A conversation with Professor Clare Gilbert and Dr. Hannah Kuper, January 14, 2016

Participants

- Professor Clare Gilbert Professor of International Eye Health and Co-Director of the International Centre for Eye Health (ICEH), London School of Hygiene & Tropical Medicine (LSHTM)
- Dr. Hannah Kuper Co-Director of the International Centre for Evidence in Disability and Reader of Epidemiology, LSHTM
- Sophie Monahan Research Analyst, GiveWell
- Josh Rosenberg Senior Research Analyst, GiveWell

Note: These notes were compiled by GiveWell and give an overview of the major points made by Professor Gilbert and Dr. Kuper.

Summary

GiveWell spoke with Professor Gilbert and Dr. Kuper of ICEH about impacts of and approaches to cataract surgery in the developing world. Conversation topics included barriers to cataract surgery, impacts of this surgery on recipients' quality of life, and potential interventions for improving cataract surgical coverage (CSC).

Overview of ICEH's activities

ICEH is mandated to conduct research to improve eye health and reduce avoidable blindness with a focus on low- and middle-income countries. ICEH's work falls into several categories:

- Assessment of need for eye treatment via population-based surveys
- Studies of eye disease risk factors
- Involvement in clinical trials for new treatments of individuals and communities, as well as new settings for previously tested treatments
- Intervention research, which tests the on-the-ground efficacy of treatments that have been shown to work in a clinical setting
- Impact studies to examine the effects of surgery for various eye diseases

Background information on cataract

When the normally transparent lens of the eye becomes opaque, this is known as lens opacity or cataract. Opacification of the lens is an aging process, reflecting accumulation of exposure to risk factors over a life-time. Apart from age, the major risk factors for cataracts are cigarette smoking, exposure to ultraviolet light and biomass cooking fuels, poor diets, certain drugs and diabetes. Females are more likely to develop cataracts than males. Cataracts are the commonest cause of blindness globally, and the second commonest cause of vision impairment. In 2010 there were estimated to be 32.4 million people who were blind, almost 11 million of whom were blind from cataract. The majority of the cataract blind live in low and middle income countries.

Opacification of the lens cannot be prevented by public health measures and surgical removal of the cloudy lens is the only treatment. Modern cataract surgery entails insertion of an artificial lens inside the eye at the time of surgery (intraocular lens), to focus light entering the eye.

The number of people who are cataract blind in a population at any point in time reflects the number of people who become cataract blind as well as those who die while cataract blind, or who have sight restoring surgery. As the population in most countries is ageing as well as increasing in size, the number of people who become cataract blind is increasing year on year. This means that the number of cataract operations required to control cataract blindness also needs to increase year on year. Cataract surgical coverage is a measure used to assess the extent to which cataract surgical services are meeting the need for surgery in the population.

Cataract impact study

Beginning in 2005, ICEH conducted a cataract impact study to examine barriers to increasing CSC and the effects of cataract surgery on recipients' quality of life as well as their visual acuity. ICEH is now carrying out a similar study for trichiasis and plans to conduct one for refractive error.

Effects of cataract surgery on financial security

Before beginning the cataract impact study, ICEH believed that most respondents would be receiving a high level of care from other household members, and that cataract surgery would therefore reduce family poverty by allowing those household members to return to work outside the home. Instead, the baseline survey found that most respondents, among whom the average age was 73, were not receiving extensive care from others. This finding attenuated ICEH's predictions of poverty reduction, together with the higher than expected age of the participants. However, ICEH still found a positive impact on families' financial circumstances one year after cataract surgery in all three countries (Kenya, the Philippines and Bangladesh), and this effect persisted at six-year follow-up. The likely mechanisms for improved finances were that after surgery the participants received less care from household members and spent more time engaged in "productive" activities.

Effects of cataract surgery on overall quality of life

ICEH found that overall quality of life tends to decline linearly with decline in visual acuity, and that quality of life improves after cataract surgery as visual acuity improves. At the time of ICEH's study, the common threshold for receiving surgery was a measured visual acuity of 6/60 or less, meaning that the respondent's vision was approximately 10 times poorer than normal vision. However, ICEH chose to use a threshold of 6/36 and found that the surgery still had a positive impact on quality of life at this level. ICEH also found that recipients of the surgery were often pleased by the resulting increased independence even if they did not regain perfect vision.

Cataract surgical need

Cataract surgical rate (CSR) refers to the number of cataract surgeries performed per million in the population, per year. It is estimated that 10,000 surgeries need to be performed per million people, per year, in order to both stabilize the number of people who are blind due to cataracts and reduce the prevalence of cataract blindness.

Outreach models for cataract surgery in the developing world

Aravind model in India

The Aravind Eye Care System in India uses income generated from wealthier, paying clients to provide free services for approximately one-third of its cataract patients. Aravind also conducts extensive outreach by contacting non-governmental organizations (NGOs) or religious groups in a given area to inform them that Aravind will be visiting on a certain date. The local group then provides a venue and conducts marketing to inform the community of the eye care team's upcoming visit. On the day of the visit, Aravind's team examines all community members who assemble at the venue. Those who are blind or visually impaired from cataract are offered surgery in the eye hospital. The NGOs often provide transportation to and from the hospital for cataract surgery for those who need it. While cataract surgery can be performed in the field, evidence has shown that temporarily converting other buildings into operating facilities yields poor results compared to surgery performed in hospital.

Other models

In another approach, an eye care team will visit a local eye unit that lacks the expertise to perform cataract surgery. The local eye unit prepares for the visit by collecting the names and contact information of people in the community who need cataract surgery. These patients are then called to return to the local unit when the visiting surgical team arrives.

Barriers to increasing CSC

The primary barriers ICEH has identified to increasing CSC are:

- Lack of awareness among patients that their cataracts are treatable
- Lack of access to cataract surgery
- High cost of cataract surgery
- Low demand for and uptake of surgery, even among patients who are informed about it and can access it at no cost

In general, creating demand for the surgery is a greater challenge than supplying it. In many places, surgical capacity is not the major bottleneck to providing surgeries.

Low uptake of surgery

ICEH's cataract impact study identified low uptake as a significant barrier to increasing CSC. As part of the study, ICEH visited communities in Bangladesh, Kenya, and the Philippines and identified people who were visually impaired due to

cataracts. ICEH offered these people free surgery, free transportation to the hospital, and counseling. ICEH visited these potential surgery recipients up to four times in all. However, only 50% agreed to have the surgery done.

Reasons for low uptake

Low uptake may be partly attributable to the fact that cataract patients are often elderly and have other impairments in addition to cataracts, and frequently rely on support from their families.

Variable quality among surgeons also affects demand. In rural areas, people often learn of surgeons' skill by word of mouth, and if they have a friend who has had a negative experience, they may be less likely to seek out the surgery themselves. Dr. Kuper highlights that poor quality of cataract surgery (and not just perceived poor quality of surgery) is in fact a major concern.

Challenges of using outreach models in Africa

The outreach models described above have not proven successful in Africa. While the Aravind model has been tested there, it has not historically worked well, as it requires a certain proportion of patients to be wealthy enough to pay for the surgery. Additionally, South Asia has more non-governmental hospitals; in Africa, the majority of cataract surgeries are performed by government hospitals, which generally lack the resources to conduct outreach activities or visits to other eye units.

Ocular comorbidities

Patients in developing countries who have other eye diseases as well as cataracts may be excluded from cataract surgery. This often depends on an assessment of how much visual function they are expected to regain from the surgery, which may take into account whether one or both eyes are affected by cataracts. In some cases, ocular comorbidities are not discovered until after the cataract surgery has been performed. For instance, during surgery, a doctor could discover a previously undiagnosed eye disease that is obscured by the cataract, which may render the surgery less effective.

Potential interventions for increasing CSC

There is little research-based evidence to indicate what interventions are most effective for increasing CSC. ICEH conducted a literature review to identify interventions specifically designed to improve access to cataract surgery, but found none.

Pakistani prevention-of-blindness program model

Some evidence of an effective approach comes from Pakistan. ICEH conducted a study in Nigeria and Pakistan to identify and compare who needs cataract surgery in both countries, as well as to compare eye care health systems and policies in an effort to explain the differences. The study found that in Pakistan, unmarried

women in rural areas had better access to cataract surgery than their counterparts in Nigeria and were less likely to be cataract-blind. This is likely because Pakistan has maintained an active program to prevent blindness over many decades with support from several international NGOs. The approach adopted in Pakistan entailed strengthening government services for cataract surgery at district level, by improving infrastructure (such as dedicated operating theatres for eye conditions), training of hospital managers, training surgeons in up-to-date surgical techniques, providing equipment for high quality surgery, and outreach support. The program has helped increase both the quality and uptake of cataract surgery, as high quality surgery is provided close to where people live. A similar approach was supported in India by the World Bank.

Many other countries could benefit from the approach adopted in Pakistan and India, which requires a systematic approach to supporting cataract surgical services in a way that is sustainable. Increasing awareness and improving access through outreach and providing transport are other important elements.

Local counselors

ICEH attempted to find funding for a program in Nigeria that would enlist women who have had successful cataract surgery to serve as counselors to others in their communities who are still cataract-blind. ICEH believes that people from these communities who have very similar backgrounds and speak the same language might be best suited to persuading others to have the surgery. However, the program was not funded.

Subsidies and support for outreach surgery

Several international NGOs support outreach in Africa, and some subsidize the cost of surgery. For example, an ICEH alumnus has worked in a part of northwest Nigeria where Sightsavers has provided equipment and subsidized the cost of intraocular lenses, which allowed the local hospital to lower the price of the surgery by twothirds. This led to a significant increase in uptake.

Staff at ICEH believe that subsidizing cataract surgeries is effective at increasing access generally, but this approach can still fail to reach the most disadvantaged members of a population. The ICEH alumnus in northwest Nigeria conducted a research project in communities relatively near the hospital offering subsidized cataract surgery, and found that a high percentage of women in the community who were cataract blind had not accessed cataract surgery as they did not know why they were blind or what could be done about it.

Increasing awareness

ICEH believes that educational efforts using mass media and community leaders have the potential to effectively increase awareness of cataract blindness and available surgical solutions. However, ICEH is not aware of any such campaigns that have been conducted on a large scale.

Mobile apps and software

Andrew Bastawrous, an ophthalmologist and lecturer at ICEH, is developing a mobile app that can be used to measure vision to identify people who are visually impaired or blind, called the Portable Eye Examination Kit (Peek). Dr. Bastawrous has also developed software that uses GPS to map the locations of people who need surgery for cataracts or trachoma. The software allows him to share with eye care providers where the highest concentrations of surgical need are located (for example, 12 people within a radius of 1–2 kilometers). The patients can then be contacted via text message and transported in groups to a hospital for surgery.

ICEH believes that Peek has good potential as an intervention in its own right, but also as a model for testing and evaluating other interventions to improve eye care access.

Other organizations

The International Agency for the Prevention of Blindness (IAPB) is an umbrella organization of 150 agencies, organizations and professional bodies involved in the prevention of blindness, as well as working with the World Health Organization. The main role of IAPB is to coordinate activities and conduct advocacy. The largest international NGOs working on the prevention of blindness in low resource settings are the Fred Hollows Foundation, Sightsavers, ORBIS International, and CBM.

All GiveWell conversations are available at <u>http://www.givewell.org/conversations</u>