

Epilepsy in Latin America and the Caribbean: a survey on needs and resources

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ABSTRACT

A survey was done on the needs and resources available to control epilepsy in the countries of Latin America and the Caribbean. Responses came from ministries of health, prominent neurologists, and epilepsy advocacy organizations. A mailed questionnaire was used, and the response rate was excellent, 89%. The survey results showed that the private sector is better equipped to deal with epilepsy than is the public sector, in terms of both specialized personnel and access to a variety of drugs. Public policies are lacking, and linkages between medical personnel and social workers are almost nonexistent. Primary care doctors and nurses are somewhat able to diagnose some types of epilepsy but do less well with other types of the disorder. There is a strong justification for the new "Out of the Shadows" initiative, in which the International League Against Epilepsy, the International Bureau for Epilepsy, the World Health Organization, and the Pan American Health Organization are working to improve epilepsy health-care services, treatment, and social acceptance.

Epilepsy is one of the most common and serious neurological disorders affecting populations worldwide (1). Despite the fact it is a treatable disorder, epilepsy frequently remains untreated in developing countries, where only 10%–40% of patients receive adequate care for their seizures (2). Recognizing this situation, in September 1997 the Directing Council of the Pan American Health Organization (PAHO) adopted Resolution CD40.R19 (3) urging the Or-

ganization's Member States to develop programs to control epilepsy. To implement the resolution, PAHO sought the cooperation of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) in jointly launching a major initiative in Latin America and the Caribbean (LAC). This effort in the Americas is part of the worldwide "Out of the Shadows" campaign initiated by the ILAE, the IBE, and the World Health Organization (WHO), which seeks to improve epilepsy health-care services, treatment, and social acceptance (2).

This PAHO/ILAE/IBE initiative will use nine programmatic strategies in providing technical collaboration to the LAC countries:

- strengthening capacity at the primary-care level to find untreated cases and to properly diagnose and treat with drugs and counseling
- assuring a steady supply of drugs at a price affordable to the countries' health services and patients
- coordinating relevant actions with such community agents as religious leaders, the police, and faith healers
- organizing required referrals to and from specialists
- establishing mutual-support groups for patients and families
- promoting the establishment of new advocacy groups and strengthening existing ones
- organizing programs for psychosocial rehabilitation and promoting public policies to fully integrate people with epilepsy into society
- preparing and implementing community health education programs in order to increase understanding of these disorders and to eradicate stigma
- establishing a system to monitor and evaluate both the processes and

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TABLE 1. Extent to which local primary care physicians are able to identify different types of epilepsy (% of countries), Latin America and the Caribbean, 1998

Type of epilepsy	Extent				Total	
	Large	Moderate	Some	None	%	Number
Tonic-clonic	38.7	48.4	12.9	0.0	100	31
Absence	19.3	38.7	41.9	0.0	100	31
Complex partial	19.3	9.7	64.5	6.5	100	31

TABLE 2. Extent to which local primary care nurses are able to identify different types of epilepsy (% of countries), Latin America and the Caribbean, 1998

Type of epilepsy	Extent				Total	
	Large	Moderate	Some	None	%	Number
Tonic-clonic	19.3	48.4	32.3	0.0	100	31
Absence	3.2	16.1	54.8	25.8	100	31
Complex partial	3.3	13.3	36.7	46.7	100	31

impact of this initiative in Latin America and the Caribbean

Working together, PAHO, ILAE, and IBE created a plan of action to implement their initiative (4). As part of the plan, PAHO and its two partners conducted a limited survey among LAC countries on their perceived needs and available resources for controlling epilepsy. This report describes the procedures used in the survey, the survey's main findings, and the implications for program and service planning.

METHODS AND PROCEDURES

A brief questionnaire was developed to explore how countries are answering some of the needs of persons affected by epilepsy and those persons' families, and the countries' available resources. The questionnaire consisted of 26 items covering public policies, human resources and training, availability of antiepileptic drugs, community attitudes, epidemiological estimates, and the existence of non-governmental organizations engaged in advocacy and support. The ques-

tionnaire was sent to the ministries of health, prominent ILAE-affiliated neurologists, and representatives of local IBE chapters. Prepared in English and Spanish, the questionnaire was distributed by PAHO/WHO offices in all the Latin American and Caribbean countries during the second half of 1998.

RESULTS

Survey compliance was high. Out of the 37 participating countries, 33 responded (89%). Twenty-four ministries of health provided information. Multiple responses came from 12 countries. Where there was more than one response from a single country, we coded the information provided by the ministry of health.

Public policies

Only 34% of the countries had public policies that specifically addressed the needs of persons affected by epilepsy. Notably, the absence of such policies was not confined to countries with a limited number of neurologists.

Competence of primary care workers

The informants reported that primary care physicians were more often able to identify epilepsy than were primary care nurses. This was true even though nurses play a pivotal role in case detection, education, and community involvement. With both physicians and nurses, the ability to identify epilepsy varied by the type of the disorder, with the ability higher for the tonic-clonic type, intermediate for absence, and lowest for complex partial. Table 1 and Table 2 summarize the findings regarding primary care workers. (When we received multiple responses on this subject from a single country, we used the most conservative response.)

Practicing neurologists

The number of neurologists varied from none in the smaller countries to almost 1 900 in Brazil. The number of neurologists in training ranged from 109 in Cuba to none in the smaller countries of the English-speaking Caribbean. Of great concern was the inequity in the distribution of human resources. Informants reported there were 3 560 specialists practicing in the private sector but only 1 875 in the public sector.

Availability of antiepileptic drugs

The availability of drugs varied by type and from the public to the private sector. In the public sector the drug most frequently available was phenobarbital, always available in 85% of the countries. On the other hand, ethosuximide was rarely available. Seventy-six percent of the countries reported that antiepileptic drugs were available for free from the public sector.

All five of the drugs we inquired about were more often available in the private sector than in the public sector. For example, in 40% of the countries ethosuximide was always available in the private sector, but the same was

TABLE 3. Availability of antiepileptic drugs in the public sector (% of countries), Latin America and the Caribbean, 1998

Drug	Availability				Total	
	Always	Most of the time	Occasionally	Never	%	Number
Carbamazepine	42.2	45.5	6.1	6.1	100	33
Ethosuximide	13.3	10.0	13.3	63.3	100	30
Phenobarbital	84.8	15.2	0.0	0.0	100	33
Phenytoin	59.4	34.4	6.3	0.0	100	32
Valproic acid	28.1	25.0	28.1	18.8	100	32

TABLE 4. Availability of antiepileptic drugs in the private sector (% of countries), Latin America and the Caribbean, 1998

Drug	Availability				Total	
	Always	Most of the time	Occasionally	Never	%	Number
Carbamazepine	90.6	6.3	18.8	3.1	100	32
Ethosuximide	40.0	13.3	20.0	26.7	100	30
Phenobarbital	84.4	12.6	3.1	0.0	100	32
Phenytoin	90.6	6.3	3.1	0.0	100	32
Valproic acid	80.6	9.7	6.5	3.2	100	31

true for the public sector in only 13% of the countries. Table 3 and Table 4 provide more details on drug availability in the public and private sectors, respectively.

Patient referrals

Primary care practitioners most often referred patients to neurologists (always or most of the time in 50% of the countries), followed by psychiatrists (29%) (in many countries persons with epilepsy are cared for by the mental health services, especially so in the public sector), and social workers (23%).

Professional societies and other epilepsy-related groups

The existence of epilepsy-related organizations in the LAC countries is shown in Table 5. Almost two-thirds of the countries have professional societies, and a slightly smaller proportion (58%) have national advocacy organi-

zations. However, in the Caribbean few of the English-speaking countries and Dutch-speaking entities have either type of organization. Community self-help groups are uncommon, being reported by only 5 of the 33 countries responding to the survey.

Educational campaigns

Forty-six of the informants, from 20 of the countries, indicated that educational campaigns had been conducted in their countries, generally in 1997 and/or 1998.

TABLE 5. Countries reporting the existence of epilepsy-related organizations and community self-help groups (% of countries), Latin America and the Caribbean, 1998

Type of organization	Existence		Total	
	Yes	No	%	Number
Professional	63.6	36.4	100	33
Advocacy & education	57.6	42.4	100	33
Community self-help	15.2	84.8	100	33

Societal attitudes

The reported attitudes varied widely. Of the 31 countries that responded to this question, 14 indicated that a negative attitude towards persons with epilepsy was common. In the other countries, attitudes ranged from neutral to somewhat positive.

Epidemiology

All the above results become more significant when compared with the needs shown by epidemiological studies. Prevalence rates from 17 selected Latin American studies published between 1974 and 1998 showed a wide range, from a low of 5.8 per 1 000 to a high of 57.0 per 1 000, with a median of 14.3 per 1 000 (4).

Based on that median prevalence rate, we estimated that in 1998 there were at least 5 million persons with epilepsy in Latin America and the Caribbean. Of that number, some 3.5 million of them were not receiving treatment for the disorder, according to L. Sanders of ILAE and E. Stein of PAHO (personal communication, 1998). This is despite the almost universal availability of such medications as phenobarbital and, to a lesser extent, carbamazepine.

DISCUSSION

Is the PAHO/ILAE/IBE initiative justified? Based on the above results, the answer is certainly "yes." The scientific literature makes it abundantly clear that epilepsy constitutes a disorder meeting the criteria of a public

health problem. What our survey additionally revealed was the extent to which epilepsy control in the LAC countries was based on a truncated model. To increase its odds of success, a sustainable model of intervention has to address components that include the individual with epilepsy, that person's family, the community and such gatekeepers as teachers and police officers, the health system, and the society as a whole. Any initiative to first control the disorder and then prevent it whenever possible may fail if it neglects any of those components.

The PAHO/ILAE/IBE initiative is starting with a baseline well above zero. The availability of some re-

sources in Latin America and the Caribbean, if applied properly, may facilitate the initiative's implementation and increase its chances for success. Epilepsy-related professional associations and national leagues exist in the majority of the LAC countries. Those groups could and should be mobilized for their own national efforts and, whenever called for, to assist the Caribbean countries that do not have such organizations. Furthermore, the competence that primary care physicians already have in identifying tonic-clonic epilepsy should facilitate those professionals' active participation in the PAHO/ILAE/IBE initiative and reduce the amount of further training needed.

The initiative will need to devote special efforts so as to promote public health policies, including the organization of self-help groups; coordinate with the social service sector; facilitate the education of persons with epilepsy, their families, and the community at large; organize advocates to work for a more equitable access to medication; and provide specialized care, given the asymmetrical distribution of neurologists. The latter issue is of major importance, since this health disorder has a rate distribution inversely related to social class. The survey also showed that psychiatrists may need to be brought into the initiative since many primary care practitioners refer patients to them.

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Manuscript received on 26 May 1999. Revised version accepted for publication on 28 June 1999.

RESUMEN

Epilepsia en América Latina y el Caribe: encuesta sobre las necesidades y los recursos

Se realizó una encuesta sobre las necesidades y los recursos disponibles para controlar la epilepsia en los países de América Latina y el Caribe. Se utilizó un cuestionario postal que fue enviado a los ministerios de salud, a destacados neurólogos y a organizaciones no gubernamentales de defensa y apoyo a los pacientes epilépticos. La tasa de respuesta fue excelente: 89%. Los resultados obtenidos revelaron que el sector privado está mejor equipado que el sector público en términos tanto de disponibilidad de personal especializado como de acceso a diferentes medicamentos. El sector público carece de políticas definidas y apenas existen relaciones entre el personal médico y los trabajadores sociales. Los médicos y el personal de enfermería de atención primaria están capacitados para diagnosticar algunos tipos de epilepsia, pero no todos. Está plenamente justificada la nueva iniciativa, denominada "Fuera de las sombras", en la que están trabajando la Liga Internacional contra la Epilepsia, la Oficina Internacional para la Epilepsia, la Organización Mundial de la Salud y la Organización Panamericana de la Salud con el fin de mejorar los servicios de atención a los pacientes epilépticos, la aceptación social de estos y el tratamiento de la enfermedad.