Addressing the burden of glaucoma in Ghana

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In each of the past 22 years, Don Budenz, MD, MPH, has gone to Ghana – first right after his fellowship training and now as Chair of the Department of Ophthalmology at UNC and founder of Christian Eye Ministry, an NGO dedicated to preventing and curing blindness in the developing world.

He keeps going back because there is still a lot of work to be done.

"I remember after my first trip, thinking if I never saw another patient in the United States no one would go blind. If I didn't return to Ghana, people would," Budenz said.

According to the Ghana Glaucoma Association, around 700,000 out of 24 million Ghanaians have glaucoma, the second highest rate in the world. There are fewer than 50 ophthalmologists in the country and even fewer willing and able to perform the surgery necessary to treat the condition. There is a general lack of cultural understanding of glaucoma, and its chronic nature is an ongoing challenge for both providers and patients.

Even with those challenges, Budenz remembers the exhilaration and long hours of those early trips. That, and the progress made in the past two decades keep drawing him back.

"You get there in the morning and there are already 100 people lined up outside the clinic, which in a lot of cases is just a converted house," Budenz said. "These patients don't have appointment times; they just want to get in line to be seen. So, you see those patients, you screen, you recommend surgery for those that need it, and then you go into the operating room and you work late into the night."

Budenz said many of the patients he sees in Ghana fit a similar profile. Their glaucoma is at an advanced stage. And 93 percent don't even know that they have it, according to research published by Budenz in 2013.

"Glaucoma is a difficult problem in general because of a low understanding of the disease coupled with the fact that people don't really have discernable symptoms until it's really almost too late," Budenz said.

With glaucoma, Budenz explains, patients will retain their central vision until very late in the disease, when they begin to develop tunnel vision. Many of the patients Budenz sees in Ghana are at that point when the patient is visually disabled and all that can be done is to slow the deterioration.

"The damage from glaucoma occurs to the optic nerve. When we are born there are approximately 1.2 million fibers going from the optic nerve to the brain. We'd like to catch people when they still have around a million fibers. If we catch them too late and there are only around 100,000 fibers left, then slowing things down helps, but patients may still
lose vision due to aging," Budenz said.

It's a numbers game.

"Our goal is to reduce the rate of blindness before death, which sounds rather stark, but truthfully if we lived long enough we'd all go blind because optic nerve fibers die just from aging. Glaucoma accelerates the process."

The challenge, then, is to catch patients in earlier stages of the disease, make the diagnosis, and begin treatment. Of course, it's not so simple.

Even in the United States, Budenz says, there is low understanding of glaucoma. It's even lower in Ghana. But, as educational efforts increase, the economy improves, and the burden of infectious disease across Ghana is reduced, Budenz is hopeful that rates of early glaucoma diagnoses will increase.

The Root of the Issue

While in Ghana, Budenz spends a few weeks at the time seeing as many patients as possible, doing as many surgeries as possible, teaching local surgeons to do what he does. He knew the burden of glaucoma was incredibly high—higher than most other places in the world—but he wanted to take a closer look. He'd just finished a Masters of Public Health at Johns Hopkins, and after reviewing the available literature, he realized that there had not been a good epidemiological study of glaucoma prevalence in West Africa.

There was a study that had been done on people of African descent in Baltimore, others in the Caribbean, and also in Tanzania and South Africa. Those studies done in Eastern and Southern Africa showed lower rates of glaucoma than the Baltimore or Caribbean studies.

Budenz and his colleagues set out to understand the scope of the problem in Ghana. They examined 5,600 Ghanaians and found that 362 had glaucoma. Of those, only 7 percent knew that they had the disease.

"There's clearly a huge ethnic diversity in sub Saharan Africa, but Americans just tend to lump everyone together. It was important to show the differences across the continent and really understand the scope of the problem in Ghana," Budenz said.

In addition to being screened for glaucoma, participants' DNA was taken and categorized into glaucoma and non-glaucoma. That information is being used currently by researchers at Duke to try and establish a genetic basis for glaucoma in people of African descent.

Changing the mindset

One of the issues in Ghana, Budenz said, is a lack of patient education related to glaucoma. For years, eye care had been a minor concern for people facing HIV and other infectious diseases. But now, as life expectancies are increasing and the economy is improving across the country, Budenz is hopeful that vision care will become prioritized and more accessible.

"The old paradigm said if people are dying before they turn 50, why would you treat a disease of aging?" Budenz said. "But, life expectancy is rising fairly rapidly, and they don't have the resources or infrastructure to treat this disease in the developing world."

Still, as rates of diagnosis increase, Budenz and his colleagues have to fight a misunderstanding that exists among both patients and other physicians.

Patients, Budenz said, have more experience with regimens involved with treating infectious disease and less experience dealing with a chronic condition like glaucoma. It has to be explained, he said, that while the surgery can help to slow the progression of the disease, regular maintenance and medication is required for life.

As for Ghanaian ophthalmologists, Budenz said there is still some hesitation to operate on patients with glaucoma.

"The complication rate for glaucoma is probably four or five percent, compared with one or two percent for cataract surgery. In cataract surgery, 99
percent of the time your patient will see better. But, with glaucoma, one in twenty patients will probably see worse as a result of a complication, and many others don't really understand why it was necessary to have the surgery in the first place because they hadn't been aware of symptoms affecting their vision yet," Budenz said.

But, despite this, Budenz and his colleagues continue to make the training of young Ghanaian ophthalmologists a priority.

"There are a few Ghanaian ophthalmologists who are doing glaucoma surgeries, and most of them are trained through our Christian Eye Ministry clinics," Budenz said.

In 2018, UNC ophthalmology residents will travel with him and observe in Ghana.

"Most of the potential residents that we interview seem to have done some international health work and we definitely want to foster that," Budenz said. "Beginning in the next 2 years, each of our four residents will be able to have an international experience with one of our faculty members. It's important for them to get a sense of the good they can do outside of the US once they finish training."

Budenz and his colleagues at Christian Eye Ministry will keep going, year after year. And in the meantime, they continue their work is to increase the capacity of the Ghanaian ophthalmologists. Christian Eye Ministry has started four clinics across the country, all with surgical capabilities. to the ministry's members continue to supplement the training of the doctors in these clinics, since many were trained in Eastern Europe where training is not as hands on as in the United States. Budenz is working with a consortium to try to get glaucoma lasers in clinics across sub-Saharan Africa, after a study involving patients from the Caribbean showed that laser therapy could be especially effective.

"We are always looking to scale things up," Budenz said. "We know we can treat this disease, we just have to be able to deploy the resources and training effectively across the Africa."