



## Commentary: Using Blindness Registers for Public Health Ophthalmology in Low Resource Settings

Sally Baxter\*

Shiley Eye Institute, University of California San Diego (MC0946), USA

\*Corresponding author: Sally Baxter, Shiley Eye Institute, University of California San Diego (MC0946), 9415 Campus Point Drive, La Jolla, CA 92093-0946, USA, Tel: +18587841625; E-mail: S1baxter@ucsd.edu

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### Short Communication

Blindness registers are commonly used to coordinate rehabilitation and support services and provide financial and social benefits to the visually impaired. However, besides facilitating the coordination of services, blindness registers can also be used as an important source of population-based data to drive quality improvement initiatives for public health eye programs. Most published research studies using blindness registry data come from developed nations [1-8]. However, using such data to plan eye services may be even more important in developing settings where health care resources are particularly scarce. Such was our experience in Belize, where our team from the International Centre for Eye Health at the London School of Hygiene and Tropical Medicine analyzed a national low vision and blindness register operated by the Belize Council of the Visually Impaired (BCVI) to inform the planning of its public eye health services [9].

The Belize Council for the Visually Impaired (BCVI) is the primary provider of primary and secondary eye care in the small nation of Belize, where eye care is not included in the government sponsored healthcare system, and private ophthalmologists are unaffordable for most of the population. For almost thirty years, BCVI has operated a register of patients with low vision and blindness. The original intent of the register was not to generate epidemiological data, but instead to coordinate rehabilitation services to those patients who met certain qualification criteria (best corrected visual acuity of 20/200 or less in both eyes, and determination by the referring ophthalmologist to gain no benefit from further medical treatment or surgery). The register captured demographic data (age, sex, district of residence) as well as visual acuity, extent of rehabilitation needed, and primary cause of visual impairment. Although not originally intended for epidemiological investigation, no other available data set of patients with eye conditions existed in Belize, and we felt that this register would provide a rich source of information about eye disease patterns in the region and be especially useful in advising the organization of its service delivery at the local level.

We re-categorized the listed causes of registration into the World Health Organization's (WHO) priority disease categories: cataract, glaucoma, diabetic retinopathy, age-related macular degeneration (AMD), childhood blindness, and uncorrected refractive error. Causes of registration not aligning with one of these were identified as "other". We performed univariate analyses examining causes of registration by age, sex, and district.

The register included 1194 patients, about equally split between men and women. Most patients were from the Belize district, but all districts were represented on the register. Cataract was the leading cause of registration, accounting for almost 40% of all registrants, followed by glaucoma, which accounted for about 20%. Diabetic

retinopathy and childhood blindness each represented about 10% of the register. AMD accounted for only 1.2% and refractive error only 0.6%, and the remainder fell into the "other" category, comprised of a wide spectrum of pathology. The majority of patients who were registered were over age 50, reflecting the age-related pathophysiology of many eye diseases. For those with childhood blindness, nearly 40% were registered after age 5. The causes of registration were fairly consistent across the different districts, with cataract the leading cause in all districts except one, where glaucoma was the leading cause.

Based on these results, we proposed several recommendations for improvement in services as well as improvement of the register itself. We then followed up with BCVI four years later to see what interventions had been undertaken in response to the recommendations. While the recommendations were multifaceted, here I will highlight a few that translated into successful public health interventions over the course of only a few years.

First, the fact that cataract was the leading cause of registration at all levels of visual impairment and in almost all districts highlighted that this was still an important area of need. Given that it is a treatable condition, cataract being identified at all in a register that was designed to capture patients with permanent blindness shows that the disease burden outstrips the availability and access to cataract surgical services. Like other developing nations, Belize does not have any ophthalmology residency training programs in the country and has relatively few practicing ophthalmologists in comparison to the population. In response to the findings on the register, BCVI worked to actively recruit more personnel, including not only more ophthalmologists but also ancillary staff such as optometrists, ophthalmic technicians, visual rehabilitation specialists, and administrative assistants/surgical coordinators, in order to boost their workforce. An adequate ophthalmology workforce is a common issue facing many developing nations [10]. Furthermore, they lowered the visual acuity criterion for cataract extraction from 20/100 to 20/30 and maintained active lists separate from the register to more effectively track patients needing surgery. They have also begun to measure changes between pre-operative and post-operative visual acuities to gauge clinical outcomes of the cataract surgery program, signifying an ongoing effort toward quality improvement.

Glaucoma also emerged as one of the top causes of blindness registration nationally, and was the top cause of registration in the Stann Creek district of Belize. This district had a particularly high proportion of Garifunas, a people of African descent. Given the well documented evidence of the increased risk of primary open-angle glaucoma, earlier presentation, and more rapid progression of disease among patients of African descent [11-16], we recommended earlier screening in this population and furthermore suggested that BCVI

start collecting information on ethnicity for its register in the future to better target future public health interventions for at-risk populations. In response, BCVI has begun an innovative community awareness program centered around glaucoma in the Stann Creek District integrating videos, community meetings, and specialty clinics to better identify high risk individuals. This was another public health initiative that resulted from the analysis of the blindness register.

Similarly, given that our analysis of the blindness register had shown that diabetic retinopathy was an increasingly common cause of blindness registration over time, we recommended improved screening efforts to facilitate earlier detection of diabetic retinopathy. BCVI has initiated a new national diabetic retinopathy screening program with assistance from Project Alliance International and the Lions Club International Foundation, using portable fundus cameras at various clinic sites and analysis of photos by ophthalmic assistants to identify those patients who need further evaluation and treatment by the ophthalmologists. Again, this was an effort driven by analysis of the blindness register and identification of a critical public health need.

The blindness register indeed represents a dynamic tool which can identify areas for public health programming and also serve as an ongoing method of monitoring and evaluation of those interventions. However, its utility can be limited if the data are inaccurate or incomplete. We found that coding a cause of blindness was particularly difficult if the patient suffered from multiple eye conditions. For instance, a review of the medical charts showed that some patients had “cataract” listed in the register simply because that it was the first diagnosis on their problem list, when in reality their blindness was from another cause (e.g. glaucoma, trauma, etc.). This may have overestimated the amount of blindness caused by cataract and underestimated the amount caused by other conditions. BCVI now uses WHO ICD-10 coding and has trained their providers regarding how to code for the blindness register to improve consistency and accuracy for future analyses. In addition, BCVI has made special efforts to increase awareness of the register among the clinics to facilitate identification and registration of new patients who qualify for rehabilitation services, in order to maximize the register’s coverage of the population as much as possible.

In some regards, working with data coming from an operationally minded blindness register in a developing country was frustrating, as many obvious limitations were present – a lack of standardized data collection protocols, no strict inclusion and exclusion criteria, and inconsistent coding. These data had not been collected with the standards required of most epidemiological research studies. Therefore, metrics such as country-wide prevalence or incidence of various diseases were virtually impossible to calculate. However, in other ways these data form a more accurate representation of “real” public health and clinical practice and more closely reflect the makeup of individuals in the community who are seeking care and interfacing with the organization. Furthermore, many of the issues we encountered while examining the data from the blindness register are not exclusive to the developing world; they exist in developed settings as well.

Avoidable blindness from conditions that are curable (such as cataract and refractive errors) or at least manageable with early

detection (such as glaucoma and diabetic retinopathy) remains a pressing public health issue globally, particularly in low income nations such as Belize [17]. Our experience in Belize was that blindness registers are a valuable tool, not only for day-to-day operational or management purposes, but also for providing population-based data to inform planning of public eye health interventions. This could be a model for other developing countries as a relatively low-cost tool to improve eye care services for those most in need.

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