Visceral leishmaniasis (KA), “black fever” in Hindi, is one of the most neglected diseases in the world, affecting the poorest segments of rural populations in southern Asia, eastern Africa, and Brazil. For these populations, access to appropriate diagnosis and treatment is difficult. There is scant investment in the development of new drugs for visceral leishmaniasis, and the most effective treatments are often unavailable or unaffordable for patients in endemic areas. The mainstay of therapy in most affected areas remains sodium antimony gluconate (SAG), a drug developed in the 1940s that requires 3–6 weeks of daily intramuscular or intravenous administration, and that carries the risk of potentially serious side effects. Diagnosis in southern Asia often rests on clinical assessment and the non-specific formol-gel test. Sustained use of more specific serologic tests is impeded by cost and logistical constraints, such as the maintenance of a local antigen supply for the direct agglutination test. Thus, in many visceral leishmaniasis-endemic areas, standard case management practices have hardly changed in 50 years. Because most affected populations are poor and rural, the impact of visceral leishmaniasis may not be apparent to national health policy makers, and treatment and control of the disease are not usually accorded high priority.

Visceral leishmaniasis is caused by the protozoan parasite Leishmania donovani. In southern Asia, infected humans are the only known reservoir, and the parasite is transmitted from one person to another via the bite of the female sand fly. The sand fly rests inside mud-walled houses during the day, and is active from dusk to dawn, when transmission is presumed to occur. The disease is also known as kala azar (KA), “black fever” in Hindi, for two of its cardinal signs: darkening of the skin and prolonged fever. Kala azar is also characterized by weight loss, fatigue, enlargement of the liver and spleen, and invasion of the bone marrow by parasites, leading to anemia, leukopenia, and thrombocytopenia. Complications include secondary bacterial infections and hemorrhage, both salient contributors to mortality. Without appropriate and timely treatment, KA carries a high mortality, with estimates ranging from 80% to 100%. Even with treatment, case fatality rates in excess of 10% are common.

In the past two decades, the Indian subcontinent has experienced a major resurgence of KA. Together, India, Bangladesh, and Nepal account for 60% of all reported cases of KA in the world. The reported incidence of KA in Bangladesh has averaged 7,000–9,000 cases per year since 1996, and these figures are considered to be substantial underestimates. The government of Bangladesh provides the standard drug treatment (SAG) to thana (subdistrict) health complexes in endemic districts. However, SAG shortages affecting both the government supply and the supply in the private sector have been common over the past three years. During periods of shortage, the local price of SAG increases substantially in private pharmacies. The official price of an adult course of SAG in Bangladesh is $20, but during 2002, we documented market prices up to three times that amount.

In addition to uncertainties about the incidence of KA, few data exist on social and economic consequences of KA for affected families and communities. A report from Nepal described the knowledge, attitudes, and health care seeking behaviors of individuals affected by KA, but did not examine the impact of KA on the community. Malnutrition is a predisposing factor for progression from leishmanial infection to disease, and delays in diagnosis and treatment increase the risk of severe morbidity and mortality. Because humans are the only hosts for KA in southern Asia, treatment delays increase the reservoir of infection and amplify the epidemic. The predisposing, enabling, and environmental factors within communities may play an important role in determining health care-seeking behaviors, treatment options, and the ability to control the disease. To collect data for planning a community-oriented KA control strategy, we undertook a qualitative study to understand the social context of KA in one endemic village. In this report, we discuss epidemiologic features of KA together with the community members’ perspective of its impact on their lives.

MATERIALS AND METHODS

We conducted the study, consisting of epidemiologic and qualitative assessments, in a village in Fulbaria Thana,
Mymensingh District chosen for its high reported incidence of KA. The study protocol was reviewed and approved by the Research and Ethical Review Committees of International Centre for Diarrhoeal Disease Research, Bangladesh, and the Internal Review Board of the Centers for Disease Control and Prevention. Informed consent was obtained from all adult participants and from the parent or guardian of all participating children. The study village covers an area of 18 km² and contains approximately 12,000 people. The village is divided into 9 paras (sections) ranging in size from ≤ 100 to ≥ 500 households. We conducted the epidemiologic assessment in the three paras reported by villagers to have had the highest rates of KA in the several years before the study, which we designated Paras 1, 2, and 3. Paras 1, 2, and 3 are approximately 1–2 km apart and separated from each other by rice paddies or by another para. Any household member who lived in the household for at least six months in the three years before the survey was enumerated. For each household, births, deaths, and in- and out-migration were recorded, and socioeconomic data were collected. Suspected past and present cases of KA were ascertained in structured interviews. The study physician (MA) then examined individuals who reported past or current KA. We defined a past case of KA as an illness with two or more weeks of fever, plus at least one of the following: weight loss, abdominal fullness, abdominal pain, and/or skin darkening, with clinical improvement after 20 days of intramuscular injections. We defined a current case of KA as illness meeting this definition, plus physical examination consistent with KA (splenomegaly and/or hepatomegaly, with or without measured fever, evidence of weight loss, skin darkening, and/or jaundice), and a positive rK39 dipstick test result (Inbios International, Seattle, WA). The rK39 dipstick is a rapid test for KA with very high sensitivity and fairly high specificity in southern Asian field conditions.13,14 All persons ill with KA at the time of interview were treated with SAG at the nearest thana health complex (THC). The qualitative assessment was conducted in Paras 1, 2, and 3, plus two other paras with fewer cases. The rationale for selecting both highly affected and less affected paras was to assess the overall impact of KA, to capture the full breadth of beliefs and perceptions, and to examine the potential for developing an intervention that encompasses the whole village. We conducted 10 focus groups with residents of the highly affected paras and four focus groups with residents of the less affected paras. Focus group techniques provide a method for obtaining rich descriptive data about an issue or problem in a setting in which people can consider and articulate their views in the context of the views of others.15 Field staff familiar with the community approached households to obtain permission from the head of household for members to participate in the group discussion. Both males and females were recruited. In addition, we conducted 13 in-depth interviews with KA patients and their family members, five interviews with community leaders, and several interviews with local health care providers. We used a semi-structured interview guide translated into Bangla to guide the discussion in all focus groups. The guide consisted of open-ended questions designed to keep the discussion focused on KA and KA-related experiences; each focus group lasted 1.5–2 hours. The conceptual and literal understanding of questions was examined prior to fieldwork, and adjustments were made to eliminate confusion and to account for the local context. All the groups were moderated by experienced moderators and were conducted in Bangla. Data were collected using detailed field notes and all focus group interviews and most individual interviews were also tape-recorded. The notes and tapes were translated from Bangla to English by a native Bangla-speaker, and then back-translated from English to Bangla by a native English-speaker fluent in Bangla. The field notes and tapes were used to produce complete transcripts of the data. Transcribed notes were coded and analyzed using EZText Software, a qualitative data analysis package developed by the Centers for Disease Control and Prevention.16 Three of the authors (IBA, CB, and CC) read the completed and checked transcripts several times, and then generated a consensus list of codes for the concepts expressed. Examples of the codes generated by this process include HLTHPROB (major health problems), KANUT (nutritional intake and practices associated with KA), and CONSECO (economic consequences resulting from KA). A complete list of codes with explanations is available from the authors upon request. The transcripts were then coded, and analyzed to identify the dominant patterns in the data.17 We present the results of the qualitative analysis and quotations that exemplify each of the predominant themes.

RESULTS

For the epidemiologic assessment, demographic data were collected for 2,348 individuals in 492 households in three paras from January to April 2002. Data on KA status were updated from January to April 2003. We were able to categorize 2,228 individuals (95%) with respect to past or current KA. A total of 189 people had KA, 56 with onset of illness before the year 2000, and 133 between 2000 and 2002. From 2000 to 2002, the average annual incidence was 2%.

Kala azar cases were not distributed equally among the study paras (Table 1). Between 2000 and 2002, 12% of Para 1 residents had KA, compared with 6% and 3% in Paras 2 and 3, respectively. In Para 1, 37% of households had at least one KA case and 15% had multiple cases of KA during the study period. Thirteen residents of the study paras died of KA between 2000 and 2002. Seven of these deaths occurred in women 15–45 years old, while four occurred in children less than 15 years old, and only two occurred in adult men (Table 2). The case-fatality rate among adult women was 19%, three times the rate among other groups (P = 0.06 by two-tailed Fisher’s exact test). For the 89 KA patients with sufficient data, the median duration of illness before treatment was four months (range = 0.5–19). Female patients were ill signifi-

<p>| Table 1 |</p>
<table>
<thead>
<tr>
<th>Population surveyed No.</th>
<th>KA cases 2000–2002 No. (%)</th>
<th>Deaths from KA No.</th>
<th>Households surveyed No.</th>
<th>Households with KA cases No. (%)</th>
<th>Households with two or more KA cases No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Para 1</td>
<td>556</td>
<td>67 (12)</td>
<td>8</td>
<td>123</td>
<td>45 (37)</td>
</tr>
<tr>
<td>Para 2</td>
<td>469</td>
<td>30 (6)</td>
<td>3</td>
<td>106</td>
<td>21 (20)</td>
</tr>
<tr>
<td>Para 3</td>
<td>1,205</td>
<td>36 (3)</td>
<td>2</td>
<td>263</td>
<td>33 (13)</td>
</tr>
<tr>
<td>Total</td>
<td>2,230</td>
<td>133 (6)</td>
<td>13</td>
<td>492</td>
<td>99 (20)</td>
</tr>
</tbody>
</table>
Kala azar (KA) cases and mortality by sex in Bangladesh, 2000–2002

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Population</th>
<th>Females</th>
<th>Males</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>KA cases</td>
<td>KA deaths</td>
<td>Case-fatality rate</td>
</tr>
<tr>
<td>&lt; 15</td>
<td>470</td>
<td>25</td>
<td>8%</td>
</tr>
<tr>
<td>≥ 15</td>
<td>649</td>
<td>37</td>
<td>19%</td>
</tr>
</tbody>
</table>

**Table 2**

Significantly longer than males (median duration = five versus three months; $P = 0.03$ by Wilcoxon rank sum test).

For Paras 1–3, the median household size was five people (range = 1–12), and the median household expenditure was $44 per month. Thirty percent of household heads worked as farmers, 35% as daily farm laborers (on other people’s land), 15% in business or services, and 7% as rickshaw pullers. While 80% of the households owned some land, the median holding was 0.2 acres (range = 0–6.5).

The qualitative assessment was conducted from July to August 2002. This assessment complemented the epidemiologic data by providing the community’s perspective on the social, emotional, and economic impact of KA. Participants living in Paras 1–3 were able to fully discuss the disease, and its effect on their health and social well-being. Participants from paras with lower KA incidence were less able to recall acquaintances with the disease, and less confident that they could identify the possible cause, treatment, or consequences. Community members reported many effects of the epidemic from untimely death of family members to major economic loss. Much of the adversity was associated with lack of access to timely, appropriate treatment, resulting in prolonged morbidity or death.

A number of people said that they knew of people with KA long ago, and had noticed that KA was coming back. Some participants said they did not know where it came from, while others attributed KA to various causes, including mosquito bites, flies, filth, polluted water, malnutrition, jaundice, anemia, seasons, and Allah. The disease is believed by many to be passed from person to person in the same household. Participants from paras with lower KA incidence were less able to correctly identify sand flies as the transmitting agent; however, this was after study personnel had conducted sand fly collections in those paras. Despite this knowledge, there were many misconceptions about the disease, its spread, treatment, and prevention.

“If a person has kala azar in a family and the others use his plate, glass, sheets, and utensils, then kala azar will spread within the household. If they keep the patient’s things separate, then it may not spread.”

Vulnerability to KA and other illnesses due to limited food intake and malnutrition was another important theme. Food insecurity is a major concern for many villagers in their daily lives. Many respondents mentioned the importance of good nutrition, especially during times of sickness, but also discussed cultural prohibitions on certain foods during illness that further limit their dietary options. Participants indicated that low incomes restrict the type and variety of foods available to them, increasing their vulnerability to KA. Other respondents mentioned that KA affecting the wage earner limits the family’s ability to purchase food, and as a consequence, the entire family may experience food insecurity and increased vulnerability.

“We think that it [KA] is from lack of food. Now there is poverty and people are poor and they cannot get the food that they need.”

Participants characterized KA by recurring fever, extreme weakness, lack of appetite, swollen stomach, and the body turning black. People also linked jaundice and KA, for example, discussants said that “first you have jaundice and then kala azar happens.” Treatment-seeking behaviors vary according to symptoms, perceived cause, length and severity of illness, and the role of the person within the household. For fever, most people self-treat or “watch and see what happens.” If symptoms worsen, or the patient appears to be affected by “karap batas” (bad winds or spirits), has diarrhea, loss of appetite, and weakness, then the Kobiraj (traditional healer) is consulted for healing water, spells, or other treatment. If treatment by the Kobiraj is unsuccessful, participants go to the “village doctor” (usually a person with little or no training). When all else fails, they seek treatment from a formally trained doctor or go to the hospital.

After several months of wait-and-see, most focus group participants would seek confirmation for their suspicion of KA at the THC, or at private clinics where costly laboratory tests may be required. If SAG is available, the patient may begin treatment at the THC; more frequently, the family must purchase drug from the market to complete the course. In addition, they must pay for syringes, the services of the nurses administering the injections, and the help of persons who facilitate access to THC personnel.

The long- and short-term costs of KA to families are enormous. Available money and assets strongly influence treatment options. Patients begin with self-care, and gradually increase to the most expensive option, which is SAG administered through the formal medical system. Participants from KA-affected households indicated that gathering the 5,000–30,000 Taka ($85–$500) necessary for diagnosis and treatment requires borrowing money, and selling or leasing land and animals, leaving the household destitute. Participants from a household with multiple cases of KA said that it would take a long time to recover from financial losses.

Along with the financial losses, there are emotional consequences of KA-associated chronic illness, the physically demanding treatment with painful side effects, and loss of life. Female participants and their mothers-in-law believed that KA resulted in pregnancy loss. Women mentioned that they had been sick with KA during their pregnancies and were not treated due to the THC protocols. Several women had miscarriages or lost babies shortly after birth and attributed their loss to KA. Many respondents described KA as a disastrous occurrence.

“When a person has kala azar, he has no income. Everyone in the house is affected because they have to take care of him and there is tension about what will happen to him. When a person has kala azar he himself is hurt, his family is hurt, his village is hurt, the society is hurt, the thana is hurt, the district is hurt, and the entire country is hurt.”
Participants from KA-affected households repeatedly expressed anger towards the health care system. They mentioned the inflated cost of medicine, fees paid to facilitate access to diagnosis and treatment, unnecessary medicines, diagnostic tests and procedures, the lack of respect they received at hospitals, and deaths due to lack of treatment or as a consequence of treatment. People with KA and their family members also mentioned that they needed more information about the side effects of treatment. Several community members described their collective experience.

“If we give more money to the hospital, they will give us some medicine. Otherwise, they will only write a slip and tell us to buy it from outside. If a [community] leader goes, then they will give him medicine. We are poor. If we have KA, they will give us no medicine. They will take a bribe and then give a little bit of medicine. Not only kala azar. If we have kala azar or any other disease, the situation is the same…”

Health care providers also faced challenges in providing care to patients with KA. For example, a medical assistant at the THC mentioned that

“After bi-weekly THC board meetings, they [the THC physicians] sent papers to the district store requesting 700 vials, but they only get 300 vials of KA medicine. The injections are not available at the market. In Bangladesh, there was one center that produced the drug. Now they stopped the production. The Indian one is also not available.”

People in both highly affected and less affected paras wished to learn ways of preventing KA. Levels of existing knowledge varied. Respondents identified various communicable disease prevention methods since they perceived KA to be a communicable disease. Since use of bed nets shows promise as a preventive strategy, all focus group participants were asked about bed net use. While some respondents indicated that bed nets protected them from mosquitoes and disease, others said that they were used solely for comfort. Many respondents reported that they could not afford sufficient bed nets for all family members. In households with insufficient numbers of bed nets, large numbers of people sleep under the few bed nets, or selected family members (e.g., children) are designated to do so. Many community members wanted to mobilize around the issue of health. Although health is considered an individual matter, respondents felt that the impact of KA necessitated collective community action. Focus group participants provided several examples of organizing around common causes.

“We started a farmer’s club. Swarirvar Choudar is an association that we started as a village. The objective of this society is to develop the village’s health, economic situation, education and communication…”

“. . . we have tried to arrange a charitable dispensary for people in the village who cannot afford treatment. . We would like to test the blood of the villagers for KA in this clinic. When we start the charitable dispensary, we will ask these two people [village doctors] to help. We will collect money from the rich people from the village to fund this.”

Our survey data confirm that KA has re-emerged as an important public health problem in Bangladesh. In our survey, there was probably under-ascertainment of KA that occurred in the more remote past compared with more recent disease; nevertheless, the increased incidence in the last three years is quite marked, and likely reflects a real change. These findings echo increases in incidence since the mid-1990s in national surveillance data.9 Our study village is just one of many where KA has devastated segments of the community, caused deaths among productive adults, driven families into debt, and increased the burden on an already strained and resource-poor health care system.

Villagers place a high value on understanding the disease. While the true cause of KA was unclear to many, they made educated guesses based on observations and past experience. Interviewees believe that KA has multiple causes (e.g., insect bites, malnutrition). Nonetheless, they identified KA as a communicable disease, and apply many prevention and treatment methods that have been successful in containing other communicable diseases.

People in the study community know that the costs of accessing care in hospitals are much higher than those incurred when they consult traditional healers, and so they tend to use a hierarchical system to deal with KA cases in their households. People with KA may be ill for months while trying to rule out common diseases that are less expensive to treat. They may also prioritize care within the household, generally seeking hospital care for children and men before adult women, who had significantly longer duration of illness than men. Delays in appropriate KA diagnosis and treatment increase the risk of complications and death, and augment the reservoir for further KA transmission. Adult women are particularly vulnerable to mortality and prolonged morbidity from KA, possibly due to poorer underlying nutritional status from menstruation, childbearing and lactation, as well as treatment delays.

The villagers clearly articulated the impact of KA on their communities, families, and households. Residents of the paras with the highest incidence of disease felt powerless in the face of dire emotional and economic consequences, and many equated a KA diagnosis with a death sentence. The economic burden of KA in a family is heavy. When wage earners become ill, whole families experience income loss, while KA in a woman may have repercussions for her children. Families are forced to lease out or sell their land, to sell animals and farm implements, and to deplete any reserve capital to pay for hospital admission, diagnostic tests, and purchase of SAG. As shortages of SAG occurred in hospitals in 2001-2002 and drug prices soared in the private sector, the economic burden for families became even greater. Households reported that treatment of KA left them in a state of insolvency. When multiple cases of KA occurred in a household, the toll was even greater, and families felt they had no prospect of economic recovery. The impact of KA in a household is compounded by the difficulty of negotiating the medical system. Households affected by KA patients described their difficulty overcoming barriers to diagnosis and treatment at hospitals, including payments for diagnostic tests, treatment, injection equipment, and small payments to those who controlled access to care. Despite these difficulties, family
members felt that accessing treatment was essential to avoid death from KA.

Our data highlight the need for interventions to improve access to KA diagnosis and treatment, and to prevent transmission of KA in highly affected communities. The villagers we interviewed are eager to learn about measures to control KA. Our data suggest that community-based programs could help alleviate the impact of KA. For example, a network of community volunteers might assist KA patients to better negotiate entry into health care facilities. The community, with the help of the government or nongovernmental organizations, could facilitate purchase, distribution, and sustained use of impregnated bed nets. Hospital personnel could work with communities to increase their understanding of the disease, diagnosis, treatment, side effects, and follow-up care. However, unless villagers have reliable access to diagnostic services and affordable KA treatment, these actions will have limited effect. Thus, to avert the growing epidemic of KA in Bangladesh, an effort that integrates a continuum of activities and services from the community to the health care facility is urgently needed.

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