

# Glaucoma blindness—A rapidly emerging non-communicable ocular disease in India: Addressing the issue with advocacy

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## ABSTRACT

Glaucoma, a leading cause of irreversible blindness, can be prevented or stabilized the progression if identified early and managed it appropriately. In India, around 12 million people suffer from glaucoma, and 1.5 million are blind due to it, so making the third most common cause of blindness. More than 75% of glaucoma are undiagnosed, which perhaps represent the submerged portion of the iceberg phenomenon of the traditional disease explanations. Though glaucoma *per se* does not lead to mortality, glaucoma blindness is categorized as a severe form of disability (category VI) out of seven World Health Organization (WHO) classification on the global burden of diseases. Indeed, there is a large gap between the prevailing burden of glaucoma and service being delivered about its prevention compared to other leading causes of blindness in India. Considering the magnitude of the problem as well as the severity of disability, a strong and effective advocacy is an urgent call to deal glaucoma problem in the country. For a resource-limited country, where mass population based-screening programs are not feasible, alternative methods like facility-based opportunistic screening and referring the high-risk groups for early detection and treatment should be aimed. However, glaucoma should not be screened in isolation from other eye problems. In fact, screening of any potential blinding ocular problems, including glaucoma, should be a clear mandate under comprehensive eye program of the WHO to achieve Universal Eye Health Coverages. This paper highlights the strategy inclusive of advocacy to curtail the increasing burden of glaucoma blindness in India.

**Keywords:** Advocacy, glaucoma blindness, India, prevention, primary healthcare

## Introduction

Globally, both blindness and visual impairment are a significant public health problem. A recent World Health Organization (WHO) estimate on vision database shows that 36 million people are blind, and 217 million have moderate to severe visual impairment (distance).<sup>[1]</sup> Very recently, The World Report on Vision 2019 WHO shows that around 2.2 billion

people, including near visual impairment by: addressed and unaddressed problem, have a visual impairment or blindness. Of this, nearly half of them are avoidable.<sup>[2]</sup> The majority of these problems are due to non-communicable ocular diseases, e.g. cataract, uncorrected refractive error, glaucoma, macular degeneration, etc. Of the total magnitude, more than two-third of visual problems are in low and middle-income countries. Further, blindness is expected to increase to 38.5 million by 2020, and 117 million by 2050 due to the continued increase of population aging across the world.<sup>[3]</sup>

Considering the natural of history of ocular diseases, the outcome of ocular problems-visual impairment, including blindness, is not usually or directly linked while estimating mortality statistics. On

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the contrary, however, the morbidity and burden due to visual loss have a significant impact on an individual's quality of life, and family and societies's economic and personnel productivity. Blindness is classified as a severe disability (category VI and VII), which positions in category VI out of seven categories of severity as explained by the WHO Global Burden of Disease.<sup>[3]</sup> The projected global Disability Adjusted Life Year (DALY) shows that refractive error alone positions at the 8<sup>th</sup> rank in 2030, but if all causes of vision impairment group into one outcome (vision loss), then vision loss may probably lie within top five of DALY loss.<sup>[4]</sup>

## Non-communicable Diseases and Glaucoma

In the past many decades, blindness and visual impairment were addressed outside the scope of non-communicable diseases (NCDs) both nationally and internationally. With the current significant epidemiological transition in the causation of blindness, i.e. a significant reduction of an infectious cause of blindness, for example, trachomatous blindness, measles, Vitamin A deficiencies whereas an increase in non-communicable causation like uncorrected refractive error, cataract, diabetic retinopathy, glaucoma, etc., it becomes an important agenda that the prevention of blindness and visual impairment are also needed to be addressed within the context of global public health improvement and development, which endorse mainly on prevention and control of NCDs pertaining to general health, e.g. cancer, cardiovascular problems, diabetes mellitus, hypertension, etc.<sup>[5]</sup> This shows that the blinding ocular diseases, including glaucoma, have a greater potential to incorporate into national and global efforts to curtail the NCD issues across various countries. Blinding ocular diseases particularly non-communicable eye diseases (NCEDs) should not be viewed as isolation from the rest of NCDs; it should be a part of health system strengthening and reformation, which designs to curb the NCDs problems. National and international policymakers and healthcare planners working on eye health should continue to focus on developing appropriate strategies and advocacy to be able to integrate effectively and efficiently within the ambit of NCDs framework and also under the umbrella program of The Universal Health Coverage, WHO. A similar approach has been highlighted in The World Report on Vision 2019, WHO.<sup>[2]</sup> This paper explores the strategy with a special emphasis on advocacy steps for the prevention of blindness from glaucoma in India.

## Glaucoma: A leading cause of blindness

Glaucoma is a group of diseases characterized by damage in the optic nerve, commonly involving both eyes, and eventually leading to visual dysfunction and blindness. Raise in intraocular pressure, aging, and family history are significant risk factors for glaucoma. However, vision loss can occur with normal pressure or even lower. Many people who have the disease, may not be aware of suffering from glaucoma, because symptoms do not usually occur during the early stage of the disease.<sup>[6]</sup> It is estimated that nearly 75% of glaucoma patients are undiagnosed in low and

middle-income countries, including India.<sup>[7]</sup> By the time, patients notice some signs and symptoms, the disease has already caused irreparably damaged. Once the vision is compromised, it cannot be restored. Glaucoma, though, a chronic condition and incurable as of now, can be controlled and prevented from deterioration of vision or reasonably can be slowed down the disease progression with medical and surgical therapy if it is identified early.

The WHO recently estimates that glaucoma is a third leading cause of blindness (8.5%) next to cataract (35.2%) and uncorrected refractive error (20.3%).<sup>[8]</sup> In this estimate, around 4 million people have a visual impairment and 2.9 million are blind from glaucoma. By 2020, it was anticipated to increase the figure to 4.5 million and 3.2 million for visual impairment and blind respectively in the global pool of visual loss. In another recent systemic review, it shows that nearly 64 million people are affected by glaucoma in people aged 40 to 80 years worldwide and expected to increase to 76 million by 2020 and 111.8 million in 2040.<sup>[2,9,10]</sup> In addition to this, the global DALY rate due to glaucoma increased significantly from 1990 to 2017, predominantly in males<sup>[10]</sup> and people with glaucoma severely compromise in social participation compared to people without.<sup>[11]</sup>

In India, the prevalence of Primary Open Angle Glaucoma (POAG) is higher than Primary Angle Closure Glaucoma (PACG).<sup>[12]</sup> Around 12 million people suffer from glaucoma; 1.5 million are blind due to glaucoma, predominantly due to PACG though it is less in common,<sup>[13]</sup> making the third most common cause of irreversible blindness. Many population-based surveys were conducted in India to assess the magnitude of glaucoma.<sup>[14]</sup> The prevalence of glaucoma ranged from 6.9% to 8.1% among the age group of 40 years and above.<sup>[15,16]</sup> In addition, aging is closely associated with glaucoma therefore, considering the fast pace of demographic transition observed in India, the number of people affected with glaucoma will be increased over time.

## Advocacy for control of glaucoma blindness

Advocacy is often defined as a strategy to gain support or political commitment for a particular goal or program.<sup>[17]</sup> It is an act of pleading for support or recommending a course of action to achieve a specific outcome.<sup>[18]</sup> India was the first country in the world to launch a national wide, centrally sponsored National Program Control of Blindness under the headship of the Ministry of Health and Family Welfare Govt. of India in 1976. The program mainly addresses to cataract and refractive error since inception.<sup>[19]</sup> With the help of advocacy from many international agencies such a Vision 2020: Right to Sight, International Agency of Prevention of Blindness (IAPB), and many public health institutions and non-government organizations, National Program for Control of Blindness and Visual Impairment (NPCB and VI), Government of India extends its priority to other eye diseases such as glaucoma, diabetic retinopathy, corneal opacities, etc., in eye care services under its 12<sup>th</sup> five-year national action plan.<sup>[20]</sup>

Though control and prevention of glaucoma blindness become a priority area under NPCB and VI India’s five-year plan, it suffers from a huge lack of program-specific goal, advocacy objectives, plan of action, or strategies in the context of glaucoma control.<sup>[20]</sup> This hinders the successful implementation of the glaucoma blindness control program in the country. Merely an inclusion in the comprehensive eye care services will not be enough in addressing blind and visual impairment due to glaucoma. There is highly a need for continued advocacy and develop a specific action plan for glaucoma within the ambit of the national program.

**How do we proceed for advocacy?**

The goal of National Program for Control of Blindness and Visual Impairment (NPCB and VI), Government of India is to reduce the prevalence of avoidable blindness at 0.3% by 2020 from the present 1% will be at stake if there is a lack of incorporating strong advocacy towards the prevention of blindness due to glaucoma.<sup>[21]</sup> This goal will not be able to achieve if the national program is not incorporated with a strategic plan for the development and improvement of glaucoma care service across the country. Therefore, strong advocacy is indeed a need of the hour in India. The advocacy for blindness prevention due to glaucoma can be focused on three important areas: first- early detection and treatment of glaucoma; second-generating an enabling environment for service delivery and third- resource mobilization for glaucoma service.<sup>[18]</sup> The seven World Health Organization steps mentioned for successful advocacy are suggested while advocating a control program for the prevention of glaucoma blindness wherever appropriate [Table 1].<sup>[22]</sup> One must be remembered that all these steps may not be applicable in each advocacy area. Suitable steps can be chosen considering the WHO steps and implementation.

**Improving early case finding service of glaucoma**

Effective advocacy needs evidence-based and high-quality data or information on glaucoma status. In India, many population-based studies conducted at local, state and national levels already prove that glaucoma is one of the major public health problems. The question is how this evidence will be utilized and translated into the best practices in the case detection of glaucoma in its early phase.

From the very beginning, it is wise to establish a goal of the program. What are the advocacy objectives? For instance, hypothetically for glaucoma, the goal could be to increase the

case finding of glaucoma by 25% by 2030, thereby decelerating undiagnosed proportion to 50% from the current baseline of 75%. It is also an essential to provide the best possible and cost-effective case finding technique. We may require, for this, a case detection or identification tool before any advocacy activity being planned.

We should draw attention to the specific target audiences who can influence or promote the effectiveness of the case finding of glaucoma. The more specific target audiences we identify; the more effective communication will be in the advocacy process. These audiences can be categorized ‘primary’ and ‘secondary audiences’. The primary audiences who have no role in case finding, are from the ministries or bureaucrats who can make policy and decide about the plan, whereas secondary audiences could be encompassed from ‘mid-level eye healthcare providers’ to ‘primary level healthcare providers’ either public or NGOs (Non-governmental organizations) or any other private sectors. Secondary audiences are the core people for the early case finding of glaucoma at the ground level. These secondary audiences can act as a player to influence the primary audiences. Advocacy to involve other sectors to increase the accessibility of the service uptake in case finding, e.g. educational sector, are also needed to be considered.

To ensure better case detection of glaucoma at the early stage, one must think of incorporating the details of the action plan while advocating the program. The action plan should be designed in a systemic way, one must know what exactly wants to do and its goal, identifying various strategies to achieve, mode of implementation where case detection should be done either eye camp or vision centers or primary or secondary level health facilities, and how to monitor and evaluate the program. Resources limited setting like India, mass community-level screening or case finding is not operable. Targeted opportunistic screening programs operated at facility level, e.g. secondary or tertiary level, even in selected primary health facilities will be the most appropriate method. This means that when a high-risk patient presents in the clinic, we should take advantage to detect any potential blinding eye diseases inclusive of glaucoma. High-risk patients like high intraocular pressure, the adult population aged 40 years and above, people with family history, diabetics, hypertension, steroid medications, a high refractive error should be educated and make them aware of at community and primary level, and motivate to get screen to nearby health or eye facilities equipped for glaucoma screening. Every such new patient visiting eye hospital irrespective of their vision status must go undergo an eye examination like tonometry, gonioscopy, and undilated or dilated fundus examination to rule out for any disc abnormality.

**Creating enabling environment for screening through advocacy**

Delivering an effective case finding service is directly linked with the hospital enabling environment. It must be addressed by advocating with appropriate audiences using seven WHO steps for advocacy wherever suitable.

Table 1: WHO seven steps for advocacy
Defining the situation
Establishing the goal and objectives
Identifying target audiences
Developing key messages to influence the audiences
Implementing an advocacy plan
Using communication channels
Monitoring and evaluating the advocacy work

1. Defining the situation: What are the current resources available for case detection of glaucoma? Is there any gap between demands and services? The required number of specific resources needs to be mapped, for instance, eye care manpower with appropriate skills, infrastructure, equipment, and supplies, etc.
2. Establishing the objectives: To influence appropriate audiences, establishing a “SMART” (Specific, Measurable, Achievable, Realistic, Time-bound) objective is critical. Once the advocacy goal is being set then the rest of advocacy steps should be designed to achieve this. When defining a goal, it is wiser to consider the opportunities and threats to achieve the goal and objectives. Setting a goal could be ambitious but it should be closed to realistic and achievable.
3. Identifying primary audiences: Primary audiences are individuals or groups who can make the decisions or involved in policy or planning of services. They have a major role in creating an enabling environment for control of blindness due to glaucoma. Secondary audiences are influencers who can influence the primary audiences. The general public can also be an audience so that they know the importance of regular screening of glaucoma.
4. Developing key messages which influence audiences: Conveying key messages to appropriate audiences is the most important element in advocacy. This will decide the success of advocacy. The message should be
  - a. 5Cs: Clear, Concise, Consistent, Compelling, and Convincing
  - b. Supported and reinforced by a combination of sources. In general, people are more likely to believe a message from more than one source.
  - c. Only one primary message and three or four secondary messages.
6. Implementing an advocacy plan: The advocacy plan will deliver the key messages to the target audiences. There may require multiple delivering of the message to have an impact. A variety of communication strategies could be employed rather a single. It could be personal meetings, official letters, reports, events and media at a large. An appropriate strategy is needed to be chosen which will be likely accessible and credible to the target audiences. For effective implementation of the plan, a good communicator or messenger who is eloquent and convincing is required. Who or which individuals or groups is the best placed to influence the audiences or the audiences’ trust or respect? For example, celebrities can be a good messenger to the general public (audiences) for motivating and convicting to increase glaucoma screening uptake.
7. Monitoring and evaluation of the advocacy work: Monitoring helps to assess whether advocacy has an impact or any need for modifying the efforts accordingly. The process of monitoring needs to frame many questions as well as indicators, for instance, are the technique working? Are we reaching the target audience? Are we using the appropriate channels for communications for achieving the objectives? A revision can be done accordingly.

#### Resource mobilization

Mobilizing resources is one of the key indicators for successful advocacy. In India, many patients are not able to afford the cost of eye care services, especially for sub-specialty eye care services. Though many charities and non-government organization (NGO), trust-based hospitals provide highly subsidized eye care services, the coverage is still very limited. For developing countries like India, revenue arises from user fees would not adequately cover the cost of capital expenditures on developing infrastructure, equipment for control glaucoma blindness. Advocacy to mobilize the fund and grant on glaucoma control should be appealed from other external funders, international agencies, CSR (Cooperate Social Responsibilities) funds, partner with NGOs, etc., apart from the government sources. The National Program for Control of Blindness and Visual Impairment, Government of India, could achieve the target for the Cataract Surgical Rate through various resources mobilization due to strong advocacy. Similarly, advocacy for control of blindness due to glaucoma within the purview of the blindness control program should be given a due priority. Simplification of government regulation while moving resources from externals are also important for eye care services. Glaucoma needs life-term medications, and over-the-counter drugs for glaucoma are very expensive, so more resources can be mobilized with good advocacy practices on glaucoma medicines.

While defining the situation, it can be estimated separately the budget for control of blindness due to glaucoma. What is the past and present allocation of budget? Details budget estimation can be shown, for example, inclusion in the state and district level yearly program implementation plan. What is the annual estimation or target seeking monetary support for

#### Practical tips to create key messages

- Message based on the existing beliefs rather than radically new or different
  - Aims and objectives of messages based on what we want to achieve. A persuasive message in advocacy calls for action.
  - Who is the target audience? What will motivate them to act or bring them to benefit? For example, if the general public is the audience, message on impact due to glaucoma and its beneficial effects on individuals and family, even in society can be included in the screening program of glaucoma.
5. Engaging media: A media can be a powerful way of communicating channels to influence the target audiences. Media provides immediate attention to the audiences. The involvement of media is a vital component of successful advocacy and making awareness to the public, persuading and motivating people. This also helps in adding credibility to advocacy messages. Commonly used media to address glaucoma issues are editorial coverage, comments, health news, public-interest case stories, advertising issues for those affected people’s lives.

case finding activities? Who should be primary audiences and what communication channels should be defined clearly in the implementation plan?

### Management of glaucoma

By convention and medical ethics, any screening program without adequate facilities for further diagnosis and intervention should not be initiated. The same is true for glaucoma. Glaucoma screening program may or may not be able to categorize the close angle or open angle types, but all facilities and infrastructure should be made be available for management of glaucoma at referral or any designated tertiary level center.

In India, all the high end and sophisticated equipment for the management of glaucoma are available in NGOs or society-run eye care hospitals and in many public sector tertiary healthcare centers. They are manned by a good number of glaucoma specialists. There are 19 Regional Institute of Ophthalmology across the country under the National Program for Control of Blindness and Visual Impairment, Government of India where all facilities for the management of glaucoma are available.<sup>[23]</sup> There can be a proper referral pathway with a referral protocol between the Regional Institute of Ophthalmology with other secondary level hospital or tertiary level with less equipped and manned.

### Primary healthcare and glaucoma

Considering the rapid increase of Non-communicable Eye Diseases,<sup>[24]</sup> the WHO has emphasized the need to address the person as a whole rather than a vertical and stand-alone program for eye care in the health system. The World Health Organization Global Action Plan 2014-19 promotes a primary healthcare approach involving health systems to address the challenges in accessing eye care services in the community.<sup>[25]</sup> It has recommended that the integration of comprehensive eye care services within the primary health to achieve Universal Eye Health Coverage, which is defined as “ensuring that all people have access to needed promotive, preventive, curative and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship when paying for this services” (WHO).<sup>[25]</sup>

Although the technical role in terms of screening, identification, and treatment of glaucoma is complex and may not be possible at the primary healthcare level, primary healthcare can cement all running programs in relation to glaucoma. Primary Care Physician (PCP) can be well-positioned in the education of patients and community, implementation of the services, integration or screening program of glaucoma.

PCPs, but not limited to them, other community health workers can play an important role in early identification of glaucoma, screening as well as in successful management of glaucoma. Studies conducted in India report that the awareness of glaucoma is poor, 13.5% in urban India,<sup>[26]</sup> and 8.3% in rural India.<sup>[27]</sup> PCPs can be involved in providing health education and awareness

to the patients or high-risk groups about glaucoma and its consequences if not treated. For example, organizing rallies, events on World Sight Day and celebrating glaucoma awareness week, etc., Patient-physician (PCP to tertiary care physician) relationship is critical in glaucoma management.<sup>[28]</sup> To ensure a successful glaucoma program, it is also critical that physicians or PCPs know where is the most competent and well-equipped glaucoma eye care centers in the area. They have a huge potential role in treatment compliance among patients receiving treatment. In fact, not every time patients need to go to glaucoma specialists to follow-up and advice on the use of medication. Once the patient received the ideal treatment regime from a specialist, PCPs can be educated about ensuring the continuity of care or medication on regular basis, avoiding risk factors (hypertension, diabetes), and even ensuring the availability of anti-glaucoma medication if exists. Therefore, PCPs can act as leverage for basic medical care to patients with glaucoma in the community.

Tele-glaucoma—a branch of Telemedicine, has been recognized and gaining attention over a decade, which can be integrated into the healthcare delivery system to improve access to glaucoma screening, detection, and follow up.<sup>[28]</sup> Tel-glaucoma service, primarily targeted remote or underserved communities, can be set up in selected primary care setting and link with eye care center that provides glaucoma services. A physician can be trained about the use of portable non-mydratic fundus camera and capture the image of the fundus of the patients., Such images can be sent to a specialist for teleconsultation. A systemic review indicates that tele-glaucoma service provides various benefits in terms of improving access, early detection, reduction in patients waiting time, increased specialist referral and cost-saving compared to inpatients examination.<sup>[29]</sup>

### Conclusions And Recommendation

Glaucoma is one of the leading causes of irreversible blindness in India, but if detected early, either it can be prevented or stabilized the progression with medical or surgical treatment. Till now, the primary focus of the National Program for Control of Blindness and Visual Impairment is on the prevention of cataract blindness. Along the side of cataract-driven program, there is a need for catering for control of blindness due to glaucoma in an efficient way. Considering the burden of glaucoma blindness, and its potential to surge in magnitude over time, there is a need of having a specific action plan for control of blindness due to glaucoma across the country. At the same time from a program perspective, glaucoma should not be screened and managed separately from other common blinding ocular problems. In fact, the objective should be detection of any potential blinding public health ocular problems giving with equal importance to each in an integrated manner under the Universal Health Coverages. Indeed, recently the WHO has promoted the involvement of community healthcare workers as a part of the interdisciplinary healthcare approach in an attempt to improve access to healthcare in developing nations.<sup>[30]</sup> To achieve this, a strong advocacy is a key strategy. Strategies for advocacy can be planned as per feasibility

and appropriateness with respect to a different setting. Making alliances, and partnerships with various other institutions and organizations will certainly help in bringing successful advocacy for control of glaucoma blindness.

The following recommendations are suggested to address the glaucoma blindness in India.

1. Opportunistic screening: A country with limited resources, mass screening is not feasible, particularly, for glaucoma. Therefore, an opportunistic screening focussing on high-risk groups should be adopted in India.
2. Integration: The WHO GAP 2014-19 indicates the Universal Eye Health Coverage (UEHC) is a part of Universal Health Coverage, and UEHC should be integrated in the health system. Screening of the potentially blinding eye disease, including glaucoma, under the comprehensive eye care programs, should be a clear mandate to achieve Universal Eye Health Coverage.
3. Advocacy: A good plan and disease-specific advocacy are required for control of glaucoma blindness. Audiences, but not limited to eye care professionals, also from the primary level who can influence primary audiences (policy makers or decision-makers) should be involved in planning advocacy steps.
4. Disease-specific guidelines: Appropriate disease-specific guidelines to control the glaucoma blindness for primary or secondary healthcare level should be developed and adopted into the healthcare system.
5. Primary HealthCare: PCPs can be well-positioned in the education of patients and community, creating awareness and knowledge about glaucoma, and its risk factors. PCPs can cement the integration and implementation of the glaucoma control program. Therefore, PCPs should be bought on board in planning for control of glaucoma blindness.
6. Physician–Patient Relationship (PPR): PPR is of paramount importance in glaucoma management. They have a huge potential role in treatment adherence among patients receiving treatment. They act as leverage for basic medical care to the patients with glaucoma.
7. Teleglaucoma: A potential area that can help in addressing the glaucoma blindness control program in remote, rural areas. PCPs can be trained about using portable non-mydratric fundus cameras and followed by teleconsultation.

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