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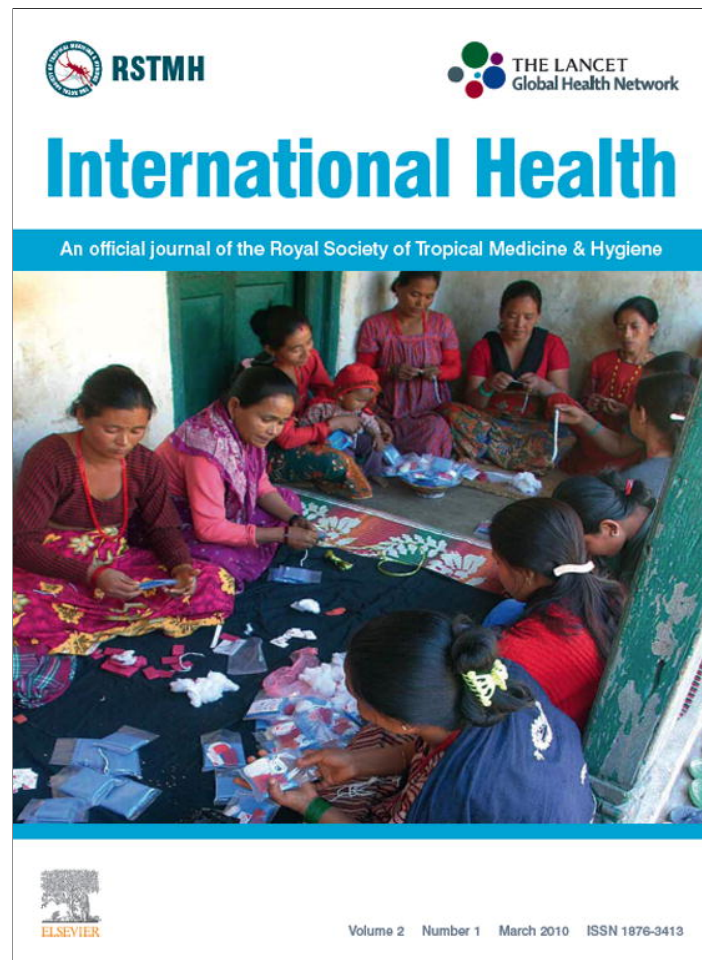


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Some sociological aspects of cutaneous leishmaniasis in patients attending a tertiary referral centre in Colombo, Sri Lanka

S.D. Fernando^{a,*}, H.V.Y.D. Siriwardana^a, K.A.R.C.W. Guneratne^a, L.C. Rajapaksa^b

^a Department of Parasitology, Faculty of Medicine, 225 Kynsey Road, Colombo 08, Sri Lanka

^b Department of Community Medicine, Faculty of Medicine, 225 Kynsey Road, Colombo 08, Sri Lanka

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ABSTRACT

Over 1800 clinically suspected cases of cutaneous leishmaniasis have been referred to the Department of Parasitology, Faculty of Medicine, Colombo, Sri Lanka for investigation since 2001. This study analyses some sociological aspects of 120 patients with laboratory confirmed cutaneous leishmaniasis. This information is important to design and implement control programmes. The disease was predominant among males. In females lesions occurred mainly on the face, while in men they were seen mainly on the limbs. Immediate medical advice was sought by 13% of the population; the others sought treatment when the skin lesion grew or failed to heal. Females delayed seeking treatment as they probably misinterpreted the lesion as a pimple. Only 39% were referred to a Consultant Dermatologist by a medical officer during the first visit. The mean duration of time from the detection of the lesion to referral was approximately eight months. Psychologically, the presence of the lesion affected less than 20% of individuals. Costs related to treatment were relatively low in Sri Lanka. Late presentation and diagnostic delay was related to lack of awareness. Educational programmes should be carried out, aimed both at health care workers and the community to ensure early diagnosis and treatment for cutaneous leishmaniasis.

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1. Introduction

Leishmaniasis is a neglected tropical disease which continues to permanently maim or impair the lives of millions of people every year due to disfigurement, disability and psychological stigma.¹ Socioeconomic, political and environmental factors are fuelling a concomitant increase in the number of cases. It is a disease affecting the economically deprived with over 80% of the affected population earning less than US\$2 per day.²

Leishmaniasis is a newly established disease in Sri Lanka. Since 2001, over 1800 clinically suspected cases of cutaneous leishmaniasis (CL) have been referred to the Department of Parasitology, Faculty of Medicine,

Colombo for investigation from all provinces in Sri Lanka. The parasite species has been identified as *Leishmania donovani* MON 37³ but the vector responsible for transmission of the disease or reservoir hosts are not known. As a broad range of factors influence the distribution of leishmaniasis, programmes to control CL, should not be based solely on epidemiological characteristics but also on sociological factors such as behaviour related to illness recognition, treatment policy and cultural practices.

Beliefs regarding causation, transmission, prevention and treatment methods of diseases varies between communities according to culture, educational background and socioeconomic factors. With the emergence of a new disease in a community, misconceptions may inhibit individuals from adopting appropriate and timely preventive and therapeutic actions. Thus, understanding perceptions regarding diseases and factors influencing them need to

* Corresponding author. Tel.: +94 11 2507333; fax: +94 11 2507381.
E-mail address: deepfern@slt.lk (S.D. Fernando).

be addressed and considered during formulation of interventional strategies. This study describes some sociological aspects in a population with skin lesions diagnosed as being caused by the *Leishmania* parasite, the results of which will be important to design and organize control programmes.

2. Materials and methods

2.1. Study design and study area

An observational descriptive study was carried out over a period of 17 months from September 2006 to February 2008 at the weekly leishmaniasis clinic held at the Department of Parasitology, Faculty of Medicine, Colombo, Sri Lanka. Patients are referred from all nine provinces of the country for confirmation of diagnosis.

2.2. Study population

The study population comprised 120 individuals with a confirmed parasitological diagnosis of CL. During the study period 173 individuals were referred to the clinic for confirmation of diagnosis, but only the data of the 120 individuals in whom the clinical diagnosis of leishmaniasis was confirmed by demonstrating amastigotes in a slit skin smear or needle aspiration or by observation of promastigotes in culture medium were considered for analysis. All 173 patients gave consent to be included in the study if they tested positive for the disease. Those attending the clinic for follow up visits were excluded. Accurate records have been maintained at the clinic since its onset and each patient is given a registration card, thereby enrolment of individuals attending the clinic for follow up visits was prevented.

The purpose of the study was explained to individuals who presented for confirmation of diagnosis and informed verbal consent was obtained to include their data for analysis only if they tested positive for the disease. Patient identity was kept confidential.

2.3. Data collection tool

Prior to the study, a focus group discussion was held at the clinic involving patients who had been referred for diagnosis. These individuals were not included in the study. Once the local terminology, beliefs and practices regarding leishmaniasis was understood, a questionnaire was formulated. The interviewer administered questionnaire which contained both open and closed ended questions was prepared in English, translated into Sinhalese and back translated into English by a second person.

2.4. Data collection

Data was collected by one of the first three authors of this publication who are trained medical officers of the Department of Parasitology. Patients, or parents/guardians in the case of children below 16 years, were interviewed when they presented to the clinic for investigations. All patients were examined by trained medical officers.

2.5. Data processing, analysis and results

Only data from those who were diagnosed as having CL during the study period was taken for analysis. Data was analyzed using SPSS 15 (SPSS Inc., Chicago, IL, USA). Frequency distribution of characteristics of the population, health seeking behaviour for a cutaneous lesion, awareness, social impact and economic burden of CL on the patients were assessed.

3. Results

3.1. Characteristics of the population

The study population comprised 120 individuals, of whom 73% (88) were male. The age ranged from 2 to 70 years (mean age 31.6) with over 60% of the females being less than 30 years as compared to approximately 60% of males who were over 30 years. The majority of the females (59%) were unemployed housewives. Of the males, 28% were from the armed forces, 26% were skilled labourers engaged in occupations such as farming, carpentry, plumbing or construction work and 14% were earning an income as shop keepers or from business ventures. Students made up 13% of males and 25% of females. The highest number of patients were from the Anuradhapura (28% of males and 36% of females) and Matara (21% and 26% of males and females respectively) districts. Only 0.5% of the study population had no formal education, while over 84% of individuals had an education above Grade six. Of these, 48% had completed their GCE Ordinary Level examination, the main national examination in Sri Lanka. Half of the population had a monthly family income of over SLRs 10 000 (approximately US\$100).

3.2. Health seeking behaviour

The health seeking behaviour of males and females differed. The lesion was usually detected as a pimple or another type of skin lesion such as a rash, wart or papule, which are commonly known by the community. A higher percentage of females (44%, 14/32) than males (23%, 20/88) detected the lesion as a pimple ($P=0.102$). In contrast, a higher percentage of males (35%, 31/88) than females (16%, 5/32) detected it as another type of skin lesion such as a wart or a rash ($P=0.114$). Fifty-nine percent (71/120) of the population did not think the lesion needed immediate special attention as they believed it would resolve on its own. At the time of lesion detection, 13% (16/120) sought western medical advice immediately as it did not appear to be similar to the usual pimples or mosquito bites.

Of the 71 people who took no immediate action regarding the lesion, 10% (7/71) sought medical advice within a month of the lesion occurring. Surprisingly, the females took longer to seek treatment compared to the males as the mean duration between noticing the lesion and seeking treatment was 4.8 months in males and 7.1 months in females ($P=0.171$). Medical advice was sought only when the skin lesion started to enlarge, became unusual in appearance or failed to heal and 30% (21/71) of

the population reported a delay in seeking treatment from six months to over one year.

When treatment was sought, 97% (116/120) opted for western medical treatment in the government or private sector. When choosing a health care facility the main factors considered were how convenient it was to visit and the accessibility of the doctor. Only 7.5% (9/120) of the population sought treatment at the dermatology clinics in either government or private hospitals at the initial visit. Following a first visit to a medical practitioner, only 39% (43/111) were referred to a Consultant Dermatologist for further management. Others were treated with creams, oils or oral medication and, as expected, 93% of these indicated that no improvement was observed. If they were not referred during the first visit, they were referred during one of the subsequent visits and the mean duration of time from detection of the skin lesion to the time of referral was 7.8 months in males and 8.4 months in females ($P=0.736$). Once a patient was referred to a dermatologist, confirmation of diagnosis was carried out at the Department of Parasitology.

3.3. Clinical presentation

The majority of patients (87%) were referred for specific investigations of a single cutaneous lesion. The percentage of males and females having multiple lesions at the time of presentation was similar (approximately 13%). In the case of multiple lesions clinical manifestations were

recorded only from the lesion that appeared first. Several differences were noted among the males and females in their clinical presentation. The most common site of occurrence of the lesion in males was on the upper limb (41%) while in females the lesions were mainly on the face (56%). On examination, the majority of males had moon crater-like ulcers (36%), while females had nodular lesions (25%). Most lesions (31% in males and 34% in females) ranged in size from 5 to 10 mm and approximately 70% were round in shape.

3.4. Awareness regarding cutaneous leishmaniasis

When the interviewer asked the subjects what they thought the skin lesion was due to 17% of males and 6% of females ($P=0.183$) indicated that this was probably leishmaniasis (Table 1). The majority of individuals (83%) did not know the cause of the lesion. A high percentage (72%) did not know that CL was a communicable disease and that the disease could be transmitted by a vector to others. Of the 34 who knew that the disease could be transmitted to others, 94% knew it was transmitted by an insect, and of these, 24% knew that the insect was a sandfly. Other than one individual who thought that it was transmitted by a mosquito, all the others seemed to be aware that this was not a mosquito-borne disease. Amongst those who thought that the disease could not be transmitted to others via an insect bite, several misconceptions were expressed regarding the occurrence of the lesion including that it was

Table 1
Awareness regarding cutaneous leishmaniasis.

	Male Number	(%)	Female Number	(%)
What do you think this skin lesion is due to?				
Leishmaniasis	15	17.0	2	6.3
Skin rash	1	1.1	0	0
Razor blade cut	1	1.1	0	0
High sugar intake	1	1.1	0	0
Do not know	70	79.5	30	93.7
Is this skin lesion a communicable disease spread from person to person?				
Yes	23	26.1	11	34.4
No	5	5.7	4	12.5
Do not know	60	68.2	17	53.1
If yes, how is the disease transmitted?				
Insect bite	8	34.8	8	72.7
Sandfly bite	6	26.1	2	18.2
Direct contact	1	4.3	1	9.1
Mosquito bite	1	4.3	0	0
Sand flea bite	7	30.4	0	0
If no, how do you think you acquired this lesion?				
Bite of a worm	3	60.0	0	0
By larvae penetrating skin	1	20.0	0	0
Spontaneous	1	20.0	0	0
Thorn prick	0	0	1	25.0
No response	0	0	3	75.0
Source of information regarding the skin lesion				
Medical practitioner	15	17.0	8	25.0
Patient who has had the disease	14	15.9	0	0
Friends	5	5.7	0	0
Public media	1	1.1	0	0
Medical personnel other than doctors	0	0	1	3.1
No response	53	60.2	23	71.9

caused by a worm, larvae penetrating the skin or thorn prick.

Over 95% of the respondents were unaware of the method/s of diagnosis of the skin lesion or its management aspects (data not shown). None of the females knew the methods of disease prevention, while only three of the male respondents, all army personnel, knew that it could be prevented by wearing protective clothes, preventing insect bites or destruction of vector breeding sites.

The main sources of information (17% males and 25% females) regarding the occurrence of this skin lesion was through a medical practitioner. It was interesting to note that almost 16% of males had received the information from another patient with confirmed CL while none of the females received information from this source. Mass media, such as television and radio, played a very minor role in raising awareness regarding this disease (Table 1).

3.5. The social impact of cutaneous leishmaniasis

A feeling of isolation and social stigma from the community was mentioned by 18% of males and 25% of females, this being indicated mainly by those who had lesions on the face. Only a small proportion (14%, 17/120) indicated that they had faced a negative attitude from their families due to the presence of lesions. Of the 57 males and 15 females who were married, 30% were encouraged by their spouses to seek treatment early.

3.6. The economic burden

When the economic burden of the disease was estimated, over 70% (86/120) of the population spent less than SLRs 1000 (approximately US\$10) on out-of-pocket costs such as medicine, transport and any special food (Table 2). The number of days absent from school or work was recorded. The mean number of days children were absent from school was 2.8 in boys and 1.8 in girls. Out of employed adults 55% of males and 40% of females were absent from work place or could not engage in self employ-

ment activities due to the skin lesion. Approximately 69% of the 72 individuals who were self employed or received a fixed salary indicated that there was no loss of income due to absence from work.

4. Discussion

Over the past few years there has been a tremendous increase in appreciation of the importance of leishmaniasis in the country and in 2008 it was established as a notifiable disease by the Ministry of Healthcare and Nutrition, Sri Lanka.

The sociological aspects of CL in Sri Lanka which have been described in this study may contribute in different ways to the level of *Leishmania* transmission and people's health seeking behaviour in Sri Lanka. These facts need to be taken into consideration when conducting awareness programmes and in formulating suitable control policies.

Leishmaniasis can have a zoonotic or a peridomestic transmission, depending on the behaviour of the vector in a given focus. The transmission of *L. donovani* in Sri Lanka is perennial but peaks during the monsoon season as there is a peak in the biting activity of the sandfly vectors.⁴ As in other studies reported from Sri Lanka the highest number of patients came from the Matara district and Anuradhapura districts.^{5,6} Globally, the preponderance of the disease in males has traditionally been tied to risks associated with their outdoor occupations.⁷ The disease was more predominant among the males in this study, approximately 30% of whom were from the armed forces. Due to the civil conflict which was taking place in Sri Lanka at the time this study was being carried out, military personnel would have been prone to sandfly bites due to movements in jungle areas. This is further supported by the fact that the highest number of cases were from the Anuradhapura district which is in the North Central Province, where many military base camps are situated. Military personnel who return from areas of conflict to their place of origin can introduce the disease into new areas. In Sri Lanka, as in most parts of the world, military personnel and farmers

Table 2
Economic impact of cutaneous leishmaniasis.

	Male		Female	
	Number	(%)	Number	(%)
Expenditure due to the occurrence of a skin lesion (Sri Lankan Rupees ^a)				
<100	19	21.6	5	15.6
101–1000	42	47.7	20	62.5
1001–5000	21	23.9	7	21.9
5001–50000	6	6.8	0	0
Mean number of school days lost ^b	2.75		1.75	
Mean number of days absent from work ^c	3.7		2.2	
Loss of income due to absenteeism from work (Sri Lankan Rupees) ^c				
No loss of income	45	67.2	5	100.0
100–1000	3	4.5	0	0
1001–5000	12	17.9	0	0
5001–10000	1	1.5	0	0
10001–100000	6	9.0	0	0

^a 100 Sri Lankan Rupees = US\$1.

^b Mean number of school days lost determined from records of 20 children attending school (12 males and 8 females).

^c Analysis of loss of income and mean number of days absent was from 67 males and 5 females who were employed (fixed salary or self employed).

have a higher risk of infection since they work in outdoor scrub jungles where the sandfly vector of leishmaniasis is most likely to be found. Women, who tend to stay in the domiciliary environment, have a reduced risk of acquiring leishmaniasis.^{4–6,8} As published in other studies carried out in Sri Lanka, single localized lesions are the most common of the varied manifestations of CL.^{5,6}

All patients included in this study were diagnosed as having CL for the first time. Thereby only a minority (14%) were aware of the occurrence of leishmaniasis in the country and the fact that the skin lesion may be due to leishmaniasis. Awareness of the disease, its mode of transmission, method/s of diagnosis and management of disease was poor. Lesions on the face can result in anxiety, depression, isolation and social stigma but due to lack of awareness regarding the disease there was a delay in seeking treatment, especially amongst the females. Only 13% of the study population sought immediate medical advice; the others sought advice only when the skin lesion grew larger and failed to heal. Delay in treatment can lead to establishment and progression or dissemination of the local infection as infected individuals can act as reservoirs of infection and thereby facilitate further spread. Easy accessibility was the key factor for patients in choosing the first health care contact. However, the majority of the first contact doctors did not consider leishmaniasis in their differential diagnosis and did not refer the patient for diagnosis and initiation of appropriate treatment. The time between the first contact with a medical practitioner and referral to a Consultant Dermatologist was approximately eight months. At the time of referral, the dermatologists were able to establish a provisional diagnosis and referred the patients for investigations. None of the patients were referred directly by a primary health care provider for investigations. This further emphasizes the importance of health education and raising awareness not only for the general population but also among health care personnel in Sri Lanka. In many countries the cost of diagnosis and anti-leishmanial drug therapy can lead to delayed case management.⁹ In contrast patient care, including leishmaniasis diagnostic investigations and drug management, is freely available for all state sector patients in Sri Lanka, including costly PCR assays and sodium stibogluconate treatment. Early and accurate case detection will invariably enhance the management process and help minimize the risk of further spread. Thus, both the general public and health care providers should be encouraged and trained to identify early symptoms and signs of the disease. Following an initial clinical diagnosis health care providers should be encouraged to refer the patient for investigations. Diagnosis of leishmaniasis needs to be excluded sooner rather than later in the process of case management.

In contrast to other countries, media appeared to play a minor role in disseminating information regarding a skin lesion suspected as being CL.¹⁰ Information regarding the disease was gathered by patients mainly from medical practitioners and other individuals who had got the disease. This further shows the importance of educating these two groups as the first step of a public awareness programme. As 96% of the population indicated that they

were not aware about prevention of CL, active educational campaigns should be carried out at community level, to enhance the knowledge of the at-risk population regarding likely vectors, reservoir hosts and preventive measures.

Lesions suspected of being CL create a burden on the national economy of many countries.¹¹ The direct cost of the disease to the patient was relatively low with 47% of the male patients and 62.5% of the female patients spending less than SLRs 1000 (approximately US\$1–10) on medicine, food and transportation from the time the skin lesion first appeared until they were referred to the Department of Parasitology for confirmation of the diagnosis. Although health care is available free of charge in all government hospitals in Sri Lanka there could be out-of-pocket expenses for transport, food and medicines. Due to the good road network and public transport, and the availability of free ambulance services for referrals from distant hospitals, the cost of seeking treatment was kept to a minimum. However, the direct financial cost to the government of diagnosis of the disease by direct smear examination and/or culture and management with local application of liquid nitrogen or sodium stibogluconate, which is the current management strategy in Sri Lanka, has not been estimated. The mean number of school days absent and the mean number of work days lost was higher in males than in females: 2.8 in male and 1.8 in female children; 3.7 in adult males and 2.2 in adult females. It is reported that 77% of men in Ecuador believed that CL diminished their ability to work.¹¹

Further in-depth studies into the social and cultural factors relating to transmission of CL would be useful in orientating control policies.

Authors' contributions: All authors contributed to the concept and design of the study; SDF supervised the entire project and data entry; HVYDS and KARCWG carried out the clinical examination of patients and completed the questionnaires; All authors contributed towards data analysis under the supervision of LCR. All authors contributed to preparing and revising the manuscript and read and approved the final version. SDF is guarantor of the paper.

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