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# Strengthening Institutional Capacity for Glaucoma Care in Sub-Saharan Africa

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*‘An enabling environment’ - A setting in which additional development initiatives can take root and thrive.*

His Highness the Aga Khan, Maputo, Mozambique, December 16, 2010.<sup>1</sup>

Sub-Saharan Africa (SSA) is advancing economically, and these are exciting times to invest in improvement of vision related quality of life for the people in this region.<sup>2</sup> In SSA, a leading cause of blindness is glaucoma, a group of diseases that have in common a characteristic progressive optic neuropathy and visual field deterioration, which can generally be arrested or mitigated with lowering of intraocular pressure (IOP). Glaucoma is a disease with a significant public health burden that warrants a commensurate, targeted response. This is a conclusion emphasized at two major meetings on the subject in recent years: The Africa Glaucoma Summit in Accra, Ghana hosted by the World Glaucoma Association (August 2010)<sup>3</sup> and a Workshop on Public Health Control of Vision Loss from Glaucoma in Africa hosted by the Prevention of Blindness Union in collaboration with International Agency for the Prevention of Blindness Africa in Kampala, Uganda (April 2012).<sup>4</sup> This clarion call is also evident when we examine the data presented by Kyari *et al.*<sup>5</sup> in their outstanding article, which leads this theme issue “Glaucoma in SSA”. A challenging picture of glaucoma emerges from the above sources:

- Glaucoma is the second leading cause of blindness worldwide with Africa disproportionately affected.
- There are an estimated 6 million people with potentially blinding or disabling glaucoma in Africa while 0.5 million are already blind from the disease.
- The estimated prevalence of glaucoma is approximately 4% among people 40 years and older. This figure is likely an underestimate as it is often difficult to diagnose glaucoma when there is coexistent media opacity such as cataract/corneal opacity, and many studies to date do not include visual field data as part of the diagnosis.
- The most common form of glaucoma is primary open angle glaucoma, which is approximately six times more

common than angle closure; however, there is a paucity of good epidemiological data, particularly with regard to other types of glaucoma such as exfoliation related glaucoma.

- The awareness of glaucoma is very low, and a large majority of patients are untreated. In fact, 90% or more of those with glaucoma remain undiagnosed. The article by Komolafe *et al.*<sup>6</sup> examines the level of awareness amongst non-ophthalmic health-care personnel and how these individuals can be empowered to play a more active role in raising patient awareness. The articles on “teleglaucoma” by Kassam *et al.*<sup>7</sup> and Kiage *et al.*<sup>8</sup> propose a creative response, that needs to be studied further, to promote access based on the provision of expert care from a distance.
- When patients do present, at least half do so with advanced disease and of these, over half are blind in one eye. The article by Josephine *et al.*<sup>9</sup> reports on important barriers to glaucoma surgery in Nigeria including fear of blindness. The article on advanced glaucoma by Gessesse and Damji<sup>10</sup> provides practical tips for managing these challenging patients, including, approaching patients through an integrated “biopsychosociospiritual” frame-work, and pearls to optimize trabeculectomy technique so as to protect vision and prevent/minimize chances of visual field “wipe out.”
- Risk factors for developing open-angle glaucoma in SSA include increasing age, higher 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. Can future programs aimed at detecting glaucoma leverage these and any other high risk characteristics?
- There is much that needs to be studied in order to arrive at better ways of managing glaucomas in various SSA contexts. One technique that may be of value in challenging cases is an aqueous drainage device, and the article by Aminlari *et al.*<sup>11</sup> offers insight in this regard.

There are many barriers, which prevent patients from receiving appropriate care including geographic, educational,

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socioeconomic, cultural/spiritual, and political considerations, as well as lack of adequate facilities, human resources, equipment, medication, laser, and surgical treatment options. Although, this is a daunting list, progress is being made in terms of acknowledging the magnitude and importance of the problem and taking steps toward addressing these challenges. Recently, a very practical guide to diagnosis and management of glaucoma in the SSA context was published, and I would recommend all involved with such efforts to read the special issue of the *Community Eye Health Journal* Vol. 25 Issues 79 and 80, 2012.<sup>12</sup> The value of eliminating avoidable blindness and visual impairment in developing countries is underscored in a recent report by price water house Coopers commissioned by The Fred Hollows Foundation and other key non-governmental organizations. Using a conservative estimate, they illustrate that for every dollar invested in preventing someone from going blind, more than four dollars in economic benefits are generated.<sup>13</sup> This estimate does not factor in further gains to quality of life that accrue from improved vision health.

An important question to ask is what can be carried out to strengthen detection and management of glaucoma at the primary, secondary and tertiary levels? Building solid tertiary institutional capacity can provide a hub for integration of primary, secondary and tertiary approaches to glaucoma care. Outstanding institutions, networked with other like-minded and like-hearted Institutions and eye care partners, can catalyze and propel advances in patient centered care, education, research, and health-care policy. Whether or not an institution achieves excellence and success in these endeavors is predicated on solid leadership and governance that nurtures a culture of respect, continuous learning and collaboration, as well as excellence in clinical, educational and research environments.

## **LEADERSHIP AND GOVERNANCE**

The quality of institutions is directly dependent on the quality of leadership that is provided, nurtured, and sustained and how this leadership utilizes the institutional framework to deliver its services. This includes setting international standards of care and effectively leading a team of eye care professionals such as ophthalmologists, nurses, optometrists, pharmacists, and counselors. Creating a learning organization that continuously transforms itself is also a key to success.<sup>14</sup> In my view, greater thought is required so that over the next 5 years, programs and processes are in place to ensure a continuous pipeline of physicians as well as other leadership talent is being developed that will serve SSA in the short term and for the long term in a sustainable manner.

Leadership in institutions is exercised through good governance, i.e., how an organization can utilize structure and process to exercise power effectively. Good governance includes the

following elements: Clear structure and organization, an understanding of vision, mandate, and responsibilities, an organizational culture that promotes continuous learning and collaboration, transparency and probity as well as team spirit and high performance, robust processes and information, and performance assessment and accountability. The quality of various institutional processes as well the physical environment (i.e., the spaces in which one works and learns) will be critical to ensuring high quality clinical outcomes and patient satisfaction, which ultimately form part of the *raison d'être* for service institutions.<sup>15</sup>

## **INSTITUTIONAL MODELS, SUSTAINABLE HUMAN, FINANCIAL AND INFORMATION TECHNOLOGY RESOURCES AND IMPORTANCE OF MEASURING RESULTS**

There are many models of eye care institutions in SSA. These include public, private, civil society, as well as emerging models of social entrepreneurship and public private partnership. These institutions also need to be viewed in the context of health care systems. Hence, consideration thus needs to be given to pragmatic issues such ensuring a stable supply chain of medications and equipment.<sup>15</sup> Structuring institutions for long term success will also require optimal utilization of finite human, financial, and information technology related resources. Developing strong professional managers who can lead various operations teams (clinical, operating, biomedical engineering, community outreach etc.) is a key ingredient in this regard.<sup>16</sup> On the financial front, sustainable sources of income are required, developing high efficiency, appropriate budget and price for various services, and effective cost-control measures.<sup>16</sup> Standard protocols, processes for continuous improvement, monitoring and empowering staff, and succession planning are methods by which the other dimensions of sustainability can be addressed.<sup>16</sup> Developing key metrics to track efficiency and effectiveness as well as a culture of accountability is also key to achieving excellence in institutional performance. The balanced scorecard is one approach, which can provide a framework for developing and tracking key performance measures, including in developing national academic hospitals.<sup>17,18</sup>

## **TEACHING AND LEARNING ENVIRONMENT AND MULTIPLIER EFFECT**

Developing an outstanding teaching and learning environment is essential to developing outstanding human resources. These individuals can then have a powerful ripple or multiplier effect, empowering various members of the eye care team, as well as student learners with knowledge and skills to detect and manage glaucoma at various levels. Over the past 6 years, I have

been fortunate to work with several tertiary care institutions in Kenya and Ethiopia in order to assist in institutional capacity development utilizing the “sandwich” educational model.<sup>19</sup> The essence of this model has been to gradually strengthen institutional capacity through international standard subspecialty training while simultaneously enhancing the patient care, teaching/learning and research environments. The model helps provide an “enabling environment” for professional growth, which we hope fosters retention of individuals and provides a gateway into long term, mutually beneficial collaborative partnerships.

“Sandwich” fellowship graduates to date have been successful in helping to modify curricula for residency training, improve standards of care for patients with glaucoma, and develop models for raising awareness of glaucoma in communities. They have also helped in detecting/managing earlier stages of disease, including via creative “teleglaucoma” approaches, as well as contributing to the development of national guidelines for glaucoma, such as those being developed in Kenya (personal communication Drs. Dan Kiage and Sheila Marco).

## RESEARCH AND KNOWLEDGE TRANSLATION

A number of centers in SSA are now well positioned to conduct research at various levels, i.e., population, clinical, and basic science as well as a partner with other regional and international institutions/entities. Conducting and publishing high-quality research will not only lead to a better understanding of how to advance patient care specific to SSA, but can also uplift the educational environment attracting bright minds and entrepreneurial investment long-term. Several interesting questions need to be addressed (the Kampala workshop<sup>4</sup> and the Kyari article<sup>5</sup> contains some excellent ideas in this regard):

- What is the prevalence of various types of glaucoma types in the various countries and subpopulations? Are subtypes such as neovascular glaucoma on the rise given the rapid increase in the prevalence of diabetes and if so, what steps can be taken to mitigate this trend?
- What is the level of awareness of glaucoma, what are barriers to awareness, and what can be carried out to improve the level of awareness?
- What are the specific barriers in SSA for access to glaucoma care, as well as for compliance and adherence to treatment and how can these be overcome?
- How can glaucoma best be detected and managed? Randomized controlled trials are needed, cost and comparative effectiveness studies, quality of life studies. Program level research is needed so as to learn from pilot studies and then replicate and scale up successful projects.
- What are underlying genetic and environmental factors that play a role in the pathogenesis of various glaucomas in SSA?

- Clinical guidelines are needed to offer best practice and thinking on detection of various glaucomas, identification of the stage of disease, and appropriate medical, laser, and surgical management options. Guidelines also need to consider treatment options for absolute glaucoma (a blind eye, which is often painful as well) and for vision rehabilitation/support.
- What tools and metrics can be utilized to monitor and study the impact of various activities/interventions on vision related quality of life?
- Health systems research is also required that includes the development of innovative health delivery models, in particular to be able to provide glaucoma care to those who are unable to afford it.

## RELEVANCE TO ENHANCING GLAUCOMA CARE

Glaucoma is an enormous problem in SSA and given the demographic trends, will be an even greater challenge in the decades ahead. Hence, it is essential that glaucoma be widely recognized as a serious public health concern and creative steps taken to eliminate avoidable blindness from this group of diseases. One of the key steps, in my view, is to strengthen institutional capacity for glaucoma care. A year ago I had proposed the idea of a special issue of MEAJO dedicated to glaucoma in SSA in order to better inform readers of the current landscape and encourage a call to action for the benefit of current and future generations in SSA. I am very pleased that this issue has now reached fruition and I would like to thank the editors of the journal for the privilege of having served as guest editor and for the opportunity to write this editorial. I would also like to thank all peer reviewers for their enormous contribution of knowledge, time and energy.

I hope that over the next decade, we are able to build solid capacity for integrated glaucoma care at the primary, secondary and tertiary levels in SSA and that glaucoma centers of excellence can partner with and continue to learn from the best that local and global stakeholders have to offer so that they can advance to better serve their patients and communities. This will necessitate continued development of a new generation of subspecialists with leadership/management skills that can entrench good governance and develop other members of the eye care team, partnerships with a variety of public and civil society players, and the creation of enabling environments for patient care, education and research where “new initiatives can take root and thrive” and patients with or at risk for glaucoma receive international standard care to protect visual function and maintain or enhance their overall health related quality of life.

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