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# Patients' associations and the control of leishmaniasis in Peru

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*American mucocutaneous leishmaniasis is an important health problem in Peru, particularly in the mountainous Cuzco Region, where 25% of all new cases reported in 1989 were located. Cases have increased considerably since the beginning of the 1980s, when large-scale seasonal migration to endemic zones occurred, particularly the forest area of Madre de Dios, following the discovery of new gold deposits there, and the deterioration in the economic situation in Peru. Following the lack of official response from the Peruvian government, hundreds of people suffering from leishmaniasis in the Cuzco area formed self-help associations with the objective of obtaining the drugs needed to treat their disease. The major achievement of this spontaneous movement, which was supported by several public and private institutions, was to encourage sick people, particularly patients with mucosal lesions, to emerge from isolation. As a result, the prevalence and incidence of the disease have now considerably decreased in the region.*

## Introduction

American mucocutaneous leishmaniasis caused by *Leishmania braziliensis* is a major health problem in Peru. The annual incidence of all clinical forms of American leishmaniasis increased from 7.6 per 100 000 to 24.7 per 100 000 over the period 1979–89 (Ministry of Health, unpublished data, 1992). Leishmaniasis poses a particular problem in the Cuzco Region, where 25% of all new cases reported in 1989 were located; currently, around 50% of all the mucosal cases treated in Peru are reported from this region. During the past decade, following large-scale seasonal migration of the population to the neighbouring forest of Madre de Dios, where small-scale farmers are employed by gold-mining companies during the rainy season, the number of new cases has increased considerably. However, the increasing prevalence in the region has also been the result of the lack of treatment because appropriate drugs were not available. In 1983, people with leishmaniasis in the town of Sicuani decided to form a patients' association to try to obtain anti-leishmanial drugs. Eight similar patients' associations were established between 1983 and 1993. In 1990, these associations joined together with health

authorities and other institutions in the region to form a committee to coordinate their activities.

This article describes how these patients' associations were formed and discusses the importance they have had in the control of mucocutaneous leishmaniasis. As far as we know, in tropical diseases, there is no evidence of other community initiatives in which sick individuals have been able to organize spontaneously and succeed in obtaining the drugs needed to treat their disease. In view of the increasing prevalence of mucocutaneous leishmaniasis caused by *L. braziliensis* (1), its public health importance and the difficulties of control (2), our findings may have relevance for other countries where this form of the disease is endemic.

## Materials and methods

### *Population movement to Madre de Dios*

Although there have been gold-mining activities in the Cuzco Region since the beginning of this century, increasing migration to Madre de Dios started in 1975, after the discovery of new gold deposits, and the marked deterioration of the economic situation in Peru. Between 1972 and 1977, the production of gold increased from 122 kg per year to 85 kg per month (3). People left their communities in the altiplano highlands, where the socioeconomic situation had been worsening, and travelled to Madre de Dios to seek work in the gold industry. Migration increased as the demand for workers grew, following an upsurge in the international demand for gold. A survey carried out in 1992 (J. Calmet, unpublished

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Table 1: Annual incidences and number of cases of leishmaniasis notified in Peru, Cuzco, and Madre de Dios, in 1984, 1989, and 1991<sup>a</sup>

	1984		1989		1991	
	No. of cases	Incidence <sup>b</sup>	No. of cases	Incidence <sup>b</sup>	No. of cases	Incidence <sup>b</sup>
Peru	2733	14.1	5212	24.7	3631	16.5
Cuzco	920	99.1	1297	127.0	722	69.0
Madre de Dios	183	43.9	147	309.4	324	653.2

<sup>a</sup> Source: Oficina General de Epidemiología, Ministerio de Salud, Lima, Peru.

<sup>b</sup> Annual incidence = No. of cases of leishmaniasis (all clinical forms) per 100000 population per year.

data) estimated that roughly 35000 people, mainly young males, migrate to Madre de Dios every year from different regions of Peru. In certain areas, half of the male population aged 15–35 years migrate every year. Most of these migrants come from the mountainous parts of the Cuzco Region.

Madre de Dios, an immense plain of tropical forest, is an endemic zone for leishmaniasis caused by *L. braziliensis* (4). The disease is mainly transmitted during the destruction and burning of the forest before mining commences, but also during the extraction activities, when people are exposed to sandfly bites. Cutaneous lesions generally require several months for spontaneous healing, and are not as serious as the mucosal lesions that appear in most cases several months to many years subsequently (5). The increase in the number of patients with mucosal lesions was observed not in Madre de Dios, where the infection is acquired, but in the mountainous areas of Cuzco when the workers returned home. The absence of sandflies in the mountains explains the lack of transmission of the disease in these areas. In the mountains, the prevalence of leishmaniasis increased and the mucosal disease became a serious problem. An investigation demonstrated that, in some areas, around 3% of the male population was affected by mucosal lesions, and that this proportion increased to 10% among 40-year-old males (CIPA, unpublished data, 1991). Table 1 shows the high annual incidences of leishmaniasis in the regions of Cuzco and Madre de Dios compared to the overall incidence for Peru.

In August, 1975, leishmaniasis was declared an occupational disease in Peru, and since then treatment has been free for everyone who acquires the condition while working in forests. However, access to treatment was very limited before the formation of the patients' associations.

### Methodology

The study into the role of patients' associations in the Cuzco Region was carried out between January and May 1993. Little patient documentation was

available and the chief methods used to gather information were unstructured interviews and collection of data from hospital and patients' associations records. People with leishmaniasis, leaders of the patients' associations, health workers and health authority officials were interviewed. Interviews were generally conducted at the workplace or in the interviewee's home, recorded on audio tapes, and transcribed. In some cases, when people only spoke Quechua, the use of an interpreter was necessary. Epidemiological information was collected at the places where patients are usually examined (public hospitals, patients' associations, private institutions) and at the region's health department.

## Results

### Patients' associations

The first patients' association in Cuzco was formed in 1983 on the initiative of a group of individuals with leishmaniasis from the town of Sicuani, who travelled through the area telling people with mucocutaneous leishmaniasis to join them; after a few months, more than 200 such individuals had joined the association. They were supported by several institutions, mainly the local Catholic Church, which spread information through its local radio station and supplied them with drugs. The patients were registered and a doctor came regularly from Cuzco to examine them; some were treated with meglumine, but severe cases were sent to hospitals in Lima and Cuzco to be treated with amphotericin B.

Between 1983 and 1993, a total of nine associations were established in the region, representing 1648 members. The largest, in the town of Ocongate, was formally established in October 1989, although its activities had started in February 1988. Between February 1988 and January 1992, a total of 441 patients were registered in this association. The distribution of these cases by year and clinical form is shown in Table 2.

Table 2: Number of cases of leishmaniasis registered at the patients' association in Ocongate (Cuzco Region) between February 1988 and January 1992<sup>a</sup>

Date	No. of cases, by clinical form:			Total
	Cutaneous lesion	Mucosal lesion	Scar	
Feb. 1988	13	44	28	85
Jan. 1989	6	15	6	27
Feb. 1989	20	18	28	66
Jan. 1990	16	27	13	56
Feb. 1990	13	20	19	52
Jan. 1991	10	11	15	36
Feb. 1991	17	20	37	74
Jan. 1992	20	15	10	45
Total	115	170	156	441

<sup>a</sup> Source: M. Tokushima, CIPA-Cuzco.

Obtaining drugs was not the only objective. People claimed that the government should make greater efforts; although leishmaniasis was legally considered to be an occupational disease, in practice free drugs were not available and no financial compensation was given to people who had acquired the disease through work. Patients also demanded better living conditions in Madre de Dios and the provision of a minimum standard of working conditions by the mining companies. Other objectives of the associations were not directly related to leishmaniasis, such as the search for other seasonal employment opportunities which could prevent people from migrating to the forest.

Each patients' association elects a directorate every 2 years and meetings take place three or four times a year. These last for the whole weekend, and questions related to the disease and to migration are discussed. Every patient is examined by a physician specialized in tropical diseases. Most people do not need treatment and attend the next meeting for a further check-up. People who require meglumine are treated by a health worker in the health centre; patients who live in isolated areas are treated by the health promoter in the community. Those who need treatment with amphotericin B are referred to hospital in Cuzco. In addition to covering leishmaniasis and other health problems, general adult education is carried out. Training courses and information activities are also organized. While health-related problems are the most important, social and political issues are also discussed, such as working or living conditions in the forest, and noncompliance with occupational legislation by the mining company owners.

In terms of cases detected and treated, the most important results have been obtained in Ocongate.

In 1992, a total of 93 patients were treated and less than 10 new mucosal cases were registered with the patients' associations. A detailed record of the patients has also provided accurate epidemiological data. For example, a clinical description of all cases of leishmaniasis registered at the patients' association in Ocongate up to December 1992 is shown in Table 3. For 180 of these patients, the interval between infection and appearance of mucosal lesions was assessed. In most cases, this interval was 1–10 years but it was 37 years in one instance and less than 1 year in nine cases. Follow-up after 1 year of treatment was evaluated in 239 cases: 163 (68%) were cured after treatment with pentavalent antimonials, but seven patients relapsed. Only five patients in Ocongate defaulted from treatment.

### The regional committee

After they had been set up, the patients' associations were supported by the Catholic Churches of Sicuani and Ocongate, a national nongovernmental organization (*Centro de Investigación y Promoción Amazonica*), the Italian Cooperation (*Programa de Salud Comunitarie en el Trapecio Andino*) and the Tropical Medicine Institute of Cayetano Heredia University in Lima, the Peru Institute of Social Security (*Instituto Peruano de Seguridad Social*) and the Ministry of Health. In 1990, these institutions established a committee to coordinate leishmaniasis control in the Cuzco Region, which subsequently received support from the regional and national health authorities. The movement, which had started as a spontaneous initiative, thus became more structured and organized. The role of each institution was determined, and a control strategy was defined.

Table 3: Clinical characteristics of leishmaniasis cases registered at the patients' association in Ocongate up to December 1992<sup>a</sup>

Clinical characteristic	No. of cases	Proportion (%)
<i>Location of lesion</i>		
Face or neck	91	18.9
Trunk or upper limbs	108	22.4
Lower limbs	282	58.6
<i>No. of lesions</i>		
1–2	351	70.7
3–10	145	29.3
<i>Clinical form</i>		
Cutaneous lesion only	270	54.4
Mucosal involvement	226	45.6
Laryngeal involvement	64	12.9

<sup>a</sup> Source: M. Tokushima, CIPA-Cuzco.

based on active case-finding, early diagnosis and early treatment of the disease, similar to that already being carried out in Bolivia, although implemented in a different way (6).

## Discussion

When the prevalence of a disease is high in a population, treatment must be available in a health centre or hospital, and patients must be able to reach the health facility. For mucocutaneous leishmaniasis in the Cuzco Region of Peru, neither of these two conditions was met in the early 1980s when the first patients' association was set up. Supply of antileishmanial drugs was not sufficient and patients remained in their communities refusing to attend hospitals and health centres, which they considered were unable to treat them. The patients treated their cutaneous lesions either with traditional medicines, which were not often effective, or with a few ampoules of meglumine bought on the black market or in local pharmacies. In both cases, skin lesions persisted for weeks or months and a significant proportion of patients developed mucosal lesions. The patients were distributed throughout the region, often living in communities remote from the bigger towns and difficult to reach. Many of them considered that their disease was no longer curable. In addition to the nonavailability of treatment, lack of knowledge among health staff had also contributed to the accumulation of mucosal cases. The formation of the patients' associations was a spontaneous movement of people affected by the disease, as a consequence of this situation.

The major achievement of the patients' associations, particularly in Sicuani and Ocongate, was to encourage sick people to emerge from their isolation. Even though the movement was supported by other institutions, it was the patients who had decided to organize themselves. They travelled to Lima and Cuzco to meet the health authorities and walked through their communities to identify other patients. Once the associations had been established, the participation of patients was important in giving and supervising treatment in the community. This probably explains the results that were achieved in Ocongate in terms of the high number of cases detected and treated, the low default rates, and the collection of accurate epidemiological data. At present, many years after the formation of the first of these associations, hundreds of patients continue to gather at the meetings that take place several times each year. There appear to be no similar activities in other countries where leishmaniasis is endemic (7).

It is important to consider the reasons for the particular success of the associations described here. The concentration of a high number of leishmaniasis cases in a small area is certainly not a sufficient explanation, since the prevalence of other diseases, such as malaria or tuberculosis, is also high in the area. A more important reason is probably the severity of the mucosal lesions and the impact they have on individuals. Difficulties in breathing and speaking are not rare, and eating becomes painful, leading to malnutrition. Patients are considered useless by the community, and are rejected by their neighbours and families. Eventually they become ashamed and depressed, remaining hiding for years in their communities, and sometimes committing suicide. Through the support of several public and private institutions, the patients' associations, even at a local level, were able to introduce the use of the latest treatment protocols — another important factor for their success. The social characteristics of the people concerned also played a crucial role. Quechua farmers are a social group that had previously been organized in political movements and had a long experience in defending their rights against the rich land-owners of the area. When the patients' associations were formed people in the communities with leishmaniasis were asked to join by similar people affected by the same disease — small Quechua farmers like themselves, living under the same conditions. They were not disgusted by the lesions, as was often the case with people in the general population and health service staff, who considered the disease contagious. The particular relationship between patients has also been a factor in the results achieved; the psychological support given by the associations has been immense.

The role of the regional committee has also been important. The institutions involved had all been working in the field for many years, had close links with the local population, and had a detailed knowledge of the areas concerned and their problems. They were therefore in the best position to determine the most adequate interventions and to choose the most suitable control activities. It was agreed that, in view of the complexity of the disease, a broad approach to its control was needed. For example, it was considered that active case detection was required, since people were reluctant to attend spontaneously the health centre in this particular area of the country. Consideration was given as to whether people should be prevented from migrating to Madre de Dios. However, it was agreed that this was not realistic, since seasonal migration is, for many individuals, the only way of improving their income. Furthermore, economic factors are not the only causes of migration, hence

ameliorating the economic situation locally might not prevent it.

Finally, it is interesting to note that, in this process, institutions and health authorities have worked together to determine policy. At least this has been the case with the regional health authorities with whom there has been close collaboration in many of the activities undertaken. However, the national authorities have often been reluctant to accept the existence of the regional committee. The experience of the regional committee is an example of how government and nongovernmental organizations can work together to develop a strategy in which neither the government alone nor the civilian component alone could have been successful.

## Conclusion

At the beginning of the 1980s, people suffering from leishmaniasis in the Cuzco Region of Peru had no access to treatment and many of the health professionals working in hospitals and health centres in the area knew little about the condition. Ten years later, many things had changed. In 1985, leishmaniasis was included in the National Control Programme of Tropical Diseases, which until then covered only malaria and yellow fever. In 1993, norms for control of leishmaniasis were defined by the Ministry of Health, and a regional campaign of diagnosis and treatment, financed by the government and the Pan American Health Organization, was set up. However, despite the progress made, there are still many patients who remain untreated.

The community has played a major role in bringing about these changes, first by forming its own patients' associations and by coordinating their activities through a committee on which different sectors of society, including health authorities, are represented. Even if the Cuzco experience cannot be applied to all situations, we believe that it is an example of successful multisectoral coordination and community participation likely to be of relevance in countries where mucocutaneous leishmaniasis is endemic.

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## Résumé

### Associations de malades et lutte contre la leishmaniose au Pérou

La leishmaniose cutanéomuqueuse américaine constitue un important problème de santé au Pérou, en particulier dans la Région de Cuzco qui, en 1989, regroupait 25% de l'ensemble des nouveaux cas notifiés. Le nombre de cas a considérablement augmenté depuis de début des années 80, époque à laquelle ont commencé d'importantes migrations saisonnières d'agriculteurs vers les zones d'endémie, notamment la zone forestière de Madre de Dios, à la suite de la découverte de nouvelles mines d'or dans cette région et de la détérioration de la situation économique dans le pays.

La leishmaniose est classée maladie professionnelle au Pérou depuis 1975 et son traitement est gratuit. Toutefois, l'accès au traitement s'est révélé très limité dans la pratique, en raison de l'insuffisance de l'approvisionnement en médicaments et de l'absence de formation du personnel de santé au traitement des lésions des muqueuses. En 1983, un groupe de malades s'est constitué en association dans le but d'obtenir les médicaments nécessaires au traitement et a parcouru la région de Sicuani pour s'adjoindre d'autres malades. Ainsi est née la première association de malades; depuis, huit autres associations de ce type ont été constituées. Le présent article examine le mode de fonctionnement de ces associations et leur importance dans la lutte contre la leishmaniose cutanéomuqueuse.

Les informations ont été recueillies lors d'entretiens informels avec des malades, des représentants des associations de malades, des agents de santé et des fonctionnaires des services de santé, et à partir des registres des hôpitaux et des associations.

Les associations enregistrent les malades et organisent des réunions trois ou quatre fois par an, au cours desquelles les malades sont examinés et diverses questions se rapportant à la leishmaniose sont débattues. La plupart des malades sont traités par la méglumine, et les cas graves sont envoyés à l'hôpital pour y recevoir un traitement par l'amphotéricine B.

Dès le début, les associations ont reçu un soutien de plusieurs organismes et organisations non gouvernementales. En 1990, toutes les associations concernées ont créé un comité régional afin de coordonner la lutte contre la leishmaniose dans la Région de Cuzco. Une stratégie de lutte, reposant sur le dépistage actif des cas, le diagnostic précoce et l'instauration rapide du traitement, a

été définie. Depuis 1993, une campagne régionale en faveur de la lutte contre la leishmaniose, financée par le Gouvernement et bénéficiant du soutien de l'Organisation panaméricaine de la Santé, a été menée. La prévalence et l'incidence de la maladie dans la région ont aujourd'hui considérablement baissé.

Cette mobilisation spontanée a encouragé les malades atteints de leishmaniose à sortir de leur isolement et à se battre pour obtenir un traitement efficace. Son succès s'explique par plusieurs raisons. La gravité des lésions des muqueuses conduit souvent les malades à se cacher, et la rencontre d'autres personnes ayant les mêmes problèmes constitue un important soutien psychologique. De plus, les agriculteurs de la région ont déjà un passé d'engagement politique et s'organisent depuis longtemps pour défendre leurs droits face aux propriétaires terriens. Le comité régional a également joué un rôle important et a collaboré avec fruit avec les autorités sanitaires locales.

Cette expérience, même si elle n'est pas transposable dans tous les contextes, constitue un exemple réussi de participation multisectorielle et communautaire, susceptible d'intéresser les

personnes travaillant dans les pays où la leishmaniose cutanéomuqueuse est endémique.

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