



Epilepsy care in the southern Caribbean



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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.

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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; NARCE, North American Regional Caribbean Congress on Epilepsy.

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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

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.

3.1. Hospital, clinic, and specialty services (Table 1)

Survey results and health resource information varied little across HCPs and administrators: for the five countries, they reported a predominance of integrated government-operated health and pharmacy systems aided by relatively easy transportation around the small islands with a pattern of referrals to central hospitals and clinics of patients with epilepsy.

In Grenada, the majority of patients are seen in a government health system consisting of clinics (7 major clinics with attached pharmacies) and one general hospital. Grenada has no neurologist and one neurosurgeon—most patients with epilepsy are referred to see one of 5 internists or 5 pediatricians who are affiliated with the main hospital.

In Saint Lucia, most patients are examined in a government health system of 33 free public clinics or at hospital emergency departments. There are no resident neurologists or neurosurgeons—most patients with epilepsy are examined by senior internists or pediatricians at subsidized clinics (\$7 US) at the main public hospitals or in the physicians' private offices. Some patients are examined at a private hospital by a visiting neurologist from Martinique and may receive EEGs (machine not operational during survey visit). A visiting pediatric epileptologist provides free clinics and EEGs for children several times a year.

In Saint Vincent and the Grenadines, most patients are seen in a government health system through 39 public clinics (\$2 US fee for filling prescriptions). These clinics are predominantly staffed by contracted Cuban physicians and by nurse practitioners. Most patients with epilepsy are referred from regional clinics for evaluation by senior internists and pediatricians in clinics affiliated with the central hospital. Many patients pay for health consultations in private clinics to avoid long waits in the government system. There are no neurologists or neurosurgeons on the island; a neurosurgeon from Trinidad visits intermittently and may consult on cases of epilepsy.

In Barbados, most patients use government health facilities and receive health care at 8 government-run polyclinics and a large central hospital. There are two neurologists, one in government and private practice and one solely in private practice. A visiting pediatric epileptologist provides intermittent consultations for children.

Most patients receive health care through 112 public clinics in Trinidad and 20 public clinics in Tobago located in 5 health districts. Trinidad has limited specialty care for its population with one centrally located neurologist working in the public system and one neurologist in private practice; four internists and one pediatrician with postgraduate neurology training have neurology practices and staff the major hospitals. Patients with acute seizures or first-time seizures are usually referred to one of 3 large public hospitals. Four smaller private general hospitals offer neurological imaging and care as well as several private clinics. Because of long waits and limited availability of specialists in the public system, physicians report that approximately 20% of patients pay to see specialists and obtain tests in private facilities. There was a reported shortage of neurosurgeons in the government system (the country's largest hospital did not have a neurosurgeon at the time of the survey). Physicians reported that this was due to relatively uniform physician salaries in the public system and difficulties in obtaining specialist certification.

Table 1
Epilepsy care resources in the southern Caribbean.

	Health-care facilities		Physicians (% of general population)		
	Hospitals ^a	Clinics	General	Pediatricians	Neurologists
Trinidad	8	132	3131 (0.3%)	35 (0.003%)	2 (0.0002%)
Grenada	4	37	50 (0.05%)	5 (0.005%)	○
Saint Vincent	1	39	36 (0.04%)	5 (0.005%)	○
Saint Lucia	3	33	53 (0.03%)	7 (0.004%)	○
Barbados	2	16	150 (0.05%)	6 (0.002%)	2 (0.0007%)

○: Not available.

^a Excluding psychiatric and obstetric hospitals and polyclinics.

3.2. AED supplies (Table 2)

Grenada, Saint Lucia, and Saint Vincent and the Grenadines provide free or subsidized AEDs obtained through the Organization of Eastern Caribbean States (OECS) procurement system. The OECS program is a collaboration of 9 eastern Caribbean countries that share a common formulary and obtain bulk medication purchases from Europe. In Grenada, approximately 85% of all AEDs used are provided by a government pharmacy program using OECS supplies. Carbamazepine and phenytoin are the most common AEDs prescribed followed by phenobarbital. Lamotrigine is not available; the OECS formulary committee added levetiracetam to its formulary following the survey.

In Saint Lucia, a government pharmacy program provides AEDs through the OECS procurement system. Carbamazepine, phenytoin, and phenobarbital are the most commonly prescribed AEDs; lamotrigine is available in private pharmacies.

In Saint Vincent and the Grenadines, a government pharmacy program also obtains AEDs through the OECS system and provides AEDs without cost. There are occasional shortages in the government AED supplies, with patients needing to purchase their AEDs from private pharmacies. Carbamazepine was the most commonly used AED followed by phenytoin and phenobarbital.

Barbados' government pharmacy system was a model for the OECS procurement system and provides free AEDs with a stable supply listed in the Barbados National Drug Formulary (30th Edition: carbamazepine, gabapentin, magnesium sulfate, oxcarbazepine, phenobarbital, phenytoin (tablet and injection), primidone, sodium valproate/valproic acid/divalproex sodium (tablet, syrup, and injection), topiramate, clonazepam, diazepam (tablet and intravenous), lorazepam (tablet and injection), and midazolam (injection)). Carbamazepine and phenytoin are the most common AEDs used followed by valproate. Neurologists may request that nonformulary AEDs be obtained for individual patients for a specific period of time as Specially Authorized Drugs (SADs). These drugs include clobazam, lamotrigine, midazolam, pregabalin, propofol. Levetiracetam was added following the survey, and midazolam and clonazepam no longer require SAD approval. Drugs not available on the formulary or as a SAD can be obtained by the physician through an agent or, at times, directly through the pharmacy at cost. The SAD committee meets monthly and reviews physicians' written requests for medication coverage for individual patients. Upon approval, these medications can be obtained within 1–2 weeks.

In Barbados, there is a formal governmental process by which drugs are added to the formulary. A physician or pharmaceutical company can present data including safety and efficacy studies and cost to a Drug Formulary Committee (DFC) composed of physicians and pharmacists. Within 1 year of the presentation, the committee determines whether or not to include the drug on the formulary. A Drug Tenders Committee also reviews drug labels and relevant literature to select which brand or generic drugs to include in the formulary. Drug verification is performed

Table 2
Antiepileptic drugs used most often in the southern Caribbean.

	Antiepileptic drugs	Cost
Saint Lucia, Saint Vincent, and Grenada	Carbamazepine, phenytoin, phenobarbital, valproate ^a	<ul style="list-style-type: none"> ■ Procured by OECS ■ Free or subsidized for most ■ \$5 dispensing fee in Saint Vincent
Barbados	Carbamazepine, phenytoin, phenobarbital, valproate ^b	<ul style="list-style-type: none"> ■ Free to citizens ■ Dispensing fee at private pharmacies
Trinidad	Carbamazepine, phenytoin, phenobarbital, valproate, lamotrigine	<ul style="list-style-type: none"> ■ Free through Chronic Disease Program

⁷th OECS Medicine Formulary accessed on March 14, 2014.

^a OECS added levetiracetam to its formulary following the survey.

^b Physicians may order other AEDs for individual patients.

by local pharmacists. Physicians are encouraged to submit reports of potential medication side effects.

Trinidad and Tobago has a national medication formulary: carbamazepine and phenytoin are the most commonly used AEDs; smaller proportions of patients are treated with phenobarbital, valproate, and lamotrigine. Patients with epilepsy may register for a Chronic Disease Program that provides free antiepileptic drugs (valproate, phenytoin, and carbamazepine) through prescription vouchers that can be filled at private pharmacies; the program reduces waits at government pharmacies. Trinidad's government pharmacy system requires AED formulations to have a bioequivalence dossier be submitted and that bioanalytic testing be done before being approved—this requirement limits availability of newer generic formulations. An application to include levetiracetam in the national formulary was declined because of the lack of a commercial sponsor.

3.3. Imaging and EEG services (Table 3)

Lack of imaging equipment and EEG services was one of the major problems identified in the southern Caribbean. In Grenada, there are no public and one private brain CT/MRI facility and no EEG services. Health-care providers estimated that less than half of patients receive imaging, usually through self-pay at the private facility or at a health facility in Trinidad. A minority of patients—usually children supported by their families and charities—travel for neurology consultations and EEG testing in other countries, usually Trinidad.

In Saint Lucia, there are no public brain CT/MRI facilities; one head CT is available at a private hospital. Health-care providers reported that the majority of patients with epilepsy do not receive imaging or EEGs. A new national hospital is expected to offer brain MRI services. In Saint Vincent and the Grenadines, there is no brain MRI or EEG, and the only head CT on the island was recently destroyed by a flood. Physicians report that less than 10% of patients receive head CT or EEG. Some families are able to pay for neurology consultations and testing in Trinidad or Barbados. In Barbados, the central hospital has a free CT; there are also 2 private CTs (cost: approximately \$400 US) and 2 private MRIs (cost: approximately \$825 US). Patients also have access to one free public and two private EEG labs (cost: \$300 US) with relatively short 2- to 3-week waits. One private clinic has ambulatory EEG capabilities (cost: \$600 US per 24 h of ambulatory monitoring). Physicians estimated that approximately 75% of patients with epilepsy received CT or MRI imaging and that more than 2/3 receive EEGs.

In Trinidad, three of the large public hospitals have head CT; MRI is available at two of the three facilities; however, significant periods of mechanical repair downtime were reported. Waiting times for MRI in the public facilities are often up to one year; patients may require hospitalization to obtain semiurgent imaging. Four private head CTs (cost: approximately \$250 US) and 4 private MRIs (cost: \$700 US) are available. Health providers estimated that the majority of patients (median estimate 69%) receive either head CT or MRI. Electroencephalography testing is available at one government hospital for no cost; however, there are waits of up to one year for testing. Three private EEG labs (approximately \$50

US) have shorter wait times (though, one technician services most EEG tests). Health-care providers estimated that approximately 50% of patients with epilepsy in the public system and 88% in private care obtain EEGs.

3.4. Summary of epilepsy care in the southern Caribbean

Government funded health care provides free or subsidized care and AEDs for the majority of patients with epilepsy in the five southern Caribbean countries. The government health systems, however, have limited resources: three islands (Grenada, Saint Lucia, and Saint Vincent) do not have resident neurologists or EEG facilities and have limited imaging. Barbados provides most patients with epilepsy with either public or private neurology consultations, along with EEG and imaging. Trinidad has limited numbers of imaging and EEG facilities in its public health system with long wait times; approximately 20% of patients pay to see specialists and obtain tests in private clinics. Visiting neurologists (e.g., from Martinique to Saint Lucia and from the US and Jamaica to several islands) and neurosurgeons (e.g., from Trinidad to Saint Vincent and Grenada) provide intermittent consultations in several islands. A major limitation in expanding EEG services in the region is the shortage of EEG technicians—only 1 EEG technician is available in Trinidad and 2 in Barbados.

Government pharmacy systems provide free or subsidized AED supplies to most patients, but with limited formularies. All of the country formularies provide carbamazepine, phenytoin, phenobarbital, and valproate. Saint Lucia, Grenada, and Saint Vincent and the Grenadines (along with 6 other Caribbean countries) participate in the OECS and share AED formularies and added levetiracetam. Part of the rationale for including levetiracetam was to provide safer treatment for women during pregnancy compared to the older AEDs in the OECS formulary.

Physician surveys and government pharmacy logs confirmed several common prescribing patterns across the countries: carbamazepine and phenytoin are the most frequently prescribed AEDs, followed by phenobarbital and valproate. Lamotrigine was available only in Trinidad and Tobago's public system and had limited use in other countries, mostly in private clinics and pharmacies. Health-care providers reported that the majority of patients with generalized seizure types on all the islands are treated with carbamazepine (a nonpreferred AED treatment in generalized epilepsy syndromes). Most physicians were not aware of risks for birth malformations associated with valproate; most physicians stated that valproate and phenobarbital were commonly prescribed to women of childbearing age. Lamotrigine and levetiracetam, AEDs with low risks for birth defects, are used infrequently in the islands. Only limited laboratory testing for AED blood levels was available in government clinics and labs—hospital laboratories at the main hospitals in Barbados and Saint Vincent provided AED levels for the common AEDs; Trinidad and Tobago hospitals measure phenytoin concentrations.

The country's HCPs estimated that only a minority of their patients with epilepsy (17% in Trinidad; <10% in the other countries) had used traditional remedies (e.g., a lizard tea or prayer), but that these patients also utilized government health care.

Table 3

EEG and imaging resources in the southern Caribbean: physician estimates of % of patients receiving EEG/imaging.

	EEG			CT		MRI		
	Public	Private	% receiving EEG	Public	Private	Public	Private	% receiving imaging
Trinidad	●	●	48%	●	●	●	●	69%
Grenada	○	○	17% ^a	○	●	○	●	46% ^a
Saint Vincent	○	○	10% ^a	○ ^b	○	○	○ ^a	19% ^a
Saint Lucia	○ ^c	○ ^c	23%	○	●	○	○	30% ^a
Barbados	●	●	68%	●	●	○	●	75%

●: Available; ○: Not available.

^a Self-pay.

^b Public CT scanner in Saint Vincent damaged December 2013.

^c Intermittent EEG services by visiting neurologists.

3.5. Limitations in care and health-care provider recommendations (Table 4)

Physicians and government health officials in the five countries reported similar limitations in epilepsy care across the region: limited access to specialty neurology care, limited access to diagnostic tests (imaging and EEG), limited AED selection, financial barriers to patients obtaining care, long wait times for visits and tests, and social and geographic barriers to patients obtaining care. Health-care providers in Barbados reported fewer limitations in these areas compared to the other islands. Many HCPs also reported difficulties for patients because of long wait times at clinics and pharmacies; HCPs in the three smaller islands noted that travel cost barriers limited access to tests and specialty care available in Trinidad and Barbados and other nearby countries.

The most common recommendations of HCPs in improving epilepsy care were as follows: 1) increased public education to improve awareness of epilepsy; 2) increased health education for patients with epilepsy, especially for adolescents and young adults to improve treatment adherence and avoid seizure triggers (alcohol use was cited as a common seizure trigger); 3) expand EEG and MRI facilities in all 5 countries; and 4) increase medical education for providers on new medications and treatment approaches.

3.6. Stigma, education, and employment opportunities

Most HCPs in the southern Caribbean felt that there was only limited stigma toward patients with epilepsy in the regions. Most of them also felt that the majority of patients with epilepsy had full opportunities for education and employment, though, many noted that this corresponded to the degree of the patients' seizure control. In Saint Lucia, for example, only 31% felt that full employment and child bearing were appropriate for patients with epilepsy.

4. Discussion

Government health-care systems provide access to basic care for most patients with epilepsy in the southern Caribbean with free or subsidized clinic and hospital care, AED supplies, and diagnostic testing (if available). The income levels of the southern Caribbean countries support key services such as vaccinations and antenatal care but generally do not support expensive, technologically driven services such as dialysis and neonatal intensive care. This is reflected in limitations in epilepsy care, with shortages in the provision of specialty neurologic care, brain imaging, and EEG. Health resources varied across the five island countries, with Barbados and Trinidad and Tobago providing neurology specialty care, EEG, and CT/MRI imaging (with very long wait times in Trinidad and Tobago); the other three countries do not have neurology specialists or regular EEG services and have limited imaging. Many of

these limitations reflect the budgets available for health care in the countries: Barbados and Trinidad and Tobago are high income countries in the World Bank country income classification and devote 7.7% and 5.7%, respectively, of their GDPs to health care; Saint Lucia, Grenada, and Saint Vincent and the Grenadines are upper middle income countries and devote 7.2%, 6.2% and 4.9%, respectively, of their smaller GDPs to health care [7].

Organizational hurdles, such as the complexities of having generic AEDs approved in Trinidad and Tobago, also limit care. Newer, relatively inexpensive generic AEDs are used infrequently in the southern Caribbean, though the OECS procurement system for Saint Lucia, Grenada, and Saint Vincent and the Grenadines permits bulk purchasing from Europe and expanded to provide levetiracetam following the survey. The reliance on first generation AEDs appeared to reflect slow changes in practice patterns as well as the limited government formularies. Most physicians, for example, reported that patient seizure types are typically not distinguished, and, even when patients are diagnosed with generalized epilepsy, they often receive treatment with carbamazepine. Similar to US neurologists [8], most health-care providers were not aware of high risks for birth defects associated with phenobarbital and valproate and often do not have access to or prescribe AEDs safest during pregnancy such as lamotrigine and levetiracetam. Health-care providers recommended several measures to correct such treatment limitations: increasing public awareness about epilepsy; educating patients with epilepsy about care issues; and increasing financial support to expand specialty care, imaging, and EEG services. Only a small minority of patients sought care from local traditional healers, and HCPs reported that most of these patients still received care in government-based clinics.

The epilepsy care survey had a number of limitations—physicians, nurse practitioners, technicians, pharmacists and government health officials, but not patients, were surveyed and interviewed. Only a cross-sectional sample of HCPs and a subset of locations within each country were surveyed, and those that attended CME courses were self-selected, although all neurologists were surveyed, and HCPs from each type of health-care environment (government hospital, polyclinic, private practice, etc.) were sampled. The survey is a snapshot of services available in 2013 and does not reflect evolving services: the OECS formulary expanded following the survey; two new hospital facilities are being developed in Saint Lucia; neurosurgery staffing has recently increased in Trinidad and Tobago with consultations now provided in Grenada; and a private visiting pediatric epileptology service has been introduced and Barbados now has public video-monitored EEG and has introduced a private visiting pediatric epileptology service. Survey accuracy was strengthened by the predominance of government health services and the small geographic areas of the islands—there was only minor heterogeneity across HCP responses, mostly pointing to differences in resources in predominant public and the limited private health services.

These findings greatly expand results from other health studies previously performed elsewhere in the Caribbean or in this region: in a study of quality of life in epilepsy (QOLIE), Jamaican patients had relatively high QOLIE scores compared to those reported in many other non-Caribbean countries [9]. Disability associated with epilepsy—a long duration of epilepsy, use of multiple AEDs, and a dependent functional status—was, however, associated with lower QOLIE scores. A survey of college students in Trinidad and Tobago showed that they had limited knowledge about epilepsy; however, they felt that patients with epilepsy in Trinidad and Tobago faced only limited stigmatization, mostly in rural areas and among the lower socioeconomic groups [4]. A screening survey of Latin American and Caribbean health practitioners reported that government health systems were generally less well equipped to deal with epilepsy compared to the private sector and concluded that improved epilepsy health-care services are needed [10]. The survey findings are limited to these five culturally-linked southern Caribbean islands, which have similar health systems. Determining

Table 4

Health-care provider survey: Most common barriers to treating patients with epilepsy in the southern Caribbean.

Limitation	Rank	Rank score ^a (0–1)
Lack of specialty physicians	1	0.44
Lack of diagnostic equipment	2	0.41
Financial barriers	3	0.35
Long waiting times	4	0.29
Limited access to medications	5	0.17
Social/cultural barriers	6	0.15
Geographical barriers	7	0.07
Other barriers	8	0.02

^a 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.

epilepsy care in adjacent French-speaking and more distant Caribbean countries, many with unique health systems, such as Cuba and Haiti, was beyond the scope of the survey and deserves further investigation.

It is difficult to provide specialty care services in geographically isolated islands, mostly with small populations and limited health resources. The Caribbean “diaspora” contributes to this problem with many US, Canadian, and European trained specialists seeking higher incomes in more developed health systems. Some physicians suggested as solutions that adjacent countries might share public health resources, similar to the OECS procurement system, e.g., shared government funding of regional CT/MR facilities and rotating neurology consultations and EEG services. Shared neurology consultations, for example, could help determine the need for imaging and EEG referrals and could update the training of pediatricians and internists who provide epilepsy care. Arranging shared specialty services across independent government health systems, however, would be difficult to coordinate, and travel to adjacent islands for epilepsy care is expensive and not feasible for most patients. Sharing medical credentialing for specialists, such as radiologists, neurologists, and neurosurgeons, was suggested by several physicians as a method to facilitate cross-island specialty coverage and, perhaps, to eventually develop a Caribbean epilepsy care consortium.

Many of the problems in providing epilepsy care reported by health-care providers are similar to those found in both developed and less developed countries [11–13]. For example, health-care providers reported that many patients (particularly adolescents and young adults) have limited awareness of epilepsy and its treatments and sometimes have poor treatment adherence or may have seizures triggered by alcohol use. To correct this, health-care providers recommended that public awareness of epilepsy be increased and that patients have more counseling on specific treatment issues, such as boating and swimming safety and the importance of treatment adherence. The recently founded Epilepsy Society of the Caribbean (ESC) can play a role in promoting public and professional education about epilepsy and can provide a forum to discuss issues such as formulating driving restrictions for the islands. Delegates participate in biennial North American Regional Caribbean Congresses in Epilepsy (NARCCE), last held in Saint Lucia in May of 2014.

Overall, these five Caribbean countries have a number of advantages that benefited care for patients with epilepsy: supportive cultures with relatively small populations served by integrated government health systems with regional clinics and hospitals and free or subsidized AEDs. Improved access to specialty care, imaging, EEG, and newer generic AEDs which are safer to use during pregnancy remains a need in the region.

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We confirm that we have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Conflict of interest

None of the authors has any conflict of interest to disclose.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.yebeh.2015.07.011>.

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