## Some Considerations on the Adequacy and Validity of Data on Leprosy in the Americas

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The interest taken by the Pan American Sanitary Bureau, Regional Office for the Americas of the World Health Organization, in the problem of leprosy in the countries of the Western Hemisphere is reflected in the priority assigned to this disease and in the assistance given to the countries throughout the years.

In 1956 a document containing recommendations on the general lines that leprosy control programs should follow was submitted to the meeting of the Directing Council of the Pan American Health Organization held in Antigua, Guatemala. Many of those recommendations are still valid today; others have had to be changed or should be revised in the light of new knowledge and technical advances.

The First Pan American Leprosy Seminar was held in 1958 in Belo Horizonte, Minas Gerais State, under the auspices of the Pan American Health Organization and in cooperation with the Government of Brazil, and was devoted to a review of modern control methods.

During the Seminar the gaps in our knowledge of the leprosy problem in the Americas came to light. As to the magnitude and scope of the problem, the report of the Seminar stated: "In this regard it should be pointed out that the lack of uniformity and system in the compilation and presentation of data and information on this subject, which is meager, makes it difficult if not impossible to evaluate them, even to compare the leprosy situation in different areas or at different times in the same area." Another part of the report stated: "The degree of organization of leprosy prevention varies in the American continent from area to area; in some, programs are barely beginning, in others there is a

complex set-up comprising a variety of health services. However, in most of them there is a lack of balance between the component parts, and in almost all of them the magnitude of the problems is unknown."

In the course of years the ideas sown at the Belo Horizonte Seminar have borne fruit. In the countries and territories of the Region, DDS is the drug of choice for the treatment of leprosy patients; ambulatory treatment with this drug is the method of choice, too. Obligatory isolation, if practiced at all, is exceptional. Laws that restrict the civil rights of leprosy patients have been abolished, and their rights and responsibilities have been restored.

Equally notable is the change in attitude in government circles, in the medical profession, and in the public at large; they are beginning to regard leprosy as one more infectious disease. In some countries leprosy services are a normal part of the general health programs and, where this is not as yet the case, for special reasons, it is a future goal.

The conceptual advances made in leprosy and its control, and the practical application of these concepts, have drawn attention to important problems, including:

1. Case-finding.

2. Data registration systems (case-reporting, data recording, tabulation, analysis, and evaluation and publication of the collected data).

3. Administration of control programs.

4. Health education and public information.

Henceforth, preferential attention will be given to the first two of these four items.

Until recently leprosy control has been in the hands of leprosy specialists, a group whose numbers have been gradually decreasing. In recent years other physicians, such as dermatologists, specialists in infectious diseases, and general practitioners, have become more interested in the leprosy

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problem, thanks to the efforts and openmindedness of the leprologists. In the near future the general practitioner will be mainly responsible for the diagnosis and treatment of leprosy patients. For this purpose, in some areas, he will be assisted by auxiliary personnel, which when properly trained, and under his supervision, will help with mass examinations and case-finding. The role of this health worker in casefinding and in the periodic supervision of cases and contacts will become more active as time goes on and will, therefore, increase in importance.

As already stated, it was the leprologist who was in charge until recently of casefinding and diagnosis, as well as the supervision of patients and contacts. This tended to reduce the size of the case-finding area. However, the findings of limited investigations were generalized and were assumed to reflect the epidemiologic characteristics of the disease. Thus, people began to talk about areas with leprosy and areas without leprosy. But as programs were expanded and more trained personnel capable of diagnosing leprosy became available, the number of cases discovered in areas formerly considered without leprosy has increased. There is no doubt that this phenomenon will continue to occur in the future.

Because of certain factors related to the organization of programs and to the intensity and regularity of case-finding, it is not at present possible to locate all the leprosy cases one would expect to find even in the most exposed groups, contacts for example.

The definition of contact and the interpretation of the term are moot points. In some countries in the Americas a contact is defined very broadly; working definitions have been adopted because the knowledge necessary for an accurate definition is not available. In other countries a contact is defined from an administrative standpoint or the definition reflects the financial resources available for investigating this group. It is because of the different criteria used for defining a contact that the conclusions reached on the prevalence of leprosy among contacts also differ. Indeed, the conclusions are sometimes diametrically op-

posed. Some investigators report that the number of patients found among contacts is minimal, while others report that with the present system of work—which should be improved—they find an important percentage of their new cases among contacts.

The prevalence of leprosy in extensive areas of countries, or in entire countries, has been estimated on the basis of the number of cases detected, in incomplete or limited investigations; in our opinion this procedure is not valid.

Whatever method is used to ascertain the frequency and distribution of leprosy in a country, the first requisite is to have personnel qualified to diagnose the disease. Once this requirement is met, and a method of work has been established, a data-registration system must then be organized.

The reporting of leprosy cases is subject to all the limitations of a disease, up to very recently, surrounded by every conceivable type of prejudice. Governmental, semigovernmental and private institutions sometimes do not notify the pertinent authorities of the number of leprosy patients they care for. Private practitioners usually fail to report the leprosy patients under their care. It will be a long time before case reporting is improved, because basically it is an educational process.

Even when cases of leprosy are notified, the notification is not always recorded, or is filed away in the memory of some official or noted on a piece of paper that is easily lost. Under these circumstances, even if a case is reported, there is no record of it. In some areas, it has even happened that the number of cases on record increased in consecutive months as a result of careful search for clinical histories in the desks of the various medical departments. These case histories belonged to patients who, although they did not appear on the records, were being cared for by official services; who had been reported but not registered; who were, therefore, not taken into account in calculating the prevalence of leprosy.

Case records are not brought up to date as quickly and as often as necessary. For example, a review of the leprosy control program in a province in one of the countries of the Region, including the up-dating

	Total		100.0	
Contacts	Not under control	144,293	.818 55.0	
U	Under control	118,525	262, 45.0	
t	None	57,396	39.9	
[reatmen	Am- bula- tory	60,199	144,487 41.6	
5	In hos- pital	26,892	18.5	
	Other	1,808	5.4	
al form	Inde- termi- nate	7,019	,653 20.2	
Clinic	Tu- ber- culoid	10,064	34 29.0	
	Lep- roma- tous	15,762	45.4	
ge	15 and above	17,890	,290   92.8	
Υ	Under 15	1,400	19	
ex	۲	7,845	.497 36.5	
Š	Μ	13,652	21 63.5	
Ð	Total		100.0	
on activ	Not under control	75,277	.038 46.4	
Cases (	der trol	89,861	167, 53.6	
	Ū C	Sub- total:	Total:	

TABLE 1.-Leprosy in 18 countries in the Americas at 31 December 1963.

TABLE 2.-Leprosy in 13 countries and 2 territories in the Americas at 30 June 1964.

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t active Sex Age	Sex Age	Sex Age	ex Age	Age	e			Clinic	al form			Freatmen	t	Ū	Contacts	
Not under control Total M F 15 al	Total M F 15 al	M F 15 al	$ \begin{bmatrix} Under \\ 15 \\ al \end{bmatrix} $	Under a 15 al	ala	15 und bove	Lep- roma- tous	Tu- ber- culoid	Inde- termi- nate	Other	In hos- pital	Am- bula- tory	None	Under control	Not under control	Total
27,817 11,119 6,311 1,357 16,	11,119 6,311 1,357 16	11,119 6,311 1,357 16,	6,311 1,357 16	1,357 16,	16,	073	10,275	6,891	4,499	1,127	20,491	24,889	7,224	145,520	135,583	
64 17,430 17,430   44.8 100.0 63.7 36.2 7.8 92	$\begin{array}{c ccccccccccccccccccccccccccccccccccc$	$\begin{array}{c ccccccccccccccccccccccccccccccccccc$	430 17,430   36.2 7.8 92	17,430 7.8   92	92 92	5	45.0	22 30.2	,792 19.7	5.0	38.95	52,604 47.31	13.73	$281 \\ 51.7$	,103 48.3	100.0

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of case records, disclosed that nearly 50 per cent of the registered patients had died. Nevertheless, they continued to be taken into account for the purpose of calculating the prevalence of the disease.

Further defects came to light when an epidemiologic study was being made.

In 1963, the number of registered leprosy patients in 18 countries reached a total of 167,038 (Table 1). Sex was given for only 21,497; age for 19,200; the clinical form of the disease for 34,653; and the kind of treatment for 144,487.

On June 30, 1964, according to information provided by 13 countries and two territories, the number of registered cases was 113,564, but the age and sex were given for only 17,430, the clinical form of the disease for 22,792, and the kind of treatment for 52,604 (Table 2).

These facts indicate that cases are not well studied or that the organization of records is defective, that the data are carelessly compiled, or that the persons responsible do not attach much importance to them.

We must accept the fact that because there is a shortage of trained personnel, both medical and paramedical, and sometimes for administrative and economic reasons, case-detection is not carried on in all the areas where the disease may exist, and that not all the cases diagnosed are reported, and that not all cases reported are registered.

Lack of care in analyzing this kind of data leads to erroneous conclusions, and these in turn prevent us from gaining a true picture of the disease and hamper the organization of control programs as well.

In this connection, I should like to call attention to two aspects: (1) the description of areas with and without leprosy; and (2) the prevalence of the disease. To correct present defects, and improve our knowledge of those two aspects, leprosy must be included in the teaching programs of medical schools so that new generations of physicians will be in a position to diagnose the disease. In addition, intensive training programs will be needed to teach the art of diagnosing leprosy to physicians who have not had the opportunity to deal with leprosy, or who were not taught the disease during their medical studies. Once

these requirements are met, case-finding must be extended to the entire country.

Until these objectives are reached and the geographic coverage of the programs is expanded, it would appear advisable to confine leprosy patients to their respective areas. It is wrong to assess the prevalence per country on the basis of case-detection in limited geographic areas or through limited investigations. The ideal is to draw up a map showing the distribution and frequency of leprosy by minor political or administrative subdivisions in each of the countries and territories in the Western Hemisphere. It might then be possible to relate leprosy to the various factors in the environment of the places where it occurs.

Again in connection with the analysis and interpretation of data, mention must be made of a fact of practical consequence for the success of a control program. In 1963, of 167,038 cases registered in 18 countries, only 53.6 per cent were under control and 46.4 per cent therefore were not. If we bear in mind that registered cases are only a small proportion of total cases, it is clear that the number of patients under control is an even smaller proportion of the total. The seriousness of this fact becomes clear when we realize that more than 50 per cent of the cases are infectious. In 1963 information about treatment was available in 144,487 patients out of 167,038 cases registered. Eighteen and a half per cent of patients were in hospitals; 41.6 per cent received ambulatory treatment and 39.9 per cent did not receive treatment at all. This is an extremely serious situation. The total number of registered contacts for 1963 was 262,818. If we accept as contacts only persons living in the same house with the patient and a figure of four of them, on the average, for every patient, the total number of registered contacts should be 668,152. However, it is only 262,818, and of these, only 45 per cent were under control. Thus a group of persons particularly exposed to the disease are being neglected.

The same facts are repeated more or less similarly in the 1964 report.

This shows that control programs in general—and there are countries where leprosy control activities are very well carried out—are not in position to reduce the in-

cidence and prevalence of leprosy. At the present time we do not know what percentage of patients must be treated and what percentage of contacts exposed to the disease must be brought under regular control in order to reduce the incidence and prevalence of the disease. However, provided case-finding has been exhaustive, a figure of 50 per cent of the patients and contacts may be arbitrarily accepted as the lowest figure for this purpose, but this target is far from being attained at the present time. In these circumstances, we should ask ourselves if there is any point in continuing leprosy control along the same lines. Surely a complete revision of leprosy control programs is urgently needed in most of the countries and territories of the Region.

This situation is a matter of deep concern to the Pan American Health Organization, which is much interested in helping the countries to correct it. For that purpose, it held the Second Pan American Leprosy Seminar in Cuernavaca, Morelos State, Mexico, in 1963. Public health administration applied to leprosy programs was the subject of the seminar, the recommendations of which have given rise to various activities.

To the extent that financial resources made it possible, PAHO/WHO has stimulated and cooperated in courses for physicians, in different countries, for the purpose of giving them advanced training in the diagnosis of leprosy.

A manual on data-registration systems was prepared and is being tested in Argentina and Venezuela. Statistical consultants' services were provided for the purpose of organizing data-registration systems, and operating them at various levels.

The administration of leprosy control programs is being studied at the present time. It is often said that the lack of financial resources limits the services of the control programs, but experience seems to show that this is not always the case. Leprosy control programs have been in existence for a long time. Their directors have asked the governments for further financial support, but they have received only limited amounts. These resources, accumulated through the years, were used

generally to recruit more personnel. But although the number of personnel increased, the results of the programs fell short of expectations. We are, therefore, faced with a surprising fact. Although the programs had a numerical target to start with, they soon abandoned it; the present targets, where they exist, tend to justify an administrative machinery which, of course, does not meet the technical demands of the problem. It would appear that if the administrative machinery set up is dynamic, efficient, and economical, and if it helps to achieve the technical objectives of the program, the output of the programs will be much greater than at present and the quality of the services will be improved. That is why the Pan American Health Organization is cooperating in this field. Specialized administrative consultants will soon begin to provide advisory services in one or two of the countries of the Region. Likewise, work methods which, from the standpoint of performance and cost, should certainly be changed, are still continued, perhaps out of habit. The matter is one of concern to the Pan American Health Organization, which will take it up at some future date.

A manual on leprosy control programs is being prepared in cooperation with distinguished scientists from the American continent.

As for personnel training, in addition to the courses already held and those about to begin, the Pan American Health Organization awards short-term and long-term fellowships to physicians every year. It has provided, and will continue to provide in the future, the services of specialized consultants who will assist the experts in the countries with the study of specific problems and personnel training.

The presentation of this paper is an expression of the concern of the Pan American Health Organization in the problems of leprosy in the Americas, the availability and adequacy of the data on which our present knowledge of the problem is based, the interpretation of these data, and the conclusions being drawn from them, not to mention the administration and execution of control programs.

## DISCUSSION

**Dr. Sartwell.** Thank you, Dr. Huerta, for challenging us to show why we go on doing the same things with the imperfections you have indicated. At one point in your comments, Dr. Huerta, I had the impression that you were a little reluctant about sampling surveys as an alternative to reporting. A weak alternative, admittedly, but one which, with the obvious defects of reporting, might be resorted to. Was that your meaning?

**Dr. Huerta.** I agree that sample survey is one method for study of leprosy. If I did not mention it, it was an omission; we recognize it as a good method.

Dr. Cochrane. Every year for the last forty, I have been hearing about the integration of leprosy in medical schools. In Calcutta I said to a doctor who visited our center, "How much leprosy did you see?" He replied, "I have never seen any. When we get a case of leprosy at the Calcutta Medical College, we push it over to the tropical diseases department." I asked the same question of a doctor from Makerere College who took one of our training courses. He replied, "No, I have never seen any leprosy." He knew all about other diseases. In New Orleans, the Board of Dermatology showed a case of leprosy, and not one single member who went up for examination by the Board recognized it. I am afraid that it is the same in Britain. There are twenty lectures on nutritional diseases in the School of Tropical Medicine. I have three, one of them of two hours' duration. Until we get universities really linked to leprosy and train people so that they can recognize early leprosy, I am afraid that all this talk about surveys and everything else will fall on deaf ears. We have to get leprosy into medical education. Every single medical school should have lectures on leprosy. A patient shows characteristic anesthesia and students never recognize it. Dr. N. Antia, at Bombay, asked his class what was the commonest cause of claw hand. They said everything

under the sun, and then he said: "Well, what about leprosy?" "Oh, leprosy," was the reply; "Only beggars get that. We're not interested in that." And, ladies and gentlemen, we are only playing with the subject. It will be so until we get people interested, as in the case of M. ulcerans—look at the amount of interest in that, and yet the number of cases of M. ulcerans is infinitesimally small compared to the number of cases of leprosy. We have gotten rid of the word "leper," but we have not gotten rid of the leper complex, and until doctors of every grade take the disease really seriously, leprosy, like the poor, will be forever with us.

**Dr. Sartwell.** That view certainly supports Dr. Huerta's point, and the applause seems to indicate that further discussion of it may not be necessary. Increasing numbers of North American universities are engaged in international research programs. The fact of an increasing number of international programs in North American schools is as cogent a reason as any I can think of for what Dr. Cochrane and Dr. Huerta call for.

**Dr. Binford.** Dr. Huerta, will you repeat for emphasis the number of registered cases in the part of South America you surveyed, and the percentage in which the sex was known. I was impressed that in such a small percentage of registered cases the data were sufficiently complete to provide information on the sex of the patient.

**Dr. Huerta.** In 1963 the number of registered leprosy patients in 18 countries reached a total of 167,038. Sex was given for only 21,497, and age for 19,200. The clinical form of the disease was given for 34,653, and the kind of treatment for 144,487. On June 30, 1964, according to information provided by 13 countries and two territories, the number of registered cases was 113,564. Age and sex were given for only 17,430, clinical form for 22,792, and kind of treatment for 52,604.

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**Dr. Sartwell.** The next paper, entitled "Asymptomatic infections in leprosy" will be given by Dr. Carl E. Taylor, Professor of Public Health Administration at the Johns Hopkins School of Hygiene and Public Health. His title is quite inadequate to express the scope and breadth of his work in India and elsewhere.