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Magnitude, Knowledge and Burden of Kala-azar: A Study of Eastern Bihar

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Introduction:

Visceral Leishmaniasis, popularly known as Kala-azar, is a vector-borne disease and spreads through the bite of sand-fly. World's 67% cases of Kala-azar occur in India, Nepal, and Bangladesh. In India, the disease endemic is with epicenter in Bihar and Jharkhand, and spread mild in Uttar Pradesh and West Bengal. Indian Kala-azar elimination programme targeted to reduce the annual incidence to 1 case per 10,000 population by 2017. Kala-azar is considered a disease of the poor or rural population having low nutrition, low education and poor quality of housing. As Bihar alone harbours 90% of India's Kala-azar cases, it becomes important that the population at risk has sufficient knowledge and appropriate practices towards the disease, disease prevention, and control. Thus, the level of KAP on Kala-azar, health-seeking behaviour and expected burden of disease become crucial to government for the success of its elimination program.

Madhepura, one of the poorest district of eastern Bihar, was selected purposively for this study. The district has remained one of the endemic districts of Bihar for many decades. In 2013, there were 13.1 Kala-azar cases per 10,000 population in Madhepura district. This district, with 95% rural population, is located in the plains of Kosi River and primarily affected by drought, famines, and flood. The district provides favorable climatic and environmental conditions for progression of the vector.

Objectives:

The objectives of the study were:

- 1) To study the incidence and prevalence of Kala-azar in Bihar and its states.
- 2) To ascertain the level of knowledge and awareness on Kala-azar disease and its vector.
- 3) To assess the preventive attitude, practices to control the progression of Kala-azar disease, in the light of existing eradication programmes.
- 4) To study the health seeking behaviour and barriers to treatment of Kala-azar, and
- 5) To measure the burden of Kala-azar disease (economic, physical, psychological, livelihood).

Data and methods:

The study used both secondary and primary data sources. The data on district-wise number of Kala-azar cases and deaths for the years 1997-2013 was obtained from State Health Society, Bihar. A cross-sectional study was carried out in the district in November 2014. House-listing done in randomly selected 24 villages from four blocks covering 3627 households with 18,432 population. A total of 345 households (with suspected Kala-azar (fever cases) cases and existing patients) and 94 Kala-azar patients were interviewed. The suspected cases (fever) were tested with the rK39 kit for Kala-azar. FGDs (community) and in-depth interviews (healthcare providers and ward members) were carried out. The data was analyzed using Excel, SPSS 21.0 and QSR NVivo 9. The incidence rate, case fatality rate, and seasonality analysis were carried out along with descriptive statistics. Ethical clearance was obtained from the Institute Review Board (IRB) of the International Institute for Population Sciences, Mumbai.

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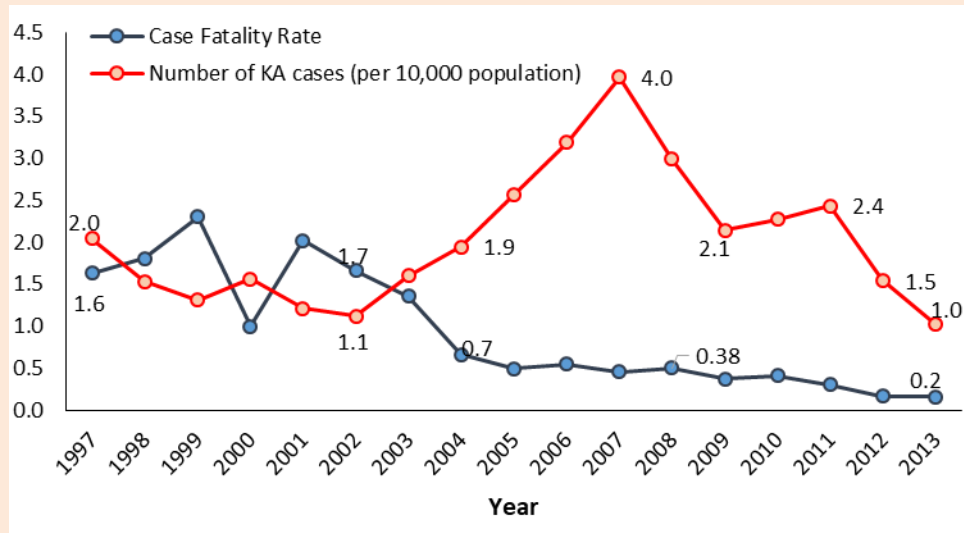
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Magnitude of Kala-azar in Bihar and Madhepura

Bihar recorded 2 Kala-azar cases per 10,000 population in the year 1997, which declined to 1 case in 2013. As per the official statistics in 2016, there were 0.6 cases per 10,000 population in Bihar. Case fatality rate in the state was 1.6 in 1997, which later reduced to 0.16 in 2013 (Figure 1). Though the disease occurred throughout the year, the peak of Kala-azar was observed during the months of March, April, and May. Muzaffarpur district has consistently contributed the highest number of cases in Bihar since 1997. Muzaffarpur, Vaishali, Saharsa, Purnia, Araria, East Champaran, Saran, Sitamarhi, Samastipur and Madhepura contributed 71.8% of the total Kala-azar cases of Bihar.

Figure 1. Number of Kala-azar Cases (per 10,000 population) and Case Fatality Rate in Bihar, 1997-2013



The number of reported Kala-azar cases in past twelve years in sampled villages of Madhepura were 646; 391 for males and 255 for females. During last two years, there were 165 cases. Based on the recorded number of cases and 10 diagnosed cases, the incidence rate of Kala-azar during past two years in Madhepura District was 45 cases per 10,000 population. In male and female population, the incidence was 46 and 43 respectively. With the increase in age, the incidence rate of Kala-azar also increased.

Profile of households

The majority of the households (92.7%) belonged to schedule caste/tribe or other backward caste, and 81% possessed Below Poverty Line (BPL) card. Half of the households were engaged in the agricultural sector, and 65.4% were living in a kaccha house. The literacy rate was 35.1%. Sixty-two percent households had at least one member, who was diagnosed with Kala-azar anytime in the past.

Knowledge, Attitude and Practices on Kala-azar and its Prevention

Fifty-two percent of total respondents (345) reported being aware of one or more vector-borne diseases, and 84% (296) heard of Kala-azar. Of the 296 respondents, 22% knew that the disease is communicable in nature. Sixty-six percent reported to have knowledge on the mode of transmission of the disease; only 19% mentioned that the disease could be transmitted through the bite of an infected sandfly while 80% mentioned mosquito bite. Seventy percent respondents were aware of one or more symptoms of Kala-azar; 93% reported fever for more than 15 days, a primary symptom of the disease. Other reported symptoms were weight loss (31%), liver enlargement (21%) and change in complexion (9%). The majority (98%) said that Kala-azar could be fatal if left untreated. The respondents opined that Kala-azar mostly affects people, who are poor (68.6%), SC/ST (28.1), and agricultural labours (13.9%).

During the survey three pictures, i.e., mosquito, house-fly, and sand-fly were shown to the respondents, and they were asked to identify the Kala-azar parasite/insect. Only 16% could identify the picture of Kala-azar vector, i.e., sand-fly. Awareness of season, in which Kala-azar spreads and biting time of vector was also found limited among respondents.

Substantial proportion reported breeding sites of Kala-azar vector were stagnant/polluted water (64%), garbage sites (33%), dark places (29%), cracks and crevices (12%), and thatched roof (12%). According to the overall knowledge score (10 questions), it was found that less than half (44%) had good knowledge of Kala-azar disease and the vector.

The majority of the respondents said that the incidence of Kala-azar in the family should not be kept secret. One-fourth opinioned that controlling Kala-azar through community participation is possible. Approximately 80% had a positive attitude towards treatability of the disease and similar proportion reported that complete cure of the disease is possible. The public healthcare facilities were the most common choice for treatment (84%). Three-fifths believed that inconsistent or incomplete treatment could affect the recovery of the patient. In total, 49% of respondents had a positive attitude (7 questions) towards treatability of disease.

Majority has adopted some mechanisms to avoid the insect (vector) bite, i.e. created smoke by burning dry leaves, used mosquito coils, and a mosquito net. Members of 40% of households used the mosquito net while sleeping. However, 75% households possessed at least one mosquito net. Ninety-two percent households had bamboo plantation in-and-around their dwellings, and 49% lived near a marshy land. 'Practice Index' (8 questions) indicates that 38% of households follow 'good practices' for prevention and control of Kala-azar. Those who were aware of Kala-azar came to know about the disease from health workers (43%) and friends/ relatives (49%). Role of radio/television in spreading the awareness on Kala-azar was limited to 5% respondents, and 9% got awareness from newspaper/ magazine.

Programs on Kala-azar in study area and its awareness

Respondents were asked about the ongoing activities on Kala-azar prevention in their villages; only 4% could spontaneously respond and mentioned about DDT spray. While asked specially about each relevant programs, 80% reported to witness occasional spray of DDT by government officials in their villages; 3% mentioned cleanliness programme; and about 1% each told about health education and awareness programme, and bed net distribution programme.

Health Seeking Behaviour

In total, 94 Kala-azar patients were interviewed. Seventy percent of the patients slept under bed net and wore clothes which covered partially their hands/legs. Kala-azar was not detected in a single visit, 57% respondents visited health facility more than once for diagnosis. Mean duration of illness before Kala-azar was diagnosed was 1.8 months and Kala-azar patients suffered for 2.8 months. Mean number of visits to hospitals for treatment were 8.1. The majority (92%) completed treatment; 52% sought treatment from public facilities. The major symptoms were fever (100%), loss of weight (42%) and enlargement of liver (27%). Health provider provided information and education on Kala-azar and its prevention to 10% of patients during the process of treatment.

Knowledge on the correct way of treatment among Kala-azar patients was good. Little less than half of the patients purchased medicine from the market and almost same proportion received medicine free of cost from the hospital. The majority (98%) had no information about the side effects of the drug. ASHAs and private healthcare providers were not aware of the duration of treatment. About 35% patients were advised for hospitalization while only 22% were admitted to the hospital. Reported barriers in treatment were high cost, poverty, poor quality of care in public facilities (lack of medicines, waiting time, poor consultation, etc.), and lack of awareness about the free treatment in public facilities.

Burden of Kala-azar

The burden of Kala-azar has been assessed in terms of economic, physical, psychological and livelihood burden.

Perceived burden at household level

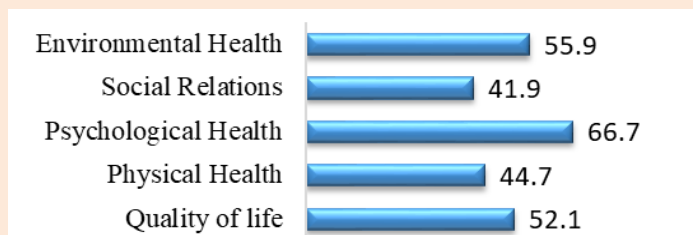
Regarding the perceived effect of illness on the individual and the family, 65% respondents (household) asserted that Kala-azar leaves marks on skin in the form of scars (38%), changes body color (19%) and leads to disfigurement (9%) (Figure 1). Forty-three percent reported that the illness may also affect the mental health of the patient, can cause stress (27%), irritation (4%), and depression/fear of death (6%). Nearly 74% opined that when a family member gets Kala-azar, the household becomes financially weak (40%), forces to borrow money (18%) and sometimes even have to sell property (0.7%).

Actual burden at patient level:

Thirty-two percent of patients reported traveling for more than 15 km to seek treatment, sixty-four percent were working before they suffered from Kala-azar; 93% lost wages due to illness and its treatment. Half of the patients also reported a loss of interest in work and 47% faced difficulty in working. Fourteen percent of patients reported that due to Kala-azar treatment, children in their family dropped out from school; in 4% of families, upcoming marriage functions were postponed or canceled. Approximately one-fifth of families faced food shortage during treatment. WHO's 36-item questionnaire was used to measure the quality of life of the patients.

Fifty-two percent of patients were assessed to be in poor quality of life; 67% have poor psychological health, and 56% had poor environmental health.

Figure 2. Percentage of Patients with Poor Quality of Life, Madhepura District, Bihar 2014



The mean out-of-pocket-expenditure on outpatient care was Rs.8260 with an average expenditure of Rs.1378 per visit. The mean expenditure on hospitalization was Rs.9905. The sources of expenditure were borrowing (81%), personal income (51%) and household savings (32%). Medical expenditure accounted for almost half of the total expenditure of the family. Only 3.2% received medical reimbursed.

Policy Implications:

The government of India is committed to eliminate the disease and prepared an action plan to eliminate Kala-azar by 2017 along with several other diseases. The findings from this study suggest that we are still far from achieving the goal of 1 case of Kala-azar per 10,000 population. Moreover, the official record suggests that we are nearing the elimination. Therefore, the study suggests strengthening the surveillance system and active case detection to cover all the cases of the disease. Kala-azar Technical Supervisor along with Auxiliary Nurse Midwife (ANM) can be given responsibility to identify the cases from their catchment areas. Private practitioners can also be involved and trained to treat the disease, diagnosis, and reporting.

Study participants were knowledgeable about certain aspects of disease treatment and management, such as place of treatment, signs/symptoms, the seriousness of the disease, effect of untreated disease, curability of the disease and impact on household economics and finances. Moreover, their awareness on various other important aspects of the disease, i.e., communicable nature of the disease, vector, mode of transmission, time/season of bite, preventive measures and role of the community in disease control, was limited. This highlighted a wide gap among different eradication strategies adopted by the government, which aimed to instill behavioral changes. We suggest further strengthening and rigorous implementation of knowledge-based strategies to increase the level of awareness about the disease, its vector, transmission and prevention. Active participation of community needs to be ascertained for effective prevention and control of Kala-azar.

The long traveling distance, doctor-patient relationship and unavailability of medicines suggest an action to improve quality of care at public facilities and expansion of services to lower level. Access to treatment and optimum utilization of public health services is suggested. Kala-azar treatment caused a major economic burden on affected families. Therefore, innovative health financing schemes may be the need of the hour. Overall, the study suggested strengthening behavioural change, communication, and social mobilization activities, with a focus on quality of care, possibility of PPP, affordable health financing and intense government commitment.

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Vision "To position IIPS as a premier teaching and research institution in population sciences responsive to emerging national and global needs based on values of inclusion, sensitivity and rights protection."

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