Epilepsy & Behavior 51 (2015) 267–272

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Epilepsy care in the southern Caribbean

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ARTICLE INFO

Article history:
Received 30 June 2015
Accepted 4 July 2015
Available online 24 August 2015

Keywords:
Seizure
Epilepsy
Caribbean
Health-care resources
Antiepileptic drug
Electroencephalography

ABSTRACT

Very little has been reported about the health resources available for patients with epilepsy in the five English-speaking southern Caribbean countries of Trinidad and Tobago, Barbados, Grenada, Saint Vincent and the Grenadines, and Saint Lucia. There is no comprehensive resource describing their health systems, access to specialty care, antiepileptic drug (AED) use, and availability of brain imaging and EEG. The purpose of this study was to profile epilepsy care in these countries as an initial step toward improving the standard of care and identifying gaps in care to guide future policy changes. In each southern Caribbean country, we conducted study visits and interviewed health-care providers, government health ministers, pharmacy directors, hospital medical directors, pharmacists, clinic staff, radiologists, and radiology and EEG technicians. Health-care providers completed extensive epilepsy care surveys. The five countries all have integrated government health systems with clinics and hospitals that provide free or heavily subsidized care and AEDs for patients with epilepsy. Only Trinidad and Tobago and Barbados, however, have neurology specialists. The three smaller countries lack government imaging and EEG facilities. Trinidad had up to one-year waits for public MRI/EEG. Government formularies in Grenada, Saint Vincent and the Grenadines, and Saint Lucia are limited to first-generation AEDs. One or more second-line agents are formulary in Trinidad and Barbados. Nonformulary drugs may be obtained for individual patients in Barbados. Grenada, Saint Lucia, and Saint Vincent and the Grenadines participate in an Organization of Eastern Caribbean States formulary purchasing system, which added levetiracetam following the survey. Newer generic AED formulations with the lowest risks for pregnancy malformation were not in use. In conclusion, patients with epilepsy in the southern Caribbean have excellent access to government clinics and hospitals, but AED choices are limited. Local medical providers reported that the major limitations in care were lack of specialty care, lack of imaging and EEG services, financial barriers to care, long wait times for care, and limited access to additional AEDs.

1. Introduction

There is limited information about epilepsy care and medical resources in the five southern Caribbean island countries of Barbados, Trinidad and Tobago, Saint Vincent and the Grenadines, Saint Lucia, and Grenada [1–4]. These adjacent English-speaking island countries are culturally linked but vary in population, economic development, and medical resources [5].

Optimal medical diagnosis and management of patients with epilepsy require a network of primary and specialty physicians, nursing and educational support, and access to EEG and brain imaging [6]. Patients with epilepsy also need access to antiepileptic drugs (AEDs) appropriate

Abbreviations: HCP, health-care provider; CME, Continuing Medical Education; OECS, Organization of Eastern Caribbean States; SADs, Specially Authorized Drugs; ESC, Epilepsy Society of the Caribbean; NARCCE, North American Regional Caribbean Congress on Epilepsy.

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http://dx.doi.org/10.1016/j.yebeh.2015.07.011
1525-5050/

for treating focal and generalized epilepsy, including during pregnancy. We queried epilepsy health-care providers (HCPs) about the major limitations in providing epilepsy care in the region, degrees of stigma, and the availability of employment and educational opportunities for patients with epilepsy.

We surveyed local HCPs and medical facilities to delineate medical resources available for treating patients with epilepsy. Profiling current health-care delivery and needs may help guide expanded care for patients with epilepsy.

2. Material and methods

Data were collected by written survey and individual interviews with epilepsy health-care providers and health facility administrators. These represented cross-sectional samples of each representative type of provider, facility, and administrator present in each country.

2.1. Epilepsy health-care provider survey methodology

The study was conducted in Grenada, Saint Lucia, Saint Vincent and the Grenadines, Barbados, and Trinidad and Tobago. Teams of 1–3 physicians and 2 research coordinators conducted 5 survey visits and collected epilepsy practice and health system data. Interviews were conducted with government health officials, pharmacy heads, EEG and imaging center directors, and technicians to determine availability and cost of clinical services, including access to specialists and EEG and imaging services. Using surveys of HCPs, pharmacists, and central government pharmacy logs, we determined AED formulations and documented their use, supply, and costs in government and private pharmacy systems. The survey of HCPs included all neurologists, neurosurgeons, and pediatricians (excepting two pediatricians on vacation) and a minimum of 20% of general physicians and nurse practitioners in the islands. Also surveyed were internists identified by other physicians as providing specialty care for patients with epilepsy. A cross-sectional survey of general physicians and nurse practitioners was performed which included all government and private hospitals (excluding obstetric and psychiatric specialty facilities), the clinics at the central hospital, and several regional government clinics in each island. Four islands had 1 to 3 major hospitals; Trinidad had 7; and all had a system of government clinics which provided the majority of health care. Most surveys were obtained either during visits with HCPs in these medical facilities or prior to medical society-sponsored Continuing Medical Education (CME) programs (e.g., 70 Grenadian health-care providers attended a CME program on epilepsy). Specialty and general practice physicians with private practices were surveyed on each island; most of them also had government practices and they were asked to complete two epilepsy care surveys. Because of Trinidad's large population, in addition to surveys at hospitals and major clinics and prior to a large CME program, a research assistant surveyed clinic physicians in its five health districts over a two-week period. Approximately 100% of HCPs agreed to complete surveys during team visits, and at CME sessions, however, approximately 20% of surveys were only partially completed. Additional attempts were made to obtain key surveys not initially completed, e.g., a translator was used to survey Cuban physicians in Saint Vincent since they staffed many of the government health clinics. Physicians and research assistants from Johns Hopkins and physician collaborators from each country conducted the epilepsy care surveys in the five island countries between November 2012 and March 2013 (Table: e-link to survey, Supplementary material).

2.2. Consent

Johns Hopkins University provided IRB approval for health surveys along with the IRB from the health ministry of each island. The Grenada Ministry of Health accepted IRB approval by Saint George's University School of Medicine. Deidentified surveys were obtained from all of the countries with exemptions from survey consents; the health ministry IRB for Trinidad and Tobago required that deidentified surveys be obtained with consents. Several health ministries requested survey summaries (Trinidad, Grenada, and Barbados).

2.3. Content of health-care provider surveys

The health-care provider survey queried physicians about the organization of health care on each island, government clinic/hospital and private service programs, their roles in these programs, types of physicians providing epilepsy care (including traditional healers), diagnostic tests available, laboratory tests for measuring AED concentrations, AED formularies by government or private pharmacies and AED use and costs, options available for drug-resistant epilepsy (2 or more failed AEDs), estimates of stigma in the country's population, nontraditional treatments used, access to employment and education for patients with epilepsy, and recommendations for key needs to improve epilepsy care.

2.4. Data analysis

Epilepsy care resources were tabulated based on physician survey totals with ranking of responses using a rank score. The rank score is the sum of ranks of individual respondents normalized to be between 0 and 1. A higher score indicates a more highly ranked answer choice. If the rank score is exactly 1.0, that means respondents unanimously ranked the answer choice #1.

These were compared to data collected in interviews with health ministry directors, hospital medical directors, and radiologists at imaging centers. Antiepileptic drug formularies, availability, and uses were reviewed in meetings with central government pharmacy directors and hospital and clinic pharmacists and confirmed with physician surveys. We also met with directors of the Organization of Eastern Caribbean States (OECS) formulary committee and the Barbados National Drug Formulary Committee. Radiology and EEG technicians provided useful information on test availability in government and private facilities.

3. Results

Two hundred eighty-six HCPs (18 to 109 per country) completed surveys, including all neurologists (4), generalists with predominant neurological practices (2 internists and 2 pediatricians), neurosurgeons (2), general practitioners (104), and pediatricians (24) in each country. Nearly 100% of HCPs accepted surveys during visits and prior to CME programs; however, 20% of surveys were partially completed (E-Table, Supplementary material). Trinidad and Tobago's larger (1.22 million), more diverse population had a greater number of health facilities compared to the other islands: a large government health system was integrated across five regional health districts with 5 hospitals and a specialty hospital center. Differing from the other countries, approximately 20% of health care in Trinidad was provided through private consultations and EEG and imaging facilities, reflecting limited resources in the government health services. Barbados' population was large (289,000) compared to the remaining 3 islands (Saint Lucia: 163,000, Grenada: 110,000, Saint Vincent: 102,000) [4–6]. In Barbados, a government operated health system with one major government hospital, one private hospital, and 8 major polyclinics provided the majority of specialty care for patients with epilepsy; patients had short wait times for EEG and CT in the public system, and private clinics also provided neurologist care and EEG/imaging. Saint Lucia, Grenada, and Saint Vincent and the Grenadines had predominantly government health systems consisting of clinics and one or two main hospitals. Survey totals were small in Saint Vincent and the Grenadines compared to other countries ($N = 18$) but reflected the small population, and all key health-care personnel were surveyed and facilities visited.