

Research Article

Blindness Registers as Epidemiological Tools for Public Health Planning: A Case Study in Belize

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For public eye health programs, blindness registers can be an important tool for informing service planning. This study examines how the Belize Council for the Visually Impaired (BCVI) used its blindness register data to drive several public health interventions. Cross-sectional analysis was performed for all active registrants ($n = 1194$) to determine the distribution of causes of registration according to age, sex, and geographical district. Cataract was the leading cause of registration (39.6%), followed by glaucoma (20.8%), diabetic retinopathy (10.2%), and childhood blindness (9.4%). The distribution of the causes of registration was fairly similar between men and women and across the various districts. However, in Stann Creek, whose population is largely of African descent, glaucoma exceeded cataract. For most causes, the majority of registrants were registered at age 50 or older. Follow-up was conducted four years later. Several interventions had been initiated, most notably bolstering cataract surgical services and creating screening programs for glaucoma and diabetic retinopathy. The register itself was also improved to maximize its utility for future use. While standardized surveys may be the most appropriate method of estimating population-based measures such as prevalence or incidence, the blindness register is still a valuable source of data for public health planning.

1. Introduction

Disease registers have widespread applications in medicine and public health. Traditionally they have been designed to collect clinical information on a single topic and track patient outcomes longitudinally over time [1]. They have also been used as data sources for population-based research. For instance, several studies have employed blindness registers to estimate the prevalence and incidence of blindness and visual impairment in various regions around the world, including Australia [2, 3], Israel [4], Singapore [5], Taiwan [6], Canada [7], Ireland [8], and England [9]. Notably, these studies have largely been conducted in developed nations. Disease registers may also drive quality improvement initiatives. In public eye health, prominent examples of this include the implementation of an eye-related indicator based on the Certificate of Vision Impairment (CVI) form by the National

Health Service in the United Kingdom, as well as the recently unveiled Intelligent Research in Sight (IRIS) registry by the American Academy of Ophthalmology. Finally, registers can also provide an entry point for nonmedical purposes, such as qualifying visual status to receive rehabilitation and support services, as well as possible financial and social benefits [9].

The World Health Organization's (WHO) VISION 2020 initiative has engendered increasing awareness of avoidable blindness, particularly in developing countries where there is a greater burden of visual impairment. This study describes how one nonprofit organization, the Belize Council for the Visually Impaired (BCVI), used epidemiological findings from a national low vision and blindness register in Belize to inform the planning of its public eye health services. Prior to this analysis, there were virtually no published data concerning the epidemiology of blindness and visual impairment in Belize.

Belize is a small nation (population 333,200) consisting of a diverse mix of ethnic groups [10], with about one-third of the population living in poverty [11]. Eye care is not included in the government-sponsored healthcare system, and private ophthalmologists are unaffordable for most of the population. BCVI addresses this access issue by providing affordable primary and secondary eye care to about 12,000–15,000 patients per year in both urban and rural settings, as well as offering rehabilitation services and promoting eye health education and awareness, and has been recognized as an example for sustainable eye care in Latin America and the Caribbean [12]. Since 1988, BCVI has operated a register of patients who qualify for its rehabilitation services. Here we analyze the BCVI register based on cause of registration, age, sex, and geographical district. These epidemiological findings were then used to generate recommendations for the organization to improve its delivery of services. Over the course of several years, the organization implemented several of these recommendations with promising results, illustrating the role of the blindness register as a critical public health planning tool in eye programs.

2. Materials and Methods

The BCVI register includes patients who qualified for rehabilitation services based on best-corrected visual acuity (BCVA) of 20/200 or less in both eyes and determination by the referring ophthalmologist to gain no benefit from further medical treatment or surgery. This analysis includes patients who were registered from 1988 until December 31, 2009. The register was compiled and managed by the BCVI Rehabilitation Coordinator, a role which was filled by the same individual throughout this whole period, based on monthly reports from the examining ophthalmologist, who varied considerably over the years. This dataset was sent electronically to the London School of Hygiene and Tropical Medicine (LSHTM), where the analysis was performed.

For each registered patient, data used included sex, age, district of residence, visual acuity in each eye, level of visual impairment (see Table 1), extent of rehabilitation needed, and primary cause of registration. Causes of registration were categorized into the WHO's priority disease categories of visual impairment: cataract, glaucoma, diabetic retinopathy, age-related macular degeneration (AMD), childhood blindness, and uncorrected refractive error. Causes of registration that did not fall into one of these categories were designated as "other." For patient confidentiality, names and addresses were removed from the dataset, and the file was given password protection. This study received ethical approval from the ethical review committee at LSHTM and was performed in compliance with the Declaration of Helsinki. Univariate analyses were performed examining causes of registration by age, sex, and district using STATA 11.

Based on the results of these analyses, recommendations were generated to help BCVI optimize service delivery. Follow-up with the organization was conducted approximately four years after the original analysis to evaluate what interventions had been performed and assess how

TABLE 1: WHO levels of visual impairment.

Category	Worse than	Equal to or better than
Mild or no visual impairment		6/18
		3/10 (0.3)
		20/70
Moderate visual impairment	6/18	6/60
	3/10 (0.3)	1/10 (0.1)
	20/70	20/200
Severe visual impairment	6/60	3/60
	1/10 (0.1)	1/20 (0.05)
	20/200	20/400
Blindness	3/60	
	1/20 (0.05)	No light perception
	20/400	

Categories of visual impairment were defined according to the World Health Organization (WHO) International Classification of Diseases (ICD-10) based on presenting distance visual acuity in the better eye.

the epidemiological findings gleaned from the blindness register had influenced the organization's public health impact.

3. Results and Discussion

As of December 31, 2009, 1194 persons were listed on the BCVI register. Characteristics of the study population are presented in Table 2. The registrants were about equally split between men (48.9%) and women (51.1%). Most (62.3%) met the WHO criterion for blindness. The majority (64.4%) were 50 years old or older at the time of registration. The highest proportion of registrants (35.8%) claimed Belize district as their district of residence.

Cataract was by far the leading cause of registration, accounting for 39.6% of all registrants, followed by glaucoma, which accounted for 20.8% (see Table 2). Other major causes of registration for blindness and visual impairment were diabetic retinopathy (10.2%) and childhood blindness (9.4%), a category which included retinopathy of prematurity, congenital cataracts, congenital glaucoma, and any corneal or retinal pathology in individuals under the age of 15. Age-related macular degeneration (AMD) accounted for 1.2% of the register and refractive error only 0.6%. Causes of blindness in the register that did not fall under one of the WHO's priority disease categories were grouped under a separate category designated as "other" causes. Taken together, these accounted for 18.2% of the register. The most common diagnosis within this category was trauma, representing 2.3% of the entire register, while other conditions included tumors and retinal pathologies such as retinitis pigmentosa. Besides trauma, none of the other individual causes within the "other" category exceeded 0.5% of the register.

The registration patterns for men and for women were similar (Table 2). The majority of individuals were registered at the age of 50 or older for most causes, reflecting the age-related pathophysiology of many eye diseases. Cataract and

TABLE 2: Causes of registration for blindness and low vision rehabilitation by the Belize Council for the Visually Impaired (BCVI) based on data from all actively registered individuals ($n = 1194$) as of December 31, 2009.

	Cataract Number (%)	Glaucoma Number (%)	Diabetic retinopathy Number (%)	Childhood blindness ^a Number (%)	Age-related macular degeneration Number (%)	Uncorrected refractive error Number (%)	Other ^b Number (%)	Total ^c Number (%)
Overall	472 (39.6)	248 (20.8)	121 (10.2)	112 (9.4)	14 (1.2)	7 (0.6)	217 (18.2)	1191 (100)
Gender								
Male	232 (39.9)	135 (23.2)	36 (6.2)	58 (10.0)	4 (0.7)	2 (0.3)	115 (19.8)	582 (100)
Female	240 (39.4)	113 (18.6)	85 (14.0)	54 (8.9)	10 (1.6)	5 (0.8)	102 (16.8)	610 (100)
Age at registration								
0–4	4 (4.1)	10 (10.2)	0 (0)	64 (65.3)	0 (0)	0 (0)	20 (20.4)	98 (100)
5–15	8 (8.8)	9 (9.9)	2 (2.2)	41 (45.1)	1 (1.1)	4 (4.4)	26 (28.6)	91 (100)
16–39	18 (16.4)	15 (13.6)	15 (13.6)	6 (5.5)	0 (0)	2 (1.8)	54 (49.1)	110 (100)
40–49	44 (35.5)	34 (27.4)	18 (14.5)	0 (0)	1 (0.8)	0 (0)	27 (21.8)	124 (100)
50+	398 (51.9)	180 (23.5)	85 (11.1)	1 (0.1)	12 (1.6)	1 (0.1)	90 (11.7)	767 (100)
District of residence								
Belize	142 (33.3)	120 (28.2)	50 (11.7)	35 (8.2)	9 (2.1)	1 (0.2)	69 (16.2)	426 (100)
Cayo	80 (41.0)	31 (15.9)	18 (9.2)	19 (9.7)	0 (0)	0 (0)	47 (24.1)	195 (100)
Corozal	67 (51.9)	15 (11.6)	18 (14.0)	13 (10.1)	0 (0)	0 (0)	16 (12.4)	129 (100)
Orange Walk	69 (39.2)	37 (21.0)	16 (9.1)	15 (8.5)	1 (0.6)	4 (2.3)	34 (19.3)	176 (100)
Stann Creek	23 (19.8)	30 (25.9)	17 (14.7)	15 (12.9)	2 (1.7)	2 (1.7)	27 (23.3)	116 (100)
Toledo	91 (61.1)	15 (10.1)	2 (1.3)	15 (10.1)	2 (1.3)	0 (0)	24 (16.1)	149 (100)

^a“Childhood blindness” includes congenital cataract, congenital glaucoma, retinopathy of prematurity, and any entity designed as “corneal” or “retinal” in those under the age of 15.

^bThe “other” designation includes trauma, tumor, uveitis, retinal detachment, retinitis pigmentosa, and other corneal and retinal pathologies in individuals over the age of 15.

^cTotals do not match the overall total study population number due to missing data.

glaucoma were the two leading causes of registration for individuals over the age of 40. Most of those listed with glaucoma were in their late 40s and above. Similarly, registrations for diabetic retinopathy occurred for individuals predominantly over the age of 50. These are chronic conditions that are best managed with early detection, suggesting that a goal of earlier registration would be appropriate. For the 15-year-olds and under group, childhood blindness was the main cause of registration, with 57% aged 0 to 4 years at the time of registration. Children on the register should ideally get appropriate support and rehabilitation, and the earlier this is possible the better.

The causes of registration were fairly consistent across the different districts. Cataract was most commonly listed as the cause of registration in all districts except Stann Creek, the district of Belize with the highest proportion of population of African descent, where glaucoma was the leading cause. Childhood blindness comprised approximately 10% of the registrations within each district.

Based on these results, we proposed several recommendations to BCVI, regarding both the distribution of disease burden (Table 3) and how to improve the register itself (Table 4).

In response to these recommendations, BCVI began several significant interventions within only four years. A few key interventions will be highlighted here.

3.1. Cataract. Cataract was the leading cause of registration at all levels of visual impairment. In theory, cataract should not be listed as a cause of permanent blindness at all because it is a treatable condition. However, the fact that it is identified here as the most commonly listed cause of registration emphasizes the ongoing burden of cataract which outstrips the availability and access to services. Cataract therefore remains a pressing public health challenge, particularly in a nation with limited resources and equity in service provision across all socioeconomic groups, such as Belize. Because it is typically correctable by surgery, its prominence among those individuals qualifying for rehabilitation services suggests that there may be limited availability of eye services and specifically surgical services. BCVI recognized the inadequacy of cataract surgical services in Belize early on; that recognition was what sparked the creation of their cataract surgery program in 2000. Since the analysis of the register, they have recruited more personnel. In addition to an ophthalmologist from the US who has been operating 4-5 months annually for many

TABLE 3: Key results based on data from the current BCVI register, their implications, and subsequent recommendations.

Result	Implication(s)	Recommendation(s)
Large disease burden in the over-50 age group	Improved case detection and service provision for older individuals are needed	(i) Publicize awareness of BCVI services among the community, general practitioners and other healthcare professionals, and nursing homes or elderly care centers (ii) Establish strong referral networks for all districts
Cataract is the leading cause of registration for low vision and blindness	May potentially be due to inadequate cataract surgical coverage	(i) Recruit more ophthalmologists to join BCVI if possible or increase surgical rates of current ophthalmologists (ii) Monitor cataract surgical rates and outcomes (iii) Provide outreach services to all districts on a regular and sustainable basis (iv) Provide early and easier access to cataract surgical services
Relatively late registration for diabetic retinopathy, glaucoma, and childhood blindness	More effective early detection and improved referral systems are needed since these are manageable conditions	(i) Institute screening programs for diabetic retinopathy and glaucoma and coordinate with general practitioners treating high risk patients (ii) Collaborate with pediatricians, nurseries, preschools, and elementary schools to promote early detection of childhood blindness and improve school vision health programs

years, they recently recruited an additional ophthalmologist from Cuba who works on a part-time basis throughout the year. Additionally, several ophthalmologists volunteer on a short-term basis, including two cataract teams from the US who operate for about 1 week each annually.

In Belize, there are no ophthalmology residency training programs in the country. Therefore the country currently depends on recruiting ophthalmologists who have been trained elsewhere. Based on a study on the global ophthalmology workforce conducted by the International Council of Ophthalmology [13], in 2010 there were 10 practicing ophthalmologists in Belize, equivalent to about 32 ophthalmologists per million population. There were no ophthalmology residents in training. By comparison, during that same year in the UK there were 52 ophthalmologists per million with 700 residents in training, while in the US there were 81 ophthalmologists per million with 1350 residents in training. However, Belize's workforce slightly exceeds the global average of 31 ophthalmologists per million. The issue of an adequate ophthalmology workforce is a widespread issue among numerous developing nations. Belize benefits from geographical proximity to the US and Caribbean nations with a greater supply of medical training programs, as well as from historical ties to the United Kingdom. However, in the absence of resources to establish comprehensive postgraduate ophthalmology training programs, the focus has been on recruiting talent from abroad and on maximizing the use of ancillary staff such as optometrists, ophthalmic technicians, visual rehabilitation specialists, and administrative assistants.

Besides increasing personnel to address surgical volume, BCVI has also reduced the visual acuity criterion for cataract extraction from 20/100 to 20/30 and maintains active lists (separate from the register) to keep track of patients who need cataract surgery so they are not incorrectly listed on the blindness register for rehabilitation. Starting in 2013, they have also begun measuring preoperative and postoperative visual acuity to gauge the clinical outcomes of their cataract surgery program. In addition, they have implemented outreach services through their primary eye care clinics via a surgical coordinator to provide easier access

to surgical services and meet patient needs at the district level. These changes signify progress toward addressing avoidable blindness caused by untreated cataract in this country.

3.2. Glaucoma. Stann Creek was the only district in which glaucoma exceeded cataract as the top cause of registration. Garifunas, people of African descent, make up the highest proportion of this district's population [10]. The increased risk of primary open-angle glaucoma among those of African descent is well documented [14–17]. Because of the more rapid progression [18] and earlier appearance of glaucoma in those of African descent [19], screening should be initiated earlier than in other populations. Ethnicity was not recorded on the register by BCVI. In theory this information would have helped illuminate how causes of registration may have varied by ethnic group and identify high risk individuals. However, in practice BCVI found it was very difficult to collect this information because so many of their patients come from mixed ethnic backgrounds and could not clearly identify themselves with any one single ethnic group.

Nevertheless, in response to this finding BCVI began a community awareness program in the Stann Creek district, going to each village with an educational video, conducting community meetings, and then conducting clinics to identify high risk individuals for earlier glaucoma assessment. While not enough time has elapsed to tell whether these community engagement activities will actually translate into decreased incidence of blindness due to end-stage uncontrolled glaucoma, they are definitely a step in the right direction.

3.3. Diabetic Retinopathy. Because the register had alerted BCVI to diabetic retinopathy as an increasingly common complication over time (Figure 1), in the subsequent years after this analysis, BCVI has taken steps to initiate a new national diabetic retinopathy screening program. With funding from Project Alliance International and the Lions Club International Foundation, they have purchased three portable fundus cameras to be placed at different clinic sites throughout the country. They have also employed two additional ophthalmic assistants to take the photos and grade

TABLE 4: Potential areas of improvement for the Belize Council for the Visually Impaired (BCVI) register.

Gap	Description	Recommendation(s)
Organization/staffing	Responsibilities for the register are split between multiple staff positions, and personnel have many other demands that take precedence over the register	(i) Include register maintenance and updating in descriptions of staff positions and contracts (ii) Develop a formal and explicit system for how the responsibilities for the register will be divided and put accountability checks in place (iii) Train personnel to carry out regular data cleaning checks
Register maintenance	Errors and inconsistencies in data entry and lack of follow-up on patient status (i.e., if referred to treatment or surgery)	(i) Develop a formal follow-up process for updating the register with set timelines (ii) Consider linking the register with other sources of information (i.e., clinics, the patient records database, the Belize Health Information System, mortality records, etc.) (i) Promote awareness of BCVI and registration in the community (clinics, grocery stores, churches, and schools) to boost referrals
Incomplete coverage of the population	The register may potentially miss many individuals suffering from low vision and blindness, including those who use private doctors and those in remote areas of the country	(ii) Build more relationships with private ophthalmologists to boost their referrals (iii) Conduct more outreach clinics to reach remote/marginalized communities (iv) Provide professional training for ophthalmologists on how to complete the register using clear definitions and criteria
Collecting relevant variables	Some key variables regarding the social determinants of health are missing	(i) Collect information on ethnicity, socioeconomic status, and residence within an urban or rural setting for all new registrants
Coding	Coding of some variables is not aligned with categories that are widely in use elsewhere	(i) Code the level of visual impairment and the cause of registration according to criteria set by the World Health Organization (WHO) in order to allow for easier cross-comparison and contextual analysis in the future
Registration process	Individuals with avoidable blindness are listed on the register for rehabilitation and support services when they should be referred to treatment instead	(i) Evaluate patients on the current register and refer them to treatment if applicable (i.e., for cataract); if all treatment fails, then keep them on the register for rehabilitation
Publicizing results	Reports from BCVI data go to funders but are not included in the public domain, and results are not widely disseminated	(i) Advocate for the inclusion of data from the register in Belize's compilation of national health statistics (ii) Send results from analyses of register data to the WHO and the Pan American Health Organization (PAHO) so that data from Belize will be included in their reports

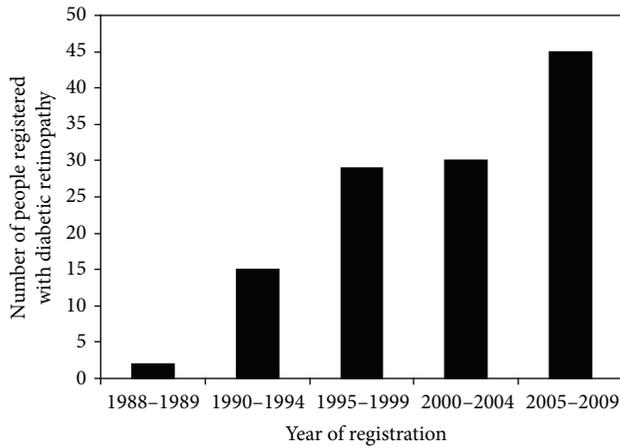


FIGURE 1: Trends in registration of blindness and low vision due to diabetic retinopathy in Belize.

them to determine whether the screened individual requires follow-up with an ophthalmologist. At the time of this report, the program is not yet fully operational but a training session has already been scheduled with faculty from Brighton and Sussex University Hospital in the United Kingdom. The goal of this program is to detect patients with diabetic retinopathy and initiate treatment at an earlier stage, thereby reducing avoidable blindness and ideally decreasing the number of people listed on the blindness register with this disease in the coming years.

3.4. Retinopathy of Prematurity (ROP). This analysis determined that childhood blindness was an important cause of blindness in Belize, and upon further investigation BCVI found that there was a markedly increased incidence of bilateral blindness secondary to ROP between 2007 and 2009 (Figure 2). Each case was followed up by BCVI's Rehabilitation Field Officers, and the suspected cause was unmonitored excess oxygenation in preterm infants. Once this cluster of cases was identified, the lead BCVI ophthalmologist alerted the staff at the one referral pediatric neonatal intensive care unit (NICU) located at the Karl Heusner Memorial Hospital in Belize City, the only NICU in the country. Two training sessions, one in 2009 and one in 2011, were conducted with neonatologists, pediatricians, and NICU nurses focusing on oxygen usage, monitoring of premature infants, and ROP prevention. Subsequently, between 2010 and 2012, BCVI reported that only one case of ROP had been registered. While it would be difficult to prove that the decrease in incidence was caused by this intervention, nevertheless it is an illustration of how data provided in the register were used to drive a public health intervention and an educational campaign aimed not at treatment but at prevention of a debilitating disease.

3.5. Improvements to the Low Vision and Blindness Register. BCVI also made several changes to the register itself in line with these recommendations in order to improve their services. One issue was potential ambiguity surrounding

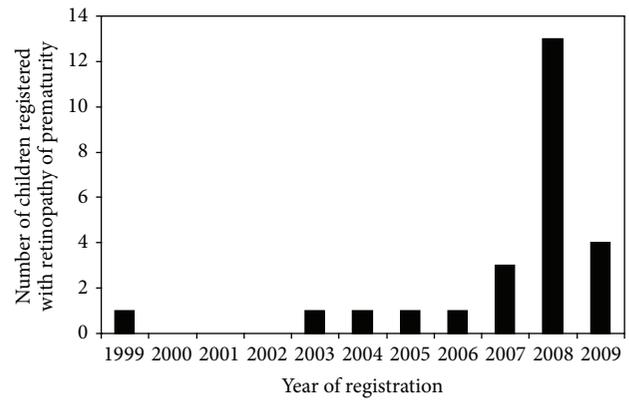


FIGURE 2: Trends in registration of blindness and low vision due to retinopathy of prematurity in Belize.

the exact diagnosis causing blindness. This was particularly true if the patient suffered from multiple eye conditions. For example, upon review of the medical charts, BCVI found that several individuals were listed as "cataract" in the register because that was the first diagnosis on their problem list at the most recent clinic visit, when in reality they had subsequently had the cataract removed and were actually blind from another cause such as glaucoma or diabetic retinopathy. This may have overestimated the amount of blindness caused by cataract and underestimated the amount of blindness caused by glaucoma and diabetic retinopathy. This reemphasizes the need for accurate registration since cataract is operable, but glaucoma and diabetic retinopathy cause visual impairment that is potentially avoidable with early detection and management but is irreversible if allowed to progress. In addition, BCVI changed their coding practices so that instead of haphazard entry of diagnoses they are now using the WHO ICD-10 codes. They have gone back to their clinic records to update much of the register and assign accurate diagnoses. This will help streamline future analyses and will be conducive to ongoing monitoring and evaluation.

Looking at the number of new registrations longitudinally (Figure 3), the overall trend indicates a gradual increase over time, although there were substantial variations. The steepest increase occurred after 2006, with the largest single increase in the number of new registrations occurring in 2009. Starting in 2009, BCVI began making special efforts to increase awareness of the register among the clinics to facilitate identification and registration of new patients who qualified for rehabilitation services. In addition, numerous efforts were made to follow up on individuals who were already registered and update the register by removing patients who had received vision-restoring treatment, moved out of Belize, or died. In the years since this analysis was performed, BCVI has continued to work aggressively to maximize the register's coverage of the population and ensure it is as updated as possible. This will improve data accuracy and better inform public health interventions in the future.

3.6. Challenges and Limitations. The data used to describe the distribution of causes of blindness and visual impairment in

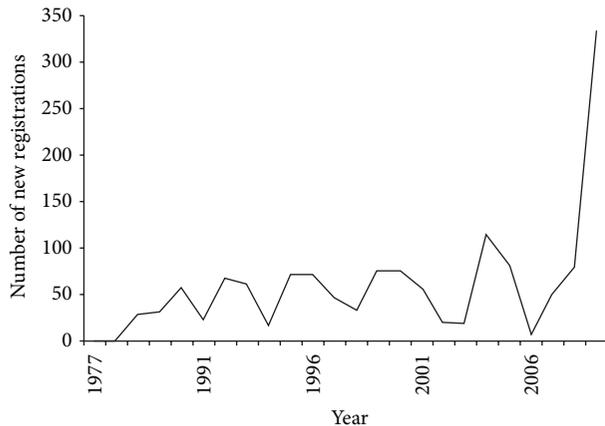


FIGURE 3: Longitudinal trends in the number of new registrations for blindness and low vision in Belize.

this study were not generated from a planned research study with unbiased sampling procedures and standardized procedures and protocols. They were drawn from a community-based source capturing only those patients who interfaced with their clinics, thereby introducing potential bias in representing the country's population as a whole. Given the lack of accurate information regarding population coverage, an accurate estimate of country-wide prevalence or incidence based on the BCVI register would be difficult to achieve. Population-based studies using standardized data collection methods would be helpful in the future for generating these estimates.

While in some respects this lack of epidemiological rigor may be a limitation, in other respects this is a more accurate representation of "real" public health practice, especially in a developing setting with limited or scarce resources. Furthermore, the process of identifying some of the shortcomings in the data collection process itself is a useful exercise to fuel ongoing improvement for the future. While the specific findings may be local in scope, the overall principles can be applied on a national scale, and this case study illustrates how data from blindness registers, even if not the most precise, can still drive significant public health interventions.

4. Conclusions

This study illustrates the value of blindness registers not only for day-to-day operational or management purposes (e.g., tracking of patients requiring rehabilitation services), but also for providing data on local disease patterns that can inform quality improvement initiatives in the long term planning and delivery of healthcare services. Avoidable blindness, that is, blindness that is theoretically curable (such as cataract and refractive errors) or at least manageable with early detection (such as glaucoma and diabetic retinopathy), remains an important issue in Belize as well as in Latin America and the Caribbean in general, a finding that has been highlighted by several other surveys in this region [12, 20–23].

Cataract is the leading cause of registration, emphasizing the ongoing need to bolster surgical services in this region.

Globally, cataract remains the leading cause of visual impairment in all regions of the world, except in the most developed countries [24]. Glaucoma and diabetic retinopathy are also common causes of blindness, illustrating the need for robust early detection programs that may help mitigate some of the visual impairment caused by these diseases when they progress untreated. This study also highlights the importance of accurate coding, regular updates and maintenance, and working toward maximal population coverage when operating a disease register to maximize its utility. Despite some of their limitations in data quality, blindness registers can still serve as incredibly useful tools in informing public health planning.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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