

The Impact of Leprosy and Physical Disability on Marital and Sexual Relationships of Married Nepali Men

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ABSTRACT

Purpose: Both leprosy and disability can have a negative impact on a person's relationships. This study aimed to gain insight into the impact of leprosy and disability on marital and sexual relationships of married Nepali men.

Method: The study used a cross-sectional design with a qualitative approach. Thirty participants were selected using purposive sampling and put in 3 groups (10 in each group):

(1) men with impairments due to leprosy, (2) men without leprosy but with physical disabilities, and (3) men without leprosy or disabilities (control group). Data were collected during semi-structured interviews and two focus group discussions, and analysed with the software programme NVivo using structured coding.

Results: The majority of the men indicated they were satisfied with their marital and sexual relationships. However, some leprosy-affected men and some men with disabilities experienced friction in their marital relationships. Fighting between husband and wife was reported by half of the men affected by leprosy. Leprosy and disability had a negative influence on the sexual relationships of some of the men, because of physical limitations, pain, or decreased sex drive. Furthermore, many participants appeared to lack knowledge about the cause of leprosy and about sexual health.

Conclusion and Implications: Men affected by leprosy or disabilities seemed to face more problems in their marital relationships than men from the control group. This was primarily related to physical limitations which resulted in the inability to work; this threatened their personal and social identity. Findings

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show that there may be a problem in accessibility or availability of sex education. In addition, some marital problems could be related to lack of knowledge of leprosy. These point to the importance of providing education on leprosy and sexual health at the time of diagnosis.

Key words: *marriage, sex education, physical limitations, identity, friction, qualitative*

INTRODUCTION

Leprosy, or Hansen's disease, is an infectious disease (Han et al., 2008; Suzuki et al., 2012) that is closely associated with health inequalities and poverty (Bhutta, Sommerfeld, Lassi, Salam & Das, 2014). Common impairments caused by leprosy are impairments of hands and feet, and visual impairments (Pannikar, 2009). Leprosy is a stigmatised disease (Sermrittirong & van Brakel, 2014) Leprosy-related stigma and disabilities may result in participation restrictions and social exclusion of persons affected by the disease (van Brakel et al., 2006). The areas of life that are affected by stigmatisation include interpersonal relationships, marriage, mobility, and social participation (including education and employment) (van Brakel, 2003). Stigma and its consequences may also lead to reduced self-esteem (Brouwers, van Brakel & Cornieljeet al, 2011), lower (family) quality of life (van't Noordende, Aycheh & Schippers , 2020; van't Noordende, Aycheh & Schippers, 2020) and poor mental well-being (Somar, Waltz & van Brakel, 2020).

The areas of life that are affected by stigma are related, for example, loss of employment may lead to inability to support one's family (Brouwers et al., 2011) and to lower self-esteem (Rao, Rao & Palande, 2000). The areas of life that may be affected by leprosy are marital relationships and the sexual relationship that is embedded in a marriage (Christopher & Sprecher, 2000; Scott, 2000; Heijnders, 2004; Try, 2006). The quality of marital and sexual relationships is a major predictor of a person's psychological well-being (Tepper, 2000; Kim & McKenry, 2002). Research has shown that for women affected by leprosy, marriage prospects decline as a result of the stigmatisation related to leprosy (Heijnders, 2004). A recent study in Nigeria showed that leprosy can also influence marriage prospects of men affected by leprosy (Dahiru, Iliyasu, Mande, van't Noordende & Aliyu, 2021).

Both existing and future marriages may fail because spouses or (future) in-laws do not accept a person with leprosy in their family (Try, 2006; Dahiru et al., 2021). In addition, some studies have found that leprosy may be a reason for divorce

(Scott, 2000; van't Noordende et al., 2020; Dahiru et al., 2021). A study in Nepal found that women affected by leprosy experienced violence and abuse from their spouse (van't Noordende et al., 2016). In addition, a study among women in Indonesia found that leprosy can negatively impact sexual health (Susanto, van 't Noordende, van Brakel, Peters & Irwanto, n.d.). No other studies were found on experiences of persons with leprosy regarding their sexual relationships. However, there are studies on the impact of disability on marriage (Tepper, 2000). Tepper (2000) found that persons with disabilities are excluded from sexual relationships because they are viewed as asexual, childlike, and in need of protection. They found that persons with disabilities are excluded because the main objective for having sex is thought to be reproduction, and persons with disabilities are regarded as unsuitable for reproduction and therefore thought not to be in need of sex.

Several studies have shown that both leprosy and disabilities may influence people's marital and sexual relationships. However, no study has specifically looked at the impact of leprosy on the marital life of men. The current study aimed to gain insight into the impact of leprosy and disability on the marital and sexual relationships of married Nepali men. This was done by comparing the experiences regarding marital and sexual relationships of married men with impairments due to leprosy, married men with disabilities not due to leprosy, and married men without leprosy or disabilities.

METHOD

Study Design

This study used a cross-sectional design with a qualitative approach, in order to gain an in-depth understanding of the experiences of Nepali men regarding their marital and sexual relationship.

Study Site

The study was conducted in Morang district, Nepal. A total of 3,054 new cases were detected in Nepal in 2016 (WHO, 2018). In 2016, Mahottari, Jhapa and Banke districts had the highest case detection rates, 4.7 in 10,000 population respectively (Health Management Information System report 2016). There are still sixteen districts that are considered high endemic for leprosy.

Study Population

There were three groups of participants in this study:

(1) Men with impairments due to leprosy, (2) men without leprosy but with physical disabilities, and (3) men without leprosy or disabilities (control group). These three groups of men were included in the study to be able to distinguish the effect of leprosy from that of disabilities in general and from other cultural factors.

Inclusion criteria:

- All participants had to be married men or men who had been married.
- All participants had to live in Morang district.
- Men affected by leprosy were included only if they had a Grade 1 disability (G1D, loss of sensation without visible impairments) or Grade 2 disability (G2D, visible impairments or disabilities) based on the WHO's leprosy disability grading system (WHO, 1988).

The study defined impairment as 'problems in body function or structure such as a significant deviation or loss' and disability as 'an umbrella term for impairments, activity limitations and participation restrictions'(WHO, 2001). Men were considered to have a physical disability if the disability was obvious to the community, based on appearance and/or if the disability caused limited functioning.

Exclusion criteria:

- Men below the age of 18.
- Men unwilling or unable to give informed consent.

Sampling Procedure

Participants were selected using purposive sampling. The participants affected by leprosy were reached through Morang district's local health clinics that provided extensive lists of men affected by leprosy. Men with disabilities were reached through local disability organisations and contacts of NLR Nepal in Biratnagar, Morang district. Men from the control group were recruited in the same villages as the other participants, based on their similarity to the men affected by leprosy and the men with disabilities, in terms of marital status, age and living area. Participants were included until data saturation was reached.

Data Collection

Data were collected through semi-structured interviews and focus group discussions (FGDs) that were conducted in May and June 2016. Interview guides were prepared based on previous research conducted among Nepali women (van't Noordende et al., 2016) and discussions with leprosy specialists. The interview guides were translated from English to Nepali. Back translation to English was done by another interpreter and checked to ensure the Nepali translation was accurate. The data were collected by two local male interviewers who were trained before conducting the interviews. Two pilot interviews were held before conducting the actual interviews in the home or in a private space in the village of the participants. All men affected by leprosy and men with disabilities who participated in the in-depth interviews were invited to participate in a focus group discussion (FGD) also.

Two FGDs were conducted - one with men affected by leprosy and one with men with disabilities. One facilitator (who also conducted the in-depth interviews) led the discussion, while another researcher wrote down the key information that was discussed. The main topics for the FGDs were the same as for the interviews and were complemented by key topics emerging from the interviews. Due to the sensitive nature of the study topic, the (female) first author (MJM) was not present during the interviews. Each in-depth interview and FGD lasted approximately one hour.

Data Analysis

The in-depth interviews and FGDs were audio-recorded, the recordings were transcribed verbatim and then translated into English by the two interviewers. The data were analysed through a structured coding that was based on the predefined topics of the interview guide. The coding of the transcripts was discussed with another researcher to determine that the coding was appropriate. In the coding process, first of all the translated interview transcripts and notes were read to get a feel for the data. Afterwards, initial codes were given to the experiences of the Nepali men. The next step was to try and identify the pre-defined themes of marital and sexual relationships in the codes which formed the coding scheme. Furthermore, the different experiences were categorised according to the three participant groups and the disability grade for the men affected by leprosy. The software programme NVivo was used to analyse the data. The findings of the FGDs were coded in a similar fashion and added to the information from the interviews.

Ethical Considerations

Ethical approval was obtained from the Nepal Health Research Council (approval number 97/2016) before this research was begun. Participants had to first sign an informed consent and, if they were not able to do so, verbal consent was voice recorded.

RESULTS

Demographic Information

Thirty men were included in this study: 10 affected by leprosy, 10 with disabilities and 10 in the control group (see Table 1). All participants were married at the time of the interview. The mean age of the participants was 35 years. Of the total sample, 17 men had an arranged marriage and 13 men had a love marriage. The majority of the participants were Hindu (n=26) and the majority (n=25) had at least one child or more. Seventeen participants lived in a single household consisting of only one family, whereas 13 were part of an extended family, which included grandparents and/or sisters and brothers. Of the men affected by leprosy, 5 had a G1D and 5 had a G2D.

Table 1: Demographic Information of the Participants

	Men affected by Leprosy (n = 10)	Men with Disabilities (n = 10)	Men from the Control Group (n = 10)
Age , mean (range)	32 (21-42)	38 (27-48)	35 (23-50)
Highest education completed			
No education	4	2	0
Primary	4	2	1
Secondary or higher	2	6	9
Employed			
Yes	7	8	10
No	3	2	0
Religion			
Hinduism	10	6	10
Other ^a	0	4	0
Living area			
Rural	5	5	8
Urban	5	5	2
Type of marriage			
Arranged marriage	7	3	7
Love marriage	3	7	3

^aThis includes Christianity (n=2), Islam (n=1) and Kirat (n=1)

Of the 9 men who indicated that they had received sex education, 6 were without leprosy and disabilities. One man with leprosy received sex education via school, and 2 men with a disability received sex education via an NGO. Other ways in which information on sexual health was obtained were via television, radio, books and relatives. All men affected by leprosy were diagnosed with the disease during their marriage. The median time since diagnosis was four years. However, 9 men with disabilities already had a disability before getting married. Five out of 10 men affected by leprosy were open about their leprosy status. Among the remaining men, only the wife and/or close family knew about their leprosy status.

Four men affected by leprosy and 8 men with disabilities (see Table 1) participated in FGDs. One FGD was held for men affected by leprosy and there was one FGD for men with disabilities.

Experiences regarding the Marital Relationship

Men affected by Leprosy

The men affected by leprosy indicated that they were satisfied with their marital relationship and that they considered their marriage very important. All of them were diagnosed with leprosy after marriage and most of them said their wives supported them after the diagnosis. One participant said:

“No, I wasn’t treated differently. In fact, my wife helped me a lot. She helped me to follow the doctor’s advice and there was a gradual improvement in me” (man affected by leprosy, 34 years old, G1D).

All the men affected by leprosy explained that they still went to the temple and attended marriage ceremonies and other social activities regardless of their disease. In addition, 8 men indicated that their community did not discriminate against them, while 2 men said they did not know how their community members felt. However, in the FGD, some men indicated that they had heard that other persons affected by leprosy were discriminated against by their community members. Most men were satisfied with their role in their household, as most were still guardians of their families because they could still earn money.

However, some men experienced problems (e.g., friction and shifting of family roles) in their marital relationships because of leprosy. These problems were said to occur because their spouses did not know about leprosy and distanced themselves. In addition, inability to work because of physical limitations was

mentioned as a cause for marital problems. This created friction in households because the wife or other family members became primary breadwinners, which meant they were also guardians of the house and in charge of making decisions. In Nepal, the men are traditionally seen as the head of their household. One man explained:

"I can't go to my work due to my leg. Neither can I pull a rickshaw. I am living on my wife's income. It's almost eight or nine years she is working. Now she is frustrated too. She tells me to get well soon and do some work. Many people offer me jobs, but I can't accept them. I am a man, but I can't do my duty, play my role. I can't take care of my family. Other people say that I live on wife's earnings" (man affected by leprosy, 42 years old, G2D).

Participants indicated that physical disabilities and (negative) community perceptions about leprosy could cause problems in marriage. Almost half of the men affected by leprosy told us they were afraid of getting (additional) disabilities in the future, which could cause marital problems because of possible unemployment and negative perceptions from the community or their in-laws. Participants indicated that negative attitudes of the family-in-law would have a more severe impact on the marital relationship than negative attitudes from the community. For example, in some cases participants indicated that the wife would be excluded from her family if she would not divorce her husband. One man, who already had a disability, explained:

"My mother-in-law had told me to divorce her daughter and she told her daughter that she would arrange another boy to marry her. My wife says, 'before his physical condition it was good but it is bad now. How can I leave him alone now, I will stay with my husband.' Now we live together and we have a good relationship" (FGD with men affected by leprosy).

Four men affected by leprosy (and one man with a disability) spoke about fights between husband and wife. Most of these men (three out of four) indicated that they do not drink alcohol. However, one man indicated that *'small violence'* occurred within his marriage; this was related to alcohol.

"I don't have much money so I don't drink usually. When I meet my friends and when I have money, I drink. I consume alcohol two to three times a week. (...) There is small violence, not big. But it's not for a long period (...) the reason (for the violence) was alcohol" (man affected by leprosy, 42 years old, G2D).

During the focus group discussion, one more man affected by leprosy (and one more man with disability) admitted he was sometimes violent towards his wife and that this was related to drinking alcohol.

Men with Disabilities

Nine of the men with disabilities said they were satisfied with their relationship with wife and children. All except one already had a disability before getting married. Most men said they were content with their household situation as they were still able to earn money and were still guardians of the family. Furthermore, except for one participant in the FGD, all participants said there was no violence in their marriage. Many participants said that they drink alcohol regularly.

Even though the men were happy with their relationship with their wives, negative attitudes from the families-in-law or the community caused difficulties in three of the marriages. One man explained:

“Her parents did not agree and we did not get family support from her family, so now she also has difficulties with her family. If a person has good physical condition and just passed class 8 and has not got a good reputation in society, and another person is physically weak and is educated and has got a good image in society, even then they will prefer to give their daughter to the (man with a) good physical condition” (man with disability, 38 years old).

Two men with disabilities indicated that negative attitudes from others do not only influence marriage prospects, but also have an impact on daily activities with their wives.

“Yes, we will go together to social and cultural activities. However, our society is still narrow-minded regarding disability. They indirectly take notice of us, but when they know me then they regard me positively” (man with disability, 38 years old).

In addition to negative attitudes causing problems in the marital relationships, half of the men were unable to work or had difficulties in working because of their physical limitations; this was said to cause problems in the household. Some participants mentioned that they were afraid of being unable to work in the future because of possible disabilities later on. One man explained that his wife handled all finances because he could not work and thus did not earn any money; he was unhappy with his role in the household because of his disability.

“At present, I do not do anything for my family due to my disability. I can't earn, walk, work like others. I want to talk with others, but they won't come and talk with me. Actually I can't do anything so there is no reason to be happy. I am very unhappy. My wife brings food from her father's house” (man with disability, 46 years old).

Another man underlined the traditional role division in Nepali households and how his role was different from other men because of his disability.

“Yes, there is much difference with others. A son has to go out of the home and do different kinds of physical work. There is a lot of difference between a mobile person and an immobilised person. If I were a normal person then I might go to Korea and earn 100,000 per month” (man with disability, 38 years old).

Men from the Control Group

All men without leprosy or disabilities said they were satisfied with their marital relationships and underlined the importance of marriage. They experienced no problems in their households. However, 4 men did mention problems that they heard were common in other households, namely extramarital relationships and alcohol abuse.

“Yes, I am happy. Some people go with another girl and ignore their family, but I am not like them” (man from the control group, 23 years old).

Three men mentioned that they drank alcohol. All of them said they were not physically violent towards their wives. However, 2 men did elaborate on being aggressive or having intense verbal fights with their wives. One man explained:

“No, there is no violence, but sometimes there will be an intense fight due to a financial problem. But I don't drink or smoke” (man from the control group, 25 years old).

In addition, one participant indicated that he is sometimes violent towards other people, but not to his wife.

Experiences regarding the Sexual Relationship

Men affected by Leprosy

All men indicated that they were satisfied with the sexual relationship with their wife. Nine men mentioned that their wife shows empathy regarding leprosy and

their sexual relationship. Though all men developed leprosy after getting married, 7 indicated that they experience no difference in their sexual relationship because of leprosy. In addition, the reported frequency of having sex was similar to the reported frequency of the other participants in the study; having sex once or twice a week was reported most often.

All men indicated that they themselves and their spouses were sexually satisfied, and that there was no sexual violence. However, despite mentioning that they were satisfied, some participants indicated that leprosy did influence their sexual relationship. For some men, leprosy was said to have decreased their sexual desire.

“She shows empathy and she never pressures me to have sex with her. The desire to have sex might be less after leprosy. So there is a difference. Before I had leprosy I was fresh and I had more desire for sex, but after taking medicine I feel that I have less interest in sex and less desire. My wife requests me not to have sex because I am weak, so sometimes I don’t feel good” (man affected by leprosy, 27 years old, G2D).

Eight of the men affected by leprosy did not know the cause of leprosy. It was unclear how much their wives knew about leprosy. One participant said he experienced difficulties with his wife because she did not know about leprosy:

“At first she did not know about leprosy. After I told her the effect of leprosy and its treatment, she understood all and now there are no problems. Before she was scared as she didn’t know about leprosy, but I told her that it won’t transfer after the treatment. Slowly there is positive change” (man affected by leprosy, 38 years old, G2D).

Participants indicated that personal problems were only discussed with their wife or the doctor. Seven men said they did not talk about sex at all with friends.

“If a problem arises relating to sex, then I will consult with a doctor in the health post. If I consult with friends then my problem will not be solved, so I have to consult with a doctor. If I have a mood of having sex, then in that situation only I talk to my wife, in other cases we do not talk (about sexual problems). With friends I talk about other people’s sexual relations, but we do not talk about our own sexual relation” (man affected by leprosy, 37 years old, G1D).

One participant with leprosy had received formal sex education. While 2 men said sex education was not of importance to them, 8 men did find sex education important because of disease transmission and because sex is seen as an important factor in marriage.

“Yes, all men and women have to take sex education; if we fail to take sex education we may be unsuccessful in our marital life” (man affected by leprosy, 33 years old, G1D).

Men with Disabilities

Though all men said their wives showed affection and empathy regarding their sexual relationship and their disability, several problems were mentioned which were all directly related to their physical disability. Common problems were being limited in acting on sexual desires or having no sex at all, and feeling pain or feeling no pleasure. One man said:

“Yes, there are lots of difficulties, we can have sex in natural way, but we cannot have sex using different methods that normal people do nowadays to satisfy their wife. We cannot do a different style” (FGD with men with disabilities).

One man, who acquired the disability after being married, mentioned he did not have sex anymore due to his disability. Another man explained that he does not experience pleasure from sex:

“No, I don’t experience pleasure. My wife has to make my leg straight after having sex. There is pain, it is difficult to have sex as (my body) below the hip is not working. My wife used to say ‘this disability should be for me, not for you’ but she is happy” (man with disability, 43 years old).

Participants said they mainly discussed these sexual problems with their wife and the doctor. Some did talk to friends about sex in general. In addition, all men underlined the importance of sex education. Reasons mentioned were to raise awareness about diseases and contraceptives and because many men had extramarital sex. One man said:

“Sex education is important because many people have sexual intercourse with many girls. It teaches us about how to have sex with other girls (safely). Many diseases are caused by sex and protection from it is necessary” (FGD with men with disabilities).

Furthermore, all men denied there was sexual violence in their marriage. However, during the FGD, 3 men did talk about sexual violence towards women with disabilities. One man said:

“There are many women suffering from sexual violence due to the speech problem. Some years ago there was a woman who could not speak and a boy convinced her and took her to a place where no one came. He had sex with her and killed her there” (FGD with men with disabilities).

Men from the Control Group

The men without leprosy or disabilities were overall satisfied with the sexual relationship they had with their wife. All thought that a sexual relationship was very important in a marriage and that mutual understanding was needed in order to have a good sexual relationship. One man elaborated on his sex life, confirming he had extramarital sex:

“I have sex two or three times in a week. We can live without getting married but we cannot live without sex. I have had sex for the first time when I was 15 and till now I have had sex with a lot of girls. If I get the opportunity to have sex with a girl, I will. Why not?” (man from the control group, 38 years old).

Most men indicated that they talked to their wife or doctor in case they experienced any sexual problems. In addition, all men said they also talked to friends about sex. Topics that were discussed included sex methods, contraceptives and the number of sexual partners. Eight participants thought sex education was important, of whom 6 had received formal sex education themselves. Sex education was said to be important given the increase in sexual violence and extramarital sex, and to get knowledge about sexually transmitted diseases. One man elaborated on the importance of sex education:

“Yes, sex education is important, because nowadays there are many diseases that can be transmitted through sex. Many people are interested to have sex with another girl other than their wife and they may suffer from such diseases” (man from the control group, 45 years old).

Sexual violence was not mentioned by any of the men in this group. However, 2 men did talk about the decision-making regarding sexual intercourse.

“Until now there is no sexual violence, because she is my wife. Why do I have to force her to have sex, I can have it next time also if she does not have desire. Firstly the male decides about having sex and only then the female makes a decision about it” (man from the control group, 26 years old).

DISCUSSION

Similarities among the Three Participant Groups

This is the first study specifically addressing the influence of leprosy and disability on marital and sexual relationships of married men in Nepal. As in other studies conducted in Nepal, marriage was considered to be of utmost importance by all

men, and embedded in their culture (Sharan & Valente, 2002). The majority of the men in this study indicated that they were satisfied with their marital and sexual relationships. All men indicated that sexual relationships were of importance in a marriage. The majority of the men in this study had not received sex education; however, many considered this important. Finally, some men in each participant group said they drank alcohol regularly.

The Impact of Leprosy and Disability on Marital Life

The majority of the men in this study said they were satisfied with their marital relationships despite having had leprosy or having a disability, and that they still participated in social events. However, some men experienced difficulties in their marriage (e.g., friction and shifting of family roles) because of negative attitudes from either their wife or community members towards their condition or associated physical impairments. This is similar to findings from a review by one of the authors (van Brakel, 2003). While most men affected by leprosy had not experienced discrimination, negative attitudes from the community did have an impact on men with (visible) disabilities, because they would be recognised and stared at in public. Indeed, visible impairments are often linked to negative perceptions and stigma (Zeldenryk, Gray, Speare, Gordon & Melrose, 2011; van Brakel et al., 2012; van't Noordende et al., 2019; van't Noordende et al., 2021).

In some instances, the family-in-law would not accept a man affected by leprosy or disability and would ask their daughter to leave him. Though several studies mention that existing or future marriages may fail because (future) in-laws do not accept the person with leprosy or disabilities, this was rare in the present study (Scott, 2000; Try, 2006; van't Noordende et al., 2020; Dahiru et al., 2021). It could be that divorce occurs more often when women have leprosy or disabilities (Try, 2006; Brouwers et al., 2011; Dijkstra, van Brakel & van Elteren, 2017). However, it should be noted that most likely divorce due to leprosy or disability was not found in the present study because only married men were included as participants. In addition, all but one of the men with disabilities already had their disability when they got married. This is an important difference between the men with disabilities and the men affected by leprosy in this study, because a condition that is already there at the time of marriage may be less likely to cause changes and friction than a condition that develops during marriage. At the same time, the diagnosis of leprosy can be a traumatic experience which occurs at a given point in time, and therefore the impact on people's marriage may be different from, for example, people who have a disability since birth.

Some men affected by leprosy or disability had difficulties working or providing for their family, or were afraid of being unable to work because of their physical limitations. This is similar to findings from other studies (van't Noordende et al., 2020). Inability to work resulted in a division of tasks in the households – the role of the man as guardian was taken over by other family members. Although this is not something that has been explored in-depth, perhaps this may have threatened the personal and social identity and self-esteem of the men, as has been found in other studies (Major & O'Brien, 2005; Goffman, 2009; Scambler, 2009). From other studies it is known that being able to work increases people's social value, and promotes dignity, independence and engagement in daily (social) life (Ebenso et al., 2007; Dadun et al., 2017; van't Noordende et al., 2021). Being able to work again after loss of a job can also increase the acceptability of persons affected by leprosy by their family and community members (Rao et al., 2000).

The Impact of Leprosy and Disability on Sexual Relationships

In the present study, men said that they were satisfied with their sexual relationships and the frequency of having sex was similar in all participant groups. These findings appear to contradict the conclusion of Tepper (2000), who found that people with disabilities are excluded from sexual relationships because they are seen as childlike or asexual. This may be because of sampling bias in the present study: only married men were included, and most men with disabilities already had their disability when they got married. However, the study did find that leprosy and disability had a negative influence on the sexual relationships of some of the men because of physical limitations, pain or a decreased sex drive.

Fighting between husband and wife was reportedly common among the married men affected by leprosy. Two men affected by leprosy admitted they were sometimes violent towards their wives. In another study by one of the authors (van't Noordende et al., 2016), married women affected by leprosy indicated that their husbands were violent towards them, which was often related to alcohol abuse and their leprosy status. In the present study, participants indicated that violence was linked to drinking alcohol but given that this was mentioned by only two participants, there is no clear indication that alcohol abuse resulted in violence towards the spouse. In addition, it should be noted that verbal fights with the wife were also mentioned by participants in the group of men without leprosy or disabilities.

A study among women affected by leprosy in Nepal found that a lack of knowledge about leprosy, insufficient access to sex education and the negative perception of leprosy can negatively influence marital and sexual relationships of persons affected by leprosy (van't Noordende et al., 2016). This is similar to the findings in the present study. In addition, poor knowledge of leprosy is associated with negative attitudes towards persons affected by leprosy in general (Seshadri, Khaitan, Khanna & Sagar, 2014; Singh, Singh & Mahato, 2019; van't Noordende et al., 2019). In the present study, insufficient access to sex education was not unique among men affected by leprosy or men with disabilities; it was something found in all participant groups. However, given that a lack of knowledge about leprosy likely had a negative influence on marital and sexual relationships of affected persons, persons affected by leprosy (and persons with disabilities) would benefit from specific sex education focusing on what they can (and sometimes cannot) do and addressing misconceptions about their condition (e.g., that leprosy is not sexually transmitted).

Limitations

The authors believe that the use of both individual interviews and FGDs increased the validity of this research. Future research on leprosy and sexual health should make use of the advantages of FGDs when addressing personal issues. A limitation of this study is that some answers were superficial and needed follow-up questions for more in-depth insights, but sometimes these questions were not asked.

Finally, a limitation of this study is that the sampling was not random and therefore the results of this research specifically apply to this study sample and cannot be generalised. There were differences in demographic information between the participants in the study. For example, men from the control group had, on average, received more education and all were employed. In addition, in contrast to the men affected by leprosy, most men with disabilities already had their disability when they married. For this reason, it is not possible to draw firm conclusions regarding the differences and similarities experienced by the men affected by leprosy and the men with disabilities on the basis of the data. It is unclear how much of the experiences of participants were determined by the fact they had leprosy or disabilities – it cannot be ruled out that some differences may have been caused by other factors. A larger follow-up study using random sampling will need to clarify how much of the impact on marital and sexual

relationships can be attributed to leprosy or disability; this is an important topic for future research.

CONCLUSION

Findings from this study confirm that marriage is an important aspect in the lives of Nepali men. The results of this study indicate that men affected by leprosy and men with disabilities face more problems (friction and shifting of family roles) in their marital relationships than men without leprosy and disabilities. The negative impact on their lives was primarily related to physical limitations, which resulted in an inability to work and threatened their personal and social identity. Furthermore, there was a lack of knowledge about leprosy as well as a lack of sex education, despite the fact that almost all men considered the latter important. This shows that there may be a problem in accessibility or availability of sex education. Some marital problems are possibly related to lack of knowledge of leprosy, which illustrates the importance of providing education on leprosy and sexual health at the time of diagnosis. An important topic for future research is a quantitative study which addresses both the frequency of marital and sexual problems among married men affected by leprosy and disability, and the risk factors for such problems.

ACKNOWLEDGEMENT

The authors would like to thank the interviewers Sagar Bhattarai and Raj Kumar Majhi, NLR office staff Smritee Bhandari, and the study participants for their contributions to this research.

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

The data that supports the findings of this study are available on request from the corresponding author (AvtN).

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