Health beliefs surrounding leprosy induced foot ulceration; an exploratory qualitative study from South Nepal

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Summary
Leprosy is a complex and multi-faceted disease responsible for significant disability in several endemic countries. Physical impairments caused by leprosy are often amplified by local sociocultural phenomena in many parts of the world. In Nepal, sociocultural phenomena such as stigmatisation and health beliefs affecting treatment compliance and health seeking behaviours are known to play an important role in the acquisition of disability. Foot-ulceration is reported to be a common sequelae of leprosy, however, presently little research has been published investigating the potential influence of patient beliefs on management of foot ulceration in leprosy affected persons.

Objective: In light of this we conducted an exploratory qualitative study to investigate the health beliefs held by patients with foot ulceration at a Leprosy hospital in Nepal.

Methods: A mixture of open-ended interviews (n = 21), three focus groups and a series of field observations were used to explore the explanatory models of foot ulceration thought to be used by leprosy affected people to understand and explain this specific comorbidity.

Results: Our findings indicated that a wide range of health beliefs were present in our sample, many of which lie outside of the biomedical understanding of illness. This included a range of non-biomedical beliefs regarding wounds and widespread application of the traditional ‘hot-cold’ model of illness used to explain foot ulceration.

Discussion: The findings of this study appear to suggest many beliefs held by leprosy affected persons concerning foot ulceration are highly complex, with some expressed beliefs potentially having a negative impact on self-management of ulceration.
Introduction

The Neglected Tropical disease; Leprosy remains a highly prevalent disease in several regions of the world, one which continues to exert significant disability and morbidity on those affected by it.\(^1\) It has been estimated that around 4 million people worldwide are living with leprosy-induced disability.\(^2\) Nepal and the neighbouring Indian state of Bihar are two such areas where a high leprosy burden has been observed.\(^3,4\) In the context of these areas, the significant physical manifestations of leprosy are often also associated with severe psychosocial consequences, which can impose significant limitations on affected individuals. The synergy between the physical co-morbidities and the social consequences such as social stigma, is a well-known phenomena and makes leprosy a disease of considerable complexity.\(^5\) As such, the influence of social factors on morbidity in leprosy is greatly significant. Previous research shows that social phenomena such as individual and community wide health beliefs play an important role in the management of the disease.\(^6–8\) A wealth of research does exist concerning the exploration of health and illness beliefs in Nepal, which highlight the great cultural diversity of the nation, whilst also highlighting the prominence of a great many systems of belief regarding health and healing. Nepal and Bihar’s healthcare systems both presents several alternative models of healthcare, including biomedicine (western medicine), Ayurveda, Tibetan traditional medicine and a range of traditional shamanistic and religious healing services\(^9\) which may be used exclusively or synergistically by individuals seeking illness resolution.\(^10,11\) A well-recognised form of folk medicine present in in Nepal and Bihar is the ‘hot – cold’ model of illness.\(^12–15\) This model postulates that a balance of forces (hot and cold) within the body may govern an individual’s health. Qualities of hot and cold may be present in certain specific illnesses, weather, foods, herbs, emotional states and even forms of magic. As such, a ‘cold’ illness such as a cough may be managed by removing cold stimuli, avoiding cold food, and increasing exposure to hot stimuli or eating hot foods, with the converse being true for hot illnesses.\(^16\)

The influence of health beliefs on leprosy management has been previously explored with regards to various facets of the disease;\(^7,8\) however, little has been published in this area with a focus on the effects of leprosy on feet, namely neuropathic foot ulceration. Of the physical manifestations of leprosy, foot ulceration is a common sequela and strongly implicated in the acquisition of disability.\(^17\) In light of this, we set out to explore the beliefs held about foot ulceration and its resolution. Therefore our research aimed to obtain information about patient’s explanatory models which relate to patient behaviour and compliance with practices relating to management of the ulcerated foot.

Methods

The primary function of this study was to investigate and record the beliefs regarding foot ulceration held by leprosy patients at the Lalgadh Leprosy Services Centre (LLSC), a leprosy hospital located in the southern Terai region of Nepal close to the border of the Indian state Bihar. This was to be achieved by exploring patient’s explanatory models of illness concerning foot ulceration according to the model described by Klienmann.\(^15\) No process for ethical approval was required within this hospital but permissions were granted from the hospital director to carry out the study, with informed consent being gained prior to data collection. Data collection was performed by a visiting podiatrist (M. deSancha) and the
hospital’s councillor (K. Jha). A mixture of conversational style interviews, focus groups, informal discussions with patients and staff, and observation was used to collect data relating to patient beliefs regarding foot ulceration. A translator was used throughout the data collection phase.

Interviews were conducted over a 2 month period, with each interview taking between one and two hours. Twenty one participants were selected for interview, with the Maithili language used for nineteen interviews and two conducted in Bhojpuri. Participants were selected purposively for interview if they had:

- A previous or active diagnosis of leprosy
- Active neuropathic foot ulceration
- Willingness and sufficient systemic health to be interviewed
- Intact bony architecture of the midfoot*

*This criteria meant that patients with mid-foot collapse and rocker bottom soles or above ankle amputation were not interviewed.

The open ended conversational style interviews were conducted starting with the open question:

“How have foot ulcers changed the way you perform daily activities?”

This was followed by further questions to trigger further dialogue and keep the dialogue focused on the subjects of interest. The question guide was split in to four main sections arranged in the following order: Impacts and meaning of foot ulcers in life, explanatory models (for example, beliefs of foot ulcer etiology, treatment and prognosis), the community perspective on foot ulcers and perspectives and experiences of self-care. The topics and themes of the question guide were selected after a review of literature pertaining to health and illness beliefs in Nepal and northern India, as well as the clinical management of leprosy. In the early stages of data collection a provisional question template was used, however this was refined in the field based on early testing and subsequent observations, as well as being heavily informed by other health professionals working at the LLSC and by the lead author’s experience and background as a podiatrist.

Three focus groups were then undertaken to explore further the ‘hot-cold’ model of illness, which had emerged as an important theme. This decision to undertake focus groups after the interviews was to ensure that our interest in the hot-cold model of illness was not made explicit to participants during the interviews. It was felt that if participants knew of our interest in this model, subsequent interviews could be influenced; leading participants to overly focus on topics they knew would be of interest to us. The focus groups were undertaken with patients from the LLSC, some had been previously interviewed and some had not. The focus groups were conducted with two groups containing exclusively men (each group \(n = 8\)), with one group containing exclusively women \((n = 9)\). Criteria for hot-cold focus groups simply required that participants have an active or previous diagnosis of leprosy.

Additional observational data was collected by spending time in the outpatients department of the foot care clinic and leprosy wards having informal discussions with staff and patients, and observing patient behaviours. This supplemented the results of the interviews and the focus groups.
DATA ANALYSIS

Interviews were recorded using a Dictaphone. The subsequent conversations were fully transcribed to Microsoft Word files. Coding of transcripts was then performed so as to isolate information concerning themes which had emerged during data collection, as well as new themes which emerged during the transcription process and during review of transcribed data. Several codes were initially used, however the majority were dropped with analysis focusing on four codes which covered themes considered most important to the study aims. Important themes coded for included superficial information about the mechanics of illness as well as emergent patterns which aided the conceptualisation of more subtle aspects of the data concerning the expression of beliefs.

Results

SAMPLE NOTES

Of the twenty one interview participants (see Table 1 for demographics), only three participants were a member of a self-care group, with only one reporting regularly attending their group.

The average participant age was 45 years (range 21 to 80). The average ulcer duration was 2 months. The most common reported occupational state was unemployed, followed by farm labourer; 60% of the sample was illiterate and 90% were male; 19% of the sample was Indian (Bihari) while the remaining 81% were Nepalese.

FEATURES OF THE DATA

Initially it was hoped that data collection would yield information which would allow for concise description of explanatory models of foot ulceration. However, due to an overarching plurality and heterogeneity observed within the participant’s expressed beliefs, categorisation according to this means was not possible. Rather several phenomena emerged which exhibited some aspects of explanatory models, but often incompletely, allowing for identification and description of trends across the sample, as oppose to the catalogue of explanatory models as was initially hoped for. Many of these trending phenomena are highly complex and the approach of obtaining discrete individual explanatory models may be potentially reductive for this type of data. Three main themes emerged during data collection and analysis. The first was widespread descriptions of disease mechanics closely resembling those of the ‘hot-cold’ model of illness, referred to in relation to several facets of foot ulceration as well as the broader condition of leprosy. The second theme related to the ways participants felt their foot ulcers were distinct from the foot wounds of people who were not leprosy affected. The third major theme emerged from the multiple views and occasional contradictions many participants expressed. This plurality was apparent in several aspects of their interview responses and reflected in some behaviours observed in the research setting.

Discussion

The collected data yielded rich and diverse reflections on how foot ulcers and other aspects of leprosy has influenced and has become incorporated into these participant’s lives. Acquiring
Table 1. Key notes on sample description.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Sex</th>
<th>Occupation</th>
<th>District</th>
<th>Self care group member</th>
<th>Reported religion</th>
<th>Literate</th>
<th>Number of admissions over number of years</th>
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<td>Hindu</td>
<td>No</td>
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<td>Cook</td>
<td>Siraha</td>
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<td>Yes</td>
<td>8/15 years</td>
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<td>No</td>
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<tr>
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<td>M</td>
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<td>No</td>
<td>Hindu</td>
<td>No</td>
<td>3/1 years</td>
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<td>M</td>
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<td>Hindu</td>
<td>No</td>
<td>7/25 years</td>
</tr>
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<td>No</td>
<td>3/1 years</td>
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<td>Christian and Hindu</td>
<td>No</td>
<td>5/10 years</td>
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<td>Hindu</td>
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<td>No</td>
<td>4/2 years</td>
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<tr>
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<td>15/15 years</td>
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<td>Yes</td>
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information about their beliefs and explanatory models initially resulted in long narratives of the participant’s experience of suffering. This revealed a great amount of emotion but revealed little on their perspectives regarding the mechanics of disease. Research by Pigg highlights that for some Nepalese people; interpretation of illness begins with the experience of suffering, which is then interpreted to reveal the underlying process. This was taken into account and the subsequent interviews were structured to allow participants to talk freely about their experience of foot ulcers. This focus allowed many aspects of explanatory models to be better elucidated. This finding highlighted the considerable complexity of the participant’s views and emotions. Further, it revealed the way in which beliefs about the mechanics of illness were closely intertwined with biomedical knowledge, experiential factors and the broader philosophies concerning fate, destiny and religious faiths.

THE HOT-COLD MODEL OF ILLNESS

During interview, most of the participants appeared to express beliefs regarding various facets of foot ulceration which appear to fit within the previously discussed hot-cold model of illness. The majority of participants appeared to hold general hot-cold beliefs similar to those described in other Nepal based studies, with many illnesses fitting into hot or cold categories, each responding to treatments which re-established the normal balance of temperature. Cold illnesses included arthritis, paralysis, cough and running nose, whereas hot illnesses described included leprosy, gastritis, and allergies.

The majority of participants believed that foot ulcers were a ‘hot’ disease state. However, there was considerable variability reported regarding the extent to which ‘heat’ played a role in the etiology and management of ulcers. Heat was a commonly cited factor in the etiology of ulceration. Many participants reported that heat from various sources was responsible for making the affected foot hot. The most commonly cited sources were heat from sandals, walking and that the anaesthetic foot is prone to excessive warmth and heat accumulation. Many reported that walking long distances caused heat to build within the foot, sandals could also trap this heat and cause it to build further. Hot weather was another major factor, as this could make sandals hot, transferring heat to the foot. Heat within the foot would lead to blister formation, or rarely cause a heal crack, which in turn would give way to ulceration. The majority also felt that walking in the hot season was far more likely to cause ulceration than walking in the cooler months.

Levels of hot and cold exposure were also considered by the majority of participants as an important factor in the management of established ulceration. Hot and cold stimuli had to be treated carefully, as it was felt increasing exposure to heat could lead to ulcers growing in size, induce a fever and cause swelling. It was widely felt that hot foods could detrimentally raise levels of heat within the already hot body. Foods such as fish, pork, buffalo, eggs, black lentils, chilli, pumpkin, okra and mangos were considered ‘hot’ and detrimental to people with ulceration. Cold foods such as rice, bread, fruit juice, bitter melon and guava were preferred as these served to rebalance the internal temperature*. The majority of participants also expressed that they felt their wounds were considerably easier to manage, be more likely to heal faster and produce less discharge during the winter months.

*It is important to note that the terms hot or cold did not denote the temperature when served, rather this reflected a quality intrinsic to the particular food capable of influencing the temperature of the body.
In light of this, many participants felt that if cooling of the foot could be achieved, this would prevent ulceration. The majority considered that the soaking aspect of self-care served to remove heat from the foot, thus restoring normal temperature and preventing ulcer formation. During focus groups, participants were asked to identify what they thought was the most important aspect of self-care. Of soaking, oiling and scraping, the majority considered soaking to be the most important for this reason. Many also expressed that self-care was less necessary in winter, as the limb is already cooler.

Three participants held or reported having held in the past a belief that witchcraft was responsible for their ulcers. These participants used the term ‘fire-arrows’ to describe a spell, sent by a malevolent neighbour or known person to impart harm on the participant. Fire-arrows were a type of hot magic which induced blister formation (much like a heat burn), leading to foot ulceration.

The origin of the hot cold perception of foot ulcers may be a due to prevalent hot-cold beliefs in the community, but this may be reinforced by interpretations of experiential factors associated with foot ulceration, including pyrexia (hot fever), blisters (as these are also associated with thermal injuries) and descriptions of burning sensations preceding ulcers. A few participants also believed ulcers were worsened by the presence of fever, evidencing their belief that high levels of body heat could serve to worsen an ulcer’s condition. However these fevers were more likely due to infection acquired through an open wound, but the notions of causality are reversed due to the more tangible experience of pyrexia – which may precede overt signs of ulcer infection. The seasonality of ulcers may also play a role, as while many patients reported summer heat as being a factor in ulcer genesis, this season does coincide with the crop planting and harvesting periods. The staff at the LLSC report that presentations for neuropathic ulcers tend to be much higher during the planting and harvesting seasons. According to the biomedical model, increased activity leads to greater periods of weight bearing on the neuropathic foot, causing tissue break down and subsequent plantar ulceration. However, it may be that the causative factor is misplaced and the more immersive sensation of uncomfortably warm summer heat, which is also congruent with hot-cold notions of illness, becomes the more logical culprit on which to blame ulceration.

WHAT MAKES A LEPROSY ULCER DIFFERENT?

Previous studies have shown that ulceration in leprosy is a major factor which may precipitate stigmatisation. Participants were asked to explain what made their foot ulcers distinct from other types of foot wounds, such as traumatic foot wounds in non-leprosy affected persons which do not lead to acquisition of stigma. The majority of participants reported that wound chronicity was the primary factor which made their foot wounds distinct from non-leprosy affected people. In a non-leprosy affected person, a foot wound (caused by a nail, or piece of glass for example) would heal quickly, often within 2 weeks. These wounds could be managed by community doctors or at home via locally available herbal medications and bandages. Such wounds were also outside of the hot-cold model of illness, and considered neutral in temperature, requiring no management to address temperature disturbances.

Leprosy induced ulceration by contrast was prone to last several months, would be likely to reoccur despite preventative strategies and required specialist management at Lalgadh. Leprosy ulcers were also numb, could be preceded by blisters and hot burning sensations and were prone to having a foul smell which attracted flies or repelled other people. Many also reported that before attending Lalgadh, they had sought the help of priests and religious
healers for leprosy ulcers. A variety of other features were described, including beliefs that untreated leprosy ulcers would lead to amputation, cancer or diabetes. A similar perspective on prognosis was described by Biene in Nepal, where chronic superficial illness which are visible on the skin or body (such as wounds or rashes) are prone to becoming deep or internal illnesses, which are often more severe in nature.

The majority of participants expressed beliefs that leprosy ulcers were caused by heat build-up within the foot, however, as with non-leprosy foot wounds, trauma such as a puncture via sharp stones or glass could initiate leprosy ulceration. A minority of patients also felt leprosy ulcers could also have more diverse etiologies, including black blood, witchcraft, as well as being able to appear ‘Aphy Ayio’ (which literally translated means: ‘by itself’).

The sense of ulcer chronicity as being a defining feature of leprosy ulcers may be in part exaggerated by some patients perceptions of how long they have had their ulcerations, as four participants who’s records indicated they had been admitted for several ulcers over several years appeared to believe the admissions had all been for one single ulcer, of several years duration. Rather than healing, they felt the ulcer had become too small to see, but remained present despite being told by doctors the ulcer had healed.

The majority of participants also expressed strong fatalistic notions when discussing their foot ulcers. Most used the term ‘Kor phutigel’ or ‘Kori’ (translated means; the curse) as their initial answer when asked about the name they or their families used to describe their ulcers. However these terms did not denote the actual name given to their wound, as one patient expressed; “it’s my curse”. On further questioning participants were able to explain their ulcer was a ‘ghao’ (wound), which was the same word used to discuss wounds in non-leprosy affected people. However, discussions relating to their ‘ghao’ usually remained immersed in the notions that their wounds were a reflection of their status as cursed individuals.

PLURALITY OF BELIEF

While most patients were able to recite healthcare education provided to them by staff at Lalgadh, many patients simultaneously displayed alternative health beliefs which appeared to exist outside of the biomedical sphere of knowledge, reflecting a possible plurality in some expressed beliefs.

Five participants expressed a belief that god could directly make foot ulcers arise ‘aphy ayio’, while simultaneously expressing that ulcers could be caused by walking or excessive labour. Some of these patients expressed uncertainty about the origins of their current foot ulcer and appeared unsure about whether to agree with staff explanations or their own religious explanations. These participants reported simultaneously aiming self-management of ulceration at both religious causes and biomedical causes; performing self-care as per Lalgadh’s recommendations, while also devoting large amounts of effort to appease deities through worship, fasting and the use of symbolic clothing and jewellery. Numerous patients at the hospital (both leprosy and non-leprosy affected) were observed to engage with biomedical interventions such as receiving surgery, medicines and injections, while also utilising traditional magicoreligious methods, such as protective tattoos and wearing of magical amulets known as ‘vooti’ on body parts affected by illness. Two participants propensity towards plurality was typified by their explanations of their religious behaviours; these participants reported they were practicing Hindus at home, however when staying at the LLSC they would join Christian services and pray to Jesus Christ.
Many participants also reported traditional beliefs which appeared to be hybridised with biomedical knowledge, as many participants agree with the biomedical notion that walking and manual labour was a causative factor in ulceration, however this was thought to be a means by which the foot accumulated heat, as per the hot-cold model of illness.

**Implications**

Many of the previously described health beliefs may have little impact on the health and wellbeing of the participants. However, the widespread investment in the hot-cold model of illness presents a number of concerning possibilities. One issue observed was the belief that sandals could play a role in foot ulcer genesis, by trapping heat in the foot and transferring heat from the surrounding environment to the foot. This belief could be a source of potential problems, as it may undermine some patient’s faith in footwear as a means of ulcer prevention. The majority of participants expressed that in lower-limb self-care, soaking was the most important and beneficial aspect due to its ability to cool the limb, with many participants expressing that sometimes they performed self-care incompletely, performing only the soaking aspect. Soaking in isolation of scraping and oiling may be detrimental to the insensitive foot, as this could lead to a reduction of the lipid profile of the skin, hastening drying of this skin\(^2\) and increasing the risk of ulceration.

Diet modification according to the Hot-cold model of illness could have a potential effect on wound healing and general nutrition, as the foods reported to worsen hot conditions such as foot ulcers tended to be those high in protein (e.g. fish, eggs, buffalo), while the cooler foods favoured to rebalance internal temperature were markedly less nutritious (e.g. rice, bread, yogurt). Protein deficiency is known to delay wound closure,\(^2\) therefore behaviour based on this belief could have significant negative impacts. Research by Rao *et al.*\(^2\) in Delhi has shown disability Grade 2 affected people have the lowest BMIs of all sub-groups of leprosy affected people. While several explanations for this phenomena exist, diet modification according to local illness models, such as the Hot-cold model, could be a contributing factor.

In light of these observations, a follow-up study examining the wider prevalence of the hot-cold model of illness in foot ulceration may be valuable. If the prevalence of hot-cold beliefs in foot ulceration is as high as was observed in this study, future educational interventions may benefit from taking steps to address or ameliorate this belief.

**Study Limitations**

This study has several limitations. The sample size was relatively small (21 interviews, three focus groups), however, this study was conducted as a pilot aimed at identifying social phenomena regarding foot ulceration which may be studied in future.

The study also focused on patients with a particular subset of neuropathic feet. This criterion meant that participants with deformity of great extent (such as rocker bottom soles or major amputation) were excluded from the study, as previous research indicates such limbs carry a heightened propensity towards ulceration,\(^2\) this led to the assumption that even with judicious investment in self-care practices, many individuals may struggle to prevent this type of limb from ulcerating. Patients attending for only leprosy reactions were also not interviewed. However, these patients may have still been able to inform on leprosy beliefs,
as these patients still existed in the same context as the interviewees and likely carried the same cultural disease labels.

Acknowledgements

This paper would not have been possible without the support and advice of Dr Hugh Cross, who’s suggestions and directions made the study possible. The input from the staff at the LLSC and Nepal Leprosy Trust also provided invaluable and these individuals continue to provide an inspiring example with their devoted efforts to manage and control the disease of leprosy and support those affected by it.

Competing interests

All authors declare that the answer to the question on competing interest form are all ‘No’, and therefore have nothing to declare.

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The funding for this study came independently via M. deSancha.

Contributorship

Maximilian deSancha: Data collection, funding, study design, data analysis, write up.
Kiran Jha: Data collection, data translation, data analysis, advised on local cultural phenomena.
Dr Anita Williams: Provided supervision of study write-up, guidance on academic writing requirements and guidance regarding qualitative research methodologies.
Dr Hugh Cross: Provided original idea for study, advice on data collection, clinical advice on leprosy, advice on local sociocultural aspects of leprosy.
Dr Krishna Lama and Dr Yamuna Rai: Advice on clinical aspects of leprosy and local sociocultural phenomena.

References