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Lay perceptions of kala-azar, mosquitoes and bed nets in Bihar, India

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Summary

OBJECTIVE To describe the lay perception of kala-azar (KA) in an endemic area of Muzaffarpur District, Bihar, India: local names, symptoms, affected persons, perceived severity and modes of transmission, as well as perceived mosquito nuisance, modes of protection and use of bed nets.
METHODS We held 16 focus group discussions (FGD) in eight remote villages with altogether 157 participants in March 2008. Separate FGDs were held according to gender, socio-economic status (SES) and with key informants.
RESULTS Kala-azar is most commonly named *pilahi*. Poor people were said to be the most affected. Knowledge about symptoms was satisfactory. Fever and prolonged fever were the most stated symptoms. KA was perceived as a life-threatening disease with a heavy economic burden. Mosquito bites were perceived as the main mode of transmission but in lower socio-economic groups, non-vector-related explanations were also provided. The main modes of protection from mosquitoes mentioned were the use of fumes and bed nets. Season was the strongest factor influencing the use of bed nets and non-affordability for not owning them.
CONCLUSIONS Although the sand fly is not recognised as the vector, the relatively good awareness of disease transmission by mosquitoes and the nuisance caused by their high density might be an entry point for adopting preventive measures to protect from mosquito bite and thereby indirectly preventing from KA. Educational campaigns targeted to the poorer segments of society are needed to enhance knowledge about KA, its mode of transmission, risks of getting infected and to increase bed net use.

keywords visceral leishmaniasis, kala-azar, disease perception, bed nets, India, sand fly

Introduction

Although endemic in 62 countries (Guerin *et al.* 2002), India, Nepal, Bangladesh, Sudan and Brazil contribute to more than 90% of kala-azar (KA) cases (Desjeux 1996; Murray 2002). KA is a deadly disease caused by *Leishmania donovani* in the Indian subcontinent, where about 190 million people are at risk (Sundar *et al.* 2008). In this region, KA is transmitted by the bite of the infected female sand fly *Phlebotomus argentipes*, which breeds in peridomestic environments and bites at night. In India, KA is mainly confined to the state of Bihar, which accounts for 90% of the country burden (Lal *et al.* 1996; Sundar *et al.* 2000). In Bihar, KA remains an important public health problem affecting poor people living in houses suitable for breeding of sand flies (Boelaert *et al.* 2009). The governments of India, Nepal and Bangladesh recently committed themselves to eliminate the disease by the end of the year 2015 (Sundar *et al.* 2008). So far, no vaccine is available and control of the disease depends on early case detection and management, and vector control. Indoor spraying of residual insecticides is the main sand fly control strategy currently applied (Ostyn *et al.* 2008).

A community intervention trial (the KALANET project) was set up in KA-affected areas of Bihar to study the efficacy, acceptability and cost-effectiveness of long-lasting insecticidal nets (LN) in the prevention of KA (Clinicaltrial.gov CT-2005-015374). In the frame of the baseline study on acceptability of these bed nets, we conducted a qualitative study to assess lay perceptions of KA, perceived mode of transmission and prevention practices. Health-seeking behaviour was explored in as much as it is related to lay perceptions of modes of transmission. We also investigated mosquito nuisance and modes of protection from mosquitoes including the use of bed nets. Indeed, all

the former factors were hypothesized to have an influence on bed net acceptability.

Methods

The study was carried out in eight villages in Muzaffarpur district, Bihar State, India, in March 2008. This district has a total population of 3.7 million, of which the vast majority live in rural areas.

Study design

To assess lay perceptions of KA, we conducted 16 focus group discussions (FGDs) in eight villages. In preparation of the KALANET project, 35 clusters with the highest reported numbers of KA cases in the last 3 years were selected in Muzaffarpur district (Boelaert *et al.* 2009). For the community trial to show efficacy of LN, the clusters with the highest incidence were chosen. For this qualitative study, other locations needed to be identified, as communication, information and sensitization campaigns on KA disease and its prevention took place in the efficacy trial clusters. Moreover, the boundaries of these clusters do not correspond to any sociological reality and are permeable in terms of spontaneous social communication between villages/hamlets, and hence, a risk of 'contamination' resulting in a bias of the results would be expected. Therefore, eight remote communities 2–5 km away from the experimental villages were identified among the initial list of high incidence locations to conduct this qualitative study.

In each village, 2 FGDs were conducted. It was assumed that lay perceptions might vary with socio-economic status (SES), gender, age and occupation. Therefore, to ensure the best possible representation of the community and to ensure homogeneity of the participants within a FGD, it was decided to conduct separate FGDs (Table 1) with key informants (KIs), men, women of different ages, and upper and lower SES groups. Key informants were local health workers, health volunteers, school teachers and informal and formal community leaders. These persons were expected to have a better knowledge of the disease, more access to information and hence could differ from other groups in their perceptions. The upper SES group was defined as people from the general caste, with a higher education (more than 12 standards) and owning land of more than 2 acre. If persons were not belonging to these groups, they were considered being from the lower SES group. Women were subcategorized in below and above the age of 30 years because younger women are traditionally not involved in any decision-making process and could have a different perception of disease and disease prevention. In total, the FGDs numbered 157 participants.

Table 1 Distribution of the focus group discussions (FGDs) among different population groups

High and medium socio-economic status (SES) (8 FGDs)	2 FGDs with men
	2 FGDs with women (<30 years)
	2 FGDs with women (≥30 years)
	2 FGDs with key informants (KI)
Low SES (8 FGDs)	2 FGDs with men
	2 FGDs with women (<30 years)
	2 FGDs with women (≥30 years)
	2 FGDs with KI

Conduct of the FGDs

The number of participants in each FGD ranged from 8 to 12. Three major themes were discussed: (i) knowledge and awareness of KA (local names, symptoms, affected persons, perceived severity and modes of transmission); (ii) mosquitoes (nuisance, prevention practices including the use or non-use of bed nets); and (iii) KA treatment-seeking behaviour. A question guide composed of 11 leading questions covered these themes. The FGDs were conducted in the local language by well-trained moderators with a sociological background, assisted by two clerks, under the supervision of a senior researcher (RM). Each FGD was conducted in a quiet and isolated space for an average duration of 45 min and was videotaped.

The moderator and clerks transcribed their notes in the local language separately on the same day. On the basis of these transcripts, a final version was prepared and subsequently translated to English by the senior researcher with the support of the video recordings.

Data analysis

Data analysis was carried out by two senior researchers (RM & PL) with the support of the NVivo 7 software (QSR International Pty Ltd., Australia). The analysis was mainly inductive. Data were encoded on the basis of emerging themes and a codebook was progressively elaborated. Trends in the data were identified by producing matrices allowing for comparison between the different groups.

Ethical approval

Ethical approval was obtained from the Institutional Review Board of the Institute of Medical Sciences, Banaras Hindu University and from the ethical committee that oversees research of the Institute of Tropical Medicine, Antwerp.

Results

Lay perceptions of KA

Kala-azar was most often named *Pilahi* (the local Hindi name for KA), followed by malaria, liver disease and kala-azar. *Pilahi* and malaria were names more frequently used in the low socio-economic groups than in the upper ones. Key informants also often referred to the disease as *Pilahi*. Other names used in the discussions relate to symptoms of other diseases such as *JarBukhar* (fever without other symptoms of illness), jaundice, red fever and *Miyadi Bukhar* (typhoid). The FGDs were quite heterogonous in terms of knowledge. In some FGDs, participants had heard of KA, in others some had experienced it either directly, either indirectly through relatives or neighbours. There also seems that some villages had more experience than others with KA. Awareness about KA seemed to be lower among younger women and low SES groups. In these latter groups, after some discussion, it became clear to most of them which disease was meant by KA, and hence they could participate in the rest of the discussions about KA.

Three groups of symptoms related to KA emerged from the data analysis. The first, mentioned most often by the participants, relate to early symptoms of the disease such as fever, loss of appetite, weakness, weight loss and anaemia. The second group comprises symptoms that appear in later stages of the disease such as stomach conditions, enlarged liver and a blackish or yellowish body. Finally, a third group seldom stated by participants is symptoms related to fever such as dry lips and running nose.

Overall knowledge of symptoms was good with fever the most commonly mentioned. In particular, participants differentiated between fever and prolonged fever. The latter symptom was better known by women and in low SES groups.

Kala-azar was often confused with malaria, as both diseases are characterized by fever as one of the first symptoms, especially among participants from lower SES groups. Their perception was that a mosquito bite transmits malaria, which causes a fever, and, if the fever persists, KA develops: '*Kala-Azar occurs because of malaria mosquito bites… First it is malaria and then if the fever continues for a longer duration, malaria converts to Kala Azar*'.

There was a common understanding, through all FGDs, that poor people are the most affected by KA: '*Poor are bitten more by mosquitoes and get KA*'. The most affected group was also defined as the physically weak and the people living in *Jhopadi* (small houses with mud walls and low roofs of bushes, bamboos or plastic sheeting).

Kala-azar was perceived as leading to death and resulting in serious economic consequences for the family of the affected persons, especially in the low SES groups. A few participants also referred to the complexity and the length of treatment. Younger women perceived more the economic consequences than the older ones.

Participants indicated mosquito bites as the main mode of transmission. Environmental factors, such as dirty surroundings (which were said to be responsible for the presence of mosquitoes), were mentioned as the second most common cause. Differences in perceived aetiology were observed by age, gender and SES. Elderly women emphasized mosquito bites and environmental factors; low SES groups mentioned mosquito bites, dirty environment but also factors not related to mosquitoes, such as edibles, as most common causes of transmission. Other modes of transmission stated in these low SES groups were urine of lizards, dirty clothes, eating untimely, etc. Transmission of KA by other affected persons or by drinking contaminated water was seldom stated. Sand flies were hardly ever mentioned and if so, only in upper SES groups, by KI and men.

Two major modes of protection from KA emerged in the group of people aware of KA: to keep the environment clean and the use of bed nets. Fume or insecticide coils were less stated as a mode of prevention of KA than as a mode of prevention against mosquito nuisance. Other actions as wearing clean clothes, insecticide spraying, using a fan or eating hygienic food were also mentioned.

On the basis of the collected data, it was not possible to reconstruct individual therapeutic itineraries. However, an overall picture can be depicted. On appearance of fever, the common practice mentioned by almost all participants (more pronounced by low SES and women) were traditional remedies (juice of crushed roots of herbal plants, unripe papaya mixed with salt, leaves of *Har Singar*, radish and spinach vegetables, snail water, etc.) and auto-medication. If symptoms persist, the next step was to see a traditional healer, an *Ojha* (who silently murmurs some words and puts ashes on the forehead of the affected person), although some participants had doubts on their effectiveness. Modern health care (Primary Health Care centre, private practitioner, hospital or private non-for-profit treatment centre) was reported as first step in the therapeutic itinerary only by persons who were well aware of the disease, of a higher SES or higher education. The difficult diagnostic procedures were mentioned by some participants of the low SES. They were aware that the disease is confirmed by blood examination and bone marrow test. Participants reported that the major hurdle for seeking treatment for KA was the cost of treatment,

which was perceived as very high. The availability of free treatment was only mentioned by two persons.

Mosquitoes

The nuisances caused by mosquitoes (such as painful bites, skin irritation at bite spot, sleep disturbance and even anaemia) were discussed at length in the FGDs, especially in the low SES groups and by the younger women groups: '*We are not able to sleep because of these mosquitoes' bites; we get swelling and wounds on mosquito bite skin surface*'. Mosquitoes were known as causing several diseases especially by younger women, men and people of upper SES: '*Mosquitoes are the main culprit of many diseases*'. Some participants also believed mosquitoes cause anaemia, because mosquitoes were sucking their blood.

Four main types of protective measures from mosquito bites were mentioned during the discussions. The most often stated was the use of fumes '*poor people produce smoke by burning garbage to protect themselves from mosquito bite*', followed by bed nets, use of mosquito coils (although mentioned as being harmful) and finally maintaining the house surroundings clean. The latter was most often stated by upper SES, while the three other modes of prevention were relatively more often mentioned by the low SES groups. Insecticide spraying was only mentioned by some participants of higher SES. Remarkably, using bed nets was a mean equally stated in the different SES groups. Although some people of the lowest SES group mentioned '*in absence of net, we cover the whole body with bed sheets to protect from mosquito bite*'.

Reasons for using or not using bed nets

In the FGDs, each participant was asked whether they used bed nets. This permits a qualitative assessment of bed net use. Participants reported their bed net use as follows: in half of the FGDs, the majority of participants were non-users, in a quarter, the majority were users and in the remaining quarter, bed nets were used by half of the participants. If a participant reported to use a bed net, it did not mean though that every member of his/her family was using a bed net.

Ten potential reasons for not using bed nets were identified but three emerged as the main ones: (i) the family does not have one, (ii) the family has fewer nets than family members and (iii) the owner of a bed net does not use it because of weather circumstances (season). Other reasons for not using bed nets were sleeping habits (on the ground or outside), lack of space and, quite surprisingly, alcohol addiction (stated in low SES groups). Remarkably, participants of lower SES groups gave more reasons for not owning a net (as economic reasons and big family), while the upper socio-economic groups gave more reasons for not using one (as discomfort and season).

Six reasons why participants were using bed nets emerged from the data analysis. The most important reason was the seasonal factor, which was linked with mosquito nuisance. People use bed nets in the summer and rainy seasons because of the high mosquito density. This was, however, less discussed in the high SES groups.

In terms of the cost of bed nets, men of low SES group stated that '*poor quality nets are sold at high price*', elder women of low SES group stated that '*poor cannot afford purchase of bed net, government should distribute net free of cost*' and young women of upper SES stated that '*even if there is no food, they purchase a bed net to protect from mosquito bites*'.

Discussion

This study provides qualitative information on lay perception of KA, mosquitoes and bed nets, looking into differences of trends in socio-economic and gender groups in the Indian Muzaffarpur district, a high endemic focus of KA for more than 30 years (Boelaert *et al.* 2000; Sundar *et al.* 2000).

The overall awareness and knowledge of KA was in comparison with results of a quantitative study conducted in the same district (Singh *et al.* 2006), lower in our study population, particularly in young women and low SES groups. This can probably be explained by the fact that this study did not take place in hot spots, but in communities less exposed to KA, as explained in the Methods section. Relatively poor knowledge was also found in KA foci in neighbouring Nepal (Koirala *et al.* 1998).

But the symptoms and the disease severity are well known. The onset symptoms of KA, namely fever and – later on – prolonged fever, are the ones known by the population, especially by women above 30 years of age. However, people do not always distinguish KA from other febrile diseases such as malaria. The other symptoms of KA (as enlarged spleen) are not very easy to notice for people, therefore it is not surprising that they have less knowledge about them.

The low SES groups have an equal or even a better knowledge of the symptoms of KA than the higher SES groups. This former group also perceived the disease as a deadly threat with a high economical burden for the family and relatives. This might be explained by the fact that these participants have had more experience with KA in their neighbourhood or with relatives and have more difficulty to cope with the high cost for treatment. Also, in all the FGDs, there was a consensus that KA affected mainly the

poor. All the above qualitative findings are in line with recent results of an economic study that indicates that KA is a disease of the 'poorest of the poor' (Boelaert *et al.* 2009). Results regarding health-seeking behaviour, although limited, are coherent with the perception of the disease, its perceived severity and the lay aetiology.

In all FGDs, the relation between mosquitoes and KA was made, sometimes indirectly through the idea of 'dirty environment' said to 'causing a lot of mosquitoes'. But the sand fly was rarely mentioned. The vectorborne character of the disease seems to be clear for the population, which confirms the findings of Singh *et al.* (2006). However, in the low SES groups, other modes of transmission not related to mosquitoes or sand flies were mentioned.

As could be expected, in lower SES FGDs, participants complained more about mosquito nuisance and mosquito density. Interestingly, the low SES groups participants stated that they do not have the purchasing power to buy the nets, while the better off did not see ownership as a problem and expressed other reasons for why people were not using the bed nets. This is congruent with the results of a quantitative survey realized in the same district, where poverty was found to be the main determinant for not owning bed nets (Vanlerberghe *et al.* 2010). It is surprising that such a low coverage of bed nets is perceived by the studied groups, because in other studies in VL-endemic areas of India, bed net coverage was above 70% (Singh *et al.* 2006; Das *et al.* 2007; Vanlerberghe *et al.* 2010). Young women indicated, more than other groups, the use of fumes to protect themselves from mosquitoes, which can be explained by the fact that they are sleeping inside the house and see this as the only measure they can apply.

Conclusions

The best way to protect from KA and to reduce its transmission is to reduce the chances of vector–human contact. This is possible only if breeding of sand flies is stopped through improvements in the peri-domestic environment and housing conditions and by protecting against their bites at night-time. Although the real vector is not recognised, the relatively good awareness of transmission of diseases by mosquitoes and the nuisance caused by their high density might be an entry point for adopting preventive measures to protect from mosquito bites and thereby indirectly preventing from KA. This has also been shown for insecticide treated nets in malaria-endemic countries of Africa (Adongo *et al.* 2005). An essential conclusion of the study is that 'imperfect' knowledge about the disease and its vector may not be an obstacle to individual or collective preventive measures, as fighting against mosquito nuisance in general corresponds to a felt need.

However, the actions put forward by the participants to reduce the mosquito burden were different from the ones to prevent KA. This provides valuable information for future local preventive promotion campaigns: people perceive disease prevention differently than mosquito nuisance protection, even if they know that mosquitoes (or vectors) are transmitting diseases.

However, bed nets or other vector control methods will not solve the problem of KA in affected villages without complementary interventions in terms of education and overall economic development. These should be obviously targeted and tailored to the poorer segments of society including younger women.

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Conflicts of interest

The authors have declared that they have no conflicts of interest.

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