard about their disease and another woman was about to get married. This could possibly be explained by the fact that most participants had no visible impairments. Moreover, according to the participants, their partners had adequate knowledge about the disease (about treatment and cause). Interviewing life partners of persons affected by leprosy about their perspectives on this would be interesting, but was beyond the scope of this study.

A few participants who did experience negative behaviour from their partners—drinking (too much) alcohol, having fights or being unsupportive—were all women. Similar behaviour was described in a study among married women in Eastern Nepal.<sup>8</sup> Several studies found leprosy and leprosy-related stigma to have a bigger 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.<sup>12,16,36,45,46</sup> A co-researcher working on the quantitative part of this study found both affected and unaffected women to have poorer mental wellbeing than men.

We found that social support from family and community members was very important to the persons affected by leprosy and was often linked to positive feelings. As suggested by other studies as well, these findings indicate the importance of including family and close friends in interventions that aim to improve the mental wellbeing of leprosy-affected individuals.<sup>12,47,48</sup>

Noteworthy is that the participants in the present study said there was less stigma now compared to the past. This was believed to be due to greater awareness and exposure to education about leprosy in the younger generation, which has been recently described by Marahatta *et al.*<sup>49</sup> The authors found that leprosy awareness among community members in Lalitpur district of (Central) Nepal had increased in recent years, and discrimination was believed to belong to the past. Studies have found a significant link between adequate knowledge and positive attitudes towards leprosy.<sup>50-52</sup> Nonetheless, in our study, negative attitudes towards leprosy were still mentioned by approximately half of the participants, indicating that the stigma surrounding leprosy is still a problem here. Participants indicated that little to no information about leprosy was provided by the health clinics. In addition, there were many local beliefs about the cause of leprosy.

We found knowledge about leprosy to be poor among the communities as well as persons affected by leprosy in Far-Western Nepal. Many cultural or religious beliefs around leprosy were found, and these often led to mental distress among persons affected. Some beliefs, such as leprosy being caused by committing a sin, made participants question themselves. Similar cultural beliefs were found among community members of persons affected by leprosy in Southern Central Nepal, including the perceptions that leprosy comes from bad blood, a curse or having committed a sin.<sup>50</sup> According to Raju & Kopparty, inadequate knowledge, understanding and negative beliefs regarding leprosy continue to fuel stigma.<sup>53</sup> This is also likely to be the case in Far-Western Nepal. Community leprosy awareness programmes using local media<sup>50</sup> and counselling after diagnosis with leprosy have been identified as successful strategies to reduce stigma<sup>54</sup> and, ideally, close relations should be included, given the importance and benefits of social support.<sup>55</sup>

Religion and, in particular, prayer, were found to be factors that helped people find peace of mind. According to the literature, religion often functions as a source of resilience in

mental health and illness.<sup>37,55,56</sup> However, certain religious beliefs can also be problematic, for example, believing that a disease is a punishment from God might lead to a delay in seeking treatment, as was found for individuals with HIV.<sup>57</sup> This should be taken into account when religious leaders are included in interventions.

#### STUDY LIMITATIONS

A limitation of this qualitative study is the specific geographical area, which limits the generalizability of our findings to the entire study population. However, we strived to improve the quality of this study by repeatedly giving the Nepalese interpreter feedback on interviewing skills and thoroughly discussing interview data and translation with her and other Nepalese colleagues. It should also be noted that the aim of this study was to get more insight into this topic in this specific area of Nepal, and findings may not be generalised to the entire population.

#### RECOMMENDATIONS

The information emerging from this study could be used in developing interventions to improve the mental wellbeing of persons affected by leprosy by taking the influencing factors into account. In our view, counselling after diagnosis with leprosy and including close relatives in this, is essential and should: (1) focus on explaining the aetiology of leprosy, the way it is transmitted and the benefits of treatment, thereby aiming to reduce the effects of cultural beliefs and stigma around the disease; and (2) strive to prevent and take care of mental health problems, such as the worries, shame and suicidal thoughts experienced by many individuals affected by leprosy. Finally, advocacy programmes to make the community more aware of leprosy, and interventions such as self help groups that focus on increasing employment options, economic empowerment, and social participation for persons affected, should be developed.

#### Conclusions

This study found that in Far-Western Nepal:

- (1) Mental distress was reported by many participants. This included shame, worries, fear, stress and suicidal thoughts. Many factors—such as (lack of) social support, participation (restrictions), activity (limitations), stigma, religion, cultural beliefs, knowledge and (negative) community attitudes were found to influence the mental wellbeing of persons affected by leprosy.
- (2) Stigma around leprosy still exists in different forms.
- (3) Both stigma and physical impairments can lead to participation restrictions and difficulties with work.
- (4) Knowledge about leprosy can positively influence attitudes towards the disease and likely, the mental wellbeing of individuals affected by leprosy.

#### Review board approval

This study received ethical approval from the Nepal Health and Research Council (NHRC) under Ref. No. 2925.

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## Conflict of interests

The authors declare no conflict of interest regarding the publication of this paper.

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## Author's contributions

WB, AvtN, LS, and LP conceived the research and designed the methods. AK, MP, MB, US, MS, and LP recruited participants. MB, US and LP collected the data and LP performed the analysis. LP wrote the manuscript. MW, WB, and AvtN edited the manuscript. All authors reviewed, discussed and agreed with the manuscript. LP is guarantor of the manuscript.

## Patient consent statement

Before each interview and FGD, written informed consent was obtained, and 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.

## Data sharing statement

Data were anonymized and analyzed by the investigators involved in the interviews (LP, MB, US) and were not shared externally.

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