

GENDER AND BLINDNESS: Initiatives to address inequity



A Report by Seva Canada and Seva Foundation

PREFACE

Seva believes that, to achieve VISION 2020 goals, eye care programs must develop explicit strategies to reach the most vulnerable populations, particularly women and girls. We encourage our program partners to disaggregate data by sex, determine gender specific barriers to uptake of services and to study strategies to increase utilization by women. More generally, Seva looks forward to collaborating with all international eye care providers to eliminate all forms of inequities in eye care .

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Cover photograph: Women cataract patients at Chitrakoot Hospital, India. Photo by Brian Harris.

GENDER AND BLINDNESS

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1. INTRODUCTION

In 2000, the British Columbia Centre for Epidemiologic & International Ophthalmology (BCEIO), located at the University of British Columbia, began a Gender and Blindness Initiative. Through a meta-analysis of population-based prevalence studies, researchers at the BCEIO found that approximately two out of every three blind people in the world were women, most of who were over age 50 years, and ninety per cent of who lived in poverty.¹ Furthermore, the researchers found that the sex ratio held true for most population-based blindness prevalence surveys from 'Western industrialized' and economically poorer countries. This sex ratio also held true, albeit for different reasons, for virtually all the preventable and treatable blinding conditions in the world, including (cataract, glaucoma, and trachoma). The sex ratio only approached *one* for age-adjusted rates of less treatable conditions such as macular degeneration.

A recent WHO report on gender inequity in health listing 125 health conditions according to age adjusted female to male ratios of respective disability-adjusted life years provided further evidence of the burden women face in terms of eye conditions. Five of the six eye conditions listed had a female to male excess of 1.2 or more. Overall, women accounted for 41.1 million DALYs compared to only 29.5 million DALYs for men.²

Table 1: Age-adjusted DALYs (125 most common health conditions)

#	Condition	F:M	Males (millions)	Females (millions)
3	Trachoma	3.05	0.812	2.475
20	Cataract	1.36	15.730	21.454
22	AMD	1.35	9.413	12.714
23	Glaucoma	1.34	2.465	3.304
29	Vitamin A Def	1.22	0.775	0.945
96	Onchocerciasis	0.74	0.355	0.264
		1.34	29.551	41.158

In no instances did biological differences explain the increased prevalence among women. Instead, women of all ages (including children) were more frequently exposed to causative factors, such as infectious diseases and malnutrition, and utilised eye care services less frequently than men. Based on these findings, in 2001, BCEIO prepared a WHO Fact Sheet for the Department of Gender and Women's Health, which has recently been adapted by the Eastern Mediterranean Regional Office of WHO.³

A Canadian Federal Partnership for Global Health Equity Program funded an initial Gender and Blindness meeting in Moshi, Tanzania from 17-21 June 2002, among women's health researchers, policy makers and programme staff. Organized by the BCEIO and hosted by The Kilimanjaro Centre for Community Ophthalmology (KCCO), the participants identified key research, policy, and programme priorities.^{4,5}

Following on the theme of gender and blindness, in 2003, the Canadian Global Health Research Initiative provided pilot funding to initiate an international collaboration among epidemiologists, anthropologists and ophthalmologists in three countries:

- i. Community Ophthalmology Program, Lumbini Eye Hospital, Bhairahawa, Nepal

- ii. Lions Aravind Institute for Community Ophthalmology, Madurai, India
- iii. Kilimanjaro Centre for Community Ophthalmology, Moshi, Tanzania

Gender inequity has been reduced in the direct catchment areas of these eye care programs through local public health initiatives as well as community-based service development (i.e. improved water supply).



The collaborative approach has augmented individual country's ability to design and conduct applied anthropologic and epidemiologic research. This 'south-south' collaboration greatly exceeds the 'north-south' collaboration with Canadian partners.

The primary finding from this Gender and Blindness Initiative is that utilization of eye care services is strongly associated with socioeconomic status, family decision-making, and female literacy^{6,7} (as a surrogate for educational attainment).⁸ Female literacy remains the strongest independent predictor of health service utilization by women themselves and of an overall population, across all socio-economic levels.⁹ Indeed, examples from Southern India show that an indirect investment in female education improves all aspects of public health, through increase use of already available health services, without any additions to the health services themselves.¹⁰

The Global Health Research Initiative funds for gender and blindness were followed by sustained local program funding in each of the original members of the network. Interest continues from non-government organizations such as Seva¹¹ and within allied organizations such as Harvard-based Women's Eye Health Task Force.¹²

Recently, new funding has led to expansion of the network in Asia from southern India to northern India, as well as central Nepal and Tibetan regions of China; and in Africa to expand from Tanzania to Uganda and Egypt. The following sections outline 'ongoing programs' and 'future expansion', respectively.

2. ONGOING PROGRAMS

2.1 Tanzania

The Kilimanjaro Centre for Community Ophthalmology (KCCO), established in 2001, operates within the Kilimanjaro Christian Medical College/Tumaini University and collaborates with KCMC Hospital, a tertiary referral hospital for 12 million people, in Moshi, Tanzania. KCCO's mission is to: "eliminate avoidable blindness through the integration of programmes, training, and research, focusing on the delivery of sustainable and replicable community ophthalmology services."

ADOPTION OF VISION 2020 "BRIDGING STRATEGY" THROUGHOUT KILIMANJARO AND OTHER REGIONS

Initial operational research (see below) indicated eye care services were not reaching the population in need, particularly vulnerable populations (women and people living in extreme poverty). KCCO developed a "bridging strategy" throughout Kilimanjaro Region and the adjacent Arumeru District of Arusha Region (total population, 2 million) to address these barriers and link communities with eye care providers. The bridging strategy increased the cataract surgical rate three-fold in three years.

KCCO facilitated the establishment of the Kilimanjaro Regional VISION 2020 Task Force to strengthen the effectiveness and efficiency of community-based programs. The Kilimanjaro Regional VISION 2020 activities were subsequently adopted in three other regions (Singida, Tanga, and Mara; total population 5 million).

OPERATIONAL RESEARCH ON UTILIZATION OF EYE CARE SERVICES

Beginning in 2002, KCCO researchers (supported by the WHO Gender & Women's Health Unit) used epidemiologic and anthropologic methods to study service utilization, including gender differences. The research highlighted the particular challenges faced by women including inadequate awareness, finances, and social support, as well as fear of the consequences if surgery failed.

Table 2: Cataract Surgical Rate (CSR) by District with male to female ratio (note: CSR is the coverage rate not the number of surgical cases).

Region	Male : Female CSR Ratio 2006	CS Rate (Total) per million popu- lation 2006
Hai	1.40 :1	711
Moshi rural	1.29 :1	855
Moshi urban	0.90 :1	1000
Mwanga	0.82 :1	699
Rombo	1.60 :1	711
Same	1.16 :1	765
Total	1.23 :1	791

GENDER AND OVERALL BLINDNESS REDUCTION STRATEGIES

With assistance from Seva Canada, KCCO worked to overcome the particular challenges faced by women by providing better female and family counselling at the 'time of recognition', transporting patients to hospital, and having local field assistants and Ministry of Health staff help identify people in need of care. As a result, utilization of services has increased and gender issues have become central to eye care program development and staff training at all levels. This effort is best reflected in the community outreach programs where the male:female ratio is 1.30:1. In contrast, the population that approaches the hospital directly for cataract surgical had a male:female ratio of 2.58:1.

GENDER AND CHILDHOOD CATARACT

Throughout most of eastern Africa cataract is the leading cause of blindness in children. KCCO research identified that families brought girls less often and later than boys for assessment, treatment and follow up care. This research led to changes in identification and referral and hospital management of children. In hospital, parents receive more intensive counselling. After discharge, cell phone contact to villages facilitates follow up reminders. Delay has decreased and follow up improved.¹³

GENDER AND TRACHOMA

In collaboration with the Carter Center, BCEIO, and IDRC, KCCO has been working to identify evidence-based interventions that will ensure that women are beneficiaries and actively involved in trachoma control activities.

2.2 Nepal

The Lumbini Eye Institute (Shree Rana Ambika Shah Eye Hospital) in Siddharthanagar is the main Gender and Blindness Initiative partner in Nepal. This tertiary care hospital and training institute has acted as the focal point for several initiatives to improve community access to services both in the lowland and hill regions.

Lumbini Eye Institute reports both out-patient and in-patient procedures by age and sex (Table 2). In the 40-60 year age group, more women (57%) than men (43%) underwent cataract surgery in 05/06 fiscal year. In the 60-75 age group the rates were reversed with more men than women. Although the total number of cataract surgical operations has increased by 7-10% each year the sex ratios have remained constant over the past 4-5 years.

Table 3: Cataract surgery by age and sex: Indian and Nepali Patients Lumbini Eye Institute July 2005 to June 2006. By Ganesh Thapa.

Age Group	Male N (%)	Female N (%)
0- 15	314: 69%	144: 31%
16 - 40	722: 43%	962: 57%
41-60	5,824: 44%	7,423: 56%
61 -75	4,000: 56%	3,115: 44%
76+	600: 72%	268: 28%
Total	11,460 49%	11,912 51%

*Table 4: Cataract surgery rate by age and sex: Nepali Patients
Lumbini Eye Institute July 2005 to June 2006. By Ganesh Thapa.*

Age Group	Male N : %	Female N : %
0 – 15	99 : 71%	41: 29%
16 – 40	131: 51%	126: 49%
41 – 60	763 : 44%	975: 56%
61 – 75	716: 53%	634: 47%
+76	192: 65%	102: 35%
Total	1,901: 50.5%	1,878: 49.5%

The Lumbini Eye Institute provides almost 80% of its out-patient and in-patient cataract surgical services to a transient Indian population that travels the short distance north to Lumbini across the open border. Lumbini Institute does not provide outreach services to India, so most of its base-hospital activity is passively dependent on this Indian population.

Lumbini hospital provides a comprehensive outreach program to the Nepali population in Lumbini Zone, including general and school vision screening as well as diagnostic and treatment camps.

Lumbini Eye Institute, as well as its satellite clinics and outreach activities, serves more adult women (54-55%) versus men (45-46%) as outpatients. The ratio is reversed for male versus female children. The Lumbini Eye Institute reports data separately for the Nepali and Indian populations.

Lumbini Hospital is linked with secondary eye care facilities (staffed by ophthalmologists and provide full cataract surgical services) in Tansen, Palpa, a hill district north of Lumbini, and in Bharatpur, Chitwan District.

CHITWAN (LOWLANDS)

The Gender and Blindness Initiative, with the help of Seva Canada, supported the development of a community ophthalmology program in the Chitwan District of

central Nepal, beginning in 2003. The goal was to increase utilization of services, particularly by women and children, by integrating eye care into primary health care. Primary health care in each 'Village Development Committee,' the basic administrative zone (10,000 people) is focused around a Health Post with three staff (a Community Medical Assistant, and village and maternal-child health workers). The Health Posts provide vaccinations and vitamin A distribution, as well as programs in reproductive health and health education.

In addition to paid staff, the Health Posts work with a number of female community health volunteers. Interested volunteers were trained by the Gender and Blindness Initiative to recognize basic eye problems and to refer people, particularly older women, to Diagnostic Screening and Treatment camps organized in each area. During these camps, ophthalmic assistants conducted clinical examination and refraction free of charge, while eyeglasses and medications were provided at affordable rates. For children below 15 years of age, glasses and medication were also provided free of charge.

Each year, approximately 16,000 people were examined and provided treatment in the Diagnostic Screening and Treatment camps and approximately 1600 people with



cataract blindness were transported to the King Mahendra Memorial Eye Hospital in Bharatpur for surgery.

A recent study of the effect of charging \$15 US (1000 Nepali Rupees) for cataract surgery in the Chitwan area reported disaggregated data. A total of 6300 patients attended Diagnostic and Screening Camps, with 2675 (43%) men and 3625 (57%) women.

From the Diagnostic and Screening Camp 271 (86% of total referred) accepted cataract surgery when the surgery did not cost \$15 (US) and 110 patients (61 % of total referred) accepted cataract surgery when charged \$15.

Table 5: Cataract Surgery: King Mahendra Memorial Eye Hospital Chitwan 03/04

Age	Male	Female	Female (%)
0-20	5	3	37
21-40	20	26	56
41-60	230	336	60
61+	673	710	51

More recently, three *Vision Centres* have been added to this area. Vision Centres are permanent community eye care facilities, staffed by ophthalmic assistants and nurses. They are designed to provide intermediate eye care and refractive services to about 50,000 people. Vision Centre staff are trained by and work as a referral source for the King Mahendra Memorial Eye Hospital in Bharatpur.

TANSEN (HIGHLANDS)

The Lions Lacaul Eye Hospital, located in Palpa, one of the three hill districts of the Lumbini zone, is Nepal's first eye hospital directly serving the hill regions. It is located 60 kilometers from the Lumbini Eye Institute, the tertiary referral hospital.

With the help of the Gender and Blindness initiative, the Tansen Centre developed a data management system and a program to monitor and evaluate cataract

surgery disaggregated by sex.

The hospital performed 250 cataract surgical procedures in each of the past two years, with approximately 50% men and women. In addition, the Tansen-based ophthalmologist and the ophthalmic assistant staff provide a regular program of outreach surgical services in all regions of the hill district.

Despite these efforts, cataract surgical coverage (cases per million) remains low for most of Nepal, estimated at 2100 per million population. The cataract surgical coverage rate is 2448 in the Lumbini Zone, and 3212 in the Chitwan District, both higher than the national average. The Gender and Blindness Initiative continues to support research into the cultural and economic reasons for this low utilization pattern.

2.3 India: Aravind Eye System

The Aravind Eye System has acted as one of the principle partners and primary promoters of the Gender and Blindness Initiative, particularly in India. Table 5 provides data on cataract surgery rates by age and sex and whether the person came to the hospital 'directly' or following a outreach screening 'camp.' As the table illustrated, efforts focused on reaching into communities (camps) are most effective in addressing the needs of women.



Table 6: Cataract Surgical patients in three arms of Aravind Eye Hospital, 2006 by Age and Sex

Group			Sex		Total
			Male	Female	
Direct - Free	Age Group	<=50	1646 36.4%	2878 63.6%	4524 100.0%
		51-60	2875 40.6%	4207 59.4%	7082 100.0%
		61-70	3104 50.4%	3053 49.6%	6157 100.0%
		>70	992 63.0%	582 37.0%	1574 100.0%
		Total	8617 44.6%	10720 55.4%	19337 100.0%
Paying	Age Group	<=50	2213 51.6%	2079 48.4%	4292 100.0%
		51-60	3209 50.8%	3104 49.2%	6313 100.0%
		61-70	3895 55.3%	3154 44.7%	7049 100.0%
		>70	1777 65.5%	938 34.5%	2715 100.0%
		Total	11094 54.5%	9275 45.5%	20369 100.0%
Camp	Age Group	<=50	1590 28.7%	3943 71.3%	5533 100.0%
		51-60	4993 41.4%	7057 58.6%	12050 100.0%
		61-70	6168 54.4%	5161 45.6%	11329 100.0%
		>70	2450 70.4%	1030 29.6%	3480 100.0%
		Total	15201 46.9%	17191 53.1%	32392 100.0%

VISION CENTRES

The Gender and Blindness Initiative has been incorporated into a new model of community care focused on Vision Centres. The overall objective is to offer primary eye care services to the targeted rural population. Each Vision Centre is designed to provide the primary eye care needs for a population of about 50,000 people. The Centres provide comprehensive primary eye care services that include:

- refraction services (including eyeglass prescription and dispensing at the vision centre);
- paediatric eye care services through active school screening;
- adult eye care;
- rehabilitation of blind; and
- other basic eye care needs.

Vision centres are comprehensive because services are provided to all the age groups at any time. Apart from screening children at the centre, regular school screening is carried out within the service area. Aravind Eye Care System currently has 12 Vision Centres and plans to increase to 26 by Jan 2008.

GENDER AND BLINDNESS DATA ANALYSIS

The Gender and Blindness Initiative supports the gathering and analysis of utilization data from the Vision Centres. The main finding to date is that the uptake of services for cataract surgery is much less than expected, by both men and women. As a result, Aravind staff plan a study of ‘barriers’ to the utilization of cataract surgery.

The issues are:

- 1) Do patients bypass the Vision Centres and attend the Theni Eye Hospital directly?
- 2) What is the geographic distribution of patients?
- 3) Which patients, identified at the community level, have not come to the Vision Centre and why?

Based on this initial data, interventions to increase utilization will be designed and studied.

2.4 Egypt, Al Noor Foundation

Egypt has sufficient clinical capacity to restore vision to most of its approximately 800,000 blind people, two-thirds of who are women and almost all of who live in poverty.^{14,15} Despite this technical capacity, rural populations rarely use these urban

and suburban services, even if the services are free, because of inadequate awareness, access, and acceptance.

In 2000, the Al Noor Foundation, funded through the Canada Fund and supported by the Kilimanjaro Center for Community Ophthalmology in Tanzania, began Egypt's first community-based intervention to bridge the gap between rural population need and eye care service delivery. The program provided eye health education to women's groups, in the first year, and primary school children, in the second year, in three villages in Menofiya Governorate (2000-2002), Lower Egypt. The project reflected the conclusions of a blindness prevalence survey in Menofiya conducted by the Al Noor Foundation. The survey detailed both the population needs of women and children, as well as the limited levels of educational attainment. The project, while transiently successful in increasing utilization of eye care services and building awareness of blinding conditions, was not sustained by the intervention communities.

In 2002, the Al Noor Foundation, also funded through the Canada Fund and supported by the Kilimanjaro Center for Community Ophthalmology in Tanzania, conducted a second project focused on gender sensitization and utilization of eye care services in two villages in Menia Governorate, Upper Egypt (selected in collaboration with Ministry of Health and local authorities).¹⁶ Al Noor hired a 'gender specialist,' who conducted interviews and led focus-group discussions in the two villages. She conducted educational sessions regarding gender issues with male and female village leaders. Along with one of the other principal investigators on the proposed research, they taught a range of village individuals (nurses, school teachers, and health unit doctors) to screen people door to door for the most common correctable visual disorders: age related cataract and trachoma. The project concluded that:

- community interventions should not focus on eye care needs in isolation from other health needs;
- targeting women in the reproductive years provides the best opportunity to improve overall use of health services, and by extension, the most efficient and effective means of reducing blindness, particularly among women; and,
- a definitive study is needed to confirm this small initial assessment of community needs and intervention strategies.

This preliminary work in Menia noted that women were less aware than men of all health services including those relevant to blindness, due to a number of factors, with literacy the most important. Women also faced more difficulties than men in all access issues – most particularly in gaining adequate funds to use the services needed for themselves and their children. Acceptance is also an issue. For example, individuals in Menia were found to fear surgery and hospitals in general and they doubted the chances of surgical success, particularly cataract surgery. Furthermore, household dynamics did not empower women to make decisions regarding use of services by themselves or their children. Villages also restricted contact between women and people from different clans and ethnic groups.

The Menia project added an additional gender element to this area of work as it utilized both men and women as community health volunteers, and analysed service utilization according to the sex of the health volunteer.¹⁷

The male health volunteers were proportionally more successful compared to the female volunteers in getting their patients for surgery: 19/107 and 19/188 for male and female health workers, respectively. Male health volunteers were thought to be more successful because they accompanied the people to the hospital and solved their admission problems. They also reported that they paid the essential hospital fees of patients not able to pay.

Similarly, for trichiasis surgery (83.3% of trichiasis patients referred by male health workers) and 47.1% of trichiasis patients referred by female health workers received appropriate services.

2006-07 INNOVATIVE PROGRAM

In a current project, Al Noor is studying the cost effectiveness of a community strategy to reduce blindness, particularly among women living in poverty. The project packages eye health with acknowledged women's health needs. Of particular interest to this proposal are new studies of health related behaviour by women and children. The proposed project is a one year, prospective, controlled observational study testing community interventions to increase eye service utilization in a District in Menia Governorate (total population 104,000).

The project focuses on utilization of existing eye care services. It adds training of community women in leadership roles to take advantage of those eye care services,



both initially during the one-year study, and as a sustainable focus for 'healthy women' particularly mothers and daughters. Additional health interventions and health personnel may be needed in this setting. The eye care services, including glasses and surgery, will be funded by the Al Noor Foundation.

The findings from this project will serve as the basis for a larger programme in Upper and Lower Egypt. The larger programme will include collaborative research with the Kilimanjaro Center for Community Ophthalmology (KCCO) in Tanzania, the British Columbia Center for Epidemiologic and International Ophthalmology (BCEIO), at UBC and the WHO-sponsored, International Agency for the Prevention of Blindness.

3. FUTURE EXPANSION

3.1 Tibetan regions of China

A population-based survey found that the prevalence of cataract blindness in the Tibet Autonomous Region of China is one of the highest in the world.¹⁸ Cataract surgical coverage (vision <6/60) for people age 50 and older (85-90% of cataract blind) was 56% overall, 70% for men and 47% for women.¹⁹ The most common barriers to use of cataract surgical services were distance to eye care services and cost.

EYE HEALTH EDUCATION

A project has begun to establish an outreach program in the Tibetan Autonomous Region. The objectives of the project are to plan, conduct and evaluate Primary Eye Care Training Workshops for rural health workers. The participants of these workshops included doctors of traditional Tibetan Medicine, county and village level health workers, and a few nurses with western-medical training. The workshops are held in county hospitals in rural nomadic areas with approximately 20 to 25 participants with various literacy levels in each workshop.

The main objectives of the workshops are to teach the participants how to:

1. detect, initiate treatment and refer people with the following conditions:
 - a) Cataract, glaucoma, ocular trauma and any ocular emergencies - identify and refer.
 - b) Trachoma, conjunctivitis, vitamin A deficiency – identify, initiate treatment and refer.
2. provide eye health education to community members for the prevention of eye disease and timely use of available eye care services.

3.2 Africa

SPREADING THE GENDER & BLINDNESS MESSAGES

The Kilimanjaro Center for Community Ophthalmology (KCCO) has facilitated VISION 2020 national and district planning workshops in Egypt, Uganda, Rwanda, Ethiopia, Tanzania, and Malawi which included gender specific programs and planning.

EAST AFRICA: ESTABLISHING A “GENDER & BLINDNESS COORDINATOR” POSITION
With support from funds from the Canadian government and Seva Canada, the KCCO is creating a position of “Gender and Blindness Coordinator” in 2007. The person in this position will be supervising gender and blindness research and be a resource person for assisting national and “district” personnel to include gender strategies in their VISION 2020 plans.

4. ADVOCACY

- Talks at the following forums:
 - i. International Agency for the Prevention of Blindness, Dubai, September 2004
 - ii. International Conference on Women & Infectious Diseases, Atlanta, USA, February 2004
 - iii. Global Alliance for the Elimination of Trachoma, Cairo Egypt, November 2005
 - iv. The Carter Center Annual Trachoma Review Meeting, March 2007
- Creation of the VISION 2020 Gender Working Group within the



- International Agency for the Prevention of Blindness, in collaboration with the Harvard-based Women’s Eye Health Task Force.
- Development of a issue on gender and blindness for the WHO Gender & Health Research (to be completed by Oct 2007)
- Creation of a “Gender and Blindness” section on the BCEIO and KCCO websites. The section provides advocacy materials, list of publications, some articles, and findings from some projects.
- WHO-sponsored Gender and Blindness Workshop for the Eastern Mediterranean Region, Cairo Egypt November 26-27th 2007

5. NEXT STEPS

- Enhanced advocacy through email, website development, and resource materials among Gender and Blindness partners.
- Develop electronic learning programmes for eye care professionals and program planners.
- Creation of “Gender & Blindness” program staff for key international regional development Tanzania for Eastern and sub-Saharan African region, Egypt for the eastern Mediterranean region, India in itself, and Nepal for the Himalayan region.

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