

ORIGINAL ARTICLES

**GENDERED EXPERIENCES: MARRIAGE AND
THE STIGMA OF LEPROSY**

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ABSTRACT

Stigma is rife in many areas of health and healthcare and it has implicit impacts that are often overlooked. Due to the continued social construction of the stigma of leprosy, it is clear that a greater understanding is needed of how stigma is experienced. This study considers the experiences of marriage of those vulnerable to stigmatisation due to leprosy and more specifically identifies different experiences of leprosy-affected women and men and the possible implications.

INTRODUCTION

The stigmatisation of those suffering from leprosy continues in Nepali societies and is a contributing factor to Nepal's relatively high prevalence rate of 3.04 in 10 000 (1), although it is feared the true rate is much higher than official estimates. In this area, the main ethnic group are the Maithili. There are an estimated 33.4 million Maithili people, of whom about 2.6 million live in Nepal.

There has been recognition of the detrimental effects that stigma may cast over women's prospects of marriage (2,3,4,5), but this will also be dependent upon the cultural context. However, research that specifically focuses on the impact of stigma on gender differentials of marriage is minimal, and the author is unaware of any that directly considers the stigma of leprosy in this context.

Marriage in Hindu culture expresses the value of fertility and reveals the status, caste and kinship structures. Therefore, it is understandable that leprosy would have an effect on experiences of marriage for persons with leprosy and their families.

Marriage is one area that may be affected by 'courtesy stigma' (6), where close family and friends of a stigmatised individual also suffer stigmatised behaviour. Bainson et al. (3) suggested

courtesy stigma of leprosy does occur, while research has found courtesy stigma deriving from a disabled individual can affect the chances of marriage for siblings (2).

The situation of girls and women with leprosy must be placed within the socio-cultural context which affects female status in general (7). Every society perceives health and disease differently and this local context plays a significant role in the construction of stigma. Evidently, the specific culture of a community or society will affect the widespread attitude towards leprosy (8). In many Hindu societies, including Nepal, leprosy is still “conceived as divine retribution for past sins” (9). Accordingly, serious consideration must be given to how religious and cultural beliefs influence the construction of the stigma of leprosy and consequently affect the disclosure of symptoms and the access to healthcare.

RESEARCH DESIGN

The research was undertaken at the Lalgadh Leprosy Services Centre in Janakpur District, South East Nepal. Field workers and hospital staff assisted in the organisation of the research, which used predominantly qualitative methods.

The research illustrates a selection of experiences of leprosy-affected people, rather than representing a wider population with participants being selected both on the recommendation of staff and randomly.

Data collection

A set of nineteen semi-structured interviews, with nine men and ten women were conducted in Nepal over a six-week period. Both Nepali and Maithili are spoken in the area, so a translator was used for the interviews. Following experience gained in pilot interviews and in accordance with Maithili culture, all interviews were gender segregated - male translators and interviewers were used with the men and vice versa. The interviews were recorded for reasons of accuracy following the consent of all participants.

Analysis

Data analysis was undertaken using thematic or ‘content analysis’, which identifies key themes and frequency of themes in the content of the interview transcript texts. The analysis process was closely connected to and supplemented by concepts identified prior to data

collection, and the key themes are linked to the wider context of the aims, objectives and research questions of the study. The analysis was structured by the key themes identified from the data and uses material from the interviews to illustrate and support the discussion.

Limitations encountered

Conducting interviews through translators raised the most concerns for the research process. The main risk was that the information obtained through translators may not be accurate. Inevitably, the direct translation of certain words, phrases or concepts often did not exist, so the translators had to re-phrase the question to obtain the information required. Such limitations highlight the importance of careful preparation for interviewing, as well as the value of recording the interviews, to cross-check the information given by the participant.

Ethical statement

It was essential for those involved in this research, to recognise their ethical obligation to prevent any harm to the participants, especially as the topics of research are of a sensitive nature. Consent to take part was gained from all participants and all participants were assured of their anonymity and were free to withdraw from participation, or withdraw any previously gained data, at any time.

FINDINGS

The key themes to emerge from the data were: Stigma: Perceptions and Behaviour; Marriage; and Attitude and Expectations.

STIGMA: PERCEPTIONS AND BEHAVIOUR

Theoretically and practically, stigma was the core element of the data and research. Two aspects of stigma - the perceptions and beliefs about leprosy and stigmatised behaviour - are inextricably linked, despite being considered here as separate components.

Perceptions

Perceptions of leprosy include beliefs about what causes the disease, how it is transmitted and the cognitive reactions that encourage the stigmatisation of individuals. Gender differentials of perceptions were detected through cultural behaviour, awareness and

understanding of normal gender relations. Normal can be defined here as conforming to the usual, regular or typical standard.

Beliefs

The interview excerpts are referenced in the following manner: (Male 15) indicates that the quote is taken from interviewee number fifteen who was male. A plethora of beliefs about the causes and transmission of leprosy were revealed. The fear of transmission was evidently the main cause of concern, as previous research also found (10). These fears were based on prevailing inaccurate beliefs.

It is still commonly believed, that touch is the main cause of transmission; yet other beliefs deem that transmission occurs through food, water, air and faeces. As one participant described:

“Usually when they [bathers at the river] saw me, they put their hands on their face [because] they thought that if they didn’t do like that the disease would be transmitted to them. They were thinking leprosy was very infectious disease, it could transmit through contact, through air, or faeces.” (Male 15)

One man was warned against sleeping next to his wife as “even the sweat transmits the disease” (Female 4). Another participant told how his work colleagues believed “...it is transmitted through air, urine and defecation. So, if you work with us we could get this disease” (Male 17).

Along with fears of transmission, beliefs of how leprosy is caused play a significant role in generating stigma against affected individuals. The Hindu belief that leprosy is a punishment for sins committed in a previous lifetime (9), was also common:

“I had been asking with God that what did I do so he gave me this type of punishment” (Male 15).

If it is believed that the individual is responsible for their leprosy, because of sinful behaviour in a past life, then this will influence the way society responds to leprosy-affected individuals. A previous study in the same area around the Lalgadh Leprosy Services Centre found that 77 % believed that individuals were responsible for their leprosy (11). Such perceptions of the causes of leprosy have implications for courtesy stigma and the effects on marriage. Therefore, not only has such a nasty disease affected individuals, but the belief is that they

must also have been sinful people to bring it upon themselves, rendering such individuals unattractive for marriage.

Gender Perceptions

The dominant patriarchal nature of Nepalese society creates an interesting setting for research into gender differentials. In contrast to the distinct gender perceptions identified by Rao et al. (5), there was a range of opinions justified on biological and social grounds, as to whether leprosy-affected men or women suffer more. In addition to opinions that either men or women suffer most, an equal number of participants felt that leprosy places an equal burden on both.

“They both get equal treatment. They force them to live an isolated life on the bank of some river or a solitary place. People don’t discriminate between males and females. If they have leprosy, they get equal treatment” (Male 1).

“Be it a male or a female, the treatment is the same. As far as I can see both sexes are treated the same way. They are ignorant people who treat differently. Wise people don’t have stigma” (Female 16).

One male identified the greater impact of leprosy on women’s than men’s lives, even though it was he who had contracted the disease:

“My wife was faced with so many big problems than me. Nobody wanted to keep her in their house, she did not get anything, she did not manage anything, because still female are dependent on men, if men refused to help her then how could she survive. Man can survive with a small piece of cloth but female can’t. I heard that many of female who had leprosy they isolated from community, they had to stay on side of river in a hut and died there, even they had their sons. No one tried to protect her” (Male 15).

This statement reflects this man’s awareness of gender roles and relations and the cultural boundaries that exist for men and women in society. It also shows that he feels women are treated worse if they have leprosy, as they are already dependent on others for their living. As one woman observed, “women suffer more” [because] “After marriage, husband is everything for a wife” (Female 19). Male dominance in society and the household, over

important decisions, income and other household members, allows men to retain more respect than women if they become stigmatised due to leprosy.

Behaviour

Two key aspects of stigmatised behaviour were identified: those people performing actions in accordance with their perceptions (family, community, work colleagues); and the type of behaviour. Existing gender relations should be recognised when considering behaviour towards leprosy-affected individuals. Negative behaviour towards leprosy-affected males and females was evident from both male and female family and community members. There was no apparent gendered pattern of those targeted by negative behaviour, at least not in this study.

An important distinction must be made between behaviour in the domestic and public arenas. The domestic sphere is the focal point of family interactions and activities. Family members come into close contact with one another through these interactions and activities. Therefore, it is within the household, that stigmatised behaviour is often most acute towards those affected by leprosy. Half of the participants recognised a difference in the behaviour of family members since their diagnosis of leprosy (Male 1, Female 4, Female 5, Female 8).

The everyday activities of cooking, eating, housework and sleeping arrangements were affected to varying degrees for most individuals (also shown by Rao et al. (5), and specific to Nepal (10) de Stigter et al.). Restrictions over usual behaviour associated with the preparation and consumption of food was a widely identified problem. Both men and women were prevented from eating within the vicinity of other family members and eight participants told how a separate set of utensils was put aside for use only by the leprosy-affected individual.

The expected gender roles for men as wage earners and women as carers and home-keepers are strictly upheld in Maithili culture, more so in rural areas, where most participants were from, than in urban settlements. In accordance with socially expected roles, leprosy-affected females experienced more restrictions on their daily activities within the domestic sphere. This is to be expected, as the majority of women's work is centred around the household, whereas men's role as primary income earner increases his value to and within the family, reducing the impact of stigma on their status.

More men than women, complained of being stigmatised by family members. This is probably because women are socialised to conform and accept their culturally assigned subservient role from childhood (5) and therefore, may be more accepting of imposed restrictions than men. Women are accustomed to restrictions on their movements and spend much of their time within the home, undertaking the duties that are expected of them. Furthermore, if a woman is forbidden from doing the very activities that ultimately defines her position in the household, her worth is immediately drawn into question (5).

Within the community, dominant perceptions generate fear among groups, which often escalates leading to collective action to banish affected individuals from the village: (Male 13), (Male 17), (Female 18).

“My villagers told me that I could not stay in village. I had to stay in outside of my village” (Male 13).

The research showed that many of the changes in behaviour by families towards leprosy-affected individuals were reflected in community-based stigma. Again, changes were most apparent through restrictions over usual (usual in this sense is understood as something that occurs on a regular daily, weekly or monthly basis and is expected or accepted of that individual) activities, such as sitting amongst people (Male 15), access to public water sources (Female 11, Male 15) and even access to roads:

“I was not allowed walking through main road. So usually I came to my house from cottage through side road and after taking food I returned through same road” (Male 15).

Such public displays of stigmatised behaviour perpetuate fear, reinforcing false beliefs, which in turn, encourage stigmatised behaviour at the household level. Yet again, the common perceptions and beliefs combined with the shock and fear of leprosy, drive these changes in behaviour.

Summary

The findings show, that perceptions and behaviour act to mutually reinforce each other. Preconceived ideas and beliefs affect cognitive responses and these responses and the primary perceptions about the disease lead to certain types of behaviour. There are cognitive

dimensions, which stimulate varying responses to leprosy and the responses, which affect behaviour towards the stigmatised individual.

Beliefs and perceptions can be identified and therefore differ at the individual, family, community and society level. The stigmatisation process will also be shaped by the cultural, religious and social characteristics of the society within which it develops, “not simply the biological characteristics” of the disease (8).

MARRIAGE

Marriage is a significant aspect of Maithili culture. It was found that the stigma of leprosy does have an impact on marriage for leprosy-affected individuals and also on the marriage prospects of relatives (courtesy stigma). The data revealed mixed experiences of marriage.

Support

Despite evidence of a number of failed marriages as a result of leprosy, an equal number of cases of support (includes emotional and financial support) were seen. Notably, the support females received was mostly from relatives rather than their husbands. A woman’s father, mother, uncle or siblings were more likely to defend her against criticism (Female 8), take her food when excluded from the family (Female 5, Male 9), or accompany her on hospital visits (Female 18), than her husband. There were two examples of support from husbands; in one case a husband was supportive initially, but eventually left (Female 5). In another case a husband was supportive, but he too was leprosy-affected (Female, 8). Unwavering support from wives to their husbands was much more evident (Male 7, Male 13, Male 17, Female 19). Often, this full support was in spite of pressure from family and community members to leave their leprosy-affected spouse. Conformity and acceptance of gender roles in Maithili culture, is one explanation for why women appear less likely to leave their leprosy-affected husbands, than men are to leave their leprosy-affected wives.

Marriage Failure

As other studies have indicated or speculated (2,3,4,5), it was found that leprosy is detrimental to marriages, both existing marriages and for the marriage prospects of unmarried individuals. The arranged marriage of one participant was cancelled when his future in-laws found out he had leprosy, despite his completion of treatment:

“All arrangements for my marriage had been done in the village where I used to work. Then...the whole village came to know that I had leprosy. So, the marriage could not take place” (Male 3).

There were four cases of marriage failure, of which three husbands left their leprosy-affected wives and one wife left her leprosy-affected husband. This is lower than the third of leprosy-affected individuals who were deserted by spouses in previous research (12). Still, in each of the cases, the reason for the spouse leaving was the fact that their wife or husband had been diagnosed with leprosy. Again in all four cases, the separation was not immediate, but occurred after a period of a few months, following diagnosis. During this time the wife or husband was pressured to leave their leprosy-affected spouse (Female 4, Female 5, Female 16, Male 15, Female 19, also Waxler, (8) 74).

The only male participant whose wife left him, described in-depth the time when his marriage broke up (Male 15). In this case, much pressure was put upon the wife to leave her husband. His leprosy was used to justify her decision, which was further strengthened by the fact that they did not have any children. It is interesting to note, that it was not only the wife’s family but also members of his own family that were persuading her to leave him. Her parents clearly preferred their daughter to divorce rather than stay married to her leprosy-affected husband, this in a society that regards divorce as a harsh fate for a woman. The uncle of one participant forced her to stay at her husband’s house despite abuse causing her “mental problems” (Female 5). But for the uncle this “...was not so big problem for him as divorce” (Female 5).

In addition to family pressure, wounds were often the cause of marital tensions. One participant believed that her husband left her because of her disease, but more specifically he left at a time when she had more ulcers (Female 5). Ulcers are a common visual signifier of leprosy and generate fear of the disease.

Secrecy

During the time of a marriage, high levels of secrecy about leprosy, were evident. This secrecy was driven by fears of not finding a bride or groom for their children or relatives. Many of the participants said they had hidden leprosy when they married, or when arranging the marriage of a family member (Female 8, Female 4, Male 13, Female 18). One man

talked about his sister's marriage and the precautions taken by his leprosy-affected father to conceal his disease:

“On the day when my sister was married my father stayed on the farm. Came back in the night, ate, slept and when he woke up in the morning, he again went to the field. This is the secret why they didn't know” (Male 6).

In the arrangement of her son's marriage one woman did not disclose her and her husband's leprosy to the bride's family, as she believed that, “if we disclosed the truth we were afraid he would have to stay unmarried” (Female 8). Concerning her granddaughter's marriage prospects, she feels there should not be a problem “...if they [prospective grooms] are ignorant of our having disease” (Female 8), which is possible, as they have no visual signs of leprosy.

Again, the prevalence of visual signs of leprosy is important, this time in affecting the opinion of prospective partners in arranged marriages. One study showed that 85% of women left home to prevent courtesy stigma affecting their daughters' chances of marriage (13).

Culture, marriage and gender relations

It is clear that in Maithili and Nepali culture, it is undesirable to marry someone who has been or is affected by leprosy. The gender implications of these findings are significant, especially in terms of marital relations. The dependence of a wife upon her husband is demonstrated in the case of a woman whose husband left her when he found out she had leprosy. She returned and stayed at her parent's house for the following ten years. She then decided that it was her husband's duty to care for her, so asked him to take her back despite him having remarried. She now lives as a house-worker with her husband, his second wife, their children and in-laws. She wants to stay with him because she wants him to take care of her (Female 18). This woman realises her dependence on her husband and her status within society as a single woman, so would rather endure the verbal and physical abuse (Female 18) of her current situation than return as a disgrace to her parents' house. Other women expressed the difficulties faced by leprosy-affected women in marriage:

“Female will be faced more difficulties than male. Because feeling of male and female is not equal. Male is more selfish than female, they think that if wife will get leprosy

then he could be get another wife easily, but female can not get another husband easily. Yes male can earn and there is much option for them but for female after marriage there is no other choice” (Female 13).

This illustrates the culturally acceptable marriage options for men and women and highlights the cultural restrictions women face in earning income and being dependent. Both these points indicate firstly, that it is unacceptable for a woman to leave her husband (for any reason), and secondly, that even if she does, she is likely to face many restrictions, whereas remarriage is not an issue for men.

Maithili culture permits men to remarry easily, yet as discussed, divorce for a woman is highly undesirable, degrading her status in society. So when leprosy is the reason for divorce, this places her in an even more vulnerable position (14). Remarriage for a female leprosy-affected divorcee is difficult. When asked if she thought she would remarry, one woman thought she would have problems in remarrying because she would not be accepted: “Even if I like someone he will not accept me because I am a leprosy-affected person” (Female 19).

One young girl remarried only months after her first husband left her, as she felt that she might not get a chance to marry again. Her second husband is also leprosy-affected (Female 5). Another young man felt:

“I think I will not be able to find a girl without leprosy, because they will doubt if I could be able to support her, but I am hopeful I will get a girl who had been leprosy affected. And if we have good understanding, we can lead good life” (Male 1).

Courtesy stigma and marriage

The transfer of stigma to those associated with a stigmatised individual, labelled, ‘courtesy stigma’ (6), was most often found to affect the families of leprosy-affected individuals (Male 1, Male 13, Male 15, Female 16). Threats against the safety of a family were used in three cases to force the family to expel the leprosy-affected individual from the village:

“Then my villagers forced to my uncle, they said “Your nephew have leprosy, so what will you do either you kick him out or you have to leave this village. That time my uncle

requested me that I should leave this village otherwise he will be in trouble, so my uncle also afraid about it” (Male 13).

Courtesy stigma was also found (in five cases) to be detrimental for the prospects of marriage of unmarried family members as also suggested by Vlassoff (13). One woman believes as well as causing the end of her own marriage, her leprosy will affect her siblings’ prospects of marriage. She also explains the actions, which are proposed to avoid any problems for the weddings.

“They also said that if I remain with their family no one would come to marry them, if I am around, no body will be ready to offer his son or daughter to my sisters and brother. I had been to my parents’ home a short while ago. During that time negotiation for the marriage of my younger sister was in progress. The family members were discussing over the problem as to what to be done with me, because if I am there, it could create some problem in the marriage. So, I should be kept in Lalgadh during the marriage so that the groom side will not know about me. They will not invite me to attend the marriage. They’d say that I am married somewhere and because of some problem, I couldn’t attend the marriage. My parents think that there will be some problem if they called me.” (Female 19).

Courtesy stigma is also causing secrecy about leprosy to protect the future of family members. No evidence was found of courtesy stigma leading to the break up of a marriage, but it was found to have prevented marriages from being arranged. When one couple was searching for a bride for their son, many proposals were offered, but nothing ever materialised (Female 8), as the community had told the prospective families that she and her husband were leprosy-affected. Another participant was told to leave the village “...because it might cause problem in the marriage of [his] brothers and sisters. It hurt me so I left” (Male 3). Evidently, pressure is placed on both the affected individual and his/her family.

From her experience this non leprosy-affected person believes that in marriage, women face more courtesy stigma than men:

“If boy is from leprosy colony (In this context the boys and girls are not leprosy-affected themselves, but live with their families at the leprosy colony) and he is educated

then he can marry with non leprosy colony girls and girls may not think about his background, she will accept it. If girl is from leprosy colony and wants to marry with non-leprosy colony person he will see her background, whether she is educated, good status, anything. I have seen lots of leprosy colony boys have married with non-leprosy colony girls and having a peaceful life, but I have seen many didi's [older sisters] marry non-leprosy colony guys, and when they found out they are from leprosy colony they left them. And also many girls got hatred from the husband's family" (Female 2).

It was also found that men are more able than women to gain social standing, to challenge the negative perceptions of courtesy stigma due to their leprosy-affected family, through educational and economic progress. This research found evidence that leprosy-affected males are more able to retain some respect, whereas women's status is degraded.

Dowry

Dowry, a gift to the bridegroom's family before the first wedding ceremony, was discussed by two participants; both felt that generally, leprosy-affected males should not expect a dowry. One male said that he did not expect to receive a dowry because he is affected by leprosy (Male 1).

From a female perspective, one participant believed that if a girl is leprosy affected then a larger dowry will be requested for her marriage:

"In Terai if you are from leprosy-affected family marriage won't happen and if they get married then lots of dowry will be asked for" (Female 2).

These examples reflect the lower status of a leprosy-affected individual in marriage. Families that accept a leprosy-affected person into their family expect compensation for doing so, either through larger dowries from leprosy-affected girls, or by not paying dowry to leprosy-affected grooms.

Summary

Cultural attitudes to marriage are central to the findings and that the traditional marital customs for men and women are strongly adhered to. It was evident that leprosy is more detrimental for married women than married men and the chances of remarriage for divorced leprosy-affected women are poorer in comparison with leprosy-affected men.

Leprosy adds another dimension to the marital position of individuals, both male and female. Underlying this, is a strong reflection of women's position in Maithili culture and how their status as an individual in society, a housewife and mother is degraded when she is also leprosy-affected. This in turn increases women's vulnerability to abuse and divorce (also proven for disabled women (14)).

These cultural and stigma based gender perceptions define the standards for males and females in the selection of marriage partners and automatically exclude certain families for consideration of an arranged marriage. The perceptions of the causes of leprosy also have implications for courtesy stigma and marriage. For instance, parents are unlikely to choose a bride or groom from a leprosy-affected family, if they believe that sins or bad spirits cause leprosy. Especially so, if as one family believed when a girl "...bears a child, even that child will have this disease" (Female 19), leprosy-affected brides will clearly be avoided.

Courtesy stigma was seen to cause tension between existing married couples and their families. Furthermore, the high level of secrecy about leprosy during the arrangement of marriages conceals the true extent of courtesy stigma. The existence of secrecy is a clear indicator of people's fears of courtesy stigma affecting their families' prospects of marriage.

ATTITUDES AND EXPECTATIONS

One recurring theme was the attitude and expectations of individuals. Though not directly applicable to the research objectives, through the data it became apparent that the individual's personal attitude towards their own situation and towards other people, influences their well-being and response to their disease. The specific context of an individual's perspective affects how each person processes and deals with knowledge and in this instance, the stigmatised behaviour they encounter. There were two distinct aspects: the ways in which a community stigmatises leprosy-affected individuals; and how stigmatised each individual feels in that situation.

Through recognition of individual attitudes affecting stigma, a distinction can be made between internal and external stigma. External stigma is expressed by society towards leprosy-affected individuals, which has comprised the majority of discussion on stigma in this study. Internal stigma occurs when an individual who is leprosy-affected or associated with a leprosy-

affected person feels stigma about their own disease or disability and therefore effectively stigma towards themselves. Internal stigma may be a result of inaccurate beliefs about the disease, or as a result of degradation by others.

Positive Attitude

A number of participants had positive attitudes, two men specifically, through their commitment to combating stigma and helping others, one through the self-help group he is a part of (Male 13) and the other through self-confidence (Male 9):

It is apparent therefore, that an individual's feelings about the stigmatised behaviour they face and how they deal with it, is as much about their personal attitude towards leprosy and themselves (internal stigma), as how society perceives and acts towards that individual (external stigma). Both members of a young married couple had positive attitudes and high expectations for their future, in finding work and building their own home (Male 3, Female 5). The wife felt they must forget the past (Female 5) and prove to everyone that they can make it, despite all they have been through (Female 5).

Internal Stigma

In four cases, internal stigma was evident and they all claimed they had experienced no external stigma (Female 11, Female 14). Yet still they made a conscious effort not to be around people (Male 7, Female 11, Female 14), because they felt uncomfortable interacting with others in the village who knew about their leprosy.

Understandably, constant experiences of negative behaviour and degradation may lower self-esteem. There were three cases of very low levels of self-esteem. One woman had a very low opinion of herself claiming: "I am not capable of doing anything", "Do you think I am worth doing something?" (Female 8). Another woman felt inferior because her deformed feet prevented her from working and hence removed her independence (Female 18). Again, the culturally defined male and female roles are exacerbated with the added dimension of leprosy. It also illustrates that within such a strict patriarchal society, women are more vulnerable to exclusion, self-stigmatisation and lower self-esteem than men, especially when leprosy is an additional source of internal stigma (16,17).

Summary

Internal stigma affects how individuals cope with external stigma, but it should also be recognised that external stigma can influence internal stigma.

The relationship between internal stigma, external stigma and the attitude of the individual is set in the context of the personal experiences and beliefs of each individual. This relationship lies at the centre of understanding how attitude and self-esteem play a crucial role in addressing stigma. An individual's positive and confident attitude towards their leprosy – as in the previous examples - can defy the actions of others, help to re-educate society about the disease, and reduce the stigma felt by that individual. This is an idealistic perspective and understandably, the poverty, reality and hardships of everyday life that so many people face, apart from leprosy, prevent or inhibit the ability to do this.

CONCLUSION

The stigma of leprosy remains an ingrained element of society, with family and community based stigma excluding individuals from activities and interaction. There are clear gender divisions in these restrictions which conform to traditional gender roles of Maithili culture. Such strict traditions were also influential over marriage and the impact of the stigma of leprosy on individuals and their families. Leprosy has a detrimental effect on some affected married individuals, while equal levels of support were also revealed.

Courtesy stigma was significantly concealed due to the secrecy surrounding leprosy at the time of a marriage. The fear of courtesy stigma, demonstrated through secrecy, indicates the considerable extent of the problem.

The attitudes of individuals, their experiences and current situation were found to be a significant element of how they cope with any stigma they face. This was an unanticipated result that emerged from the data and it would be interesting and valuable for further research to be conducted in this particular area.

A gender-aware approach is essential for the consideration of the problems specifically suffered by leprosy-affected women and men, in understanding how local culture can influence local perceptions and attitudes and therefore an individual's experiences of leprosy. Furthermore, such a gender-aware approach is vital to enable a full understanding of how

leprosy affects marriage for women more frequently and more seriously than for men, in recognition of the cultural context these experiences occur in.

Throughout all areas of analysis visual signs were found to be significant in causing stigma, especially in affecting prospects of marriage. This demonstrates a need for an emphasis on the prevention and reduction of deformity, as a part of a holistic approach to leprosy and stigma elimination.

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