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#### SPECIAL REPORT

# STOP Glaucoma in Sub Saharan Africa: enhancing awareness, detection, management, and capacity for glaucoma care

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#### ABSTRACT

**Introduction**: Glaucoma in Sub Saharan Africa (SSA) poses a daunting challenge. Communities are often unaware of the serious implications of glaucoma and are faced with limited access to specialists, making early detection and management difficult. For those who have been diagnosed, socioeconomic barriers limit access to treatment.

Since 2006, we have been involved in an innovative program we term 'STOP Glaucoma in SSA'. The four main pillars of this program include building capacity, enhancing awareness, and improving glaucoma detection and management. The aim of this initiative is to train the first generation of highly qualified glaucoma subspecialist leaders and to develop centers of excellence for glaucoma care throughout SSA that are interconnected. Our ultimate aim is to reduce the burden of blindness from glaucoma in SSA. **Areas covered**: Our review addresses background context, provides learning from the first decade of this program, and offers solutions to help tackle the scourge of glaucoma in SSA.

**Expert commentary**: Research in ocular genetics, primary congenital glaucoma, ophthalmic nanomedicine, and cost effective therapies will continue to improve our understanding of glaucoma as well as access to quality care for glaucoma in SSA.

#### 1. Introduction

Glaucoma is a leading cause of blindness globally, with a disproportionately high impact on Sub-Saharan Africa (SSA) [1]. For the purposes of this review, SSA is defined as the cluster of countries within Africa, excluding the more developed northern and southern countries. In those over the age of 40 years, the prevalence of glaucoma ranges from 4% to 5% in eastern and southern Africa and 6-8% in western Africa [2,3]. The prevalence of glaucoma increases with age and is a major public health issue due to the aging population and increasing longevity [4]. A recent review found that the prevalence of glaucoma in Africans aged 40-80 years was 8.3 million in 2013 and is expected to increase to 10.3 million by 2020 and 19.1 million by 2040 [5]. These estimates likely underestimate the burden of glaucoma since many cases remain undiagnosed and the disease can affect individuals younger than 40 years, including primary congenital and other forms of pediatric glaucoma [6,7].

Glaucoma, or more properly the glaucomas, consists of a cluster of conditions identified by a characteristic optic neuropathy and progressive loss of visual field. There is limited epidemiologic data about various forms of glaucoma in SSA countries. What is clear, however, is that primary open-angle glaucoma (POAG) is the most common form and is associated with a younger age of onset and a more aggressive course compared to European-derived decade of

governance

**KEYWORDS** 

**ARTICLE HISTORY** 

Glaucoma; fellowship

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training; Sub-Saharan Africa;

teleglaucoma; leadership &

populations [6,8]. Reasons for the aggressive phenotype which can lead to blindness are unknown and likely related to a combination of genetic and environmental factors [9]. Along with POAG, exfoliation-related glaucoma also appears to be a major challenge in parts of SSA [10].

Risk factors for POAG in SSA include increasing age, higher intraocular pressure (IOP), lower systolic blood pressure (BP) to IOP ratio (BP/IOP), lower mean diastolic ocular perfusion pressure (diastolic BP minus IOP), thinner central corneal thickness, and a positive family history of glaucoma [11]. Early detection of glaucoma is uncommon, with the majority of patients presenting late, often with blindness in one eye [12]. In most African countries, over 90% of glaucoma cases remain undetected in contrast to 50% in Canada.

The detection and management of glaucoma in Africa continue to face enormous challenges which are summarized in Table 1. With almost no support available to the blind (or partially blind), the socioeconomic impacts of this disease are extremely concerning. Approximately half of the average glaucoma patient's monthly income is spent on antiglaucoma medications, examinations, transport, and time away from work [13]. Most patients also opt for medical management compared to surgical treatment due to high initial costs of surgery [13] along with fear of losing vision with surgery. When we consider that 66% of patients may be

#### Population

- Low literacy levels among rural populations.
- Low awareness of glaucoma in most populations.
- Lack of glaucoma-support programs for patients.

Cultural

- Cultural perception among patients and some ophthalmologists that glaucoma is a sentence to blindness.
- Ophthalmologists hesitant to perform trabeculectomies as the patient's vision typically does not improve (compared to cataract surgery); concern that doing surgery may be associated with a risk of losing reputation within their community.

Socioeconomic and geographic

-Socioeconomic and geographic barriers that prohibit access to quality care.

Poor access to detection and treatment

- Low ratios of health workers to population. The majority of district eye clinics are run with poorly equipped lower cadres of eye care workers who are limited to diagnosing advanced symptomatic stages of glaucoma.
  Few glaucoma specialists, with the majority concentrated in East Africa.
- Supply chain difficulties in nearly all countries, with limited availability of
- medication and lasers, including selective laser trabeculoplasty and diode. - Only select centers offer surgery, which is often of variable quality. In
- addition, the rate of failure for trabeculectomy surgery is higher in blacks versus Caucasians.

Poor compliance and follow-up

- Compliance to treatment and follow-up care is difficult.

Educational

- Lack of locally applicable guidelines for glaucoma care.
- Limited centers to train for glaucoma care.
- Few national glaucoma societies.

#### Table 2. Principles to guide glaucoma care in Sub-Saharan Africa.

Key principles that will inform approaches to tackle glaucoma

- Africans taking initiative and creating locally appropriate and sustainable solutions.
- Long-term views of sustainability of training, research, and service programs.
- Health system approach integrating solutions into other elements of eye care and health-care strategy programs.
- Continuing to build centers of excellence for glaucoma care, training, and research.
- Developing partnerships locally, regionally, and internationally. This includes support from COECSA, AOF, WGA, and other key organizations.
- Consideration for local contexts (culture, socioeconomic, geographic, and demographic factors).
- Optimal utilization of resources (human, IT, and financial).

COECSA: College of Ophthalmology of Eastern Central and Southern Africa; WGA: World Glaucoma Association.

noncompliant with medications, mostly due to financial barriers, it is clear that many patients fall into a viscous cycle, with worsening visual outcomes [14]. In poverty-laden communities within SSA, blindness can have an immense impact on the welfare of a family, particularly if the primary bread winner is affected. This often leads to children dropping out of school to support their family, falling prey to the vicious cycle of poverty. This article offers background as well as learnings from the STOP Glaucoma program and focuses on solutions that we believe will help tackle blindness associated with the devastating impact of glaucoma in SSA. The key principles that should guide glaucoma care in SSA are highlighted in Table 2.

#### 2. Progress over the last decade and lessons learned

Tackling glaucoma in SSA was not a feature of the initial WHO Vision 2020 plan, likely because of other pressing priorities, the lack of solid evidence supporting cost-effective screening and management protocols, and lack of human resources to address this difficult group of diseases. Given this scenario, we have been engaged in a series of strategic initiatives since 2006 that we have termed 'STOP Glaucoma in SSA.' The aim of this project is to train alaucoma subspecialist leaders and to develop centers of excellence for alaucoma care throughout SSA that are interconnected and foster an International standard of patient-centered care, education, and research. The longer-term aim is to progressively reduce the rate of glaucoma-related blindness in SSA. Spearheaded by many of us as a collaborative initiative, this program has been supported by numerous individuals, civil society partners, and granting agencies that we acknowledge with much gratitude (see Acknowledgment section). Support from the University of Ottawa and the Eye Institute of Ottawa was invaluable in the early years of the program. Over the past 8 years, solid support has been provided from the University of Alberta and the Department of Ophthalmology and Visual Sciences.

The STOP Glaucoma program is multidimensional and focuses on four key pillars aimed at improving patients' vision-related quality of life (Figure 1).

- (1) Capacity building: To build professional capacity and strengthen participating institutions with an integrated approach to serve primary, secondary, and tertiary eye care needs. This is partially accomplished through training subspecialist leaders who can subsequently train fellows, residents, ophthalmic nurses, and technicians, as well as colleagues to international standards of glaucoma care (Figure 2). Additionally, we provide strategic planning support to institutions that wish to develop glaucoma centers of excellence and engage in education and research.
- (2) Enhance awareness of glaucoma and reduce stigma associated with the disease: To develop glaucomarelated awareness among communities, health professionals, and public and civil society institutions.
- (3) Glaucoma detection: To effectively detect and manage glaucoma in underserviced populations with the assistance of glaucoma specialist teams as well as leveraging technology as appropriate (e.g. teleglaucoma) [15]. Teleophthalmology models also have the capacity to detect other common causes of blindness such as cataract, diabetic retinopathy, and macular degeneration.
- (4) Glaucoma disease management: To support an efficient and effective supply chain for essential equipment and medications, laser (e.g. selective laser trabeculoplasty [SLT]), and appropriate surgical approaches for the treatment of glaucoma to prevent blindness.

Progress related to the four pillars is discussed below along with lessons learned:



Figure 1. Pillars of the STOP Glaucoma Program.

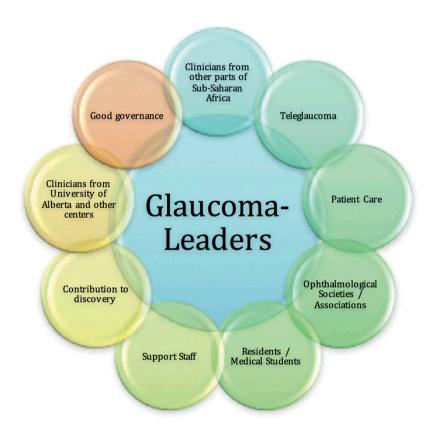


Figure 2. Graduates from the 'Sandwich' fellowship program are glaucoma leaders who have a widespread influence and impact.

#### 2.1. Capacity building

Human resources have been developed with the 'sandwich' and traditional fellowship training programs that we and others have developed and implemented. The sandwich program involves training specialists in glaucoma as well as leadership/management while concurrently enhancing their home institutional capacity [16]. This is to enable graduates to plant strong roots within an enabling environment that promotes development of professionals and teams with a greater likelihood of retaining good people [16]. The training involves rotations in Africa and abroad, such that fellows gain a broad range of experiences. Fellows learn about critical elements of infrastructure, the manner in which an eye clinic/glaucoma service works, and develop a network of connections that will serve them well in the future.

Through professional and institutional development, the sandwich educational model has resulted in a positive ripple effect. Six fellows have been trained in East Africa and are now flourishing, becoming key leaders in advancing research, education, clinical care, and development of a regional glaucoma community. Key impacts made by fellowship graduates include modifying glaucoma curricula for residency training, developing day surgery programs for glaucoma (as an alternative to inpatient care), improving glaucoma standards of care, studying teleglaucoma approaches to detect and manage earlier stages of disease, and developing platforms to raise awareness for glaucoma within communities. Also notable is the formation of longterm partnerships between institutions and with the College of Ophthalmology of Eastern Central and Southern Africa (COECSA), exemplified by the formation of a glaucoma community of practice within COECSA and ongoing collaborative research projects as well as development of National glaucoma guidelines.

Dr Damji and his colleagues at the University of Alberta (Drs Michael Dorey and Marianne Edwards) continue to learn as they share their knowledge and skills with trainees from SSA. This mutually beneficial professional relationship extends to residents and fellows from the University of Alberta, who have an opportunity to participate in the program through visiting sites in SSA and gaining exposure to African fellows who teach in Edmonton. The VISION 2020 LINKS Programme has also supported and facilitated sandwich fellowships by linking training institutions in the UK and Africa. Glaucoma training, for example, has been facilitated by Professor Peter Shah at University Hospitals Birmingham, UK.

Glaucoma subspecialists in SSA have engaged in a variety of research programs supported by colleagues in the west. Examples include a randomized trial of trabeculectomy with and without express mini shunt, a randomized trial comparing retrobulbar alcohol and chlorpromazine for absolute glaucoma, trials comparing SLT with topical treatment, and studying outcomes from Ahmed valve implantation [17,18]. Innovative teleglaucoma programs predicated on the principles outlined by Kassam et al. have also been studied in Ethiopia and Kenya [19]. Other research endeavors include inquiry of glaucoma awareness and access to care in Tanzania, motivational interviewing, and the presentation of glaucoma and acceptance of treatment in Nigeria [20–22].

Another key development in SSA has been the organization of various committees and working groups that have promoted increased focus on the issue of glaucoma in SSA. The World Glaucoma Association (WGA) organized the First African Glaucoma Summit in Accra, Ghana in 2010 [23]. The meeting brought together participants from 27 countries in Africa, with a focus on discussing challenges of recognition, education, and management of glaucoma in Africa. Eight topics were discussed, including the proposition of action plans (Appendix 1). Included in one of those action plans was the formal establishment of a National Glaucoma Task Force to promote effective communication among African Glaucoma teams and professional exchange in Africa. More recently, during the 2015 World Glaucoma Congress in Hong Kong, the WGA organized a symposium titled Tackling Glaucoma in Sub-Saharan Africa to launch its African initiative [24]. The initiative aims to 'provide recommendations on a network for collaboration and resources for education for African health-care workers and identify other ways WGA could have an impact on glaucoma education and care in Africa.

In 2012, the Prevention of Blindness Union in association with the International Agency for the Prevention of Blindness Africa Region hosted a workshop on Public Health Control of Vision Loss from Glaucoma in Africa in Kampala, Uganda [25]. The workshop, along with earlier discussions from previous meetings, aimed to develop strategies to control glaucomarelated visual loss in the region (Appendix 2). Additionally, a 2013 edition of the *Middle East African Journal of Ophthalmology (MEAJO)* was dedicated to glaucoma in SSA with the purpose of informing readers of the current state of glaucoma and encouraging them to take action.

These reports and workshops highlight the need for improved standards of care to tackle the unique climate of glaucoma in SSA. The COECSA glaucoma community of practice has since developed a set of guidelines, which summarizes clinical experiences of glaucoma specialists working in the region. COECSA hopes to add to these guidelines through evidence from randomized controlled trials and research in COECSA regions.

#### 2.2. Awareness

Glaucoma awareness campaigns have been initiated in various centers throughout Kenya and Ethiopia, often coinciding with world glaucoma week. As an example, in 2014, a Glaucoma Awareness Campaign distributed 5005 brochures and posters in the Oromiya Region in Ethiopia. This resulted in 500 individuals over the age of 40 years receiving glaucoma screenings. Similarly, 3143 individuals were screened in Western Amhara, Ethiopia, of which 2500 were medically treated. A 'glaucoma guide' was also prepared and distributed to all regions of Ethiopia through the Ethiopian Federal Ministry of Health. Patient awareness of glaucoma has risen from 4% to 28% in Ethiopia based on leveraging public media [26].

#### 2.3. Glaucoma detection

Detection of glaucoma in clinics at various centers has improved due to eye care teams led by subspecialists. This includes detection of primary congenital, juvenile, adult onset, and various other forms of glaucoma (e.g. traumatic, uveitic, and neovascular). With the support of Grand Challenges Canada, 1002 Ethiopians over the age of 35 years were screened through an innovative teleglaucoma program, and a significant number (7%) of new cases of glaucoma were detected. In addition, several hundred cases of other eye diseases, including diabetic retinopathy, were detected. We have learned that empowering frontline nursing and optometric personnel to make point-of-care decisions about diagnosis and referral is more powerful than waiting for busy clinicians to grade images some time later. A similar program was also conducted in Nyamira, Western Kenya, led by the Aga Khan University in Nairobi and in collaboration with the Innovation Eye Center in Kisii. A total of 1180 individuals were evaluated via teleglaucoma, and the prevalence of glaucoma in this study was approximately 3% in individuals over the age of 35 years. Another approach related to detecting and staging glaucoma with a smartphone-based portable eye examination kit (PEEK) was evaluated at Kilimanjaro Christian Medical Centre (KCMC) in Moshi, Tanzania.

#### 2.4. Glaucoma disease management

Tens of thousands of patients have been treated with medication, laser, or surgery in centers where glaucoma specialists are now based. Patients with ocular comorbidities have also been managed that otherwise would not have received care. Over 200 new health-care team members have received direct training to support this enhanced capacity for patient management. There are also more general ophthalmologists and newly trained graduates of residency programs capable of delivering high-quality glaucoma management involving medication, laser, and surgery. Glaucoma subspecialists are also capable of managing congenital glaucoma with goniotomy, trabeculotomy, trabeculectomy, aqueous drainage devices, and diode laser cyclophotocoagulation.

Glaucoma subspecialists in SSA have already begun hosting Surgical Training Workshops in their respective communities (Dr Sheila Marco and Dr Dan Kiage in Kenya, and Dr Abeba Giorgis in Ethiopia). This includes didactic sessions as well as hands-on training in wet labs.

SLT offers an effective technique for treating glaucoma [27] in SSA, and these lasers have been provided as donations via the STOP Glaucoma program to the Aga Khan University and Addis Ababa University. SLT reduces eye pressure effectively in many patients with glaucoma, by either replacing the need for expensive eye drops or supplementing the effect of drops. The laser typically works for a number of years and can be repeated to keep eye pressure low [28]. SLT has also been introduced in Tanzania by the Christian Blind Mission through funding from the Seeing is Believing Innovation Fund [29]. Several trials are currently underway to investigate the long-term clinical efficacy and cost-effectiveness of SLT in SSA. SLT in the developed world has the potential to become one of the most efficient, safe, and cost-effective methods for treating glaucoma prior to surgery.

There also appears to be a stigma associated with glaucoma surgery. This stigma is based on patient as well as physician perceptions. A 2002 study investigating the acceptability of surgery as initial treatment for POAG found that 58% of patients refused surgery [30]. Of those that refused, the most common reason was that there may not be any visual improvement after surgery. Patient beliefs, which can be influenced by nonscientific means, promote glaucoma as 'the terror of blindness' [31]. Many physicians avoid treating glaucoma, expressing that there is no visual gain and the potential for many surgical complications [32]. Employing educational campaigns to target patients and health-care personnel through literature and media will be essential in establishing glaucoma as a treatable condition. Evidence suggests that we can continue to raise public awareness of glaucoma, particularly through television and radio [31,33]. Furthermore, there is a correlation between higher levels of education and a greater level of glaucoma awareness [33]. Through glaucoma education at health institutions and high school curriculum, glaucoma knowledge among the public may be increased.

#### 3. Solutions

The STOP Glaucoma initiative has improved the lives of thousands of people in Kenya and Ethiopia. It will now focus on developing training programs within established centers in East Africa so that others can continue to benefit, and there can be ongoing ripple effects from this initiative. There are a number of key objectives over the next decade:

- (1) Development of community sites/outreach centers for glaucoma detection. Supported by institutions which are emerging centers of excellence for glaucoma care in East Africa, this will involve investing in IT infrastructure/equipment and training frontline eye care personnel. Guidelines have been developed for glaucoma in SSA and education and skills training related to these guidelines will take place over the next 3–5 years.
- (2) Training experts in glaucoma to international standards through the following:
  - a. Initiating COECSA-led regional glaucoma sandwich fellowship program initially in Ethiopia and then in Kenya. Building on our successful model [16], the program will develop leaders in glaucoma care by rotating fellows through various centers of excellence in addition to courses in leadership and management. The University of Alberta will continue to support this initiative and train additional fellows as required.
  - b. Workshops to train ophthalmologists in the detection and management of glaucoma, with opportunities for refining surgical techniques through hands-on wet lab sessions. Based on the current success of this model, we expect clinical and surgical skills of ophthalmologists in SSA to improve significantly.
  - c. Improve residency training curricula in glaucoma and introduce training of support staff such as technicians and nurses. There is a dire shortage of ophthalmic technicians [34] and nurses, and to our knowledge, there is no ophthalmic technician training program in SSA. We will explore the feasibility of a technician and ophthalmic nurse training program. Graduates from this program will provide support for eye care throughout Kenya, Ethiopia, and other parts of Africa.
- (3) Community-based awareness initiatives. Over 90% of those with glaucoma in SSA are unaware that they have the disease. Working with partners in Ethiopia and Kenya has allowed us to engage in strong awareness campaigns, promoted through media, diabetic and hypertension clinics, and word of mouth. As an example, a text message regarding glaucoma was sent in March 2014 and 2015 to 14 million people in Ethiopia by Ethio-Telecom. A similar message was also transmitted in Amharic, a local language in Ethiopia via local radio stations. These awareness initiatives have resulted in more patients asking about glaucoma and their eye pressure, improved compliance of glaucoma patients with their treatment and follow-up, and acceptance of surgical management options. There are also opportunities to collaborate with COECSA and nascent Kenyan and Ethiopian Glaucoma Societies to further strengthen awareness campaigns.
- (4) We will continue to validate new mHealth platforms such as the PEEK, which allow the delivery of healthcare services through mobile communication devices [35]. The use of mHealth solutions provides an opportunity to transfer knowledge and reach remote regions

where patients are unable to seek ophthalmic care [36]. It also offers an opportunity for the collection of data and coordination of services to facilitate treatment campaigns for regions with the greatest need.

- (5) Equipping emerging centers of excellence with key infrastructure needs. This will be done through partnerships with government as well as civil society organizations. An enabling physical environment for glaucoma care requires adequate space and appropriate planning, support staff, diagnostic equipment including a visual field analyzer and optical coherence tomography, therapeutic equipment such as SLT, and various surgical instruments.
- (6) Collaborative research and innovation related to the goals of the STOP Glaucoma program. Research programs have begun at centers where sandwich fellowship graduates are practicing and will be expanded via support from local and international centers.
- (7) Advocacy working with government and others to develop and implement incentives and policies to aid in reducing the costs of medications. Improving the supply chain by establishing tax exemptions, forming purchasing efficiency, promoting market competition and generic products will also be essential to reduce the cost of medications.

Knowledge translation of the STOP Glaucoma project will be essential. The outcomes of the project will be disseminated through peer-reviewed publications, media coverage, and conference presentations. We will also continue to develop stewardship reports for distribution to partners involved.

#### 4. Expert commentary

Treatment of glaucoma in SSA is challenging. In addition to the strategies covered as part of the STOP Glaucoma program, there are exciting new approaches to understand the etiologies of glaucoma as well as delivering therapies that need to be explored.

Population differences in glaucoma prevalence suggest that there is a genetic basis to glaucoma, which also appears to be ethnicity specific [37,38]. Although several gene defects have been associated with glaucoma, they account for only a fraction of cases [39]. Further research in ocular genetics may lead to the identification of new genetic risk factors, including factors specific for individuals of African origin. For example, Liu et al. have identified some important genetic associations in patients of African ancestry [40,41], and Caroline Klaver and her team from Rotterdam, Netherlands, were recently awarded a grant in pursuit of the Genetics in Glaucoma patients of African descent study, aimed at identifying new genetic causes of POAG with the use of genome-wide exome array analysis [42]. Examining gene-environment interactions may provide valuable information on the multifactorial origin of glaucoma.

Another area of concern in the SSA population is primary congenital glaucoma (PCG). PCG is a common form of infantile glaucoma, typically diagnosed in the first year of life and presenting at an advanced stage. Estimates have placed the mean age of diagnosis at 3 years in Nigeria, 4 months in Australia, and 11 months in the United Kingdom [43–45]. The disparities among developing and developed nations underscore the challenges faced by SSA nations in the management of glaucoma. With the known result of delayed diagnosis and management, there is a need for more effective and timely screening of children to reduce the rate of avoidable blindness in SSA. This will mean working more closely with frontline personnel as well as pediatricians and other physicians to ensure that they are familiar with presentations of PCG at birth and can refer patients expeditiously. Public awareness of the identifiable symptoms will be an effective method for early presentation of affected children by their parents.

Advances in the delivery of drugs and surgery need to be leveraged. Currently, the most common method of ocular drug therapy is drop form. Delivering adequate amounts of drug to target tissues is difficult as less than 10% of drug is absorbed into the eye and approximately 1% reaches the aqueous humor [46]. Issues of patient non-compliance, improper technique, and financial barriers compound these challenges in SSA [1]. Although more human studies are required to validate its efficacy, the role of nanotechnology in the delivery of drugs is intriguing. Liposomes, for example, are artificial lipid bilayers of phospholipids that have been shown to increase bioavailability, bioefficacy, and sustained release of medication [47]. Given the challenges we face in drug delivery in SSA, ophthalmic nanomedicine may play an important role.

Low-cost advances in glaucoma surgery (e.g. with devices that promote minimally invasive surgery) as well as tube surgeries also need to be explored. When comparing the cost of medical versus surgical management of glaucoma in Nigeria, it was shown that a one-time surgical fee is a more cost-effective option than medical therapy [48]. However, Africans have a greater risk of surgical failure, likely attributed to racial differences in wound healing which predispose these patients to scar formation [49]. Although adding antimetabolites increases the success of surgery, it also increases the risk of postoperative complications [50]. Thus, current strategies for the management of glaucoma in SSA have been inadequate. Future therapies must consider cost-effectiveness of therapy and ensure compliance with treatment and follow-up.

There are also a number of key questions that need to be addressed that are included in Table 3.

Leveraging technology to communicate and share knowledge and perspectives, facilitating e-learning, as well as collaborative research across borders will be important. Strategies to facilitate this beyond e-mail and listservs are being considered.

#### 5. Five-year view

Over the next 5 years, we aim to strengthen and develop additional centers of excellence for glaucoma care in SSA. This will necessitate continued training of glaucoma leaders, emphasis on good governance, partnerships with a variety of stakeholders, and the creation of enabling environments where new initiatives

#### Table 3. Key questions/areas that need to be addressed.

- Epidemiological data: what is the incidence and prevalence of glaucoma types in various communities? This includes exfoliation, normal tension glaucoma, angle closure, lens related, neovascular, etc. Data need to take into account age, gender, ethnic background, comorbidities, and geographic/regional patterns.
- Normative data are needed for various subpopulations on intraocular pressure, pachymetry, angle anatomy, optic disc anatomy, visual fields, and imaging instruments (i.e. optical coherence tomography, heidelberg retinal tomography, and laser polarimeter)
- 3. What are the underlying genes and environmental factors in pathogenesis of various glaucomas?
- 4. What are the barriers for access, compliance, and adherence to treatment? How can these be overcome?
- 5. How can glaucoma be effectively detected and managed in African populations? What is the role of technology and teleglaucoma (including eHealth and mHealth)?
- 6. Knowledge, attitude, and practice studies are important related to eye care workers/health-care force. Models related to collaborative detection and care are essential to develop and study, including comparative effectiveness research.
- 7. Operational research: evaluation of interventions/efficacy of health systems, situation, and gap analysis, particularly related to disparity in care. Program-level research is needed to learn from pilots and subsequently replicate and scale successful projects.
- 8. Evolving clinical guidelines are needed to offer suggestions on optimal protocols for detection as well as medical, laser, and surgical management of various glaucomas. Guidelines also need to consider treatment options for absolute glaucoma (a blind eye which is often painful) and for vision rehabilitation/support.
- 9. What tools and metrics can be utilized to monitor and study the impact of various activities/interventions on vision-related quality of life?
- 10. Health systems research is necessary to optimize utilization of finite resources.
- 11. Coordination of glaucoma research as well as a strategy to translate knowledge for the benefit of the scientific community and patients will be important.

can take root and thrive. For further details regarding this approach, please see an editorial on 'Strengthening institutional capacity for glaucoma care in Sub-Saharan Africa' [51].

Given the demographic trends in glaucoma as well as its impact on vision-related quality of life, it is essential that we recognize glaucoma as a serious public health issue in SSA and form strategies for effective detection and management. As such, it is essential to join forces with successful screening and treatment programs that are already in place. We hope that advances in research at various levels (basic, clinical, population, and health systems) will help establish more effective, sustainable, and cost-effective approaches to tackling various forms of glaucoma in SSA.

#### **Key issues**

- Glaucoma is a leading cause of blindness globally, with a disproportionately high impact in Sub-Saharan Africa. The most common form in SSA is primary open angle glaucoma.
- Large-scale public awareness campaigns including attention to high risk groups are required to enhance understanding of and early-detection of glaucoma.
- Resources for diagnosis and management of glaucoma in Sub-Saharan Africa are very limited and this underscores the need to optimally utilize finite resources.
- Subspecialty training models, including the Sandwich fellowship approach equips physicians with enhanced knowledge and surgical skills as well as leadership training while permitting institutional capacity development and

formation of partnerships between African Institutions and educational institutions in the West.

 A focus on education and research as well as implementing soon to be released COECSA glaucoma guidelines will be very helpful in sharing knowledge and building capacity for glaucoma care in various Sub Saharan African countries.

Continued training and collaboration, both locally and globally, will continue to facilitate the development of glaucoma centers of excellence within Sub-Saharan Africa.

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#### **Declaration of interest**

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

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#### Appendix 1. Summary report of the first African Glaucoma Summit, 6 and 7 August 2010, Accra, Ghana [23]

#### Topic # 1 – Glaucoma Education – Action plans recommended:

- (1) Train a new generation of trainers in Glaucoma sub-specialty.
- (2) Propagate monographs for undergraduate training in different medical schools.
- (3) Develop Education Committees at the level of Glaucoma Associations in different countries.
- (4) Provide training materials and resources from other countries, e.g. Goniscopy lenses from Aravind Eye Center in India to Africa.
- (5) Facilitate grouping and collection of resources through Ophthalmological Societies, to be presented in 3 languages (English, French, Portuguese).
- (6) Encourage Sandwich Programs between Africa and West and between African countries.

### Topic # 2 – Best Choices of Treatment for Glaucoma in Africa – Action plans recommended:

- (1) Trabeculectomy should be the Gold Standard of treatment.
- (2) All cases should have anti-metabolites.
- (3) There is a need for more information on Laser Trabeculoplasty results in Africa.
- (4) Selected patients may benefit from combined trabeculectomy and cataract surgery.
- (5) The use of Glaucoma Drainage Devices or Shunts may be beneficial especially in virgin eyes.
- (6) Research of novel surgical techniques and new drugs in Africa should be encouraged.

#### Topic # 3 – How To Incorporate Glaucoma Management into Existing Ophthalmological Programs – Action plans recommended:

- (1) Develop and empower each level of health care.
- (2) Train health-care workers to screen at primary level before referral to ophthalmologist.
- (3) Opportunistic screening is more relevant in the African setting.
- (4) Management of cases detected during screening should be considered.

### Topic # 4 – Screening Methodology for Advanced Glaucoma Cases with Imminent Risk of Blindness – Action plans recommended:

- (1) Counseling should form an integral part of Glaucoma Screening Management.
- (2) Increase awareness of Glaucoma through Media.
- (3) Set up an efficient Referral System.
- (4) Ensure Inter-professional Integration and Development of the best African Practice.

### Topic # 5 – 'Centers of Excellence' for Glaucoma in Africa – Action plans recommended:

- A special committee will recommend at least 5 locations for establishing Centers of Excellence in different regions in Africa.
- (2) These centers will adopt a Business Model for their activities.
- (3) Teaching and appropriate research should be entrenched.
- (4) Social and leadership roles should be developed.
- (5) Diagnostic and Therapeutic Tools are important components of these centers.

#### Topic # 6 – How To Enhance Awareness of Glaucoma in Public, Government, and among Health-care Professionals – Action plans recommended:

- (1) Glaucoma should be included in Vision 2020 Program.
- (2) Research should be carried out in Centers of Excellence and local hospitals.
- (3) National Strategy for glaucoma Management should be developed in different countries.
- (4) Glaucoma Team should comprise of: Ophthalmologist, Pharmacist, Nurse, Optometrist, and counselor.

#### Topic # 7 – How To Establish Permanent, Viable Direct Communication Routes with our African Colleagues – All hail the communication revolution and

Topic # 8 – How To Involve Community and Industry Support in Our Program?

#### Action plans recommended for the latter two sessions:

- (1) Establish communication needs for all members of eye care team.
- (2) Develop Glaucoma website.
- (3) Establish resource centers for post-graduate training.
- (4) Encourage linkage between African Ophthalmology Forum and Glaucoma Associations.
- (5) A 'National Glaucoma Task Force ' (NGTF) to be formally established.

#### Appendix 2.

# Kampala Resolution, Kampala, Uganda, 18 April, 2012 [25]

#### Public health control of vision loss from glaucoma in Africa Kampala resolution

The group adopted the following resolutions:

**Recognizing** that an estimated 6 million people are affected with potentially blinding or disabling glaucoma in Africa, while 0.5 million are already blind from the disease; Taking cognizance that glaucoma is the commonest cause of irreversible blindness worldwide and in Africa in particular;

**Mindful of the fact** that aging is a risk factor for glaucoma, given that the African region is witnessing a rapidly increasing number of elderly persons aged 60 years and above;

**Aware** that needless blindness from glaucoma impacts negatively on health and well-being, undermines the quality of life, and affects economic productivity;

**Recalling** resolution WHA59.25 on avoidable blindness and WHA53.14 on non-communicable diseases;

Acknowledging the link between poverty and disability;

**Noting** that the World Health Organization urges governments to adopt good policies on aging and health.

We, Glaucoma specialists, health specialists, and other specialists from the development sector, state representatives, service providers and managers, and advocates, assembled at the Kampala Meeting on Public Health Control of Vision Loss from Glaucoma, held on 17 and 18 April 2012, together,

Declare that,

Glaucoma is an emerging priority for all eye health interventions as an integral part of the elimination of avoidable blindness.

Glaucoma is a chronic non-communicable disease that requires lifelong treatment.

Being of African descent is a risk factor for glaucoma; it appears earlier and rapidly progresses to vision loss.

Glaucoma is a disease of public health significance and needs public health control strategies.

We call upon, supranational and national professional organizations, ophthalmological societies and advocacy organizations, civil society organizations, national and international development organizations, consumer groups, and corporate sector,

 To highlight the importance of controlling vision loss from glaucoma as an integral part of eye health care and in health and safety policies.

- To urge Ministries of health to incorporate glaucoma in Non-Communicable Disease programs and Ministries of Finance and Trade to waive duties and taxes on drugs needed for life-long treatment of glaucoma.
- To advocate to the technology sector and pharmaceutical companies to work with professional organizations and consumer groups in the development and distribution of affordable diagnostic and other equipment and drugs with particular application to the African population.

#### The Electronic, Print, and Social Media

 To highlight and communicate to the general public, in consultation with professional organizations and consumer groups, issues of glaucoma, to disseminate information on effects of untreated glaucoma and the potential role of the population, patients, and disability groups in the public health control of vision loss from glaucoma.

#### Reaffirm our commitment to

- Improve and apply the knowledge base with particular reference to populations of African descent.
- Strengthen the organizational and institutional capacities within public health, eye health and control of non-communicable diseases and other key stakeholders to implement initiatives aimed at controlling vision loss from glaucoma.
- Create opportunities to develop networks of key stakeholders in addressing the issue of glaucoma holistically at supranational and national level.
- Develop closer coordination between government ministries, departments, civil society organizations, and consumer groups for purposes of undertaking concerted interventions on glaucoma at the national and local levels as an integral part of eye health development.