

**GENDER AND BLINDNESS: EVALUATING GENDER SPECIFIC
COMMUNITY INTERVENTIONS IN UPPER EGYPT**

by

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Abstract

The prevalence of low vision and blindness is commonly high in developing countries. The majority (70%) of blindness burden is avoidable. Socioeconomic status and other community development aspects are highly affected by this burden. Cataract and Trachomatous Trichiasis are the major causes of avoidable blindness. Females are more affected by these diseases and less likely to use eye care services than males. Recently, the concept of multi-component intervention models was introduced to the research arena. There is a need for an integrated model that tackles different axes of blindness focusing on women.

The current study adopts an integrated gender sensitive interventional model where community health education is its major component in addition other components including; screening and referral of eligible cases, breaking down barriers to eye care utilization, and capacity building of local eye care providers. In this study, we attempted to evaluate the effectiveness of the proposed mode through a community interventional trial. The intervention was applied to two villages in rural Upper Egypt where two other villages served as control.

The proposed model managed to increase community knowledge, enhance attitudes and practice along with reducing most of its specific barriers to eye care service utilization. As a result, service utilization at the local hospitals increased by 20.6 %. Cataract and Trachomatous Trichiasis surgical uptakes also increased by 36.9% and 41.4% respectively. The local provider's efficacy improved by 8.9 % increase in post operative visual functioning score. Patient satisfaction improved by 16.6% among cataract patients and by 11.1% among trichiasis patients. Selection of local provider as the first choice increased by 31.1%. Consequently, the prevalence of cataract reduced by 16.3% (18.4% female specific), and trichiasis prevalence by 5.7 % (8.2% female specific). The overall prevalence of low vision and blindness decreased by 13.3 % (14.1% female specific) and 7.2% (9% female specific) respectively.

Integrated community based interventions that tackle different aspects of the prevention of blindness are highly effective. Gender sensitive community health education should be the major component of such models. These models could be modified and tailored to address specific needs of target communities.

Preface

This current study is based on a joint scientific project between the University of British Columbia (UBC), Vancouver, Canada and the Al Noor Magrabi Foundation, Cairo, Egypt. The project was funded by the Canadian Institute for Health Research (CIHR) and further supported by the British Columbia Centre for Epidemiologic and International Ophthalmology (BC-EIO). The research idea was initially submitted by myself to the University of British Columbia in 2005. The department of Health Care and Epidemiology, Faculty of Medicine, UBC and the BCEIO have provided technical and academic support to the study in addition to financial support through equipping Samalout Eye Hospital, Menia, Egypt with surgical tools. Most of the field work and other related activities were done with support of the Al Noor Magrabi Foundation's research, clinical and fieldwork teams. Ahmed Mousa was responsible for designing and implementing the study, supervising fieldwork teams, training of local teams, data management, and analysis.

An excerpted version of chapter 4 (qualitative results) was published in the Community Eye Health Journal in June 2009. Mousa A, Ezz El Arab G, Rashad E. Reaching Women in Egypt: A Success Story. Community Eye Health. 2009 Jun;22(70):22-3. I conducted all data management and analysis tasks and wrote both methods and results parts of the manuscript. Dr. Ezz El Arab contributed to clinical related parts of the study and managed this area of the manuscript, while Dr. Rashad was responsible for the qualitative parts related to medical anthropology, and managed this part of the manuscript. The three of us wrote together the discussion and conclusion.

The current study did not involve testing or the conduct of any new therapeutic or surgical techniques. However, according to CIHR policy, ethical approval was obtained from the University of British Columbia (UBC) Committee; "*The University of British Columbia Behavioural Research Ethics Board, Office of Research Services (format version of August 23rd, 2005)*" in March 2006. Approval # (H06-80425) Gender and Blindness – Egypt.

Table of contents

Abstract	ii
Preface	iii
Table of contents	iv
List of tables	vii
List of figures	ix
Acknowledgements	x
Dedication	xi
1. Introduction and conceptual framework	1
1.1 Introduction	1
1.2 Rationale for the study	1
1.3 Study question and hypothesis	2
1.4 Study significance and verification	2
1.5 Literature in community health interventions for prevention of blindness	5
1.6 Characteristics of the required interventional model	19
1.7 Conceptual framework	21
2. The intervention model: methodological concepts and implementation	24
2.1 Introduction	24
2.2 Proposed intervention model	25
2.3 Study goal and objectives	40
2.4 Study design	40
2.5 Ethical approval	41
2.6 Outcome measures	41
2.7 Study population	41
2.8 Statistical methods	42
2.9 Study duration	42
2.10 Building upon previous experience and literature	42
2.11 Description of intervention	43
2.12 Geographic and demographic selection of the study site	46
2.13 Application of intervention coping with study design	47
3. Developing the health education intervention: engaging with the community and its barriers to eye care services	62
3.1 Introduction	62
3.2 Community perceptions to blinding diseases and eye care services	62
3.2.1 Knowledge	63
3.2.2 Awareness	64
3.2.3 Attitudes	65
3.2.4 Practice	66
3.2.5 Barriers	68
3.2.6 Perceptions	69
3.3 Focus group discussions	72
3.3.1 Focus group discussions with health visitors	72
3.3.2 Focus group discussions with community leaders	73
3.4 Reforming the health educational message in the light of the qualitative data	75

4. Results	79
4.1 Introduction	79
4.2 General characteristics of the sampled villages	79
4.2.1 Demographic, geographic, and political characteristics	79
4.2.2 Health facilities on village level	79
4.2.3 Access to secondary and tertiary health facilities	80
4.3 Characteristics of the households and residents	82
4.4 Assessment of visual impairment and its causes in all villages before and after intervention	83
4.5 Results of screening and health education	84
4.6 Comparing pre to post intervention indices	85
4.7 Principal causes of visual impairment and blindness in intervention villages	87
4.7.1 Principal causes of visual impairment & severe visual impairment	87
4.7.2 Principal causes of blindness	88
4.7.3 Comparing pre and post intervention principal causes of low vision and blindness	89
4.8 Change in prevalence of the two main targeted diseases of avoidable blindness	91
4.8.1 Change in the prevalence of cataract	91
4.8.2 Change in prevalence of trichomatous trichiasis	92
4.9 Change in determinants of visual impairment among the population of the intervention sector	93
4.10 Barriers to eye care service utilization	98
4.11 Eye care service utilization	102
4.12 Change in quality of visual life after surgery as a surrogate to service improvement	108
4.13 Change in patient satisfaction with surgery results	109
4.14 Second focus group meeting with community leaders	111
5. Discussion and limitations	111
5.1 Creation of a new model	111
5.2 Importance of communications and advocacy	112
5.3 Classification of the model	114
5.4 Community perceptions and the knowledge, attitude, and practice gap	119
5.5 Barriers to eye care service utilization	122
5.6 Capacity building of local providers	125
5.7 Traditional healing	128
5.8 The concept of integrated models	127
5.9 Limitations	128
5.9.1 Constraints	127
5.9.2 Limitations	128
6. Conclusion and recommendations	129
6.1 Conclusion	132
6.2 Recommendations and potential areas for future research	135
6.2.1 Recommendations	136
6.2.2 Areas for future research and / or enhancement of the provided model	137
Bibliography	140
Appendices	150

Appendix 1: Pre and post intervention assessment questionnaires	150
Appendix 2: Semi structured interview guidelines	166
Appendix 3: Additionally collected data from control villages	171

List of tables

Table 2.1	Sample indicators and calculated sample size per each village	48
Table 3.1	Results from the two groups meetings	75
Table 4.1	Demographic characteristics of the sampled villages	79
Table 4.2	Overview of the performance of the two local hospitals prior to intervention	82
Table 4.3	Sample coverage of pre and post assessments	83
Table 4.4	Distribution of screened households and individuals with specific findings	84
Table 4.5	Surgery uptakes by referred patients	85
Table 4.6	Change in vision following intervention	85
Table 4.7	Change in vision following intervention disaggregated by gender	87
Table 4.8	Principal causes of visual impairment & severe visual impairment in the pre intervention phase	87
Table 4.9	Principal causes of blindness in the pre intervention phase	88
Table 4.10	Comparing pre and post intervention principal causes of VI/SVI in intervention villages	89
Table 4.11	Comparing pre and post intervention principal causes of blindness in intervention villages	90
Table 4.12	Comparison of pre and post intervention prevalence of cataract	91
Table 4.13	Comparison of pre and post intervention prevalence of trichiasis	92
Table 4.14	Adjusted odds ratios (logistic regression) of vision loss for pre intervention determinants (all males and females)	94
Table 4.15	Changes in pre and post intervention risk factors	95
Table 4.16	Results from logistic regression on pre intervention female specific determinants	96
Table 4.17	Post intervention female specific risk factors	97
Table 4.18	Comparing pre and post intervention female specific characteristics	98
Table 4.19	Different types of studied barriers and their main domains	98
Table 4.20	Comparing male to female barriers in the pre intervention phase	99
Table 4.21	Difference in prevalence of barriers between pre and post intervention ...	100
Table 4.22	Differences in prevalence of male specific barriers between pre and post intervention phases	100
Table 4.23	Differences in prevalence of female specific barriers between pre and post intervention phases	101
Table 4.24	Comparing barriers results from questionnaires and interviews	102
Table 4.25	Numbers of eyes which had surgeries pre and post intervention	103
Table 4.26	Cataract and TT surgical coverage rates pre and post intervention	103
Table 4.27	Cataract and TT surgeries per patient's preference	104
Table 4.28	Trends and patterns of outpatient service utilization in samalout and menia eye hospitals	104

Table 4.29	Trends and patterns of cataract surgery uptake in samalout and menia eye hospitals	105
Table 4.30	Trends and patterns of TT surgery uptake in samalout and menia eye hospitals	106
Table 4.31	Change in surgical win rates from 2002 – 2008	107

List of figures

Figure 1.1	Simplified conceptual framework of the study	22
Figure 2.1	Samalout district showing intervention and control sectors	46
Figure 2.2	An illustration of intervention model phases	49
Figure 2.3	Intervention organizational chart	58
Figure 4.1	Principal causes of low vision in pre intervention phase	88
Figure 4.2	Principal causes of blindness in the pre intervention phase	89
Figure 4.3	Change in principal causes of low vision	90
Figure 4.4	Comparing pre and post intervention major causes of blindness	91
Figure 4.5	Trend and pattern in outpatient volume in local hospitals	105
Figure 4.6	Cataract surgery uptake in both hospitals by gender.....	106
Figure 4.7	TT surgery uptake in both hospitals by gender	107
Figure 4.8	Increase in surgical win-rate over the last 7 years	108
Figure 5.1	Relationships among different domains affecting service utilization..	115
Figure 6.1	Major axes for prevention of blindness	133

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Dedication

To the great souls that were guiding me behind the seen;

To the soul of Moulana Sheikh Mohamed Salama Ibrahim, who encouraged and spiritually guided me, and still doing...

To the great souls of my father and mother who grow me up on respectable values and built the foundation of my personality on basis of honesty and sincerity...

I dedicate this work and hope that they accept this humble dedication...

Chapter 1: Introduction and conceptual framework

1.1 Introduction:

Egypt has sufficient clinical capacity to restore vision to most of the visually disabled persons (among who almost two thirds are women). According to the Egyptian ophthalmologic society report (2005), there are around 4000 Egyptian ophthalmologists of whom 40% are performing surgeries. Nevertheless, those ophthalmologists (including surgeons) live in urban areas. Despite this technical capacity, rural populations seldom use these urban and suburban services, even if these services are free. The main reasons are poor awareness, difficulty accessing these services, low acceptance rate, and other undisclosed factors. The challenge, therefore, is linking people and populations in need with the available clinical services.

The two major avoidable causes (cataract and trachomatous trichiasis) account for approximately 63% (55 % and 8 % respectively) of the blindness burden. People affected by these two diseases are the groups who are expected to directly benefit from the current work.

1.2 Rationale for the study

There is a need for a model that can easily utilize currently available resources and lead to the reduction of avoidable blindness. This model should be cost effective, sustainable, and easily applicable to this population. Additionally, it should connect with women living in poverty through the packaging of eye health with locally recognized women's health needs.

There is also need for studies that examine the *effectiveness of community based interventions*. As described in detail later in this chapter most studies simply report population-based factors associated with who does and who does not accept services^{1,2}. Accordingly, this type of research does not test whether interventions actually result in a difference in service utilization. In contrast, this study evaluates the impact of community eye health education for women on the utilization of cataract and trichiasis surgical services in two villages in Upper Egypt.

¹ Brilliant GE, Brilliant LB. Using social epidemiology to understand who stays blind and who gets operated for cataract in a rural setting. Soc Sci Med. 1985;21(5):553-8.

² Snellingen T, Shrestha BR, Gharti MP, Shrestha JK, Upadhyay MP, Pokhrel RP. Socioeconomic barriers to cataract surgery in Nepal: the South Asian cataract management study. Br J Ophthalmol. 1998 Dec;82(12):1424-8.

1.3 Study question and hypothesis

This study answers the following question:

1. What is the effectiveness of an interventional model, focusing on community health education of women, on the prevalence of low vision and blindness among people living in rural Upper Egypt?

It is hypothesized that building a gender sensitive community based interventional model that increases awareness of eye diseases and available services will effectively and efficiently increase service uptake and decrease the burden of low vision and blindness in this area.

1.4 Study significance and verification

The need for this study was identified and verified by the Ministry of Health and Population in Menia Governorate, the National Mother and Child Care Program, local government officials, and village leaders. Moreover, the International Agency for the Prevention of Blindness in the Eastern Mediterranean region highlighted the great impact of visual disability on other serious health problems including mortality rate, other comorbidities, and psychiatric diseases.

Background

Egypt's population (72 million) is characterized by a high fertility rate (3.1%) and high annual rate of population increase (2.1%) with the population projected to reach 95.9 million by the year 2025. More than half of the population (57%) lives in rural areas in household (extended family) settings. Approximately 15.6 % of Egyptians are totally illiterate^{1,2}. The Growth National Income (GNI PPP per capita) is 4,680 US\$, where the percentage of people earning less than 327 US\$ per year (poverty line) is 21%.

Egypt spends only 2.2 % of its GDP (92.9 billion US\$, 2006) on health, and 4.5% on education. Clean piped water is available for 98% of urban areas and 91.6% of rural areas. Moreover, 53.6% of urban households and 26.4 % of rural households have periodic garbage collection systems³. Skilled doctors and well equipped facilities are unequally distributed, with a bias towards urban areas. Each rural village has at least one

¹ Demographic Highlights for Egypt [Internet]. 2006 [updated 2008 May. 19; cited 2009 Jun 29]. Available from: http://www.prb.org/Datafinder/Geography/Summary.aspx?region=10®ion_type=2

² Demographic Indicators for Egypt [Internet]. 2006 [updated 2008 Jun. 11; cited 2009 Jun 29]. Available from: <http://www.census.gov/ipc/www/idb/country.php>

³ El-Zanaty F, Way A. Egypt Demographic and Health Survey. Cairo: Ministry of Health and Population, National Population Council, El-Zanaty and Associates, and ORC Macro; 2006 Feb. 238 p. Report No.:FR176.

village health unit providing primary medical care that includes a general practitioner, some nurses, and health workers.

The prevalence of blindness in Egypt is high, especially in rural areas where it reaches 7.9% among adults 50+ (8.1% for females and 7.7% for males). The prevalence of low vision is also very high (38.2% among people over age 50; 39.8 % for males, and 32.3% for females). Major avoidable causes of blindness are similar to the regional causes which are; cataract or uncorrected aphakia (64.0% overall; 58.5% among men and 67.4% among women), corneal opacities due to trachoma and other causes (30.2% overall; 27.9% among men and 31.6% among women), and others including glaucoma, refractive errors, retinal conditions (5.8% overall; 13.6% among men and 1.1% among women). The cataract surgical coverage rate (CSCR) is still below the WHO recommended figure where it is estimated at 50,000/year. For a total population of 72 million, the CSCR for the year 2005 (# Cataract procedures/million) is 714. The target recommended by the WHO and the International Agency for the Prevention of Blindness (IAPB & Vision 2020 Initiative) for Egypt is between 2000 and 3000. This situation is even worse in rural area where only 13% of eligible individuals (similar for men and women) undergo surgery. . Among cataract surgical patients only 9.4% receive an intra ocular lens (IOL). Nonetheless, among the patients with aphakic surgery, 44% get a presenting vision of 6/60⁶⁻¹⁰. Available data suggest that vitamin A deficiency is not a public health problem or a main contributor to blindness in Egypt as it is in other African countries.

The prevalence of active trachoma (follicles (TF) and/or intense inflammation (TI)) is high among children aged 1 to 15 years old reaching 36.5%. It is twice more common in rural areas than urban areas (OR: 1.89), meanwhile, the prevalence of Trichomatous Trichiasis (TT) in adults is 6.5%. Women have an age adjusted odds of Trichiasis of 1.68 compared to men. This disease is 2.11 more common in rural areas versus urban areas. TT is the second most common avoidable cause of visual loss accounting for 8% of blindness and 13.2% of low vision cases. Overall, Trichiasis surgical coverage is 34.4%, which is slightly higher among men than women. The

¹ Fouad D, Mousa A, Courtright P. Sociodemographic characteristics associated with blindness in a Nile Delta governorate of Egypt. *Br J Ophthalmol.* 2004 May;88(5):614-8.

² El-Bayoumy BM, Saad A, Choudhury AH. Prevalence of refractive errors and low vision among school children in Cairo. *East Mediterr Health J.* 2007;13(3):575-9.

³ Saad A, El-Bayoumy BM. Environmental risk factors for refractive error among school children. *East Mediterr Health J.* 2007;13(4):819-28.

⁴ El-Gilany AH, el-Fedawy S, Tharwat M. Causes of blindness and needs of the blind in Mansoura, Egypt. *East Mediterr Health J.* 2002;8(1):1-12.

⁵ Aboel Fetoh NM, Esmail AM, Eltorkey MA. Epidemiology of trachoma in a sample village of Sohag Governorate. *Egypt. J. Community Med.* 2008;26(1):59-69.

outcome of Trichiasis surgery is still very poor in 44.4% of cases due to poor surgical techniques and high recurrence rate especially in rural areas¹.

Avoidable blinding conditions from a gender perspective

Cataract

Developmental or age-related cataract is the leading cause of blindness worldwide (70%).² Its prevalence remains low (<1%) until approximately the fourth decade when it rises to as high as 5-10% of people over the age of 50 (13% of the Egyptian population)³, depending on regional surgical coverage rates. Cataract surgical coverage varies widely in different countries. Typically the lowest coverage occurs in countries with the lowest per capita income. Women have a slightly higher age-adjusted incidence of Cataract compared to men, but this biological difference (0.1%) is small compared to the large difference in prevalence between men and women⁴. Cataract blindness has some specific aspects as follows:⁵

- Women account for 65% of Cataract blindness.
- Women are less likely to have Cataract surgery than men.
- Women have poorer surgical outcome than men.
- Poverty creates gender specific barriers and access to cataract surgical services.
- Women face particular attitudes i.e. '*they are less likely to need surgery*'.

Trachoma

Trachoma is a form of chronic contagious conjunctivitis caused by *Chlamydia trachomatis*. It is characterized by frequently repeated infections in childhood, which lead to thickening and scarring of sub-conjunctival tissue and gradual shrinking of the lids. Scarring of the upper eyelids can lead to in-turned eyelashes (trichiasis) resulting in a varying degrees of corneal opacity and consequent loss of vision. Trachoma is most contagious in its early phases, and may be transmitted directly through hand to eye contact or indirectly by handling infected materials (clothes or towels) or borne by flies. Prevention involves face washing, reducing fly populations and improving hygiene^{6,1}.

¹ Ezz al Arab G, Tawfik N, El Gendy R, Anwar W, Courtright P. The burden of trachoma in the rural Nile Delta of Egypt: a survey of Menofiya governorate. Br J Ophthalmol. 2001 Dec;85(12):1406-10.

² Thylefors B, Négrel AD, Pararajasegaram R, Dadzie KY. Global data on blindness. Bull World Health Organ. 1995;73:115-21.

³ Egypt Population and Housing Census. Cairo: Central Agency for Public Mobilization And Statistics; 2006.

⁴ West SK, Valmadrid CT. Epidemiology of risk factors for age-related cataract. Surv Ophthalmol. 1995 Jan-Feb;39(4):323-34.

⁵ Lewallen S. et al. 2002, Op. Cit.

⁶ West SK, Munoz B, Turner VM, Mmbaga BB, Taylor HR. The epidemiology of trachoma in central Tanzania. Int J Epidemiol. 1991 Dec;20(4):1088-92.

Although the prevalence of active disease is similar for boys and girls, adult women tend to have more active disease than adult men, probably due to their more frequent interaction with children.² As a result, women account for about 75% of all Trachomatous Trichiasis (misplaced eyelashes that impinge on the cornea and conjunctiva) and subsequent blindness due to corneal scarring.¹⁷ Trachoma is declining in many countries, but remains as the second leading cause of blindness in Africa.³ Trachoma remains hyper-endemic in Egypt, and some other African countries.^{4,5}

1.5 Literature search for developing the community-based health intervention for the prevention of blindness

A literature search was conducted using electronic databases: Pub Med, Medline, EBSCO, Science Direct, Elsevier, UBC library, WHO Hinary, Google scholar as well as hand searching of references in relevant articles. The search strategy utilized the key words: prevention of blindness, cataract and trachoma, health education strategies, community-based interventions, gender sensitive interventions, and synonymous alternatives. Meshwork, forward and backward techniques were used to track related articles. The search period was 1980–2006 for developing the intervention model and continued to 2010 for documenting and discussing the results.

Publications were included if they were studies of community-based health interventions that included an educational component and focused on prevention of blindness. The preferred study design was a randomized, controlled comparison of intervention and non-intervention communities that measured the impact of the health intervention on utilization of health services and the impact on health outcomes. It was also critical that the study be conducted in a low income country. Due to the very small number of relevant studies available, the inclusion criteria were broadened to include research that presented community intervention models of all types, but they needed to examine the prevention of blindness in a low-income setting.

¹ Emerson PM, Lindsay SW, Walraven GE, Faal H, Bogh C, Lowe K, et al. Effect of fly control on trachoma and diarrhoea. *Lancet*. 1999 Apr 24;353(9162):1401-3.

² Wolfson EM, Fedewa I, Young SA. Trachoma: a woman's health issue. Revised ed. New York: The Global Alliance for Women's Health; 1999. 27p.

³ Lewallen S, Courtright P. Blindness in Africa: present situation and future needs. *Br J Ophthalmol*. 2001 Aug;85(8):897-903.

⁴ Munoz B, Aron J, Turner V, West S. Incidence estimates of late stage of trachoma among women in a hyper endemic area of central Tanzania. *Trop Med Int Health*. 1997;2:1030-8.

⁵ West SK, Congdon N, Katala S, Mele L. Facial cleanliness and risk of trachoma in families. *Arch Ophthalmol*. 1991 Jun;109(6):855-7.

The primary search yielded 377 journal articles, book chapters, conference presentations, related websites and project reports. Twenty-five of these met the inclusion criteria and full articles were retrieved. Most studies were excluded because they did not study a low-income country or focus on eye care, while others only studied a limited health intervention such as distribution of medication, without health education component. .

Of the 25 include papers, 9 studies provided material useful to the development of the community intervention model used in this project in Menia. The 9 studies are described in detail below and their contribution explained in terms of five axes: 1) cataract services, 2) trachoma services, 3) gender specific interventions, 4) study design, 5) community health intervention models.

1. Interventions to increasing cataract service uptake (specifically by women)

In the year 1991, Girija Brilliant and colleagues¹ studied the social factors that may control surgical utilization in India. The study aimed to address underutilization of cataract surgery and to describe the community behaviour as related to a range of social characteristics. Moreover, it compared the cost effectiveness of eight proposed intervention strategies for increasing awareness and acceptance of cataract surgery. The proposed interventions were based on four different health educating approaches to convey messages about cataract. Cataract screening and follow up surgery were offered to residents in the age 40 years and older in a probability sample of 90 villages. Ten villages were assigned to each arm and other 10 were used as controls.

Interventions details were: (1) house to house visits by a male trained aphakic motivator, where he was able to do screening, (2) house to house visits by a basic health worker, (3) screening at a central village location, and (4) Mass media campaigns conducted in a weekly market place through a van with video display at the back. Two ophthalmic assistants accompanied these educational campaigns and they provided eye examination for self selected subjects. Two economic incentives were alternatively added to each of the four health education interventions; (a) providing free surgery and free eye glasses which were offered in all sites, (b) providing free transportation to and from the hospital in addition to offering free meals during surgery.

Important study findings showed that; female specific prevalence of cataract is much higher than male's prevalence. One third of cataract patients who underwent surgery were still blind. The most effective intervention was the aphakic motivators with full economic incentives. All educational methods had little effect on increasing the awareness to

¹Brilliant GE, Lepkowski JM, Zurita B, Thulasiraj RD. Social determinants of cataract surgery utilization in south India. The Operations Research Group. Arch Ophthalmol. 1991 Apr;109(4):584-9.

cataract surgery. Cost was not the principal deterrent to surgery. Beliefs, feeling no need, and lack of social support were the effective factors. Females were more likely to cite lack of someone to accompany them and fear of surgery. The need for continued health education was underscored by the finding that; one fifth of the bilaterally blind didn't wish to have surgery. Gender is a very important factor affecting acceptance of surgical procedures. However, it is confounded by social and economic factors. The study suggests that; "health education without economic incentives may not be effective, people from the same community may be highly effective than externals even if those externals have better education, training and prestige. Door to door visits may improve the surgical acceptance rate". The study also recommends merging screening with educational campaigns as a method for increasing surgical uptake within a gender sensitive perspective where males were more likely to accept surgery than females.

This study was unique in comparing 8 different permutations that are built on and accounting for the community perceptions. It is the first study that doubts cost as an "actual" barrier. It also sheds the light on the fact that female specific barriers are really different from male specific barriers. The authors raised the issue that gender as a factor should be controlled in order to measure the actual effect size of other socioeconomic factors. However, one of its disadvantages is neglecting the provider's related barriers. On line with the previous paper, it assumes that everything will be fine if we motivate the patient to seek services at the hospital.

Snellingen et al study¹ aimed at determination of possible reasons for non-acceptance of surgery, and to explore whether impairments of visual and psychological functions influence the decision making process of accepting surgery. In this study, inhabitants aged 40 + were invited to eye examination by specially trained local health and social workers. Confirmed cataract patients were invited to subsidized cataract surgery plus free transportation at the local hospital. One year later, those who refused Cataract surgery and their guardian relatives were interviewed.

Findings from this study showed that; males were more likely to accept surgery than females. This difference increases as visual acuity decreases. However, blind patients were more likely to accept surgery than other groups. At the one year follow up of non acceptors, the majority of this group were females, illiterate and with a significantly low visual functioning score. The most effective barriers were; logistics, and economic related, followed by; fear of surgery, and lack of time. Visual dysfunctions were self reported as; need for help during bathing, going to toilet, eating, dressing, visiting neighbours, and working in the field. Psychosocial impairment included; feeling a burden

¹Snellingen T, Shrestha BR, Gharti MP, Shrestha JK, Upadhyay MP, Pokhrel RP. Socioeconomic barriers to cataract surgery in Nepal: the South Asian cataract management study. Br J Ophthalmol. 1998 Dec;82(12):1424-8.

on the family, feeling rejected, and having lost self confidence. After one year of the initial screening, 37.5% of the sample had further deteriorated vision, although 66.7% of those reported that they are now more willing to have surgery. The study concluded that; offering free/subsidized surgery is not solely enough. Opportunity cost of being off work and the lack of self motivation are also important. It also highlighted that “patients with increased need for personal assistance are more likely to accept surgery”. There is a lot of misconception between doctors and patients (and his/her relatives or guardians) in terms of perception about the need for and the value of surgery. Snellingen emphasized that “some of the increased male willingness to accept surgery is attributed to culture where males are more mobile, while females are confined to the household”. There is a need to cross the wide gap between health systems and the community.

One of the advantages of this study is including visual functioning index and accounting for its impact on both psychological and quality of life aspects. It also highlighted that; decision making is a process rather than an action. This process goes through pathways in which family and other nearby relatives may interact. It also noted that; even if services are qualified and available, there is still a need to meet the unmet need by crossing the gap between the recipient and the provider.

On the other hand, one of its disadvantages is the discontinuity of intervention. Whereas, inviting people from the villages to be screened, referring those with decreased vision to the eye camp, and finally referring those confirmed with cataracts to the local hospital through three steps of identification and referral will result in a considerable number of decrements (during invitation), drop outs (at the camp), and no show up (at the hospital).

In 2002, J Xu and colleagues¹ conducted a community interventional trial to test various strategies to improve cataract surgical rate in three counties in rural china. Xu was looking forward to accelerate the surgical rate in order to decrease the backlog and cope with the increasing annual incidence of disease. The study applied two different interventional strategies in three different arms with similar settings. Each arm was already served by a local county hospital with a small ophthalmology department. At the first arm; they trained primary health care workers in recognition and referral of Cataract patients. At the second arm; the intervention was to reduce the charged fees for intra-capsular Cataract surgery to compromise the fees of the extra-capsular surgery. This reduction was announced by radio and TV which are widely followed by the local people. Both models were merged and applied together in the third arm. Patients who were identified and referred to hospital or those came forward to the local hospital in response

¹ Xu J, Zhu S, Li S, Pizzarello L. Models for improving cataract surgical rates in southern China. *Br J Ophthalmol.* 2002 Jul;86(7):723-4.

to the media campaigns were enumerated and followed to see whether they eventually had surgery.

Important study results revealed that; the Cataract surgical rate (CSR) has increased from baseline as follows; (from 89 to 309) in the first arm where the screening and referral training was applied. In the second arm where the reduction of fees was applied and announced, CSR has also increased (from 63 to 487). Finally, in the third arm where both interventions were applied, the CSR has drastically increased (from 114 to 1120).

The study concluded that; “logistics of mobilizing cadres needed to identify, refer, and operate on thousands of individuals in need for cataract surgery is formidable”. Especially in countries like China, where the need is high and increasing. It is clear that the synergetic power of combined interventions is even greater than the additive power of single interventions (Screening and referral increased the CSR by 3 folds, lowering the cost by 5 folds, both methods together by 10 folds). Any implemented intervention should be cost effective in order to be applicable. There is a need for a more realistic model that considers improving economies of scale and adopting outpatient surgical procedures, hence, can lower the surgical fees.

This community interventional trial adds a new important component by training of a large number of medical staff on screening and referral of Cataract patients to get served at the local hospital and compare it to one of the major barriers which is cost. However, the paper wasn't clear about how was this intervening conducted. i.e. is it from door to door or aggregated / central? Moreover, the authors had a very good opportunity to give us more information about this specific community, for ex. What were the major barriers? They assume that only knowledge and / or awareness and cost are the major barriers that should be tackled. Although the study hypothesis is promising, results were only expressed in terms of counts / percentages which may not be enough to efficiently evaluate the intervention outcomes. Despite these disadvantages, the study has mathematically proved the synergetic power of including more than one effective component in one intervention model to increase Cataract surgical uptake.

In 1985, Girija E. Brilliant and Lawrence B. Brilliant¹ evaluated the effectiveness of community awareness & beliefs towards cataract surgery. Important study results revealed that; females were more affected by cataract than males, cataract surgical coverage (CSR) is very low in Nepal with male's utilization level higher than females, cataract surgical rate (CSR) is affected by literacy, gender, and geographical residence. Relatives accompany and family supports are the main predictive factors for accepting surgery. Quality of provided service was quite poor as one fourth of patients who underwent cataract surgery either remained blind or needed corrective glasses.

¹ Brilliant G. et al. 1985 , Op. Cit.

Traditional treatment for Cataract is still utilized via what's so called couching technique. Only 52% of the interviewed sample was aware of cataract surgery. Transportation, communication, living in rural areas and health resources are the most important factors that lower such awareness level. Sex has confounding implications on knowledge about and access to health resources. Gender wise, "males were more aware if physicians were available, while females were more aware if traditional healers were absent and if their socioeconomic status was good".

In Conclusion, the study highlights the importance of community health education as a method for increasing surgical uptake. This health education should focus on rural areas and should be directed to the whole family as relatives and family decisions are important factors affecting service utilization. The delivered message should highlight Cataract as a cause of blindness; it can be cured by an effective, painless and available surgery. This surgery should be done prior to complete vision loss. It should also highlight that traditional healing may lead to dangerous outcomes. Village health workers are the most effective educational agents. Messages are less effective if disseminated through radios, TVs, newspapers, etc. female awareness of surgery is totally different from male's awareness. Socioeconomic and other household characteristics affect women more than men. Women also have exclusive domestic role in rural areas. Thus, a community channel is required to reach those women. Successful operations are the best motivation to service uptake.

One of the advantages of this paper is that it tried to understand the community perceptions and to find in depth reasoning behind low service uptake in presence of almost available and free services. It gives a clear picture about the required practical model of intervention and its important components. It also highlights the differences between males and females in terms of the impact of the socioeconomic characteristics on CSR. Despite recommending opening a channel to reach women, what is missed by this study is how exactly this channel would be opened. The study prefers health workers as message transmitters; however, this may not always work in some conservative communities. Also, it assumes that; increasing awareness by itself may decrease barriers or encourage people to seek service. In fact this may be partially true, but in presence of two important other components; one, is to have a supportive mechanism for decreasing each specific group of barriers, and two; assessing the provided services in terms of quality and other service provider's related barriers.

Barriers to eye care service utilization is the third underlining axis in the process of service uptake. Cost barrier, is always on top of the prioritized barriers. Cost, can be further classified into several subclasses of cost-related berries, of which are; direct cost (service cost), and indirect cost (transportations, food and beverage, days off work, etc.). The cost barrier (including its subclasses) is highly effective in poorer developing countries with high population size where resources are scarce and less is spent on

healthcare. In 2004 Muluken Melese¹ and colleagues attempted to assess the use of eye care services and reasons for a failure to use such services. Results of this study showed that; Cataract surgery was the primarily needed service for the blind, followed by Trichiasis surgery. Surprisingly, the majority of people were aware of their vision loss problems, while one third of them reported that they have previously used eye care services. Factors associated with low service uptake were; Gender (female), visual impairment level (blind), and laterality of visual disability (bilateralism). The study concluded that; the majority of causes of low vision and blindness were treatable (Cataract) or preventable (Trachomatous Trichiasis). Indirect costs are the major barriers to eye care service utilization. This suggests that efforts are needed to create mechanisms that can bridge the communities and eye care facilities. Melese indicated that “a holistic approach that deals both with the quality of services and the effective socio-cultural factors is badly needed”. The study also recommended that “organization of Trichiasis surgery at peripheral health centers and screening programs which identify and facilitate transportation to hospitals for Cataract patients is one of the successful approaches (outreach caravans)”. Two other important issues were highlighted by the Melese study: (1) “the indirect burden of accessing eye care on the family may be lessened by encouraging patients to have surgery earlier (before they need assistance to reach the hospital), and by improving the efficiency of existing services” and 2 “Promotion of services must be gender sensitive to ensure that specific roles of women are considered. Training and placement of Cataract surgeons in rural hospitals would also enhance provision of eye care for the rural population”. There should be a way to create intra-community support that can overcome barriers like need for accompany or someone to take care of children. Community health education, early detection and referral in addition to implementation of primary health care systems would also lessen the financial burden of blindness.

The Melese study has the advantage of looking at people from four different perspectives as regards; gender, disease-specific, severity of visual loss, and bilateralism aspects. Meanwhile, it attracts the attention that training and capacity building of local service provider is one of the critical issues. It also highlights the importance of establishing a mechanism for early detection and early referral of cases which can – by its turn – reduce the barriers effect. By this, it added new dimensions to be considered by model developers. Another important point is that intervention programs should deal with avoidable causes such as cataract and TT, whereas, it may result in immediate and observable decrease of the burden within a manageable intervention. Conversely, targeting diseases such as glaucoma, and retinal diseases, may require sophisticated

¹ Melese M, Alemayehu W, Friedlander E, Courtright P. Indirect costs associated with accessing eye care services as a barrier to service use in Ethiopia. *Trop Med Int Health*. 2004 Mar;9(3):426-31.

interventions that are usually difficult to provide and may have less impact on the condition, especially on a wide scale.

A major limitation of this study was interviewing persons with visual acuity $< 6/18$ which may not give a good indicator of barriers because this group includes a large number of individuals with mild refractive errors, who are not actually visually impaired people (case mix). Another limitation – which is highly related to the previous one - was excluding patients with Trachomatous Trichiasis from the interviewed group because they may have a within-normal vision, while it is important to understand the perception about eye care among both groups, and their specific barriers when seeking services. Especially, when the study found a significant difference between Cataract and TT patients. In classification of barriers by gender, it was clear that both Cataract and Trichiasis patients tended to report barriers related to cost (either direct or indirect). In contrary, female patients tended to report social support barriers i.e. *"no one to accompany"*, or *"no one to take care of the children"*. This should attract our attention to the necessity of tackling social barriers as well as financial barriers and attribute them to disease specific and gender specific characteristics.

2. Increasing trachomatous trichiasis service uptake, and characteristics of available models

The Melese study supported the fact that; “trachoma is a leading cause of preventable blindness in Ethiopia like in most of the African and Asian developing countries”. The second successive step is to implement intervention models whether they were disease specific or integrated to target blinding diseases.

One of these models is application of the SAFE strategy to combat trachoma, where “S” stands for Surgery, “A” for antibiotics, “F” for face washing and “E” for environmental changes. The SAFE strategy was highly successful in controlling trachoma in different countries¹. Thus, it has become the most commonly recommended strategy to eliminate trachoma by WHO and the Vision 2020 Initiative. However, two major issues should be considered; first is long term effect or simply “*sustainability*”, and second, the cost effectiveness and applicability. Trachoma levels were found to increase again after a moderate period of more or less six month of SAFE application particularly among children². Also, the cost effectiveness of the SAFE strategy was widely variable

¹ Kuper H, Solomon AW, Buchan J, Zondervan M, Foster A, Mabey D. A critical review of the SAFE strategy for the prevention of blinding trachoma. *Lancet Infect Dis.* 2003 Jun;3(6):372-81.

² Ngondi J, Gebre T, Shargie EB, Adamu L, Teferi T, Zerihun M, et al. Estimation of effects of community intervention with antibiotics, facial cleanliness, and environmental improvement (A,F,E) in five districts of Ethiopia hyperendemic for trachoma. *Br J Ophthalmol.* 2010 Mar;94(3):278-81.

worldwide. For example; in a study in Gambia, the economic burden of blindness due to Trachomatous Trichiasis (TT) was approximately 90 US\$, while the overall cost of surgery plus antibiotics (receiver and provider) was found to be 10 US\$¹. Generalizability of such successful approach is specifically conditional per se. As a matter of fact; only two components are quite applicable; these are surgery (including training & building local providers capacity), and face washing (including school and other community specific programs, etc.). Meanwhile, the antibiotic is quite expensive to be used in mass distribution, and the environmental changes require strong governmental programs. Thus, alternative models should be in place to replace these current models and overcome its limitations.

Moreover, an effective model must also consider both medical and non medical factors as much as applicable and doable. Targeting biological and medical factors will only solve 40 % of the problem per se, whereas providing a community health promotion model will overcome the majority of such problems². In prevention and control of low vision and blindness, almost 90% of both biomedical and non-biomedical factors (ecological, demographic, socioeconomic, and cultural) are well known. Tackling the majority of these factors by one model is the challenge. Including a health educational component within the model will help to increase knowledge, raise awareness, and lead to the required behavioral changes^{3,4}.

Within this context, in 2006, Tansy Edwards and colleagues⁵ tried to evaluate the impact of a health education program on the prevalence of active trachoma in children 3 to 9 years old in Ethiopia. Intervention was planned to take place concurrently with Azithromycin administration and distribution of educational materials.

The study results showed that; the prevalence of active trachoma in the first arm (NGO intervention include; A, F, E) was significantly lower than that of the second arm (NGO intervention includes; S, A, F). Knowledge of trachoma, trichiasis, and its prevention methods have significantly increased in intervention villages. The percentage

¹ Frick KD, Keuffel EL, Bowman RJ. Epidemiological, demographic, and economic analyses: measurement of the value of trichiasis surgery in The Gambia. *Ophthalmic Epidemiol.* 2001 Jul;8(2-3):191-201.

² Antonovsky A. The Salutogenic Model as a theory to guide health promotion. *Health Promot. Int.* 1996;11(1):8-11.

³ Harris EM. Assessing community development research methodologies. *Can J Public Health.* 1992;83:S62-S6.

⁴ Syme SL. *Towards a Health Policy for the 21st Century.* 1st ed. London: Redwood Books; 1996. Chapter 2, To Prevent Disease: The Need for a New Approach; p.21-32.

⁵ Edwards T, Cumberland P, Hailu G, Todd J. Impact of health education on active trachoma in hyperendemic rural communities in Ethiopia. *Ophthalmology.* 2006 Apr;113(4):548-55.

of disposing rubbish away of house has also increased. However, there was no evidence on improving or changing the presence of animal feces, or flies within the household. Although reported children's face washing has much improved and that more children were observed with clean clothes, “mothers used the same towels and shawls to wipe their children's' faces”. The paper concluded that; “most probably the reduction in active trachoma was not due to health education messages as there were no behavioral changes reflecting translation of such message into action”.

Tansy study has some limitations that may have obstructed comparison of different health educational methods. For example; all interventions were applied in presence of the mass distribution of Zithromax[®] and the BBC broadcasted message. Thus, most of the effect of the reduction in trachoma prevalence may be attributed to the effectiveness of the very strong (3rd generation) antibiotic and the widely publicized BBC broadcasted messages. Furthermore, the control arm was lacking the actual definition of control, i.e. “*the arm with no intervention or placebo*”. Hence, the researchers in fact weren't comparing intervention to no intervention; they were comparing three different types of interventions. So, they are only evaluating the effect of an additional component to a baseline model.

Because of this limitation, the study didn't manage to isolate the effect of health education as an important component of the model. The importance of health education comes from the fact that; it is the component that tackles cultures, beliefs, misconceptions, customs, and other related community perceptions. Hence, it provides the baseline knowledge necessary to change behaviors towards either seeking service among TT patients or avoiding spread out of infections among trachoma patients.

3. Increasing health service uptake specifically by females

Although prevention and control of low vision and blindness should go through a national wide plan that's usually adopted by ministries of health, the role of NGOs is increasingly encouraged as governments in developing countries usually have very limited resources compared to developmental needs. Also, one of the successful approaches is to incorporate health care axis within other developmental packages. This is not only true for eye diseases, but also for other systemic diseases as well. In Bangladesh, there are a lot of NGOs that work in community development, those NGOs work with the World Bank to improve the health and livelihood of the poor through micro activities focusing on women. In 2003, Syed Masud¹ and colleagues conducted a study to investigate whether overall economic improvements due to NGOs activities will improve health and increase service uptake. The study compared patterns of seeking

¹ Ahmed SM, Adams AM, Chowdhury M, Bhuiya A. Changing health-seeking behaviour in Matlab, Bangladesh: do development interventions matter? Health Policy Plan. 2003 Sep;18(3):306-15.

health services using data of two successive surveys undertaken in 1995, and 1999 in Matlab, Bangladesh. The study compared 3 groups {A: (NGO) members households}, {B: Poor non member households}, and {C: Non poor households} regarding prevalence of diseases and pattern of service seeking.

Important study results showed that; “in both 1995 and 1999 surveys, women have greater morbidity rates than men”. Between surveys, self care increased dramatically from 25 % to 55 %. Consequently, “consultations with both traditional and informal medical practitioners have also increased”. Meanwhile, it was noticed that over 20 % of ill people rely on qualified medical care. The study also yielded that; males as well as older patients were less likely to use Self care than females and younger patients. Households outside the NGOs served areas and those in poor villages were more likely to treat themselves. Males were more likely to seek formal medical care than females.

The cross sectional nature of the Masud study would have allowed detection of associations between potential risk factors and the outcome of interest. However, there is some evidence that NGOs developmental impact would increase the women uptake of service; this is clear between the two surveys comparing the two groups (people with and without NGOs intervention). Women appear to experience slightly greater morbidity than men irrespective of their socioeconomic group. The substantial and continued reliance of women on unqualified providers emphasizes the need to raise social awareness about the value of women's health and well being, and to overcome persistent cultural and financial barriers.

One of the interesting conclusions of the Masud study, which are highly supported by some other studies,¹ is that women classify diseases according to their own perception and pre-existing beliefs into two categories; diseases caused by supernatural forces, in which they seek traditional healers, and other natural diseases, where they go for modern medicine. There is also evidence from the literature that the prevalence of self care is increasing, particularly in countries where there are significant cost barriers to access healthcare or where the quality of medical care is perceived to be declined². Similar studies done in India, Nepal, and Tanzania proved that; targeting women – who are the most affected, less service utilizing group – can effectively improve the overall situation of blinding diseases¹.

¹ Mahbub A, Ahmed SM. Perspective of women about their own illness: BRAC-ICDDR,B Joint Research Project Working. Dhaka: BRAC Research and Evaluation Division; 1997. 32 p.

² Bloom G, Standing H. Pluralism and marketisation in the health sector: meeting health needs in contexts of social change in low and middle-income countries. Brighton, Sussex: Institute of Development Studies; 2001 Jan. 35 p. Report No.:IDS Working Paper 136.

4. Clinical trials are the best methods in evaluating interventions while incorporating health workers would increase its effectiveness

Another perspective of using community inhabitants and workspace colleagues in delivering health educational messages was explored by Lind Forst and colleagues in 2004¹. This study tackled the issue of training community health workers on diagnosis and management of diseases. The study provided evidence on this approach's impact on connecting people to the available services and bridging cultural gaps through providing community health education, social support, counseling, and advocacy. The study highlighted that "this concept was tackled by 140 nationwide community health worker's programs". Moreover, a review of literature by Forst and colleagues found out 275 citations to 20 articles (8 of them were clinical trials) evaluating community health workers effect in preventing eye injuries in workspace.

Important results of this study showed that; "training and usage of work colleagues as promoters has a great impact on using protective eyewear as opposed to non trained or absent promoters". However, using untrained promoters was still better than their absence.

The major advantage of this study is that it was conducted within an RCT study design. Thus, although (Lipscomb 2000)² discussed 7 similar intervention studies that all increased knowledge and reduced eye injuries, none of them was an "RCT". Meanwhile, faculty staff and NGOs contribution added a lot of value in addition to collaboration with workers and the business owners. The Forst study concluded that; there is also a need for a longitudinal cohort study that would look at sustainability of eyewear use among this community. The study had also raised three important issues; first, involving health workers from the same community, second, involving local NGOs in collaboration with the academic expertise, and third, the importance of sustainability after the end of the program. However, some of these study limitations are due to; having different types of workers who may work on seasonal bases or change their work location during the season. Thus the studied community is unstable. Also, workers are hired in a tree system (relatives or friends). There was a need for multi-staging approach to control for that potential bias which may have violated the validity of the "RCT".

¹ Forst L, Lacey S, Chen HY, Jimenez R, Bauer S, Skinner S, et al. Effectiveness of community health workers for promoting use of safety eyewear by Latino farm workers. *Am J Ind Med.* 2004 Dec;46(6):607-13.

² Lipscomb HJ. Effectiveness of interventions to prevent work-related eye injuries. *Am J Prev Med.* 2000 May;18(4 Suppl):27-32.

5. Crucial concepts and considerations in developing and implementing health education models for prevention of blindness

In 2006, a land mark review paper was done by Hubley and Gilbert¹ that covered the major considerations while developing a health educational intervention. These include:

Importance of human behavior: In promoting human behavior to prevent blindness, “one part is to encourage the adoption of eye health promoting behavior, while another part is to discourage behavior that damage eye health”.

The concept of eye health promotion: This concept is relatively new (1986 Ottawa Charter)². It implies 3 main areas of action: health education, reorientation, and advocacy. To achieve behavioral change, two critical requirements should be fulfilled; “addressing the underlying influence on behavior, and selection of the appropriate methods and target groups”. This requires a deep understanding of the influences on behavior before planning for health promotion. This understanding can be fulfilled with qualitative research methods. Barriers and behaviors can be classified into main domains where each health education program should be designed and tailored to address the specifically targeted group of barriers.

Choice of the setting for health education: The ideal “*community based program*” that adopts “*community participation*” should involve the community in “*deciding their own health priorities, solutions, resources, implementation, and monitoring & evaluation methods*”. However, this approach is not widely applied. Application of such programs is ranging in methodologies from extremely pre-made decisions to participatory development approaches. Studies have found that community based approaches using volunteers and community groups can have an impact on eye health knowledge and on the incidence of trachoma. One of the strengths of community based approaches is joining them with other strategies (multi-sector approach).

Implementation methods: Many different methods can be used including; mass media and face to face communications. Pre and post tests and interviewing people are important to measure the impact of such campaigns. Messages should be simple, relevant, and acceptable, able to attract the attention to the issue, and easily understood. This approach is quite successful for simple changes in absence of significant barriers. In situations involving persistent behaviors, more intensive community based approaches should be used such as face to face discussions.

¹ Hubley J, Gilbert C. Eye health promotion and the prevention of blindness in developing countries: critical issues. Br J Ophthalmol. 2006 Mar;90(3):279-84.

² Ottawa Charter for Health Promotion. An International Conference on Health Promotion. Copenhagen: WHO Regional Office for Europe; 1986 Nov. 21p.

Importance of capacity building of services: Health educational interventions can never work alone; service improvement should go side by side with it to absorb the increase in demand for service. Thus, improvement should address locally identified barriers - including clinical and non clinical aspects - quality of service, clinics timing, operating sessions, separate men & women waiting areas, culturally accepted food, availability of prayer areas, clean environment, etc. another very important issue is providing good information to patients regarding adherence to treatment regimens, follow up, possible side effects, prevention of recurrence, etc.

Advocacy: Advocating to leaders and policy makers should be implemented. Advocacy includes all activities designed to raise awareness of the importance of blindness prevention among policy makers and planners, to increase resources for blindness prevention, and for integrating blindness prevention into other programs. This may lead to enactment and enforcement of existing laws or require development of new bylaws & rules. Advocacy can be done on three levels; international & regional (endorsement of vision 2020, the right to sight initiative by WHO, May 2004)¹, national (advocate to policy makers, media campaigns, local (district level) meetings, public awareness, and working with local NGOs, and professional associations).

In conclusion, Hubley and Gilbert summarized the concept of eye health promotion as an integrated approach for prevention of blindness in a systematic way. It provides a very interesting categorization of human behaviors promotion outlining what should be encouraged and what should be discouraged to achieve prevention and / or control of blinding diseases. Moreover, it provides details about empirical methods to implement such interventions in terms of material, data collection techniques, and community involvement. This paper also highlights the fact that design of health education material should be preceded by studying community perceptions in order to identify best possible interventions.

6. Overall conclusion

As an overall conclusion, the reviewed studies in each of these sections created a general framework that can be summarized as follows;

The prevalence of low vision and blindness in most of the developing countries is high. Most of the known blindness is avoidable. Cataract and Trichiasis are the main causes for this type of blindness where they both constitute around 70 % of its burden. Females, are more likely to suffer such diseases and less likely to seek services. To combat this needless blindness certain procedures of prevention and treatment are needed. Application of such procedures in a sporadic / disaggregated way will never

¹ Elimination of Global Blindness Agenda item 14.17 56th World Health Assembly. Geneva: World Health Organization; 2003 May. 2p. Report No.:WHA56.26.

solve the problem, because, there will be always a deep root of some of the causative factors. Hence, the most convenient way is to adopt a holistic approach for prevention of blindness. Communities – especially poor and rural ones – have either minimum or incorrect knowledge or misconception about eye diseases and the available services. So, to propose this approach, one of the main components should be community health education to raise the community awareness alongside with advocating to policy makers both to gain support and allocate some resources. Nonetheless, other considerations such as potential barriers and associated factors should be understood and encountered through implication of related components or activities.

1.6 Characteristics of the required interventional model

Based on the above considerations, the characteristics that should be considered in any proposed model are:

- Mainly targeting avoidable blinding diseases (namely Cataract and Trachomatous Trichiasis).
- The major component of intervention should be community health education within a context of community health promotion. It should be focusing on increasing service uptake especially surgical services for the needy people. However, it should be conducted to the whole family.
- Other necessary components may include; screening, referral, and breaking down barriers.
- The model should be tailored to fit with specific community characteristics, social and cultural factors.
- The model should work on both the organization of provided services and the community needs; this can be done through capacity building of local providers.
- The model should be focusing on women and / or become gender sensitive.
- Offering free or subsidized surgeries and free transportation at least at the beginning are two effective components of any successful model.
- On the long ran, the model should also work on a strategy to decrease the cost of surgery.
- Objectives and activities of the model should be both realistic and applicable.
- The model should contain a strategy to maintain sustainability as necessary to avoid recurrence of high rates of blindness.

Characteristics of the disseminated message

As the major component of the proposed model is health education, the crucial component of this health education is the message to be delivered to educate the targeted community. This message should be characterized by being; simple, understood, relative, attract the attention, and suits the community culture. This message also should avoid

being scary, and committed to highlight possible side effects as it highlights expected benefits.

Who are the best candidates to deliver these messages?

Experiences have concluded that; health workers from the same village are the best message transmitters. Although they may be of less training and qualifications, they are more effective than external well trained health educators. Moreover, teachers, local ex-patient, volunteers, medical staff, external experts, and traditional healers can be also involved in addition to local health workers.

How should these messages be delivered?

House to house visits are of the most successful approaches. However, this luxury may not be always achievable. Radio and media, face to face, and gatherings (markets, etc.) are also effective ways of delivering these messages. Another successful way is to incorporate it within other health programs (ex. Vaccination, maternal health, etc.) given that the original program should be well established and showing remarkable success, and enjoying enough resources.

Why focus on women?

Findings from gender and blindness studies noted that “approximately two out of every three blind people in the world are women, older, and ninety per cent of whom live in poverty”¹. Women are more frequently exposed to causative factors. Nonetheless, this high risky group utilizes eye care services less frequently than men.² Consequently, many efforts were done by researchers in different countries³. Experiences from these countries concluded that; gender inequity has been reduced by those eye care programs through local public health initiatives as well as through improving broader community-based services such as water source and sanitation projects. This reduction has much affected the overall blindness in these countries. Findings from these studies recommended that; utilization of eye care services is strongly associated with socioeconomic status and female literacy⁴. Courtright (2004) state that; “female literacy remains the strongest

¹ Abou-Gareeb I et al, 2001, Op. Cit.

² Courtright P. et al, 2001, Op. Cit.

³ Courtright P. et al, 2003, Op. Cit.

⁴ Mwende J, Bronsard A, Mosha M, Bowman R, Geneau R, Courtright P. Delay in presentation to hospital for surgery for congenital and developmental cataract in Tanzania. *Br J Ophthalmol.* 2005 Nov;89(11):1478-82.

predictor of health service utilization by women”¹. Meanwhile, Nirmalan 2003 indicates that “indirect investment in female education improves all aspects of public health, through increasing utilization of the already available health services”². Recommendations were issued to extend such programs to Egypt as well as other similar African & Asian countries.

Evaluation of the model and measuring its outcomes

There are many suggested methods to monitor the proposed model’s activities and evaluate its overall outcomes. However, some of these methods can fit better with the nature of avoidable blindness diseases as the major target of such models:

- It is preferred if the model contains pre and post intervention assessments of low vision and blindness and its determinants.
- One of the convenient outcome measures is the increase in total number of surgeries done. Out of which also specific surgical rates and specific surgical delivery rates (sometimes called surgical win-rates) can be calculated.
- Change in gender equity in treatment seeking.
- Change in beliefs and concepts about eye care utilization among the community.
- Change in level of awareness.

These are the major points that could be concluded from the demonstrated review of literature. These points were considered as guidelines, tailored, and incorporated in developing our model as will be detailed in the following chapters.

1.7 Conceptual framework

Previous research in Menia governorate integrates with the previous results were it limits the problem in four main domains; gender bias, low quality of service, community perceptions and barriers to service utilization. additionally, pilot gender sensitive intervention studies highly recommend training women from the same communities on gender sensitive approaches, screening for primary eye conditions, visual impairment and blindness and use them later on in a women to women approach^{3,4}. For

¹ Courtright P, West SK. Contribution of sex-linked biology and gender roles to disparities with trachoma. *Emerg Infect Dis.* 2004 Nov;10(11):2012-6.

² Nirmalan PK, Padmavathi A, Thulasiraj RD. Sex inequalities in cataract blindness burden and surgical services in south India. *Br J Ophthalmol.* 2003Jul;87(7):847-9.

³ Des Meules M, Kazanjian A, Maclean H, Payne J, Stewart DE, Vissandjee B. Women's Health Surveillance Report: Introduction. *BMC Womens Health.* 2004 Aug 25;4 Suppl 1:S1.Bibliography.enl Page 2

⁴ Des Meules M, Stewart D, Kazanjian A, McLean H, Payne J, Vissandjee B. Women’s health, surveillance report: A multi-dimensional look at the health of Canadian women. Ottawa: Canadian Institute for Health Information; 2003 Dec. 85p.

this model to succeed, two more components should be included; improving the available health services and breaking down of barriers focusing on women particular barriers. By this concept, the current study is aiming at; increasing the overall access to eye care services through *gender-specific*, rather than *gender-neutral*, interventions. In summary; breaking links of the closed circuit that can lead to achieving convenient prevalence of low vision and blindness as explained in the following plot (figure 1.1).

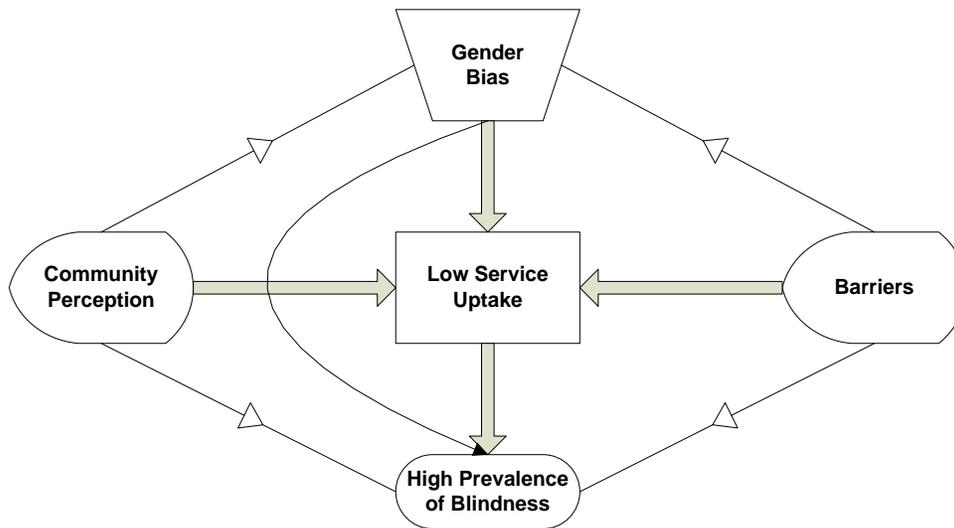


Figure 1.1 Simplified conceptual framework of the study.

Participatory research tools

The current study pays particular attention to establishing and maintaining meaningful participation of the community that involves learning the realities of the people who are not usually heard from or consulted. To gain this knowledge, medical anthropological and sociological inputs are implied. It is well known that questions vary from site to site. Thus, in each instance, a value-based framework is developed to capture these differences. The advantages of using participatory research tools are well documented¹. Angeles (2000) recommends that tools are usually combined, modified and adapted to local contexts to obtain best results and to gather the most accurate data using multiple viewpoints. The challenge is to identify what is meaningful from the perspective of the community - in which - services are provided².

¹ Angeles LC. Using gender-aware participatory research methods in community poverty profiles, project planning and policy assessment. For the Gender and Participation Workshop. Nui Cod Lake: Localized Poverty Reduction in Vietnam Program. Centre for Human Settlements. UBC. CANADA; 2000 Oct. 54 p.

² Angeles LC, Gurstein P. Planning for participatory capacity development: the challenges of participation and north-south partnerships in capacity-building projects. Rev Can Etudes Dev. 2000;21(Special Issue):447-78.

Knowledge transfer-exchange (KTE)

The concept of knowledge exchange - transfer is thoroughly tackled in the current study. The intervention model is based on understanding the unmet needs of the target community and the corresponding barriers that hinder obtaining such needs. The proposed model is also developed to identify, categorize and engage all concerned stakeholders and share their perspectives and insights from the beginning and during the process. Stakeholder's inputs are considered in various phases from planning to implementation including monitoring and evaluation activities. Moreover, the proposed model pays special attention to the specifications of the target community including; culture, religion, customs, traditions, habits and beliefs. As the ultimate goal of the current study is to bridge the gap between the community and the local eye care services, a theory for intervention phases and activities is formulated. This theory is derived upon a baseline assessment of medical, cultural and socioeconomic characteristics of the target community. Consequently, this theory is translated into an integrated strategy of intervention, which - by its turn - is further translated into a group of successive actions. the multi-disciplinary, multi-phases nature of these actions are designed to cover all possible dimensions of the low vision and blindness problem among this specific community. Replication of this model to similar / different communities or settings is quite possible, but will require conduction of baseline assessments to increase its probability to succeed.

Based on the provided conceptual frame work and in the light of the cited literature, the coming chapters demonstrate the methods for developing an integrated model for prevention of low vision and blindness that focuses on the major two avoidable causes; cataract and Trachomatous trichiasis, and targeting women as the group at high risk. The methods section includes developing and implementation of program logic model as a tool for implementation, monitoring and evaluation of the program in addition to justifications and explanations for different model components (Chapter 2). The following chapter (chapter 3) explores the need for understanding community perceptions and the appropriate methods to achieve this understanding before developing the model. It also presents important findings and its role in developing different model components specifically the conveyed messages and the targeted barriers. Chapter 4 demonstrates quantitative results including the major outcome indicators in two different comparative manners. Comparing pre to post intervention figures (evaluating the change), and comparing intervention to control villages in terms of the major indices (evaluating the impact). Fifth chapter discusses the achieved results within the context of the relative literature. Finally chapter 6 concludes the study; provide a debriefed message to the scientific community and highlights potential areas for future research.

Chapter 2: The intervention model: methodological concepts and implementation

2.1 Introduction

Blindness has three main axes; disease encountering, availability of eye care services, and barriers to access these services. Intervention programs can focus on avoidable diseases, empowering service utilization, and breaking down barriers. Most intervention programs usually focus on one approach, targeting one or two diseases and their related barriers. This methodology has been adopted by the WHO and many other prevention of blindness agencies. The literature shows that people may be aware of their disease and have access to treatment however barriers may prevent them from seeking services^{1,2}. Barriers can be categorized into six domains: cost, health status & mobility, decision making, other family & work related barriers, quality and accessibility of eye care, knowledge about the disease complications, and awareness of service availability. Therefore, it is necessary to identify approaches to overcome this Knowledge, Attitude and Practice (KAP) gap. The challenge is to select the best preventive or therapeutic methods to control and/or prevent blindness.

Cataract and Trachomatous Trichiasis constitute the major causes for avoidable blindness. This is also true in the Menia governorate where a blindness survey was conducted earlier (2002). Numerous evaluation studies showed that other approaches can be successful. However disadvantages of these approaches have included: First, they can be considered as an individualized effort targeting either a single disease or a single type of barrier. Second, they have not been designed by incorporating an in-depth understanding of the community perception, beliefs, traditions, and specific circumstances of each community. Third, these sporadic efforts are temporary because any program will be limited by a time frame and a tight budget unless it is a part of the core service. Fourth, sporadic and single perspective approaches do not usually link those in need for service to service providers. Thus, these limitations would never make an intervention sustainable unless we bridge the gap between service recipients and providers. Fifth, it is known that working from a one sided approach is not cost effective, in terms of budgetary issues, logistics, and manpower.

¹ Zhou JB, Guan HJ, Qu J, Yang XJ, Peng D, Gu HY. A study on the awareness of cataract disease and treatment options in patients who need surgery in a rural area of Eastern China. *Eur J Ophthalmol.* 2008 Jul-Aug;18(4):544-50.

² Du Toit R, Ramke J, Naduvilath T, Brian G. Awareness and use of eye care services in Fiji. *Ophthalmic Epidemiol.* 2006 Oct;13(5):309-20.

From this viewpoint, there is a need for models that could accomplish the following. First, identify cases and refer them to the appropriate service after exposure to health education sessions. Second, can design an intervention based on an in-depth understanding of the barriers that prevent patients from getting service. The context successful model should also continue its role after referral of identified patients and should work to facilitate getting the service and monitor receiving such service, and work on building up the capacity of service providers too. There is increasing evidence that women are affected about three times more than men by eye diseases. Moreover, they utilize less healthcare services than men. This fact is enough to explain – through a simple arithmetic calculation – the rationale for targeting women by any proposed intervention. Looking at the potential impact of that, we can say that setting women as a priority for intervention would rapidly increase the volume of served patients and hence decrease the burden of blindness. Therefore, a gender specific approach was recommended by many intervention studies.

2.2 Proposed intervention model

The proposed model in this study consists of three chronologically arranged components (stages). Some of the stages overlap to achieve its goals, while others are executed in temporal order.

Major phases:

The model is classified into three major phases, where each phase includes several sub-phase components;

A. Pre-intervention phase

A.1 Communications.

A.2 Advocacy.

A.3 Pre intervention assessment.

B. Intervention phase

B.1 Understanding community perceptions, culture, and traditions.

B.2 Assessing local service providers.

B.3.Capacity building of local service providers.

B.4 Conduct community health education.

B.5 Focus on Women; needs, priorities, empowering, and impact.

B.6 Surgical case identification .

B.7 Referral of confirmed eligible cases.

B.8. Helping people to get served.

C. Post intervention phase

C.1 Follow up - referred cases and service providers.

C.2 Conduct of outreach caravans.

C.3 Post Intervention assessment.

C.4 Monitoring and evaluation of the intervention.

C.5 Empowering the community to maintain self sustainability.

Model overview

A. Pre-intervention phase

A.1 Communication

Communication is considered as an essential component of any health educational intervention. Early work in health care communication was done 20 years ago by the communications department of the National Cancer Institute (NCI), USA. The rationale for using communication as a pre-intervention step is that communication with all partners and stakeholders helps to establish mutual understanding between the health educators and the local community. Local community should understand, why and what for the health education program is being conducted. Conversely, health educators should understand the community's view on the issue, in order to identify the best strategy and key local personnel that will be required to successfully implement their programs. One of the most accurate definitions of health communications is; *"the art and technique of informing, influencing, and motivating individuals, institutions, and public audience about important health issues"*¹. While as a process, it is identified as a *"systematic and*

¹ Davis RM. Healthy people 2010 objectives: Draft for public comment. BMJ 1998 Nov;317:1513.

*strategic approach*¹". This means mere transmission of information does not always equal effective communication². Moreover, experts further divide this process into 7 successive phases; (1) Problem definition and description, (2) Audience input, (3) Strategy selection, (4) Develop message to be disseminated, (5) Determine appropriate settings for delivering the message, (6) Determine channels for communicating the message within the selected settings and (7) Determine health communication methods³. Thus, it is an essential step to determine the best method to approach a community which if done correctly leads to the best possible strategy to achieve goals.

In the field of prevention of blindness, a community based approach should also consider the pattern of influences and decision making process within family units and the community. This includes involving family members, elders, guardians, local leaders and traditional healers. These influences are often rooted in local culture and traditional health practices. Communication can be also used to raise awareness about issues such as risk factors, symptoms, consequences, potential benefits of treatment, in addition to the availability of services⁴. Effective actions therefore involve moving from a patient only approach to one which involves the family and community in decision making and initiating action. These concepts were first outlined in the Alma Ata declaration in 1978⁵.

A.2 Advocacy

Advocacy is an essential step that should precede an intervention program. The ultimate goal of advocacy is to gain the necessary support and resource allocation to conduct a successful intervention. Two main areas are conceptualization and the target audience. Conceptualization includes providing clarifications about importance, necessity, safety, effectiveness, and benefits related to the intervention. Determining the target audience is required before proceeding with the rest of the advocacy process.

¹ Clift EC, Freimuth V. Health communication: what is it and what can it do for you? Health communication: what is it and what can it do for you? J Health Educ.1995;26:68 – 74.

² Ratzan SC. Revolutionizing health: communication can make a difference. J Health Commun. 1999 Oct-Dec;4(4):255-7.

³ Bensley RJ, Fisher JB. Community Health Education Methods: A Practical Guide. Sudbury: Jones and Bartlett publishers inc.;2003.

⁴ Musa J. The use of an eye care communication program to detect those with Glaucoma and other blinding conditions. International Agency for Prevention of Blindness (IAPB) Newsletter.2004;42:4.

⁵ Hubly J. COMMUNITY PARTICIPATION 'Putting the Community into Community Eye Health. Community Eye Health. 1999;12(31):33-4.

Communication and advocacy are related due to the shared nature of its components. However, there is a distinct boundary between them. Legislative advocacy can be defined as: "*Contact made with a policy maker or legislator to discuss a social or economic problem on behalf of a particular interest group or population as long as no specific bill number is mentioned*"¹. Advocacy is not only targeting policy and decision makers, but it should be also target the community based acting NGOs, civil society and even grassroots organizations. The first type is known as direct lobbying, and the second is known as grassroots lobbying. Both types aim to appeal to community leaders to take action to influence specific legislation.

After advocate selection is complete, a clear advocacy action plan should be set. This action plan should be broken down into a number of tasks. Steps of advocating legalization is classified (by Bensley 2003)² into five steps. These include (1) Identification of the issue, (2) Understanding how policy issues become legislation, (3) Identification of potential partners, (4) Motivating grassroots support, and (5) Identification and working with policy makers.

To whom should we advocate? What do we need to tell them? and what do we need them to do?

In prevention of blindness models, four major groups should be advocated to. These are "*Policy and decision makers*", "*Health sector personnel*", "*Civil society, NGOs, and Community leaders*", in addition to "*community grassroots*". Inherently, we should expect that each group will need a different strategy according to their level of knowledge, perspective, and interest within the context of our requirements. This fact can be further explored as follows:

A.2.1 Policy and decision makers

The message to this group should be to define the issue and its importance with a special reference to the political impact of treatment and prevention. *The ask*" (requirement) component should be clear as politicians will ask "*then, what would you like me to do?*" Their role will be to implement and activate policies that would help in prevention of blindness and give necessary instructions to facilitate the intervention. They may also allocate capital resources like vehicles, buildings for meetings & training, and human resources to contribute in activities, etc.

¹ Vernick JS. Lobbying and advocacy for the public's health: what are the limits for nonprofit organizations? Am J Public Health. 1999 Sep;89(9):1425-9.

² Bensley RJ. 2003, op. cit., p. 359 – 366.

A.2.2 Health sector personnel

Health sector personnel are crucial in health intervention programs for two main reasons. First is that they have the baseline knowledge about the current situation¹, and they are the authorized individuals to deal with and act on. Second, they are trusted by local communities more than external experts. Moreover, they will be the personnel who will be asked to sustain any intervention and continue its activities after the initial program concludes. Advocacy to health sector personnel may be easier than other sectors as they already have an understanding of the whole issue. Difficulties dealing with health sector personnel are that they usually have an exhaustive list of other priorities. They may see the issue as important but not a priority, especially in areas which suffer multiple endemic diseases. One of the good approaches is to highlight the impact of improving hygienic behaviors on overall health status. Strategies for appealing to this group can be to merge primary eye care activities with other tasks of interest like maternal and childhood health. They can be asked to provide help through their governed facilities and manpower. It is also necessary to get their declaration and accreditation of the results.

A.2.3 Civil and elected societies

This group primarily includes parliament members, senators, village mayor, community based associations, local NGOs, and all types of informal lobbies. In addition it may also include religious leaders (Muslim Sheikhs and Christian Priests) who may be of great impact. The message to these leaders must highlight the important benefits to the community and its impact. Community leaders can be asked to increase the community compliance to intervention activities, while NGOs can provide help through its trained staff and experiences with the community.

A.2.4 Community grassroots

All previously described advocacy categories aim to stimulate this group to increase their service uptake. Formal, informal, and health sectors are the catalysts of the utilization equation, but are not the reactive agents. The community grassroots are the ones who will take the action of behavioral change, preventive methods, precautions, and seeking treatment. Before delivering the message there should be a provision about the community profile. For example, if the majority of the individuals are farmers, factory workers, or illiterate the message needs be formulated to suit the interest of this population. Some people cannot be easily reached like the elderly or the illiterate. In

¹ Courtright P, Lewallen S. Improving gender equity in eye care: advocating for the needs of women. *Community Eye Health*. 2007 Dec;20(64):68-9.

these situations, modifications should be implemented like using pictures rather than text, talking to educated grand children or guardians.

The message to this group should highlight the causes and manifestations of the disease, its complications, availability, accessibility, and safety of services and potential beneficiary outcomes. The required actions are to seek service when symptoms are present, to reduce utilization of traditional and self healing methods, to comply with treatment instructions, to seek surgery whenever recommended, and to advocate to others whenever possible¹. In conclusion we want to promote behavioral change among the community and to increase demand, and hence, increase the uptake of eye care services by the community.

Advocacy for intervention programs should be conducted in a stepwise temporal order. Some groups will need to be targeted prior to groups of other categories in order to facilitate buy in and support of the following group. One logical flow pattern is to go from policy makers to health sector, then to community leaders, and finally to the community grassroots.

A.3 Pre intervention assessment

A "*situation analysis*" is an essential step that should precede any planned intervention. This step will not only measure the baseline prevalence for comparison purposes, but also will influence how many trained personnel and how many / what type of equipment are required (preliminary needs assessment). Moreover, "estimation of the number of people that are likely to become blind over a given number of years will guide planning of service provision, and evaluate whether the number of cataracts being done is enough to prevent the cataract backlog from increasing"². A systematic sampling approach through random walk is highly recommended to collect this data as it can geographically cover most of the intervention villages in terms of landscape.

B. Intervention phase

B.1 Understanding of community perceptions, culture, and traditions

Collection of quantitative data gives a statistical view of the selected villages and its population, disease prevalence, its determinants, risk factors, and barriers. However, quantitative data cannot give a plausible explanation for why these diseases persist, and how people think about them. This emphasizes the need for qualitative studies. Such studies provide an in-depth understanding of the targeted population that is helpful to

¹ Hubley J. et al. 2003, op. cit.

² Gilbert C. Epidemiology in practice: An introduction, J. Comm. Eye Health. 1997;10(21):8 – 10.

better tailor the proposed intervention. This understanding works in integration with the quantitative figures, and this is not possible unless we use qualitative techniques. It is worth saying that social and cultural factors are as important as clinical ones. The aims of this qualitative research are “to understand the community and provider perceptions and the potential motivations & its impact on health behavior”¹.

B.2 Assessing local service providers

A local provider can be defined as ‘the nearest accessible eye care hospital that can provide affordable eye care (up to tertiary level) with acceptable quality’. This definition implies the criteria of: being accessible and having affordable prices for major surgery. Affordable prices have been defined in the literature as the amount equivalent to one month salary². Local provider’s characteristics are usually applicable for governmental hospitals. Local eye care facilities need to be major partners in any proposed intervention. However, selection of governmental health care providers does not mean ignoring the role of nongovernmental and private sector providers. Collaboration between community, NGOs, private sector and formal sector of eye care providers would work collaboratively to maximize the program benefits³. Although working with rural communities is usually targeting the poor class of these communities, the intermediate and upper classes will be affected as well; however this latter class will most probably seek services at the private sector to assure high quality and more comfortable care.

As the ultimate goal of the model is increasing service uptake by our targeted community, we need to evaluate whether the service provider is capable of providing this service in a good quality, and to a high volume. Four essential areas need to be assessed in order to evaluate eye care service providers. These are Space, Personnel, Equipment, and System

- (A) **Space**; should be capable of comfortably accommodating a large number of patients and eligible for expansion or re-allocation of units. Gender and culture related issues such as privacy, prayer areas, etc. should be considered.
- (B) **Manpower**; areas to be investigated include competency, skill, knowledge, experience, and capability to skill & knowledge upgrade.

¹ Green J. Qualitative methods. *Community Eye Health*. 1999;12(31):46-7.

² Melese M, Alemayehu W, Friedlander E, Courtright P. Indirect costs associated with accessing eye care services as a barrier to service use in Ethiopia. *Trop Med Int Health*. 2004 Mar;9(3):426-31.

³ Molyneux DH, Nantulya V. Public-private partnerships in blindness prevention: reaching beyond the eye. *Eye (Lond)*. 2005 Oct;19(10):1050-6.

- (C) **Equipment;** existence of necessary equipment that includes diagnostic, investigative, therapeutic, surgical, and administrative tools are crucial at any hospital.
- (D) **System:** is everything regulating work processes and documents it, this would include; medical filing, policies and procedures, standardized care (clinical guidelines), efficient communication of documents and records, quality of financial documents, rules and bylaws, organizational chart and hierarchy of decision making, and all other administrative and financial regulations.

B.3. Capacity building of local service providers

One of the major obstacles to the provision of eye care or low vision services is “the lack of cooperation between eye care and education/rehabilitation programs”¹. Conversely, some health education programs may have a disappointing impact on eye health² that's why, a key challenge regarding sustainable continuation of an ongoing community intervention is to establish effective coordination among various eye care service providers³. Space, Personnel, Equipment, and System, each of these four areas need to be evaluated for improvement. However, this may be very expensive to develop such as improving equipment or space renovation. Other areas may need time to be improved such as developing new surgical skills and implementing new systems. Furthermore, some identified areas for development may require a political decision to change such as bylaws or regulations that need be adopted by all ministry of health and population hospitals nationwide. The ideal solution is to develop a model that maximizes benefits and relies on utilization of already available resources. This includes developing strategies for reallocation of space to maintain smooth and effective patient flow, utilization of unused space by other departments, obtaining additional funding (through fund raising efforts) to buy necessary equipment, reallocation of staff, and modifications in working hours. These actions are achievable with proper planning and can be done with minimum cost but of a great impact on work productivity. Capacity building of local service providers is an essential part of any healthcare intervention model. The community should learn that there have been some effective changes in the local eye care

¹ Van Dijk K, Riyanto AT. Eye Health Care as a Prerequisite for Successful Inclusion [Internet]. 2007 [updated 2007 Jun 4; cited 2009 Mar 17]. Available from: <http://www.idp-europe.org/eenet-asia/eenet-asia-4-EN/page20.php>

² Hoare K, Hoare S, Rhodes D, Erinoso HO, Weaver LT. Effective health education in rural Gambia. *J Trop Pediatr.* 1999 Aug;45(4):208-14.

³ Lin Y, Yu YJ, Zhao ZY. Improving capacity building by implementing

comprehensive eye care project, experiences from Kuandian County, China. *Chin Med J (Engl).* 2005 Nov 20;118(22):1925-8.

hospital, and these changes will meet their current needs. Thus, establishing confidence in the local provider should be supported by actual and effective changes in the facility itself.

B.4 Conduct of community health education

The prevailing emphasis in health education interventions is “understanding the factors that affect life style choices and individual health behaviors related to health status and then to implement appropriate change”¹. Thus, the conduct of community health education is not simply developing a message and delivering it to the community. The new concept of health education is more of a “*health promotion*” than a “*health education*” process. Relationship between health education and community (including perceptions, traditional beliefs, behaviors, the targeted disease to be controlled, and the desired outcome) is very important². Hubley and Gilbert emphasize that “changing long existing behaviors that might be deeply rooted in culture is never easy. However, well planned educational programs can be effective, provided two critical requirements are fulfilled; the underlying influences on behavior are understood and appropriate methods, target groups, and settings are well selected. For these reasons, effective eye health promotion involves combining three components: health education directed at behavioral change to increase adoption of preventive behaviors including uptake of services; improvements in health services such as patient education and increased accessibility & acceptability; and advocacy for political support for blindness prevention policies”³. In addition further steps are required that will: 1) Encourage message receivers to seek health care services. 2) Screen and identify cases in need of services and refer them to nearest appropriate providers. 3) Enable these individuals to utilize this service which can include breaking down some of the barriers as much as possible within the program context.

There are many methods to conduct a health educational message. The two most important methods are mass media and face to face communications⁴. Both methods have advantages and disadvantages. Broadcasting is fast, easy, and can cover a large

¹ Israel BA, Checkoway B, Schulz A, Zimmerman M. Health education and community empowerment: conceptualizing and measuring perceptions of individual, organizational, and community control. *Health Educ Q.* 1994 Summer;21(2):149-70.

² Hubley J, Gilbert C. Eye health promotion and the prevention of blindness in developing countries: critical issues. *Br J Ophthalmol.* 2006 Mar;90(3):279-84.

³ *Ibid.*, at 279.

⁴ *Ibid.*, at 281.

proportion of population in a short time. Face to face is slower, more labor intensive, and resource consuming, but this method provides opportunities for direct engagement and participation of individuals from the same communities in delivering the education message.

B.5 Focusing on women; empowering, considering needs & priorities, and the expected impact

Despite “having no specific biological reason to be more susceptible to eye diseases”¹, women have the highest prevalence (two to four times more than men) particularly in the developing world. This is due to three main reasons; 1) Women live longer than men, and thus, are at great risk of blindness from age related causes, 2) Some blinding conditions such as trachoma and cataract are more likely to affect women than men and 3) Women and girls don't access eye care services as often as men and boys². Women should be targeted not only because they have the highest prevalence of blindness, but also because women and girls are primary caregivers in most societies especially in developing countries³. Women need to be empowered to seek eye care services because of many gender related barriers that hinder them from seeking services. Most of these barriers are socioeconomic and cultural. Due to such socioeconomic barriers, mothers and housewives may prioritize their children and husbands who are the main source of family income⁴. A robust community intervention model must take into consideration these complex factors and find convenient approaches for resolution. This should include breaking down social barriers, motivating the community to empower them to seek services, in addition to conduct of a specific message about the importance of increasing service uptake by these women in need and the positive impact on the family are constructive suggestions. Encouraging these women to get served will drastically decrease the overall burden of blindness. Not only because women contribute 64% of the worldwide blindness⁵, but also because they highly affect the magnitude of childhood blindness.

¹ Courtright P, West SK. Contribution of sex-linked biology and gender roles to disparities with trachoma. *Emerg Infect Dis.* 2004 Nov;10(11):2012-6.

² Courtright P, Lewallen S. Improving gender equity in eye care: advocating for the needs of women. *Community Eye Health.* 2007 Dec;20(64):68-9.

³ Courtright P. et al. 2004, op. cit.

⁴ Geneau R, Lewallen S, Bronsard A, Paul I, Courtright P. The social and family dynamics behind the uptake of cataract surgery: findings from Kilimanjaro region, Tanzania. *Br J Ophthalmol.* 2005 Nov;89(11):1399-402.

⁵ Abou-Gareeb I, Lewallen S, Bassett K, Courtright P. Gender and blindness: a meta-analysis of population-based prevalence surveys. *Ophthalmic Epidemiol.* 2001 Feb;8(1):39-56.

B.6 Identification of cases

Screening of a sample to assess the magnitude of blindness in pre and post intervention phases is important in intervention programs to know how many people are blind at a certain point of time, and how many people are likely to become blind in the near future (prevalence and incidence)¹. However simultaneous identification of cases which are in need of services is also crucial. Integrating screening with community health education is a successful and cost effective approach. In a similar study in Tanzania comparing two different health promotion methods, uptake of trichiasis surgery was substantially improved by village promotion². This study applied health education through trained school teachers also conducted screening for people at high risk for trichiasis (over 40 years of age) and followed a cohort of 200 patients for a complete year. Thus, screening and referral of cases should be an essential component of health promotion programs.

B.7 Referral of cases

Identification of eligible cases should also be combined with referral of those cases to get services. This action involves special preparation and specific logistics, as it must include other partners in the process such as the local authorities, ministry of health and population, local NGOs, civil community including volunteers, and the targeted hospitals. Case referrals present many types of barriers and will tax the intervention program. Referred patients should be diagnostically confirmed before sending them to hospitals. Hospitals should be aware and well prepared to receive these individuals by having the necessary equipment and skilled workforce in place. On the other hand, cases should be previously registered in lists, knowledge and information about the process should be disseminated to them clearly through a brief counseling process. Barriers to reaching hospital should be investigated and addressed prior to initiating case referrals.

B.8. Helping people to get served

After referral of cases to the hospital, people will be in the position between increased awareness and acceptance of service. It is at this time where other barriers may affect their acceptance decision. In this critical situation, people will need some

¹ Gilbert C. Epidemiology in practice: An introduction, J. Comm. Eye Health. 1997;10(21):8 – 10.

² Mahande M, Tharaney M, Kirumbi E, Ngirawamungu E, Geneau R, Tapert L, et al. Uptake of trichiasis surgical services in Tanzania through two village-based approaches. Br J Ophthalmol. 2007 Feb;91(2):139-42.

facilitation to get served. Experiences from similar programs and other developing countries show that support at the beginning may assist the start up and then it will be automatically sustained. For example, hiring a bus to collect patients (transportation barrier)¹ is very helpful. Agreement with hospitals and ministry of health systems to provide free or subsidized surgeries is also highly effective (direct cost barrier)². Most other barriers can be dealt with in similar ways. Another example would be elderly people who need assistance coming to the hospital; or mothers and others who are taking care of children can be helped by asking neighbors or relatives to assist them. Community (including civil society organizations) should be sensitized to support those referred cases in different ways according to type and nature of their specific barriers.

C. Post intervention phase

C.1 Follow up with both referred cases and service providers

Whereas referral of cases and helping them to get to hospital are two essential steps, follow up with these cases is equally important. It is essential to include follow up task in the job description of the program personnel and provide them with appropriate training for this task. Follow up is the responsibility of both parties; with the service providers, to assure commitment to all procedures and agreed-upon steps, and also with the referred patients themselves to make sure that they had satisfactory service, and to monitor any emerging or unexpected barriers. It may be also helpful, but not essential at this step, to re-contact the responsible health authorities and reorient them with the program phases. This is one of the reasons for involvement of local health authorities which becomes increasingly important in execution of health programs³.

Once the patient is successfully admitted to the hospital, follow up should assure that this patient will have a safe and successful surgery in a friendly and comfortable atmosphere. This is quite important because this patient can be a patient motivator to convince other patients who are waiting in the list or hesitating / refusing to have surgery. In a study done in both Brazil and Peru⁴, cases refusing surgery were re-visited twice to

¹ Ravindran RD, Thulasiraj RD. Aravind Eye Care System Developing sustainable eye care. *Cataract & Refractive surgery today*. 2006;3:45-7.

² Mahande M. et al. 2007, op. cit.

³ Minder G. The making of an Indian community project by international networking. *International Agency for Prevention of Blindness (IAPB) Newsletter*. 2006;50:11.

⁴ Jose NK, Contreras F, Campos MA, Delgado AM, Mowery RL, Ellwein LB. Screening and surgical intervention results from cataract-free-zone projects in Campinas, Brazil and Chimbote, Peru. *Int Ophthalmol*. 1990 May;14(3):155-64.

motivate them to accept the surgical intervention. Explanations about the surgical procedure and the benefits of surgery resulted in an increased acceptance rate.

C.2 Conduct of outreach services

Outreach caravans are usually conducted to deliver quality care services to distant and underserved areas where people are in need of service but have difficulty obtaining because of some barriers (distance, age, cost, knowledge, etc.). In these caravans, a medical team with portable equipment and necessary medication visits rural villages and screen an average of 400 eye patients in one day. Free medications, minor procedures are usually provided to eligible cases, where cases in need for major procedures or sophisticated investigations are referred to the eye hospital. Merging this service into a model that includes screening and referral components will establish confidence between the local service provider and the community. The caravan has the potential to decrease surgical backlogs and facility tertiary care in required cases. Benefits from outreach caravans would include: distribution of free drugs, providing optical care and distribution of free spectacles, performing minor surgeries on site, and facilitating referral of patients in need of major surgery or who require specialized investigations. All services provided onsite will help as advocacy tools to increase uptake of services by local villagers. This approach is widely accepted globally and is recommended as an essential part of any national plan to implement the vision 2020 strategies¹.

C.3 Post intervention assessment

The purpose of a post intervention screening is to evaluate the impact of the intervention on reduction of both the prevalence of avoidable blindness and the disease backlog. To achieve this goal, both pre and post intervention assessments should be conducted using standardized methods. This refers to calculating sample size, standardized collected data, and implementation procedures. The collected data should enable calculation of important indices like surgical rates and provide information related to service uptake, barriers, and satisfaction. It is also important to evaluate the change in other related issues like change in pattern and trends to seek services. A study in south India during the period from 1987 to 1989² aimed to compare and evaluate eight different strategies of four interventions with two levels for each. In this study, comprehensive analysis of pre and post assessments provided very useful information about surgical

¹ Bubikire S. Plan Implementation / Uganda: Identifying priorities and pathways. International Agency for Prevention of Blindness (IAPB) Newsletter.2006;50:9.

² Ellwein LB, Lepkowski JM, Thulasiraj RD, Brilliant GE. The cost effectiveness of strategies to reduce barriers to cataract surgery. The Operations Research Group. Int Ophthalmol. 1991 May;15(3):175-83.

coverage, and the corresponding reduction in cataract surgery backlog due to specific interventions in each arm. The analysis was based on considering the post intervention surgical coverage as a function of the pre-intervention coverage and surgical acceptance (backlog reduction) during the intervention period.

There are different approaches for how post-intervention assessments should be conducted. One way is to examine the same sample (examine people at pre-intervention assessment). The rationale for this approach is to evaluate the impact of a certain intervention in a clinical trial study design. In our study, which is a community based intervention, it may be preferred to re-examine the community as a unit by randomly sampling its population. The rationale for this approach is to test the intervention impact on the whole community as a unit of analysis as socioeconomic characteristics of the community are unlikely to have change. However, the major aims are to detect changes in community perceptions, knowledge, attitudes, behavioral changes, persistent barriers, emerging new barriers, hidden or disclaimed barriers, new experiences and achieved results with service providers and its staff, and corresponding surgical outcomes as well¹.

C.4 Monitoring and evaluation of the intervention

Any intervention process has fixed objectives and main goal(s). To achieve such goal(s) a certain number of tasks should be precisely identified. During execution of these tasks, three pieces of information need. First, are we on the right track? Are we doing what we said we were supposed to do? Will completion of these tasks achieve our goal(s)? These questions lead to a number of other subsidiary questions such as is the project staying on budget, are time frames being adhered to, etc. and if not, what is the diagnosed error? How can the project be put on track? What are the potential alternative solutions? Monitoring is the process that provides answers to these questions. This task is concerned about activities (actions, and tasks) and is the appropriate tool for detecting whether or not the project is progressing as planned. This process is carried out for the entire duration of the program (fieldwork) activities. Evaluation is another component of intervention projects. Appropriately designed evaluations will help to detect whether or not an intervention is achieving its desired outcomes. It is a process that should be done at specific times throughout the course of intervention.

To conduct monitoring and evaluation, there should be some reliable and valid measurement tools. Such tools will examine specific key performance indicators (KPIs) that indicate whether or not the corresponding actions were done, and to what extent they were correctly done. These indicators are not always considered a gold standard. In most

¹ Hewitt M, Denman S, Hayes L, Pearson J, Wallbanks C. Evaluation of 'Sun-safe': a health education resource for primary schools. *Health Educ Res.* 2001 Oct;16(5):623-33.

programs they are tailored according to the type and nature of the program. In prevention of blindness studies, specifically those with intervention programs, establishment of a monitoring and evaluation systemized plan will help to improve the implementation of interventions in accordance with the program objectives¹.

It is essential to engage stakeholders in both the monitoring and evaluation processes. This includes community leaders, village health unit GPs, community representatives and key informants. This will enable planners to determine whether or not induced changes are in accordance with the identified goals of the program.

One useful tool in this process is "*program logic models*". It is a tool that facilitates both the monitoring and evaluation processes. The idea behind a program logic model is similar to the reflection tool developed by Arnold et al (1999). Arnold suggested building evaluations as a reflection on the process, throughout the event².

C.5 Empowering the community to maintain self sustainability

It is essential for the community to be willing and capable of continuing disease control and care seeking activities. This concept is identified as: "*the ability of people to gain understanding and control over personal, social, economic, and political forces in order to take action to improve their life situation*"³. However, one of the great challenges is to maintain the programs positive impact after the program ends. This is why decision makers need to be involved with implementation of the program. This should ensure their participation in the post implementation phase⁴. It is common in intervention programs to have an immediate outcome. However, within a short period these achievements plateau and no on-going benefit occurs. However, intervention programs that adopt integrated solutions are more capable of maintaining its achievements⁵. The advantage of both

¹ Accelerating the elimination of avoidable blindness: A strategy for the WHO African region. Provisional agenda, item 7.4, 57th session. Brazzaville: REGIONAL COMMITTEE FOR AFRICA; 2007 Aug. Report No.: AFR/RC57/15

² Norheim L. Community Development for Health – A resource guide for health workers. Lancaster: Public Health and Health Professional Development Unit and the North West Lancashire Health Promotion Unit. Lancaster University; 1999 Nov. p40.

³ Israel B. et al. 1994, op. cit.

⁴ Johnson K, Hays C, Center H, Daley C. Building Capacity and Sustainable prevention innovations: a sustainability planning model. *Evaluation and Program Planning* 2004;27:135-149.

⁵ Kuper H, Solomon AW, Buchan J, Zondervan M, Foster A, Mabey D. A critical review of the SAFE strategy for the prevention of blinding trachoma. *Lancet Infect Dis.* 2003 Jun;3(6):372-81.

achieving immediate improvement and maintaining such improvement can be combined¹. The impact of increasing health awareness through community health education was found to extend the effect of surgical intervention programs for longer durations. This is mainly due to the behavioral change impact which is more likely to become institutionalized into the usual routines of practice than an intervention approach that is dependent on an outside stimulus, or which imposes practice tools and approaches that have been developed elsewhere².

2.3 Study goal and objectives

Primary goal

The goal of the proposed study is to increase utilization of available eye care services by women in Egypt. This will be primarily done by educating women and women's health advocates in selected rural communities in Menia governorate, Upper Egypt, about blinding conditions.

Secondary objectives

1. To increase awareness of avoidable blinding eye diseases.
2. To significantly increase utilization of eye care service for Cataract and Trachomatous Trichiasis surgeries.
3. To increase the capacity of local eye care providers.
4. To reduce the gender gap in service uptake.
5. To evaluate the effectiveness of the proposed intervention model in reduction of avoidable blindness.

2.4 Study design

The current study is a randomized controlled community intervention trial, evaluating a gender specific community based intervention to increase eye care service utilization. The study adopts pre and post intervention assessment tools to fulfill this evaluation. It also comprises a mixed (quantitative and qualitative) approach to data collection and analysis.

¹ West S, Taylor HR. Community-based intervention programs for trachoma control. *Int Ophthalmol.* 1988;12(1):19-23.

² Stange KC, Goodwin MA, Zyzanski SJ, Dietrich AJ. Sustainability of a practice-individualized preventive service delivery intervention. *Am J Prev Med.* 2003 Nov;25(4):296-300.

2.5 Ethical approval

Ethical approval for the current study was sought on both local and international levels. Locally, ethical approval was obtained through the Al Noor Magrabi Eye Care Group “*Research and Ethics Committee*” on February 20th, 2006. Further approval was given by the Egyptian ministry of health and population. Academic and international ethical approval was received from the University of British Columbia (UBC) Committee; “*The University of British Columbia Behavioural Research Ethics Board (BREB), Office of Research Services (format version of August 23rd, 2005)*” in March 2006. Approval # (H06-80425) Gender and Blindness – Egypt. All collected data were stored and secured at Al Noor Magrabi foundation office (both hard and electronic copies). According to agreement with both UBC and the Canadian Funding Agency (CIHR), data would be kept as hard and soft copies in safe location for at least 5 years where any proposed new research can be applied after seeking new approval. All data were analysed and dealt with anonymously where the researcher was the only one having access to decoded names and personal information. This was only required for any necessary adjustment and / or research supporting purposes. Safety, security, and confidentiality issues were considered according to the Canadian Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS). The researcher had been TCPS certified through UBC in September 20th, 2005.

2.6 Outcome measures for pre and post intervention assessment

Two major outcome measures were used to evaluate success of the intervention;

- (1) Change in the overall magnitude of low vision and blindness as measured by the prevalence of visually impaired proportion to the normal proportion between pre and post intervention assessments.
- (2) Change in service utilization as measured by total number of people seeking local eye care service providers (outpatients), and the change in number of performed surgeries (Cataract and TT as targeted avoidable blinding diseases in particular).
- (3) An additional measure was used to evaluate success of the interventional model: Decrease of the gender gap between males & females in terms of; prevalence of blindness, service utilization, and pattern of barriers.

2.7 Study population

The study population is comprised of women in all households within the intervention villages and the surrounding satellites. The intervention population is the total population of these villages, which totals 24,109 inhabitants. The total population of the control villages was 24, 908 inhabitants.

2.8 Statistical methods

1. Quantitative data analysis methods were used to compare pre and post intervention outcomes, indices, ratios, and other related comparative numerical values. In addition to investigating associations between outcome measures and different determinants.
2. Qualitative data analysis methods were used to analyse results of focus group discussions, and semi-structured interviews.
3. SPSS 17, Medcalc 11.4.2, Stat Pack 11, and NVivo 7.0.281 were used to analyse data and report results as per each type of data and analysis requirements.

2.9 Study duration

The current study was conducted within a framework of approximately four years. The intervention duration was 18 months (April 2006 to September 2007).

2.10 Building upon previous experience and literature

A number of projects related to prevention of blindness had been previously executed in Menia Governorate. Those include: "*Trachoma rapid assessment*", a "*Survey for blinding eye diseases*", and a pilot study to test "*gender specific intervention in prevention of blindness*". Moreover, there were a program for "*cataract outreach caravans*", and a program for application of the "*self sustainability model*" in eye care. All of these studies and intervention programs were conducted through local and international NGOs activities in collaboration with local health authorities and academic expertise. Experiences from these projects were utilized in designing of the current study to test the effectiveness of planning and implementing of an intervention model from a gender perspective. The ultimate goal of gender specific interventions is to promote health and human rights of women¹. To achieve this goal, reports and learnt lessons from the previous field work studies facilitated a much better understanding of eye care profile in the governorate, advocated well for the capacity of prevention of blindness programs, provided guidance regarding opportunities, mistakes to avoid, and identify areas to further work on. Hence, these past endeavors have established a good platform for the current study to build on.

¹ Kismodi E. Human Rights related to sexual and reproductive health [Internet]. 2007 [updated 2007 Mar 7; cited 2010 Jan 13]. Available from: http://www.gfmer.ch/Medical_education_En/PGC_RH_2007/pdf/Human_Rights_RSH_Kismodi_WHO_2007.pdf

2.11 Description of the intervention

The intervention consisted of five different components: (1) Conduct of health education message from door to door covering the whole village. (2) Screening for cataract, trichiasis and other blinding eye diseases. (3) Referral of eligible cases to local eye care providers. (4) Assisting referred cases to obtain hospital service. (5) Follow up with cases at the hospital and monitor their results. The major component of intervention was delivery of the health educational message. The messages contained seven main items aiming at providing correct knowledge and increase the awareness about:

1. Magnitude and causes of avoidable blindness in the area,
2. Identification of the two targeted diseases (Cataract and Trachoma) and related complications i.e., Trachomatous Trichiasis and Corneal Opacity.
3. Risk factors, hygiene and importance of maintaining good eye health,
4. A detailed message about cataract including types, causes, and treatment (surgical procedures).
5. Detailed message about trachoma (in both children and adults) that included information related to infection methods, causes, prevention, complications, and its treatment.
6. A detailed message about Trichiasis, its causes, complications and its treatment. ,
7. A specific message about gender issues. This includes its relationship to prevention of low vision and blindness, how to decrease the gender gap in disease prevalence, service utilization patterns and the corresponding impact on the family, and the overall magnitude of blindness.

Developing the health education materials

The health educational material was developed over a period of two months through a series of brain storming sessions with experts and community stakeholders. The idea was to produce material in a format that would be accepted by the community as well as serving as an effective component of the intervention that covered all of the seven messages. Criteria utilized in the development of this material were that it had to be simple and concise in delivering the message. It needed to contain more pictures and less text in order to suit culture and the prevalent illiterate population. It had to reflect the main problems and barriers of the community as well as being interesting to read, and easily memorized. The final health education material product consisted of two main parts. Part one was a one page (hard cartoon) year calendar and the second part was a mini-poster flipping handout. The calendar contained a mixture of caricature and real pictures with a brief message in simple text underneath each picture. The idea behind the calendar was that it would be kept for the whole year within the household. We included a removable block with the day, month, year, prayer times and other useful information (like holidays, etc.) that add further benefit to the calendar and therefore hopefully extend

the duration it would remain in each household, The handout was made of a strengthened material containing informative pictures expressing the seven messages in more detail. The pictures consisted of a mixed collection of picture of the intervention village in addition to some international education pictures (WHO trachoma classification pictures). A number of other pictures were added by a professional caricaturist to help explain the ideas behind the messages. At the back of each page was basic information reminding the health visitor about the important points of each visit. The material was pre-tested in a small sector of the larger village (Manquateen) where it proved to be widely accepted and effective. Minor changes were applied before final production of the health educational material.

Implementation of the intervention

At the intervention sector each of the two villages was divided into a number of sectors (9 sectors in "*Manquateen village*" and 6 sectors in "*Ibrahim Basha village*") according to: population size, natural geographic landscape, demographic and logic classification and previous experiences of the village health workers in distribution of childhood vaccination. A team consisting of two health visitors was assigned to cover each sector. The team walked from house to house upon a previously plotted plan. They entered the house, introduced themselves and the study (highlighting purpose, importance, and expected benefits), announced their mission, and then utilized the handout to transfer the seven educational messages to the household inhabitants.

At completion of introducing all messages, they asked if anyone in the household had Cataract and / or Trichomatous Trichiasis. If positive the team tried to confirm this by using the skills they gained in training. If negative or the family was unsure the team proceeded by screening of all household members over 40 years of age. The reason for asking the family about known cases in the household was to assess their knowledge about such diseases.. Moreover, it was important to determine whether the family recognized and understood the material. After this step, the health visitor registered the identified patients in need for service and informed them about service availability at nearest eye care facility which was "*Samalout Eye Hospital*". If the individual was reluctant to go to this facility recommendations were given to visit "*Menia Eye Hospital*" which is the major eye hospital of Menia governorate.

The health visitor then informs the patient they will receive a referral form within one week that will contain their appointment date. At the end of each day health visitors submit their registration lists to their direct supervisor. The supervisor was responsible for preparing a referral list and dispensing referral forms to the listed patients. The referral form contained a notice about the disease, the required service, and the hospital appointment date. The reason the referral form was controlled by the supervisor was to better organize the flow of patients coming to the hospital without over burdening the

outpatient clinics. The goal was not to exceed the hospitals' capacity to see these patients along with the regular walk in patients. This system was also planned to maintain quality service to referred patients. Individuals being referred were also provided with a brief explanation by health visitors about how to proceed with referral to the hospital. Cases that needed special assistance (due to different barriers) were put on a special list where new appointments were collectively set for them (maximum of ten patients per list) in specific alternative days. On these days, the corresponding health visitors prepared transportation (hiring a small microbus) to transfer them to and from the hospital. Supervisors conducted regular follow up visits to the hospital to investigate the flow of referred patients, while health visitors arranged household follow up visits to the referred cases.

Some patients preferred to seek services at the central governorate hospital "*Menia Eye Hospital*" rather than the local hospital "*Samalout Eye Hospital*". Others preferred to have surgery in the private sector, or "*Menia university hospital*" if they could afford payment for surgery. Moreover, to encourage local people to get cataract surgeries, two outreach caravans were conducted in collaboration with Al Noor Magrabi Foundation. These caravans provided free examination, free transportation, and in eligible cases provided free cataract surgery at Magrabi headquarters hospital in Cairo. This step was necessary at the beginning of referral phase to show off successful results. A second round of health education was conducted to cover all missing households and to increase service utilization.

Capacity building of local eye care providers

In order to bridge the gap between the community and the local hospital, two additional actions were taken after assessing the local provider's needs and problems;

1. Donation of surgical equipment. Due to shortage of equipment the Samalout eye hospital could only perform a limited number of cataracts (and other) surgery per day. However, five complete cataract sets were donated by Al Noor Magrabi foundation and 155 surgical tools were donated through the British Columbia Center for Epidemiologic and International Ophthalmology, UBC. This surgical equipment allowed the hospital to increase the number of performed surgeries per day.
2. A visit was arranged by senior eye consultant from Magrabi eye hospital and an accompanying team to Samalout hospital. Consequently, opportunities for surgical training were offered to the local surgeons in addition to recommendations to improve performance.
3. Hospital sustainability team from Al Noor Magrabi foundation visited the local hospitals and made many recommendations regarding how to improve services, systems, reallocation of space and human resources, and patient flow.

Capacity building and service improvements were announced within the intervention villages to encourage local people to seek services at Samalout eye hospital. This was one of the major goals of this study.

2.12 Geographic and demographic selection of the study site

This study was applied to a selected geographic area based upon certain specific criteria. These criteria included having regular village circumstances with no natural boundaries, or any very specific topographic landscape, having good access to healthcare and eye care facilities; available transportation for the population; and average population size representing common rural villages. These criteria were important to define because of the nature of Menia governorate. This area is roughly 20 kilometers by 120 kilometers with some villages on the eastern side of the Nile that has a desert climate while others have significantly different geographical features. The total population of Samalout district is 585,185 inhabitants living in throughout 51 villages¹. The population of the intervention villages was 24,109 inhabitants that represent the whole district (Samalout district population). Whereas, success of the intervention would lead to generalization of the tested approach to whole district and extend to the Governorate (total population 4.2 millions in 9 similar districts).

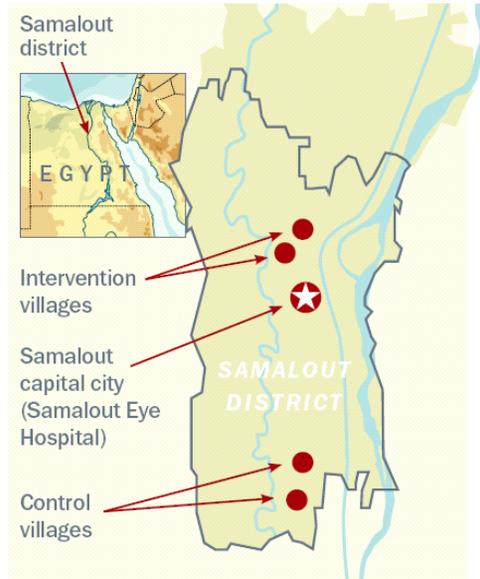


Fig. 2.1 Samalout district showing intervention and control sectors

¹ Egypt Population and Housing Census. Cairo: Central Agency for Public Mobilization and Statistics; 2006.

2.13 Application of the intervention coping with the study design

The design of this study is a controlled interventional trial. Therefore the intervention model was applied to two villages while monitoring two other villages as control. These four villages were selected after a community based survey for blinding eye diseases that was conducted in 2002. The criteria of selection of all the four villages included having a:

1. High prevalence of avoidable blinding eye diseases (mainly cataract, trachoma, and Trachomatous Trichiasis).
2. Low pattern of eye care service utilization.
3. Unequal pattern of service utilization between males and females (gender bias).

Pre and post assessment activities including quantitative and qualitative data collection and training of village supervisors were conducted to both arms. Door to door screening, referral, and support to get the service were only done in the intervention villages. Precautions for contamination were considered while training; focus group discussions, quantitative and qualitative data collection and meetings with all health workers, policy makers, and stakeholders. The two intervention villages were treated as one block (sector) as were the two control villages. The distance between the two sectors was around 40 kilometers. The intervention villages were to the north of Samalout and the control villages were to the south.

Inclusion and exclusion criteria for screening and referral

All household inhabitants regardless of age and sex were targeted in our door to door intervention program. Residents above 40 years of age were included in our screening and referral for Cataract and / or Trachomatous Trichiasis surgeries. All listed patients (for surgery) were supported to seek service except for those who refused to get served or asked to postpone receiving service. All participants who were ineligible for surgery were excluded from the analysis.

Sampling and sample size calculations for pre and post assessments

An appropriate sample size was calculated to estimate the representative number of people to be examined in all the four villages (intervention and control). Sampling technique was "Systematic Random Sampling". Essential data for sampling calculations were; the magnitude of target population, estimated prevalence of disease (using 2002 survey), power ($1 - \beta = 80\%$), type I error ($\alpha = 0.05$), and corresponding Confidence Intervals of 95%. Calculation of the sample size was done according to the standard WHO manual¹ for health surveys. Results provided a

¹ Lwanga SK, Lemeshow S. Sample Size Determination in Health Studies, A Practical Manual. Geneva: World Health Organization; 1991. 80 p. Report No.:WA 950-9241544058

number of equivalent samples ranging from 112 to 147 in the four villages (due to different population sizes). Sample size was fixed to 150 inhabitants per village (within the age interval 40+) in order to minimize confusion for the field team and to allow a contingency for unexpected shortage in coverage.. Sample and indices are briefed in the following table:

Table 2.1 Sample indicators and calculated sample size per each village

Village	Population	Pop. 40 +*	Cat. %**	TT %**	Sample
Ibrahim Basha	4465	857	17.9	17.5	150
Manquateen	19644	4430	32.3	12.5	150
Nazlat El Amoudin	15279	3267	11.1	11.1	150
Taha EI Aamida	9629	2124	28.3	11.3	150

*Calculated

** Estimated from the 2002 survey

Development of intervention implementation plan

A detailed task oriented action plan was developed to facilitate execution of each activity & enable indicators for monitoring and evaluation. In this action plan each objective was described and transformed into a group of actions; each action was further divided into a number of tasks. Each task had an assigned person and a supportive team in addition to a deadline for completion. This categorization was in order to keep on a timely program and avoid any conflicts or overstretching the field team. Sticking to the action plan has enhanced the performance of most of tasks.

Developing of program logic model and its essential components

Program logic model was used as a tool for identification, organization, and evaluation of different phases of the model¹. The following plot illustrates the core parts of the program logic model.

¹ John JM, Dwyer SM. Using program logic model that focuses on performance measurement to develop a program. Can J Public Health. 1997;88(6).

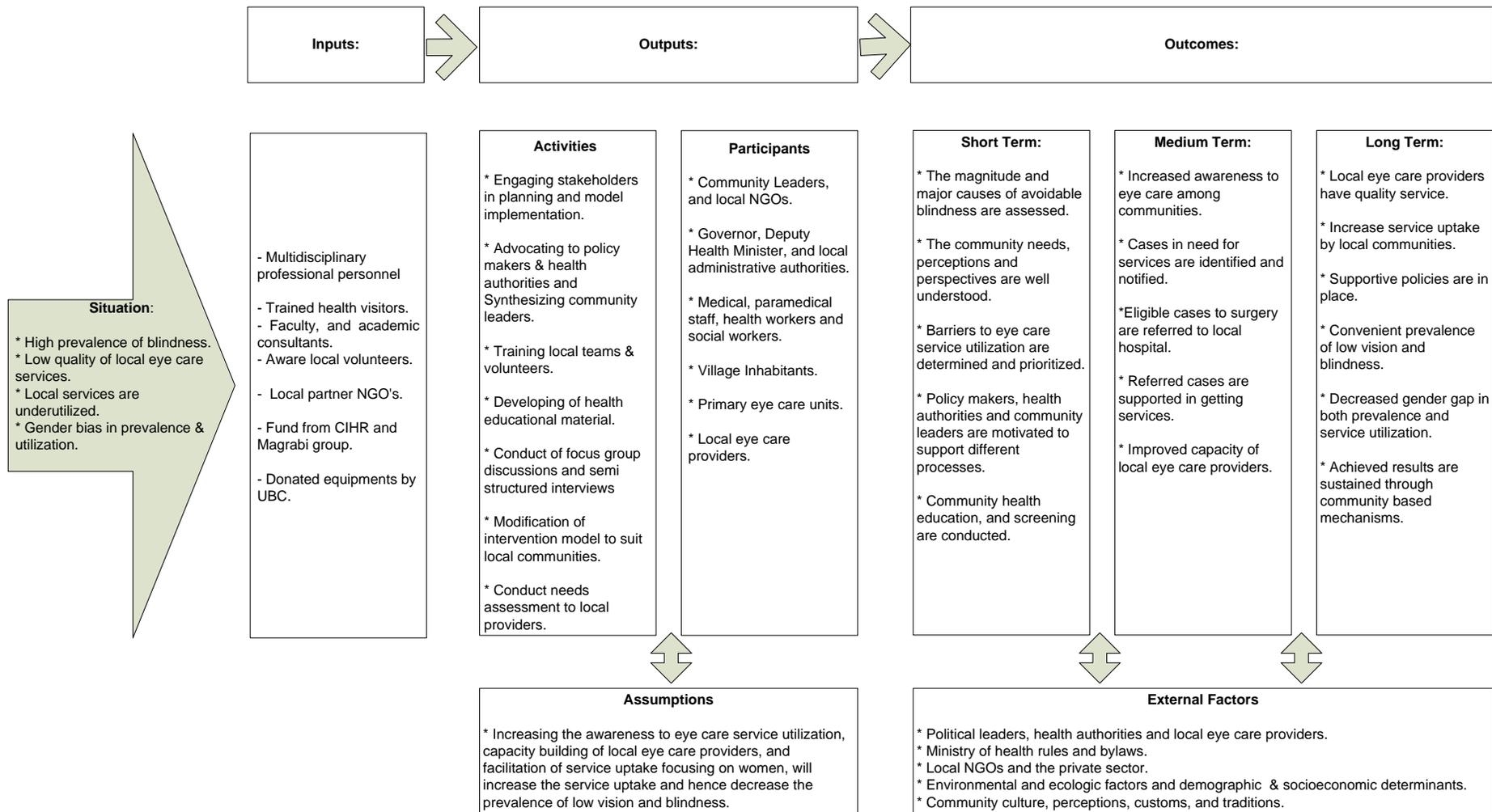


Fig. 2.2 An illustration of intervention model phases

Situation analysis

Problem statement

Rural communities have a high prevalence of avoidable blinding diseases, namely Cataract and Trachomatous Trichiasis. These communities tend not to be aware of this problem or its causes or means of prevention. Moreover, the utilization pattern of available eye care services tends to be low due to negative community attitudes, low quality of provided services, and other barriers. Women, who have a higher prevalence of diseases than men, also have the lowest pattern of service utilization.

A. Problem impact

Low vision and blindness have resulted in low socioeconomic profile of the community and hence, hindered the development process.

Audience:

A. The most affected communities

Communities with a poor population, high prevalence of illiteracy, minimal access to eye care facilities, little knowledge about eye care are the most affected.. Women are the most affected group within these communities.

B. Potential partners / supportive groups

Ministry of health and population, local NGOs, civil society organizations, community leaders and active personnel including volunteers all need to be involved.

Resources / Inputs

A. Human resources

- Multidisciplinary professional personnel including ophthalmologists, anthropologist, and epidemiologist.
- Trained health visitors.
- Faculty, and academic consultants.
- Aware local volunteers.

B. Involved collaborators

- Cooperative local authorities.
- Collaborative local NGOs.
- Cooperative community leaders & other stakeholders.

C. Financial resources

- Canadian Institute for Health Research (CIHR).
- British Columbia Center for Epidemiologic and International Ophthalmology.
- Al Noor Magrabi Foundation & Magrabi Eye Care Group.

D. Knowledge transfer, education, and training

- Training handouts, brochures, guidelines, manuals and flyers.
- Sharing previous surveys, pilot intervention results, research findings and publications with the community and the audience.
- Distribution of health education material to all villagers in the form of a year calendar.

E. Equipment

- Five Cataract Surgical Sets donated by Al Noor Magrabi Foundation.
- Donation of 155 pieces of surgical tools by the British Columbia Center for Epidemiologic and International Ophthalmology.

F. Other resources

- Free examinations and surgeries provided by local health authorities and the Al Noor Magrabi Foundation outreach program in collaboration with Magrabi Eye Care Group.

Activities

- **Communication** with necessary and interested partners.
- **Advocating** to policy makers, local health authorities, and community leaders.
- **Training** of:
 - Health visitors to conduct health education.
 - Medical staff to conduct screening.
 - Interviewers to collect qualitative data.
- **Conduct** of pre and post intervention screening.
- **Identification** of eligible cases for surgery.
- **Development of:**
 - Training material and handouts.

- Interview and qualitative data collection guidelines.
- Health education material and the corresponding guidelines.
- **Capacity building** of local eye care and health services providers.
- **Referral of** eligible cases to surgery and other eye care services.
- **Confirming** eligible cases for surgery.
- **Production and testing** of health education material.
- **Conduction of** follow up with:
 - Surgical cases.
 - Community as regards health education impact.
- Maintaining** program sustainability through community leaders and local authorities.

Key performance indicators (on activities)

- Response and cooperation of policy makers and other partners (actions taken).
- Number of trained health visitors, medical staff, etc.
- Results of screening.
- Number of identified and referred patients.
- Handouts and guidelines in hand and in place.
- Change in number of outpatient reviewers (at the local hospital).
- Change in community knowledge.
- Change in magnitude and pattern of barriers.
- Number of done surgeries.
- Patient satisfaction with services.

Outputs

- Engaging stakeholders in planning and model implementation.
- Advocating to policy makers & health authorities and Synthesizing community leaders.
- Training local teams & volunteers.
- Developing health educational material.
- Conduct of focus group discussions and semi structured interviews

- Modification of intervention model to suit local communities.
- Conduct needs assessment to local providers.

Outcomes

A. Short term outcomes

- The magnitude and major causes of avoidable blindness are assessed.
- The community needs, perceptions and perspectives are well understood.
- Barriers to eye care service utilization are determined and prioritized.
- Policy makers, health authorities and community leaders are motivated to support different processes.
- Community health education, and screening are conducted.

B. Medium term outcomes

- Increased awareness to eye care among communities.
- Cases in need of services are identified and notified.
- Cases eligible for surgery are referred to local hospital.
- Referred cases are supported to get required service.
- Improved capacity of local eye care providers.

C. Long term outcomes

- Local eye care providers have quality service.
- Increase service uptake by local communities.
- Supportive policies are in place.
- Decreased prevalence of low vision and blindness (within WHO identified limits).
- Decreased gender gap in both prevalence and service utilization.
- Achieved results are sustained through community based mechanisms.

External influences

- **Institutional** : political leaders, health authorities and local eye care providers.

- **Public** : local NGOs and the private sector.
- **Community**
 - Effects of community culture, perceptions, customs, and traditions.
 - Environmental and ecologic factors and demographic & socioeconomic determinants.

Overall goal

To decrease the prevalence of avoidable blindness specifically among women who are the most affected members of the community.

Desired situation (To be)

- The Community is quite aware of blinding eye diseases and able to develop more positive attitudes towards seeking service.
- Local service providers have the capacity to provide higher volumes of service within a standardized fashion.
- Service utilization pattern shows equal rates among women and men in all regions including rural areas.
- Incidence and prevalence of low vision and blindness is within the international limits as identified by the WHO.

2.12 Implementation of the model

Advocacy and community sensitization

Key persons were identified for advocacy. This included describing the necessity and importance of the model and the actions that will be required to implement.

A. Political leaders and health authorities

A preliminary meeting was conducted with the governor, the secretary general, the deputy health minister and their assistants. A brief explanation on program activities and its importance were provided and formal approval was requested. A memorandum of understanding was later signed that identifying each partner's role and commitment. Training of participants was done under the direct supervision of the local ministry of health office. Instructions were disseminated to local hospitals and village administrative and health units to support this study. This approval was necessary in order to access diagnostic and therapeutic interventions.

B. Local developmental NGOs

Two local NGOs (Salama Mousa Foundation and Women Development & Promotion Society) were selected from 50 NGOs working in Menia. Criteria of selection for NGOs included: must be working in Health and / or Education, are working in or near the targeted villages, and have well established capacity and infrastructure.

A memorandum of understanding was signed with each identified NGO. This identified each partners' role, responsibilities and commitments.

C. Community natural leaders

Communication was done with community leaders over a number of repeated visits. The aim was to explain the intervention activities and its beneficial impact on the villagers' health. We were careful to address all inquiries from their side. The selected community leaders included 15 different village personnel; the Parliament member, the Senator, the Mayor, Village administrator, Head and members of the Village Governing Committee, the Village Sheikh and Priest, Schools Headmasters, in addition to a famous Female Lawyer acting as Secretary General for female affairs in the governing party.

D. Engaging stakeholders in planning, monitoring and evaluation

Through the community leaders and the local NGOs, we were also able to contact stakeholders at second level of leadership and grassroots level. This included the Director of the Village Youth Club, School Teachers, Health Unit General Practitioner and his staff (Nurses, Doctor Assistants, and Health Workers), several Village Local Committee Members, as well as some Women Leaders (women with higher education who are employed in critical posts in the governorate). At the grassroots level, we also held sessions with women groups of the farmers' housewives during their assembly days for immunization and vaccination at the village health unit. As a result we managed to gain community patronization to the intervention.

Training and capacity building of different cadres of local staff

A "*training needs assessment*" was conducted based on estimated disease prevalence, the corresponding required services, and concurrent capacity of local service providers. Identified training needs were listed and prioritized according to the actual requirements of specific intervention tasks. Accordingly, a number of training manuals were developed including necessary introductions and guidance when performing required activities. All handouts were then packed in one booklet to enable interested trainees to read through other teams' material. The training manual was tested after discussions with the local MoH and NGOs staff, where valuable comments were considered.

A. Training of medical doctors

Ophthalmologists were trained in the diseases of interest (Cataract and Trichomatous Trichiasis) following the WHO standard grading guidelines¹ which cope with the corresponding *Chlamydia Trachomatis* lab tests². *General Practitioners* received some training about preventable and curable eye diseases. Their task was to perform primary eye care activities, examine and refer cases to the local eye hospital for further investigations and treatment. Eye surgeons were given an orientation about the preferred procedures including "*Small Incision Cataract Surgery (SICS)*" and "Bilamillar Tarsal Rotation for TT".

B. Training of nurses

Due to shortage in ophthalmic nurses and difficulties to allocate some of them for fieldwork, general nurses (from the village health units) in addition to some ophthalmic nurses were trained on fieldwork activities. Training focused on two issues - to assist doctors who are doing the screening and to complete the medical examination forms.

C. Training of health visitors

Health visitors were the corner stone for this intervention model. They are categorized into two major groups;

- (1) "*Health workers*" of the village health units. They are responsible for the conduction of village enumeration for vaccinations, and doing the "*from door to door immunization*" plus conduction of health related messages. Another important component to this group is that they usually know all the villagers by name.
- (2) "*Volunteers*" - were comprised of either elementary school teachers or unemployed graduates.. The importance of volunteer efforts in prevention of blindness is well established in the literature as a cost effective method³.

Health visitors were trained to identify blinding eye diseases, concepts of primary eye care, to perform sampling procedures, interviewing skills, advocating to the community, transmission of the health education message, and to complete the corresponding questionnaire forms. They were reoriented twice during conduction of the intervention activities. A meeting was held after conduction of the first round of

¹ Prevention of Blindness and Visual Impairment: Priority eye diseases [Internet]. 2009 [updated 2009 Feb. 10; cited 2010 May 17]. Available from: <http://www.who.int/blindness/causes/priority/en/index2.html>

² Wright HR, Taylor HR. Clinical examination and laboratory tests for estimation of trachoma prevalence in a remote setting: what are they really telling us? *Lancet Infect Dis*. 2005 May;5(5):313-20.

³ Hubley J. et al. 2006, op. cit.

health education. During the meeting we listened to their problems, got their feedback, and recommendations. Health visitors also contributed with case referrals and patient follow up with local hospitals. A large number of health visitors was initially trained in three batches. From this group of 43 a total of 30 were finally selected according to their response to training and interest in the study. . This enabled easy replacement of two volunteers who quit during implementation due to family issues and other commitments.

D. Training of local guides

Four local guides were trained in simple fieldwork activities such as orientation related to the intervention and its importance, involved partners and their activities, and help with communication skill development. Their mission was to have knowledge about village geography in order to guide different teams during assessment and conduction of health education. They were selected from the village health unit administrative staff because of past experience with similar activities.

E. Training of interviewers

Interviewers were selected from local NGOs staff. Selectees needed to be females, well educated, and had previous experience in similar work. To assure quality of interviews, the nominated interviewers were trained with conduction of semi-structured interviews using a pre developed training manual. Each interviewer was then provided with a cassette recorder designed for conduction of these types of interviews. After receiving their training, interviewers were mainly asked to conduct personal interviews with 24 different people in 24 different households. These individuals were either Cataract or TT patients. They were then sub-classified into six different categories: diseased, normal, household head, males and females, having good or poor household hygienic characteristics. Household's heads who were interviewed were selected upon these criteria from the study database.

Developing of a hierarchical system for the intervention implementing team (intervention organizational chart)

A team organizational chart was developed after training to systematize work flow in a stream of successive consequent steps. Briefly, this team consisted of the principle academic investigators, the researcher, 2 coordinators (one local from "*Salama Mousa Foundation*" and one central from "*Al Noor Magrabi Foundation*"), 8 field supervisors (2 in each village), and 30 health visitors from the intervention villages (18 in Manquateen village and 12 in Ibrahim Basha village with this number being in relation to the population size of each village), and finally 2 interviewers. The researcher was supported by a steering committee consisting of one financial controller, one medical

consultant, one local academic consultant, one medical anthropology consultant, one executive secretary, and 2 data managers.

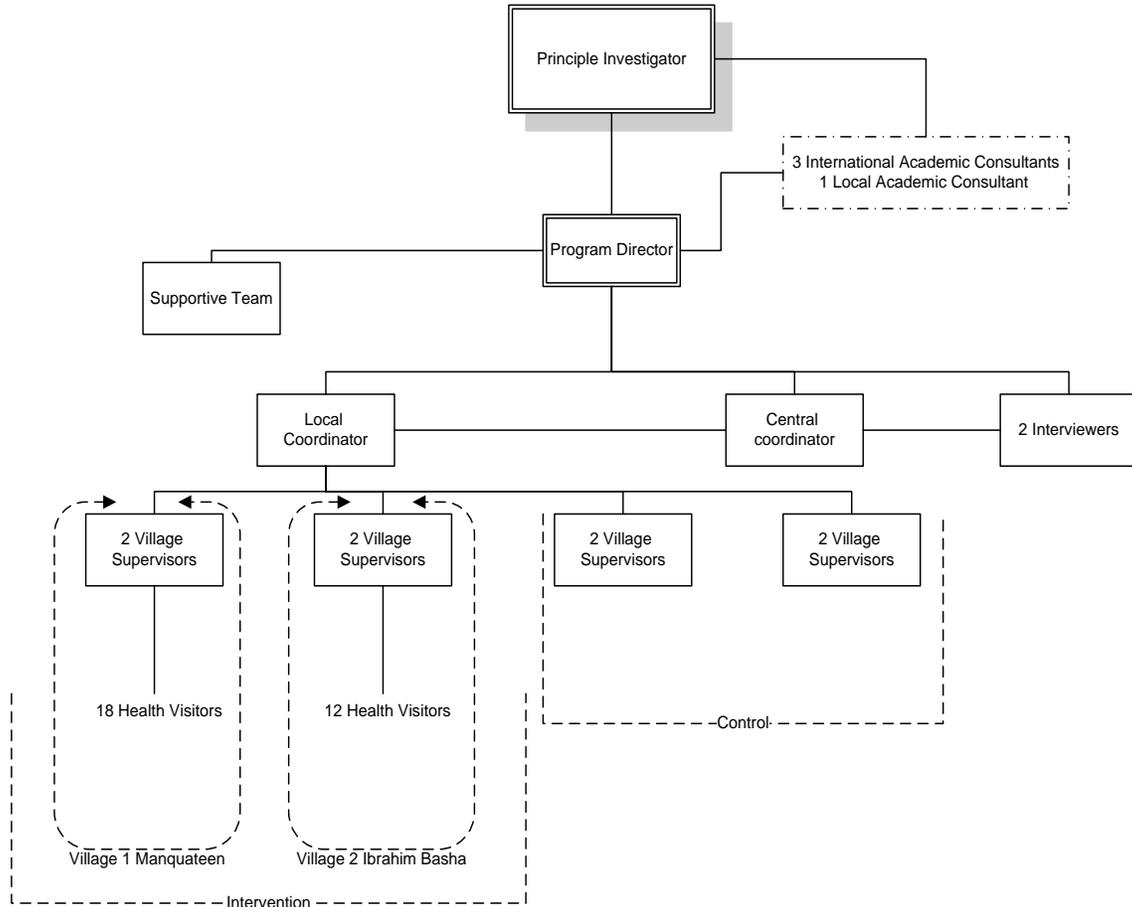


Figure 2.3 Intervention organizational chart

Pre intervention assessment

The assessment was applied to both intervention and control sectors and included medical and non medical aspects. The main objective was to assess the magnitude and determinants of avoidable blindness. Eight forms were used in this process:

1. Village form,
2. Household form,
3. Eye examination form,
4. Cataract form "A",
5. Cataract form "B",

6. Trichiasis form "A",
7. Trichiasis form "B", and
8. Visual functioning and quality of visual life form.

The village form was applied once for each village containing demographic and general information about the village. The household form was applied to the selected households within the sample. An eye examination form was applied to each of the examined inhabitants at the age (40 +) within each household. If the inhabitant was a "cataract patient" with no previous service received, "cataract A" form was completed. Alternatively, if the inhabitant had received cataract surgery then a "Cataract B" form was completed. . This was similar, for "Trichiasis patients" who either were asked to complete "Trichiasis A" form (Trichiasis with no treatment) vs. "Trichiasis B" form if previous surgery was done. Visual Functioning form was filled for all patients with cataract A or B, and Trichiasis A or B forms to evaluate visual functioning score and quality of visual life corresponding to status of disease or outcome of received service.

Post intervention assessment

Post intervention (quantitative) assessment was conducted through same sampling procedure of the pre intervention assessment. The main goal was to detect the overall change within the community as a unit of analysis in a comparable way. Assessment was done in all four villages, using all of the eight forms to enable a wide range of information for analysis purposes.

Hospital and health units' data (service data)

Hospital registration data were requested through the governorate health authorities. Data included outpatient and surgical volumes registered in the two hospitals of interest (Samalout Eye Hospital and Menia Eye Hospital). The aim was to monitor changes in patient volumes through between 2002 – 2008. Also, in control villages, quantitative data was collected such as the number of individuals seeking service at village units, their satisfaction with services, and complaints related to the utilization process.

Qualitative data collection

Qualitative data were collected in order to achieve better understanding of the different community perceptions, to investigate barriers to service utilization, and to enhance the intervention. This was done using three different aspects.

Focus group discussions:

Focus group discussions were conducted with two highly effective groups:

A. Health visitors and volunteers

After the program was initiated and during testing the health education messages, we conducted a meeting with the health visitors and their supervisors to listen to their ideas about how the people were receiving the message and how we could improve our messages. We also wanted to hear about what barriers were present and the potential advantages and disadvantages of the intervention. It was more similar to a SWOT analysis than to a group discussion. Another meeting was conducted with the same group after cases had been referred to the hospital and a number of surgeries were already completed. We discussed further steps and tried to get feedback about the change within the community.

B. Community leaders

Two meetings were conducted with community leaders. One at the beginning of the program to advocate, gain support and get understanding of the community needs. A second meeting was held when all the intervention villages were provided with the health education material. The reasons for these discussions were, first to investigate how the community, including leaders, looked at our health educational message and to get their feedback. The second issue was to seek their help in encouraging referred cases to seek eye care services. During the last meeting, achievements, sustainability and maintaining success were discussed.

Semi structured interviews

Four female interviewers (recommended by one of the local NGOs) were trained on qualitative interview techniques by the researcher with support of an academic medical anthropologist. Two interviewers were selected to conduct these interviews after training. Specific guideline were developed and distributed to them. Data collected from the interviews were utilized to improve the health education message and other intervention activities based on understanding specific community perceptions, KAP gap and barriers.

Targeted population for interview was classified into two main categories; cataract and trichiasis patients. Within each category a number of subclasses were further identified:

- Cataract patients (C)
 - o Patients currently with cataract and never had a previous service (C1).
 - o Patients with cataract and had a previous service (C2).
- Trichiasis patients (T)
 - o Patients with Trachomatous Trichiasis and have bad household conditions (T1).

- Patients with Trachomatous Trichiasis and enjoy good household conditions (T2).
- Patients without Trachomatous Trichiasis and have bad household conditions (T3).
- Patients without Trachomatous Trichiasis and enjoy good household conditions (T4).
- Gender groups:
 - In all the previous categories two households were selected for interview. One headed by a male and one headed by a female to evaluate and understand gender related differences.
- The study database (from screening) was utilized to identify candidates in each group where 24 households were selected for interviews (two in each category) in addition to alternative candidates.

Collecting data from control villages

Additional data were collected from the control villages through village supervisors to understand the community perceptions towards eye care and their attitude when they have an eye problem. In addition, we wanted to know what their barriers to service were, and whether there was a gender bias in service utilization. To fulfill this aim, a series of questions were developed and explained to the health supervisors in these villages. These data were collected twice to establish a baseline and to detect any change at the end of the program duration.

Involving media in our activities

Media support was sought to empower our intervention and increase compliance to change due to its effective impact in dissemination of educational messages. It also played role in acquiring support from other organizations plus gaining community confidence in intervention. In this regard, we advocated for our program through articles in local and national newspapers as well as in local radio and TV interviews (TV channel 7 for Menia and Upper Egypt radio broadcast). We also used the local youth club to hold youth meetings to discuss eye care problems and its consequences. During this process we were aware of avoiding two negative methodological impacts on our study; contaminating our control villages, and creating horror of a serious eye disease outbreak. We arranged to overcome both negative impacts through our village supervisors who were given approved answers to community investigations in both sectors (intervention and control).

Chapter 3: Developing the health education intervention: engaging with the community and its barriers to eye care services

3.1 Introduction

This chapter reports baseline research findings regarding the non clinical factors that may affect the volume and pattern of health service utilization in the intervention and control villages. These data include individual and community knowledge, awareness, attitudes, and patterns of eye care service utilization. In addition, the chapter reports on community perceptions on the quality and extent of local eye care services in governmental and private institutions.

The data are derived from three major sources. (1) Semi structured interviews conducted with villagers from the intervention villages which include; knowledge, attitudes, practice and barriers to eye care services. These baseline data contributed in developing the intervention. (2) Focus group discussions with community leaders and health visitors, which helped in implementing the proposed model, and (3) Data collected from control villages and utilized to compare them to intervention villages in addition to evaluate the impact of the model on the intervention villages. Details of the interview questions and other collected data are detailed in appendix 2. The chapter also compares the assessed barriers from quantitative and qualitative techniques, in addition to presenting some other data collected in an aggregative fashion from the control villages.

3.2 Community perceptions of blinding diseases and eye care services

At the time of the pre intervention baseline prevalence study of blinding diseases, semi-structured interviews were conducted in intervention villages with 24 household heads focusing on the two targeted avoidable diseases (cataract and TT). Interviewees were selected from the pre assessment database upon the mentioned criteria previously explained in the methods section. These interviews were not conducted in the control villages.

Cataract patients were classified into:

- Those who sought services.
- Those who did not seek services.

Trachoma Trichiasis patients were categorized as;

- Those with TT
 - With good household characteristics.
 - With bad household characteristics.
- Those without TT.
 - With good household characteristics.
 - With bad household characteristics.

Criteria for having good or bad household hygienic characteristics were defined as; having good and available water sources, sanitation systems, clean house, and absence of cattle and kraals within the household. Male and female household heads were interviewed to compare and contrast their perceptions in each Category. Interview results were classified into six main domains; Knowledge, Awareness, Attitude, Practice, Barriers, and Community perceptions.

3.2.1 Knowledge

A percentage of 30.8% of respondents did not know what either cataract or TT is with no difference between males and females. TT patients were less likely to report “*don't know*” (22.2%) than cataract patients (33.3%). Around 30% of the respondents didn't really know which organ such disease affects with males more than females, and without any specificity by disease. Among those who were aware of these eye diseases, cataract (50%) was the most common, followed by TT and trachoma (40%), while glaucoma (10%) came third.

Although villagers were not able to precisely differentiate between infectious and non infectious diseases in terms of causes, around one fourth of respondents attributed eye diseases to less cleanliness (22%). They understood cleanliness as less dirt, dust, and not using the same towels and clothes. This statement was more or less equally reported by males and females. TT patients (44.4%) were more likely to report hygienic factors as causes than cataract patients (25%). Moreover, those at high risk (the group with poor household characteristics) were less likely to report cleanliness as a cause (33.3%), while (50 %) of those who enjoy good household characteristics emphasized poor cleanliness as the major cause of eye diseases in general.

Half of the housewives believed that doing housekeeping and cooking were the main causes of eye diseases (51%). A considerable number of them (41%) held a fatalistic belief that eye disease is a destiny “*this is something from god and can't be avoided*”. The community recognized that hereditary caused some blinding eye diseases especially among rural communities where congenital cataract and glaucoma, and retinopathy of prematurity are highly prevalent. However, villagers thought that this was applicable for TT also “*TT is a hereditary disease, my wife has it because her mother also had it before she died*” [Ibrahim Basha: Male, 60 years, TT patient, Household characteristics are bad.]

The majority of respondents reported that; cataract and TT diseases can be cured (76.6%; with 85.7% among males, 66.7% among females). This may reflect the community potentiality to believe in curing such diseases. However, 21.4% of the respondents thought that these diseases can't be cured, and females were twice as likely as males to hold this opinion. Most of those non believers either had bad experiences with the disease themselves or heard from others about their negative experiences. None of the TT patients reported that it can not be cured, while those who reported a problem with cure were all from the cataract group. “*My neighbour's eye was turbid, the doctor*

advised him to get cataract surgery, since then, he can't see with this eye any more" [Ibrahim Basha: female, 60 years, not a TT patient, household characteristics are bad}.

Knowing the potential complications was found to affect decision making for undergoing surgery. It also affected the timing and prioritization of such decision. In our sample, 46% of the respondents reported vision loss as the possible complication of these diseases, while 30.7% of them reported that they don't know about complications. The majority of those who reported that they don't know were males. On the other hand, females tended to report less acute complications like flow of tears, eye inflammation and some decrease in visual acuity. TT patients were more likely to report mild complications than cataract patients who mentioned decreased vision as a major potential complication.

3.2.2 Awareness

Awareness of eye health and blinding eye diseases represents a higher level of knowledge, including the ability to identify groups at high risk, recognize the problem, and rely on proper sources of information. All three components were used to create an overall estimation of the level of awareness. A large proportion of respondents were able to self recognize their eye problems (84.6%) with females more than males and cataract patients more than TT patients. Again, this may be because TT would not affect their vision until its latest stages (formulation of corneal opacities).

In terms of awareness of groups at high risk, household heads identified children as the highest risk group (35.7%), with females more likely to report this group than males. Males tended to refer to both women and children as the groups at risk based on their direct observations "*Mothers and children are the most affected groups because we have a traditional habit, where always the mother carries her child on her head or shoulders (like horse riding), thus, they always infect each other"* [Ibrahim Basha: male, 40 years, not a TT patients, household characteristics are good]. Following children, both males and females equally reported that females as the second group at high risk "*Females are more likely to get eye diseases because they easily cry a lot and because they always work hard in housekeeping and they are the ones who clean the kraal, these issues should be affecting their eyes more than males"* [Ibrahim Basha: male. 64 years, not a TT patient and household characteristics are good]. Meanwhile, a small group of males think that all community categories are equally susceptible to eye diseases. Interestingly, none of the groups identified males as the group at high risk. The high risk groups were similarly reported by TT and cataract groups.

One of the most important factors affecting the level of awareness was the source of information. Doctors were the major source of information for 61.5% of the respondents. This property was equally distributed between males and females. Women tended to report their relatives as a source of information more than men. The respondents did not distinguish between cataract and TT conditions regarding this issue.

3.2.3 Attitudes

The attitude domain implies three main aspects; how do people react when they have an eye problem, what are their preferences in the selection of service provider, and which child – in terms of gender – do they prefer to send for services. Females were more likely to seek services at the village health unit as it is more accessible to them. Alternatively, people of low socioeconomic class (53.4%) more commonly sought services at the local hospital (Samalout eye hospital).

Males more than females and more TT than cataract patients preferred to go directly to the private sector and to look for a reputable ophthalmologist outside the district. This attitude constitutes the second highest preference among respondents (30.8%) with equal magnitude between males and females *“How come that everyone goes to the village health unit gets the same ointment and eye drops whatever his complaint is? That's why we always go to a private clinic in Samalout”* [Ibrahim Basha: male, 64 years, not a TT patient, and household characteristics are good]. This may also be due to bad experience *“When I was a child, I went with my mother to public free services in Samalout, I found a nurse standing in the court and holding a bottle of medication, she was dropping in every child's eyes from the same bottle, since then, I realized that free services are totally useless”* [Ibrahim Basha: Male, 48 years, not a TT patient and household characteristics are good]. Seeking a specialist outside the district was also of equal level between males and females, however, severity of disease may be a critical factor for selection of such provider *“If someone is sick, we take him to the hospital in samalout, but if he is seriously sick, then we take him directly to the private clinic outside the district”* [Ibrahim Basha: male, 70 years, TT patient, and household characteristics are bad.]

Investigating the gender biased selectivity attitude towards sending children to receive services, the majority of respondents didn't have any specific preference; also, being of cataract or TT group wasn't an issue. Among those who were biased, females were more biased in preferring boys than girls. In their opinion, one of the reasons is to please the father: *“I would prefer to send my daughter than the boy, because she is my only love, but I know that my husband will prefer to send the boy because he helps him a lot in the field. So, we will end up by sending the boy. Even we – the women – prefer to send our husbands to the hospital because they are the ones who need better vision to go out for work and look after the family, we – women – are anyways staying at home, minimum vision is enough for us to do the necessary housekeeping”* [Manquateen: female, 70 years, TT patient, household characteristics are bad]. Another very persistent perception among these communities is that the boy will follow the father as a main source of income to the family: *“We know that God has created both boys and girls, but we always say that boys do carry the name, and girls bring the shame. At the end, the boy is the future man who will be the family's source of income”* [Manquateen: female, 75 years, TT patient, and household characteristics are good]. Alternatively, males preferred to send their daughters: *“I'd prefer to send my daughters to the hospital than my boys. Tomorrow, she will grow up to be a bride. I want her to be a very good looking lady to be admired by her fiancé. She needs that to get the best opportunity for marriage. A boy can easily find his way to marriage even if he is single eyed”* [Ibrahim Basha: male, 48 years,

not a TT patient, and households characteristics re good]. Despite most of the villagers sending their girls to schools, they prefer girls to be less publicly exposed. Consequently, girls less easily move around alone compared to boys, even to the hospital or to a private clinic. This concept may result in very strange attitudes, for example: *“If both the boy and the girl are sick, we can take the boy to the hospital, and later on the girl can use the same medication”* [Manquateen: female, 40 years, cataract patient]. This attitude in favour of boys may constitute the most difficult challenge to community programs as the rationale behind it is more fundamental and culture based than the scarcity of resources, or the economic priorities of the family.

3.2.4 Practice

The majority of respondents (77%) had never sought services before for any reason. Among those who sought services, males exceeded females, and cataract patients exceeded TT patients in seeking eye care services. This pattern reflected the patient’s experience of disease. The regular TT patient – especially at early stages of disease – starts with epilating (self removal of painfully pricking eyelashes using tongs or forceps or so), this gives him/her a long duration of a comfortable feeling until the eyelashes grow again. Later on, when this temporary solution is no longer valid because of repeated multiple fibrosis, seeking services becomes a must: *“My wife used to do epilating before, until she finally went to Samalout hospital and had TT surgery, she is now cured, and never complained about rubbing lashes again”* [Ibrahim Basha: male, 60 years, TT patient, who sought service].

Seeking services was followed by compliance to treatment in this community (69.2%) where females (83.3%) more compliant than males (57.1%) and TT patients (77.6%) than cataract patients (50%). Resistance to compliance among cataract patients was most commonly attributed to fear of major surgeries not only for them but for their children too: *“If my grandson will have any eye problem, I will allow him only to be treated with eye drops or ointments, but I wouldn’t allow him to go for surgery”* [Manquateen: Male, 74 years, cataract patient who didn’t seek service.

Most of the fear of surgery in this population was related to illiteracy and decreased knowledge. Villagers believed that the eye is so sensitive that any intervention will damage it regardless of how professional is the surgeon or how equipped is the facility *“People here don’t go to the ophthalmologist because they believe that the eye is constituted from a liquid kind of thing, and that any intervention can easily damage it forever”* [Ibrahim Basha: Female, 45 years, not a TT patient, household characteristics are good]. Not only that, but they also describe the delicacy and accuracy of the ocular system and its functioning mechanisms as similar to watch, hence, any intervention may fix one part and cause dysfunction to another. *“You know, eye is exactly like the watch, if someone scratch its glass, or open it to try to fix the machine, either it will be spoiled or will not be as accurate as it was before”* [Ibrahim Basha: Male, 88 years, Cataract patient].

This is also clear comparing compliance to medical treatment (70%) to surgical service uptake (23%). In this aspect, TT and females were more likely to adopt this behavior than cataract and male patients. However, this doesn't necessarily mean that surgery is totally refused by this community. Patients accepted surgery when it was the only option for them either to maintain the remaining level of visual acuity or when there is a probability to improve it. So, when surgery is the only option, acceptance of surgery becomes increased to 61.5 % (more than doubled) with equal levels between males and females. Nevertheless, reluctance to acceptance of surgery is higher among males and cataract patients where females take the risk twice as often as males. Most probably this is because they think that they are at the edge of getting blind anyways, and then risk taking becomes wealthy. Moreover this courage would even exceed decision making for themselves and gets extended to their own children. *"My mother had an eye problem, blue water (glaucoma), she was advised to go for surgery, and she refused, finally she became blind. So, if my son will be advised to go for surgery, I would take him to the hospital this is much better than getting blind at the end"* [Manquateen: female, 52 years, cataract patient].

Satisfaction with surgical outcomes implies two important parts; satisfaction with surgical procedures and its outcomes and satisfaction with the service provider's aspects¹. Less than 50% of the respondents have reported satisfaction with surgical procedures. These results weren't different among males and females, while there was a remarkable difference between cataract and TT patients. Cataract patients tended to be less satisfied with the outcome than TT patients. As regards service providers, only 38.5% have reported being satisfied with providers after a direct experience that was either gained by them or by a very close person.

In rural communities, people tended to have a group discussion regarding serious health issues. Expressions like: *"we looked for a reputable ophthalmologist"* may reflect how the decision of a group rather than an individual. Cataract patients who were badly treated at the hospital or had to visit the hospital several times before getting booked for surgery reported dissatisfaction about the service. Another reason for dissatisfaction was the unexpected direct costs. For example some patients were promised free surgery but were asked to buy surgical consumables when the hospital ran out of stock. In another example, one of the female cataract patients reported an unexpected high level of satisfaction to the provided services. This patient had a cataract surgery, despite the final outcome was good, it was so ambiguous that she stayed at the hospital for around one month! The only plausible cause for that – from our viewpoint - is that she had a serious post operative complication (endophthalmitis?). So astonishing that she was so satisfied appreciating the hospitality and the intensive amount of care that she received. Her indices on the quality were that; *"she didn't pay any money"* for surgery and that she was accommodated at the hospital for one month for free. *"Doctors told me that you have yellow water (rural Upper Egyptians call cataract the white water, but she didn't even*

¹ Colin J, El Kebir S, Eydoux E, Hoang-Xuan T, Rozot P, Weiser M. Assessment of patient satisfaction with outcomes of and ophthalmic care for cataract surgery. J Cataract Refract Surg. 2010 Aug;36(8):1373-9.

manage to mention that), I went to the hospital, While operating, the doctor was talking to others and chatting with me, I spent one month at the hospital, after I operated, I didn't pay any money, since that, I can see very well.” [Manquateen: female, 70 years, TT patient, household characteristics are bad].

A few number of TT patients were unsatisfied either with surgical outcomes or with provider's performance. Those who were dissatisfied were mainly the ones who had either multiple recurrences or a very bad experience with surgery. *“I went to the local hospital, because I had no money, the doctor gave me local anaesthesia and was chatting with me and others during surgery. When he started the laser machine, I smelled smoke and burning meat odours clearly, I was so scared and so irritated till he finished”.* [Manquateen: Female, 75 years, TT patient].

3.2.5 Barriers

Barriers to eye care service utilization were also included in the pre-intervention interviews to supplement the findings from the questionnaires. The more commonly reported barrier was expenses including direct (hospital fees, consumables, etc.) and indirect expenses of surgery (transportation, accommodation, food and beverage, days off work, etc. as classified by the literature)^{3-51,2,3}. The cost barrier exceeded all others (with a large difference (38.7%), with males more than females. The second most common barrier was low quality of services and mistrust of local providers, where males and females were almost the same. These two provider-related barriers were followed by a group of personal-related barriers including distance, ignorance, fear and no one to accompany. Self-reported barriers were focused on 7 out of the 10 measured barriers by the quantitative questionnaire.

There was a noticeable difference between cataract and TT patients in terms of reported barriers. For example, *“expenses”, “feeling no pain”, and “mistrust”* were specific barriers to cataract patients, whereas, *“ignorance”, and “low quality”* of services were more specific to TT patients. A third set of barriers including; *“fear of surgery”, “distance”, and “no one to accompany”,* were almost the same for both groups. This categorization facilitates understanding and interpretation of barriers as disease specific.

¹ Melese M, Alemayehu W, Friedlander E, Courtright P. Indirect costs associated with accessing eye care services as a barrier to service use in Ethiopia. *Trop Med Int Health*. 2004 Mar;9(3):426-31.

² Muralikrishnan R, Venkatesh R, Prajna NV, Frick KD. Economic cost of cataract surgery procedures in an established eye care centre in Southern India. *Ophthalmic Epidemiol*. 2004 Dec;11(5):369-80.

³ Chang MA, Congdon NG, Baker SK, Bloem MW, Savage H, Sommer A. The surgical management of cataract: barriers, best practices and outcomes. *Int Ophthalmol*. 2008 Aug;28(4):247-60.

3.2.6 Perceptions

The linguistic definition of perception is: what a person intuitively recognizes or his way of seeing and understanding things. Community perception has five main concepts. (1) What people perceive. (2) The way they conceive these things. (3) The process of perceiving. (4) Knowledge gained by such perceiving and (5) becoming aware of something via their sense. Thus within each community, there is a common understanding about certain issues, as time goes by, this understanding turns into a common belief. Keeping this belief in their background, people accordingly behave. Understanding these concepts is an essential step before getting started with behavioral change programs. Within this context, the current study is interested in understanding three main areas which are; (1) Specific community perceptions about local eye care providers. (2) The community perceptions about traditional healing, and (3) The community perceptions about methods of prevention and control of blinding eye diseases.

Specific community perceptions about local eye care providers

A considerably large group of respondents (38.5%) saw their local service providers as places of poor quality. They explain this poor quality with two major indicators that they frequently observe, (1) *“they always prescribe the same medications”*, and (2) *“they only give us just pain killers”*. Meanwhile, despite that the ophthalmologist may need to prescribe *a medication that’s unavailable in the free pharmacy s/he is* – in fact - still tied to the patient’s capability to buy it. Some of them mentioned that; *“when we recommend an external medication; the patient will immediately say {I am poor}, I can’t buy this medication from the private pharmacy, please give me the alternative free medication”*. So, the community itself – unintentionally – would partially contribute to forming a barrier to care by creating a standard of only utilizing free medication.

Similarly, TT patients who usually seek eye care services at a late stage when they are suffering flow of tears due to pricking eyelashes may still argue *“Doctor, I don’t want to go for surgery, please give me an ointment that would calm my burning eyes”*. Later on, these patients are themselves the ones who blame the ophthalmologist because the medication is not working. Reporting these requests for free medicine and ointment was more common in males than females and in cataract patients more than TT patients.

Usually, cataract patients tend to describe local services as of low quality, while TT patients tend to report local service as qualified. However, those TT patients may complain other issues like ignorance and long waiting times. These results, if attributed to disease activity and impact, would yield the conclusion that; disease type and severity in addition to the required level of intervention are the most effective components in constructing the community perception of local providers.

Another highly related issue is the common villagers' behavior towards drug use. Villagers are used to buy of medications from the pharmacy without any prescription. They are used to do this due to personal experience or upon others' recommendations. In some occasions, they have simply asked the pharmacist after explaining their complaint. However, qualitative data revealed that; there is a link between traditional healing and the mentioned auto-see approach. This link was highlighted by one of the respondents when he reported that this was one of the grandfather's ways of traditional healing that they invented themselves. Those elderly villagers have realized the effect of antibiotics in curing bacterial infections; this curative power was then misused by them to apply to any injury especially if it is accompanied by ulcer. As time went by, and they became more confident and dare to use antibiotics on their own, it exceeded applying it directly to the skin to use in the eye. *"In the old days, when I was young, we used to buy Penicillin ampoules from the pharmacy, break it, and pour it into the eye, for sure the eye would be immediately cured, unfortunately, it is no longer available in pharmacies nowadays"* [Manquateen: male, 76 years, TT patient].

The community perceptions about traditional healing

One of the alternative solutions to rural communities is traditional healing. Communities, usually go for traditional healing options as a result of strong belief in these methods, advice by ancestors and ease of access^{1,2}. However, it was realized that most of the respondents started their comments stating that; *"that was in the past, but not nowadays"*, then start to provide a list of the known traditional healing methods. Within this context, traditional healing methods are either; (1) methods that were previously well known and widely used, but are no longer used nowadays, and (2) methods that are still in use by villagers.

Methods that are no longer used include (1) Tarfa Stone, a specific stone that is usually brought from a certain mountain shedding on the eastern bank of the Nile. This stone is ground and its powder is used as regular kohl. (2) Totia powder, also known as Nile totia, it is a specific type of mud calcification that's usually constituted on the Nile banks. Most probably it contains sulphur component in an anhydrous form. It was commonly sold at the village's groceries in a cheap price. *"We like totia because it is cheaply sold everywhere, we bring it, smash it with water and apply it to the eye"* [Ibrahim Basha, Male, 71 years, TT patient, household characteristics are good]. After totia being smashed with little water, the sign that it got ready, is its color change from blue to white

¹ Leonard KL. African traditional healers and outcome-contingent contracts in health care. *Journal of Development Economics* 2003;71:1-22.

² Rhee DJ, Spaeth GL, Myers JS, Steinmann WC, Augsburg JJ, Shatz LJ, et al. Prevalence of the use of complementary and alternative medicine for glaucoma. *Ophthalmology*. 2002 Mar;109(3):438-43.

(where most probably the anhydrous sulphate gets hydrated), then they apply it directly via swap into the inner lid of the sick eye. (3) Wormwood plant, where they smash it till the volatile oil appears and it turns into a liquid form, and then apply it to the sick eye. (4) Sheshm powder, usually applied to the inner eyelid using a swap. What makes this one different is that they sometimes use it as prophylaxis to keep the eye healthy. It most probably contains an antiseptic component. Shshem was – till near decades – commonly seen in farmer’s eyes. (5) Donkey’s urine; which was mentioned by a considerable number of female respondents as a very common and highly effective method: *“When I was a little child, my eye was so sick, my grandfather pored donkey’s urine into my eye, then it was immediately cured”* [Manquateen: female, 75 years, TT patient]. The method of using such urine was elaborated giving rationale by many females: *“Donkey’s urine should be used immediately while it is still hot, but we should put a white piece of cloth between it and the eye. People accepted to do this because they suffered, when you hardly suffer, you can accept anything that’s going to cure your eye.”* [Manquateen: female, 70 years, TT patient].

Methods that are still in use include (1) Mother’s milk, which is usually used by breastfeeding mothers for their newly born children. (2) Tea; is also widely used among villagers when the eye is red or swelling due to inflammation which is usually accompanied by burning feelings, they apply some boiled tea to the affected eye. Needless to say that; the idea of using tea comes from the anti-inflammatory effect of the tannic acid and its derivatives. Although the villagers may not be aware of the chemical components they realize its effect on the long run. (3) Fresh onion juice is another widely used traditional healing drug. The recommended method here is to grill the onion in the oven (usually while baking bread), and squeeze it into the children’s (or adult’s) sick eyes. Another reported method is to apply it via a swap to the inner eyelid.

The community perceptions about methods of prevention and control of blinding eye diseases

Community perceptions about disease prevention were expressed in terms of four hygienic principles: cleanliness, avoiding dirt, hands and face washing, and using clean & separate clothes & towels. Hands and face washing was the dominant selection by respondents (37.5%). It deserves this prioritization as it is the direct determinant of infection with trachoma and inflammatory diseases. This concept was more emphasized among males than females, TT patients than cataract patients.

The ‘fatalistic’ perception was also frequent among respondents, they think that *“this is something from God; it can neither be prevented, nor avoided”*. This perception does not seem to be related to religious belief in this community that contains an almost equal number of Christian and Muslim individuals. This perception seems to be also due to misunderstanding or misleading deduction of results: *“Doctors always say avoid dust*

and dirt, this will keep your eyes healthy, I am a Muslim, I do five prayers with {wadow} (washing hands, dace, and feet before prayer) every day, in spite of that, I got the eye disease. I also know an elderly lady who died at the age of 90's, she never had any eye disease” [Ibrahim Basha: Male, 88 years, Cataract patient]. This perspective may require the health educational message to elaborate more on the difference between cataract and TT diseases. This fatalistic perspective was found to be equal between males and females, cataract and TT patients.)

3.3 Focus group discussions

In integration with the semi-structured interviews and in order to improve the intervention model four focus group discussions were held with two selected groups; Health Visitors and the Community Leaders.

3.3.1 Focus group discussions with health visitors

Two meetings were held with this group consecutively. These meetings were held at the main meeting hall at the ministry of health and population building in Menia city, and the main hall of the local village health unit in Manquateen village. **The duration** of the meetings ranged from 2:30 hours to 3 hours interrupted by a short break with refreshments. Side discussions were allowed to encourage exchange of opinions and ice breaking between different groups (from different villages, and with the supportive team). **The facilitators** were mainly two trained ladies from the local NGO “Salama Mousa” supervised by an expert medical anthropologist from the research team. **The major objectives** of these meetings were to get an impression about the villager’s perception about eye diseases, the project, and the delivered messages. **Selected participants** were mainly the female health visitors who were working in the intervention villages who represent different socioeconomic levels of the community. They also reflected household inhabitants viewpoints, and gave feedback about common and unique positive and negative situations, problems, difficulties, etc. that they have faced. Some of the health visitors asked their supervisors if they can bring their sisters, or some interested housewives who wanted to share in discussions. The selected ladies varied in their educational level between B. Sc. Degree (8), high institute (4), secondary school level (17) and almost illiterate or hardly read and write (9). **Selected Calendar Date:** was after the program has already got started and the health visitors were already transferring the message within the villages. We seized the opportunity of having two of these thesis supervisors visiting the field to request them to join these meetings. These **discussions and its results** are summarized in the following points:

- Traditions and customs of this community were against doing any unknown interventions to the eye. The eye was considered as a “gem”. The people believed that tolerating decreased vision was much better than total loss of vision.
- At first in the discussions, the participants explained that their health seeking behavior were to ask “*the health worker*” of the village health unit, or to “*consult the pharmacist*” about a good brand of eye drops or eye ointment for conditions

such as “redness” which means “inflammation” or what they called a “turbid eye”.

- They remember that their grandfathers used to consult the village barber who conducted simple surgical interventions like opening abscesses, circumcision, and wound stitching. That barber was usually registered at the village health unit and had some training to work as a paramedical assistant to a general doctor. This category is no longer there. It was also famous to go for elderly experienced ladies (grandmothers) who enjoy trusted expertise. This was also applicable with other systemic diseases like fever and measles.
- There were many nongovernmental organizations working in these villages. Villagers were familiar with visitors who would pass by and deliver developmental messages. However, they weren’t convinced that these messages were serious or actually aiming at them specifically. This issue resulted in some reluctance to our health visitors at the beginning. Interventional components of the model like screening, distribution of free medications, referral of eligible cases to hospital, helping people to get to the hospital and assisting them to get served helped in changing that negative attitude where the villagers have touched concrete impact.
- There was a long history of mistrust between the villagers and local providers especially with Samalout Eye Hospital. So, when positive and / or eligible cases were asked to go to this hospital, they were reluctant. To overcome this reluctance, we asked the health visitors to deliver the message that; the capacity of the local governmental hospital has been upgraded as an essential part of this program activities and that such development included supplying new and up to date equipment and conduction of an advanced surgical training.
- Many of the health workers themselves were suspecting the reaction of the hospital. They feared that the referred cases would not be treated well there, which may result in losing their creditability, or facing criticism by their own communities. The resolution for that came later on, when the project invited the deputy minister of health, the director of therapeutic health department, and the two directors of the local eye hospitals to one of our meetings. This seemed to - build a lot of confidence through providing formal commitments to the program. Health visitors expressed their satisfaction and pleasure about their training, and the assigned jobs they performed. They were eager to know more about community based interventions and they were delighted to have a remarkable and effective contribution to health promotion in their communities. They kept asking about the next steps and they were also keen to maintain sustainability of the achievements.

3.3.2 Focus group discussions with community leaders

Two focus group discussions were held with the community leaders of the intervention villages. Community leaders in rural areas were identified by their high impact on the community. The selected locations for these meetings were the house of the mayor of Manquateen village, and the governmental building of the village administrative unit. The duration of the two meetings varied. The first meeting was during the day time that

lasted for around 90 minutes while the second meeting was held in the evening at the Mayors' house. This meeting, which was held near the end of the program, lasted for around 3½ hours. **The facilitators** of these meetings were the same social workers used in the focus group meeting with the health workers (nominated by the local NGO and the medical anthropology consultant). **The major objectives** of these meetings were different from the health workers' meetings. The first meeting was to gain support from these leaders in order to have a good impact on the community. The second meeting sought an overall evaluation of the program, including feedback on implementation of activities and methods to sustain achieved results. **Selection of participants** involved advice from three local NGOs who worked in these villages with their community leaders. These groups included; the mayor of Manquateen village, the administrative director of the village, mayor of Ibrahim Basha village, sheikh of the village (Manquateen), priest of the village (Ibrahim Basha) a parliament member, and a senator, director of the village primary school, director of the village preparatory school, vice director of the secondary school, member of the local community council, head of the youth club, female famous lawyer, the undersecretary for women affairs, and female deputy director of the primary school. **Discussions and its results** are summarized in the following points.

- Community leaders expressed their worry that the program was applied in their villages because of a known outbreak that threatens these villages. They also inquired whether the intervention implied a clinical trial of new medications, and / or surgical techniques. We reassured that; (1) the program had been ethically approved on both local and international levels. (2) The program was implemented through direct collaboration with the ministry of health and population and that it did not involve experimentation with drugs or surgical techniques.
- The leaders were also worried about potential disappointment by the referred cases to local hospital. They explained that their worry was due to their political and social responsibilities to the community. The project personnel provided reassurance that the local providers of eye care would be supported and their surgical capability and capacities improved. With these improvements, the leaders were asked to encourage people to seek services.
- Community leaders supported the idea of conducting outreach caravans that start by sending some cases to Cairo hospital. They agreed that showing high success rate to the villagers will encourage them to seek surgery. Furthermore, the leaders were informed that an eye consultant from Cairo hospital would join the local team during operating on the first group of patients.
- The community leaders were also interested in the quality of eye care at Samalout eye hospital in the future. Further details were given to them in this regard.
- The community leaders also recommended extension of the project to include satellites and 11 small hamlets that fit within their administrative zone. The interventions were expanded as requested.

Compiling results from both groups

Results from the focus group discussions are compared in table 3.1. It highlights the main interest of each group and its contribution to improve the model from different perspectives.

Table 3.1 Results from the two focus group meetings.

Comparative item	Women group	Community leaders
Major Focal Point	Community based issues on micro level.	Community benefits on macro level. Mostly concerned with governmental commitments.
Focus area	Behavioral change on household level	Overall changes on village level
Highlighted Problems	Traditional Healing, customs, beliefs, and frustration with previous NGOs developmental work.	Suspicion with intervention objectives; fear of project resulting in more frustrations.
Highlighted Barriers	Fear of quality of services	Fear of bad treatment at the hospital
Effective change (Contribution)	Changing community perceptions and behaviors	Changing community attitudes and practices
Impact on the community	High impact on micro-level (individual level)	High impact on macro-level (community level in general)
Continuity of role playing	Not expected to be long lasting	There is a definite opportunity to play an important role in the future

3.4 Reforming the health educational message in the light of the qualitative data

As a result of the semi-structured interviews and the two focus group discussions with the health visitors, their supervisors, and the first discussion with the community leaders, there was a need to reform the health educational message and to provide some additional guidelines and recommendations to the health visitors. This did not imply any substantial change either in the main messages or in the used material, only the way the messages were delivered and how its content were explained to specific communities and community members. The modifications sought to empower community members with useful knowledge and to support positive attitudes to the project. At the same time the modifications sought to ease fears about eye care services and their quality. The modifications and additions are summarized below:

- **Increasing awareness**
 - The community was encouraged to hold group discussions where "*eye care issues*" were openly discussed.

- **Primary eye care**
 - The village "*health unit*" general doctors were consulted in case of any eye disease to provide advice and / or refer when needed. During this process, patients were counseled to learn the name of disease (scientific and vernacular), manifestations, communicability and precautions, prevention, treatment and its availability & safety, current improvements in surgical procedures, the conducted training at local hospitals, and the newly supplied equipments.

- **Prevention of blinding eye diseases**
 - It was emphasized that personal cleanliness was the first way of preservation against blinding eye diseases especially those resulting from infective diseases (Trachoma, Conjunctival inflammations, etc.). Therefore, mother's hands and child's face & hands should be kept clean most of the time and specifically after any activity. It would be great if she can keep a little clean towel or a piece of cloth near her hand during daily jobs where she can keep her hands clean, and wash the child's hand and face as soon as he/she returns home, and particularly before bed time. Also, the father –being the lead- should immediately wash his face and hands once he is back to home. These behaviors will create the habit as a norm within the household and will prevent around 90 % of the infective eye (and other) diseases.
 - The whole family was involved in efforts to prevent flies from standing on their eyes, never to rub their eyes by their naked hands particularly when they are not clean or during doing any activity that includes touching dust or soil.
 - Sleeping beds, sheets, billows, and towels should be kept clean, periodically changed and washed, and preserved for personal use. Setting, living and dining areas should be kept clean through avoiding any left material (particularly nutritional remaining) that would attract flies and enable bacterial growth. Also, domestic animals and birds should be kept out of these areas.

- **Knowledge about eye diseases**
 - Identification of the targeted diseases was emphasized. Meanwhile, the community should be educated about some other infectious eye diseases like trachoma, and bacterial inflammations that usually result in "*redness of the eye*" and "*running secretions & pus discharge*". People should also know that these types of diseases are usually the most infectious ones especially from "*child to child*" and from "*child to mother*".
 - People should know that some eye inflammations may show similar manifestations where doctors are the ones who can easily differentiate among them, consequently, prescribe the correct medications, and assign its appropriate dose.

- It should be mentioned that some *"very useful and curative medications"* of some diseases may result in *"risky or severe complications"* if used in other diseases (for ex. drugs with cortisone help relieving inflammations quickly but increases the intraocular pressure [IOP] which may develop acute glaucoma. This can be concluded in four recommendations; (1) *"Never prescribe the drug that cured your eye to someone you know, who may have similar symptoms"*, (2) *"Never use the drug more or less times/days than the prescribed dose by your doctor"*, (3) *"Never repeat / re use the drug without medical consultations"*. and (4) *"Never keep a used eye drug more than one month because it can get contaminated and / or expired and hence, harm your eyes)"*.
- People should know that some invasive diseases may not present with acute or even clear manifestations until it reaches a severe stage. Thus, it is much better to consult the doctor as soon as some mild manifestations show up.
- **Seeking and utilization of eye care services**
 - Patients were encouraged to seek service once they know or feel that they need such service. Postponement of medical consultations may result in partial / permanent loss of vision.
 - When people seek service they should feel free to ask the doctor about their disease in terms of; name, severity, treatment regimen, prevention, complications, etc.
 - People should know that referral for subspecialty means a lot of professionalism and not the opposites. In such case people should keep seeking primary eye care and then show considerable compliance and follow the referral instructions. Referral may be from a GP to an ophthalmologist or from an ophthalmologist to another ophthalmologist of another subspecialty. In this case, people should accept this action with a high level of satisfaction and appreciation as being on the right track. Within this context, people should be aware that Ophthalmology has more than 12 subspecialties where it's better to target the right subspecialty.
 - Intensive utilization of calmativ and pain killer drugs (whether it is local eye drops, ointment, or systemic tablets) will never solve the problem, on the contrary, it will lead to more complications as it will mask the alarming symptoms.
 - Temporary interventions like epilating rubbing eye lashes would stimulate re-formation of new lashes; hence the lid will suffer more fibrosis that increases the number of rubbing lashes, finally leading to corneal opacity.
- **Gender related issues**
 - We should establish the concept that; giving same priority to women's health within the family will have a direct impact on the whole family in many different aspects. Thereby, Mothers should understand the criticality of their role within the family. So, sacrificing her right to give priorities to other items will not help the family anymore. Meanwhile, the whole family should encourage her to seek service.

- Likewise, delay or ignorance of daughters treatment will result in a huge dilemma (*daughter is the future bride and the house light*). She is the first assistant of her mother and she will be the future mother of the coming generation. As the mother is keen to train her on housekeeping activities, her health should be also taken care of.
 - If mothers and girls are not prioritized, infection and re-infection rates will keep the disease in a closed cycle within the household (disease pocket) and consequently a huge economic burden will take place.
- **Barriers to eye care service utilization**
 - People should abandon the wrong concept that "*free and subsidized services*" would reflect a "*low quality service*" and "*Bad treatment at hospitals*". Concrete evidences from clinical & surgical outcomes of done surgeries at local hospitals should be announced. The majority of these cases now enjoy post operative "*excellent vision without glasses*" (in cataract cases), and a "*relieved pain forever*" (in Trichiasis cases).
 - As per instructions of health authorities, dealing with patients will be in soft, nice, and descent way, also hospital staff has received awareness sessions in dealing friendly with patients.
 - Advanced anesthetic techniques used in eye surgeries are mostly local (in both Cataract and Trichiasis surgeries) where there is no more fear of general anesthesia risks.
 - Time of surgery has become so decreased due to conversion to modern techniques and using more advanced equipments.
 - Meanwhile, duration to stay at the hospital has been much shortened, where most of the cases would leave the hospital the same day.
 - Post operative complications are now very minimal (less than 5 %).
 - Barriers like distance, expenses, and other community specific barriers have been almost solved through local and community leaders, health authorities, joined efforts of governmental bodies, NGOs, and Civil Society associations.
- **Holding of a re-orientation session**
 - Finally, a meeting was held with the health visitors, their supervisors, and the two coordinators were they were oriented with the newly considered modifications (including rationales and aims).
 - All modifications were considered during conduction of the second round of awareness.
 - Health visitors were provided with a written copy of the new handout and asked to review it well, discuss it with their supervisors in their periodical meetings before conduction of the second round of health education.

Chapter 4: Results

4.1 Introduction

This chapter focuses on the quantitative results used as indicators for the success of the model. These indicators mainly explain the change in magnitude of targeted blinding diseases and the pattern of service utilization. For this purpose, baseline data at both intervention and non-intervention villages are presented followed by differences between pre and post intervention indices in a comparative manner. Data from non-intervention villages are also utilized to compare and contrast changes attributed to intervention.

4.2 General characteristics of the sampled villages

4.2.1 Demographic, geographic, and political characteristics

Table 4.1 Demographic characteristics of the sampled villages

Sector	Village name	Population	Size (Acre)	Area (M2)*	No. of hamlets	Hamlets population	Total population
Intervention	Ibrahim Basha	4,465	125	499,641.58	1	693	5,158
	Manquateen	19,644	352	1,409,600.00	11	10709	30,353
Control	Taha El Aamida	9,629	250	1,000,000.00	4	2,115	11,744
	Nazlat El Amoudin	15,279	935	3,740,000.00	1	4,000	19,279

*Area includes green fields.

All villages are within the same distance to Samalout city (the capital of the district) being, on average 20 kilometers. Meanwhile, they are all around 30 kilometers from the capital of the governorate (Menia city).

4.2.2 Health facilities on village level

Within each village, there is a village health unit (VHU) which, is usually staffed by a general practitioner and a small number of nurses in addition to few health workers and administrative staff. The major mission of the VHU is to provide primary health care services including; simple outpatient screening, treatment of cases with uncomplicated symptoms, and referral of cases in need for secondary or tertiary care to the general “central” hospital “*Samalout General Hospital*”. The VHU is not usually well equipped except for some simple examination tools and instruments that are necessary for screening. The VHU is accessible to villagers most of the day and even partially at night,

and is around 1 km from the center of the village. All four villages had their own VHU except for “*Ibrahim Basha*” village which is dependent on its neighbors’ “*Manquateen*” VHU because of its relatively small size. The distance from the center of “*Ibrahim Basha*” to “*Manquateen*” VHU is around 5 kilometers.

In addition to the VHU there is the village pharmacy which is open until midnight. People have access to medications (including antibiotics, etc.), even without formal prescription.

4.2.3 Access to secondary and tertiary health facilities

Cases who are in need for surgical intervention or any other sophisticated investigations are referred to the nearest secondary or tertiary health facility according to disease severity and / or required intervention. The nearest eye care facility is “*Samalout Eye Hospital*”, which is around 20 kilometers from the villages. Transportation is usually by local taxies, which are available all the time. In addition to “*Samalout Eye Hospital*”, people can seek eye care at “*Menia Eye Hospital*”, which is 30 kilometers from the four villages. The average expenses of transportation is 3 Egyptian pounds (0.6 US\$).

Samalout eye hospital

Samalout Eye Hospital has limited capacity. It has four eye doctors, who can perform cataract surgeries with IOL implantation using both intra-capsular and extra-capsular techniques. The operating theatre is equipped by a good binocular surgical microscope with a digital screen and a side tube that was donated earlier by an international NGO. However, it was never used to its maximum capacity. None of the staff can perform “*Phaco-emulsification*”¹ or “*Small incision cataract surgical technique*”². Trachomatous trichiasis surgery is only performed through “*Snellens’ technique*”³ which is known to have a high recurrence rate. None of the staff can perform “*Bilamellar tarsal rotation technique*”⁴ due to lack of training.

¹ Phaco-emulsification is a cataract surgery where an ultrasound instrument is used to break down and suck the lens; it is the most common technique nowadays but still expensive.

² SICS, is a similar technique to phaco, but all the steps are done manually without need to the ultrasound expenses, it is of high success rate, low complications and recommended for producing high volume of surgeries.

³ Snellen is an old technique known with a considerable recurrence rate, and may leave some disfigurements.

⁴ BLTR is a good technique recommended by the WHO, where it proved low recurrence rate and normal eye lid view.

Surgeons are able to do simple glaucoma surgeries (not all know advanced techniques) but none of them conduct retinal or other posterior segment surgeries. They used to transfer some cases either to a private center in Menia city (if the patient can pay), or alternatively to the university hospital where the fees are subsidized. The operating theatre lacks a good ventilation system, safe sterilization system, and air conditioning. Moreover, movement to and from the operating theatre is allowed to staff during surgery. Instrument maintenance and sterilization are primitive resulting in two hours waiting time between cataract patients as only two complete cataract sets are available at the hospital. Under all these conditions, surgeons only perform two cataract surgeries per day. Most of the staff is often engaged in private sector facilities; however most of these private facilities are not performing intraocular surgeries.

Menia eye hospital

Menia Eye Hospital has six ophthalmologists; however, only four of them are eye surgeons. Additionally, four ophthalmologists are on unpaid leaves to work in the private sector either in Egypt or in other countries but are still registered at the hospital. The operating theatre is large with a good ventilation system and air conditioning. Sterilization is advanced and movement to and from the operating theatre during surgery is prohibited. Nurses and paramedical staff are more skilled. The available surgical microscope is an ordinary microscope but without a digital monitor, unlike Samalout Eye Hospital. None of the surgeons is performing small incision cataract surgeries. The hospital has five complete cataract sets. Nevertheless, sophisticated cases are usually referred either to a private center or to the university hospital. Patients in need for B scan investigation prior to cataract surgery are referred to the university hospital. Only one surgeon is able to perform bilamellar tarsal rotation technique for trichiasis cases, though he is not performing it routinely.

Capacity of local eye hospitals

The average (per - month) flow of patients in the outpatient clinics is around 3,417 patients in Samalout Eye hospital; among them, around 5 cataract and 5 trichiasis cases are being operated. Meanwhile, around 6,614 patients are seen in Menia Eye Hospital and, out of them, only 10 cataract cases and around 9 trichiasis patients are operated monthly. These data are according to the formal registration systems at the two hospitals for the year 2005. (Table 4.2).

Table 4.2 Overview of the performance of the two local hospitals prior to intervention.

Year	Eye Hospital	Performance of the two hospitals before intervention						
		Out-patient (OPC)	Cataract surgeries			TT surgeries		
	No.		% of OPC	% of 40+ OPC	No.	% of OPC	% of 40+ OPC	
2005	Samalout	41,003	59	0.14%	0.65%	54	0.13%	0.60%
	Menia	79,367	118	0.15%	0.68%	103	0.13%	0.59%
	Total	120,370	177	0.15%	0.67%	157	0.13%	0.59%

The surgery figures are quite low. International figures suggest that cataract surgeries are usually 10 % of total examined at the outpatient clinic and the anticipated surgical needs for the area are about 20 times the current figures. This indicates the large backlog and unmet need of avoidable blindness in this rural area in Upper Egypt.

Educational facilities on village level

Within the four villages, there are a variety of educational facilities including; nine schools in Manquateen: 6 primary (grades 1 – 6), and 3 preparatory (grades 7 – 9). These schools are also serving the nearby village “*Ibrahim Basha*”. Students have to go for school in Menia when they reach grade 10. In the non-intervention sector, there are 11 schools: 6 primary, 3 preparatory, one secondary (but technical education), and one for religious education (secondary level also). Most of the schools suffer from overcrowding.

4.3 Characteristics of the households and residents

A total number of 2,354 households were visited within the intervention sector, (388 households in “*Ibrahim Basha*” village, and 1966 households in “*Manquateen*” village).

In intervention villages, 14.6% of the household heads are over 70 years, where 19.1% of them are women. The average rate of crowdedness within household is 5 persons per house. However, 12.6% of houses have more than 7 children and 27.2% of the houses have more than 10 persons living together in an extended family setting. Overall, 24.7% of houses have ≤ 3 rooms, 68.8% had 4-6 rooms, and only 6.5% have more than 7 rooms. The majority of houses are built using cement (60.5%) and bricks (17.4%), while around one third are built using cheaper or low quality material. Only 40% of these households have a separate kitchen, while the rest (60%) cook in the living room.

Clean water is available through the general network at 83.6% of the houses, and through a village tap in 6.3% of them. Traditional pumps are used by 8.8% of the households while 1.3% of households use other sources of water. A safe sanitation

system via a general (septic) network is available to only 5.2 % of the houses; 76.1% of households use inside latrines, 8.4% use outside latrines, and 10.3% do not report a sanitation methods.

Within the villages, 46.6 % of households do not have animals, 45.4 % kept animals inside the house and only 8 % kept them in a separate kraal outside the house. Animal waste is observed inside in 24.4% of the households. Disposal of garbage is done safely by 26% of the households (using collection service), while 74% deposit garbage in a dump, throw it away (27.8 %) or use it as a fuel (15.5 %) or as fertilizer (31.2 %).

The major source of income of households (usually through household head) is part time farming (53.2%) as being hired on-call. Other sources are; owning land (8.2%), owning shops (16%), and (22.2%) are government employees. The remaining 6.3% are either unemployed or have no major source of income.

4.4 Assessment of visual impairment and its causes in all villages before and after intervention

The sample included 150 adult inhabitants from each village (intervention and non-intervention) for pre and post intervention assessments. The coverage rate of the sample in all villages, pre and post intervention was over 85% (Table 4.3) which indicates reliable coverage rate.

Table 4.3 Sample coverage of pre and post assessments.

Village	Sample	Pre intervention		Post Intervention	
		Total Examined	Coverage %	Total Examined	Coverage %
Ibrahim Basha	150	138	92.0%	133	88.7%
Manquateen	150	131	87.3%	136	90.7%
Total intervention	300	269	89.7%	269	89.7%
Nazlat El Amoudin	150	128	85.3%	132	88.0%
Taha EI Aamida	150	134	89.3%	134	89.3%
Total non-intervention	300	262	87.3%	266	88.7%

4.5 Results of screening and health education

Screening and health education visits were conducted to 2,354 households within the two intervention villages. These visits yielded preliminary identification of 141 active trachoma cases, 97 trichomatous trichiasis cases and 302 cataract cases, in addition to 853 cases either with other eye diseases (including refractive errors) or in need for further investigation. (Table 4.4)

Table 4.4 Distribution of screened households and individuals with specific findings

Village	No. of HH Visits	Suspected (not confirmed)				
		Active Trachoma	Trichiasis	Cataract	Others (including glaucoma and refractive errors)	total
Ibrahim Basha	388	11	17	47	201	274
Manquateen	1966	130	80	255	675	1119
total	2354	141	97	302	876	1393

Confirmation of cases was done through two visits by senior ophthalmologists in collaboration with the local NGOs and the Ministry of Health and Population. At the first campaign, 132 cases out of 302 referred (*suspected*) cataract patients (43.7 %) were confirmed as having (mature) cataract and eligible for surgery. Among them, 92 (69.7 %) accepted surgery (were willing to go to the hospital). At the second visit, the field team confirmed an additional 23 cases for cataract surgery which significantly increased the total acceptance rate to 87.1%. Overall, 155 (51.3%) of the identified 302 people as having cataract were diagnostically confirmed by the clinical team. Meanwhile, trichiasis patients did not require any additional confirmation and were all referred directly to the hospital.

Hospital records showed that 124 (80%) patients received cataract surgery and 64 (69.6%) patients received trichiasis surgery. Follow up with health workers has also shown that 8 cases were postponed by the outpatient clinic due to systemic diseases (diabetes, etc.), 3 cases were postponed from the OR for similar reasons, and 53 didn't show up in referral days (Table 4.5).

Table 4.5 Surgery uptake by referred patients

Condition	Referred (% of total)		Received surgery (% of referred category)	
	Men	Women	Men	Women
Cataract	41 (26.5%)	114 (73.5%)	37 (90.2%)	87 (76.3%)
Trichiasis	27 (27.8%)	70 (72.2%)	22 (81.5%)	42 (60%)
Total	68	184	59	129

4.6 Comparing pre to post intervention indices

Overall change in visual acuity

In the intervention villages 269 people were assessed before intervention and 269 after intervention. Similarly, 262 were assessed in the non intervention villages before intervention and 266 after. During data management / cleaning, some records were removed leaving 263 and 256 people pre and post intervention, respectively in the intervention sector, and 258, 245 people pre and post intervention, respectively in the non intervention sector. Comparing pre to post intervention assessments, the prevalence of people with normal vision (vision 6/18 or better) in the intervention villages significantly increased from 60.1% to 73.4 %, an increase of 13.3 %, (95% CI [4.49 – 21.46], $p = 0.0018$), while in the non-intervention villages, normal vision increased from 60.9% to 63.7%, an increase of only 2.8%, which was statistically insignificant (95% CI [-5.94 – 11.48], $p = 0.57$), (Table 4.6). This can be considered as the primary indicator on success of the intervention. Two additional comparisons are considered hereinafter; first, the overall prevalence of normal versus visually impaired eyes (vision <6/18), and comparison of changes by gender.

Table 4.6 Change in vision following intervention

Vision group	Pre-intervention		Post-intervention		Change	
	Intervention villages	Non-intervention villages	Intervention villages	Non-intervention villages	Intervention villages	Non-intervention villages
Normal vision	158	157	188	156	13.4%	2.8%

Vision group	Pre-intervention		Post-intervention		Change	
	(60.1%)	(60.9%)	(73.4%)	(63.7%)		
Visual impairment & SVI	80 (30.4%)	78 (30.2%)	62 (24.2%)	77 (31.4%)	-6.2%	1.2%
Blindness	25 (9.3%)	23 (8.9%)	6 (2.3%)	12 (4.9%)	-7.2%	-4.0%
Total	263	258	256	245	-	-

Changes in visual impairment & severe visual impairment, and blindness

In the intervention villages the percentage of people with visual impairment and severe visual impairment (VI/SVI) decreased 6.2 % after the intervention ($p = 0.13$), while in the non-intervention villages the percentage of people with VI/SVI increased by 1.2 % ($p = 0.84$). Meanwhile, the overall burden of blindness (<3/60) decreased significantly in intervention villages from 9.3% to 2.3%, a decrease of 7% ($p = 0.0013$), 95% CI (2.81 – 11.42). A decrease in the prevalence of blindness was also detected in in the non-intervention villages of 4%, however, this reduction was statistically not significant ($p = 0.11$), (Table 4.6).

Gender specific changes in intervention villages

The gender specific prevalence of normal cases significantly and equally increased by 13.4% for men ($p = 0.04$), and 13.5% for women ($p = 0.019$) respectively. Consequently, the prevalence of VI/SVI was significantly decreased for both men and women by; 8.7 % ($p = 0.18$) and 4.7% ($p = 0.43$) respectively. Male specific prevalence of blindness improved, decreasing from 5.7% to 1%, a decrease of 4.7% ($p = 0.14$), 95% CI: (-1.01 – 11.0) while female specific prevalence of blindness significantly decreased 8.8% from 11.4% to 6.8% ($p = 0.006$), 95% CI: (2.61 – 15.28). This suggests that the overall reduction in prevalence of blindness may be attributed to the greater reduction in blindness among women (Table 4.7).

Table 4.7 Change in vision following intervention disaggregated by gender

Vision group	Pre Intervention					Post Intervention				
	Male	%	Female	%	Total	Male	%	Female	%	Total
Normal	71	67.6%	87	55.1%	158	81	81.0%	107	68.6%	188
VI/SVI	28	26.7%	52	32.9%	80	18	18.0%	44	28.2%	62
Blind	6	5.7%	19	12.0%	25	1	1.0%	5	3.2%	6
Total	105	100.0%	158	100.0%	263	100	100.0%	156	100.0%	256

4.7 Principal causes of visual impairment and blindness in intervention villages

4.7.1 Principal causes of visual impairment & severe visual impairment

The principal causes of VI/SVI were cataract (53.8%), refractive errors (32.5%), trachomatous corneal opacities (3.8%) and retinal detachment (1.3%) in addition to some other causes (8.8%), (Table 4.8). Disaggregating results by gender revealed that the first two leading causes for men and women were the same: cataract and refractive errors. Women accounted for all 3 cases of trachomatous corneal opacities (3.75%).

Table 4.8 Principal causes of visual impairment & severe visual impairment¹ in the pre intervention phase

Rank	Cause	Frequency	% of total causes
1	Cataract	43	53.8%
2	Refractive Errors	26	32.5%
3	Trachomatous Corneal Opacities	3	3.8%
4	Retinal Detachment	1	1.3%
5	Other Corneal Opacities ²	0	0.0%
6	Other miscellaneous causes	7	8.8%
	Total all causes	80	100.0%

¹ Low Vision is identified here as Visual Acuity <6/18 and ≥3/60.

² Other Corneal Opacities means a corneal opacity of causes other than trachoma, i.e. non-trachomatous corneal opacity (may be due to trauma, inflammation, or as a complication of an infection that led to corneal ulcer).

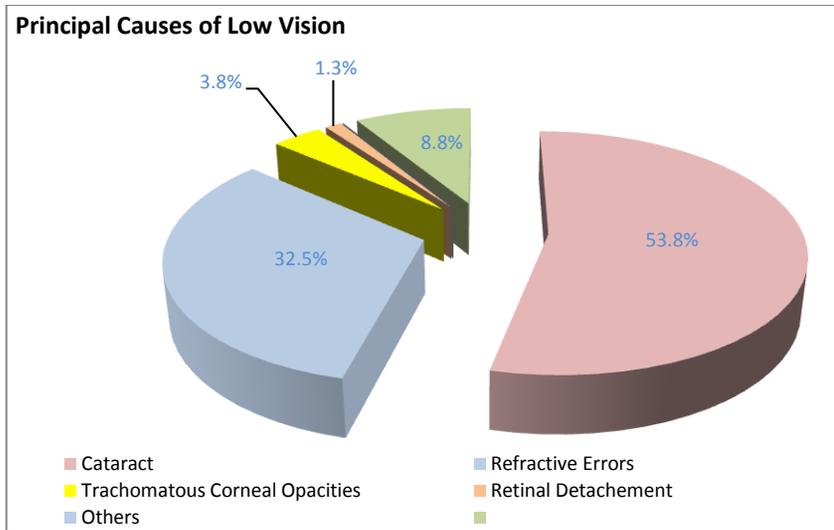


Figure 4.1 Principal causes of low vision in pre intervention phase

4.7.2 Principal causes of blindness

Cataract (60.4 %) was the main cause of blindness, followed by refractive errors (14.6 %), trachomatous corneal opacities (12.5 %), other corneal opacities (10.4 %), and absence of globe (2.1 %). Gender specific causes were similar for men and women; however, men accounted for 2 of the 3 individuals with trachomatous corneal opacities (66.7%), (Table 4.9).

Table 4.9 Principal causes of Blindness ¹ in the pre intervention phase

Rank	Cause	Frequency	% Cause
1	Cataract	15	60%
2	Refractive Errors	4	16%
3	Trachomatous Corneal Opacities	3	12%
4	Other Corneal Opacities	2	8%
5	Absence of Globe	1	4%
6	Retinal Detachment	0	0.0%
	Total all causes	25	100.0%

¹ Blindness is identified here as visual acuity <3/60.

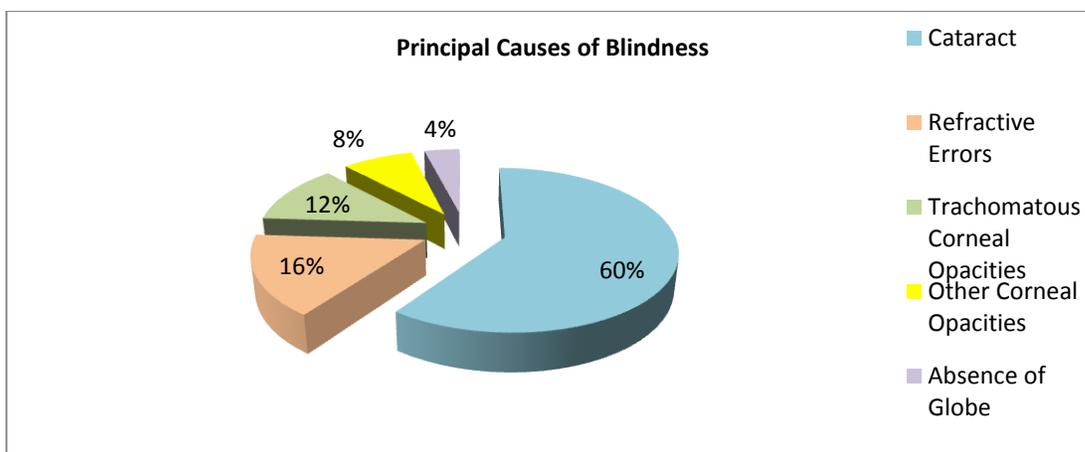


Figure 4.2 Principal causes of blindness in the pre intervention phase

4.7.3 Comparing pre and post intervention principal causes of low vision and blindness

This comparison is aiming at determining whether implementation of the intervention model has affected the pattern of principal causes of low vision and blindness.

Pre and post intervention principal causes of VI/SVI

Pre-intervention 80 patients had VI/SVI while after intervention 62 patients had VI/SVI. The greatest reduction in VI/SVI was related to cataract. (Table 4.10) From a gender specific perspective there were almost similar reductions of both cataract and refractive errors (19.6% reduction in cataract among males and 16.8% reduction among females).

Table 4.10 Comparing pre and post intervention principal causes of VI/SVI in intervention villages

Cause	Pre			Post		
	No.	%	Rank	No.	%	Rank
Cataract	43	53.8%	1	22	35.5%	2
Refractive Errors	26	32.5%	2	26	41.9%	1
Trachomatous Corneal Opacities	3	3.8%	3	8	12.9%	3
Retinal Detachment	1	1.3%	4	0	0.0%	0
Other Corneal Opacities	0	0.0%	0	2	3.2%	4
Other miscellaneous causes	7	8.8%	-	4	6.5%	-
Total All Causes	80	100.0%	-	62	100.0%	-

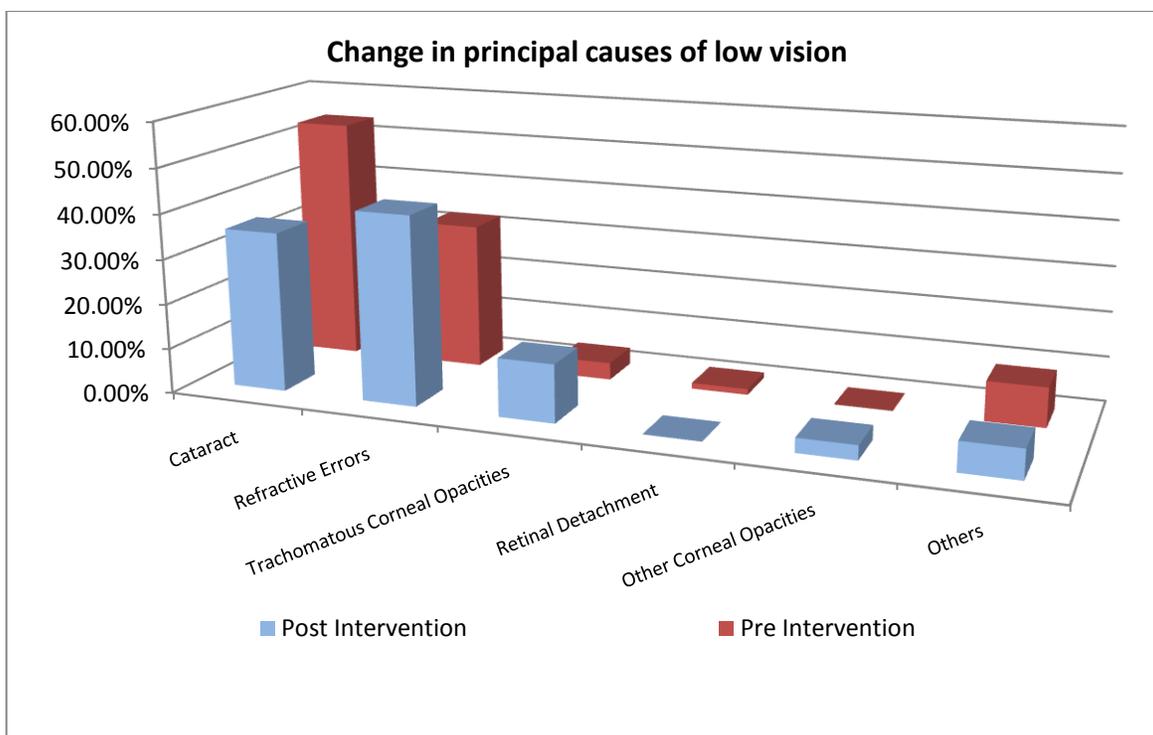


Figure 4.3 Change in principal causes of low vision

Pre and post intervention principal causes of blindness

In terms of blindness, cataract remained the major cause of blindness followed by trachomatous corneal opacities. Of note is the reduction of refractive error as a cause of blindness (Table 4.11). Gender wise, reductions were similar for men and women except for cataract where a greater reduction was recognized among females than males (16.2 % and 3.8%) respectively.

Table 4.11 Comparing pre and post intervention principal causes of blindness in intervention villages

Cause	Pre intervention			Post intervention		
	No.	%	Rank	No.	%	Rank
Cataract	15	60%	1	3	50.0%	1
Trachomatous Corneal Opacities	3	12%	3	2	33.3%	2
Absence of Globe	1	4%	5	0	0.0%	0
Refractive Errors	4	16%	2	0	0.0%	4
Other Corneal Opacities	2	8%	4	1	16.7%	3
Total All Causes	25	100.0%		6	100.0%	

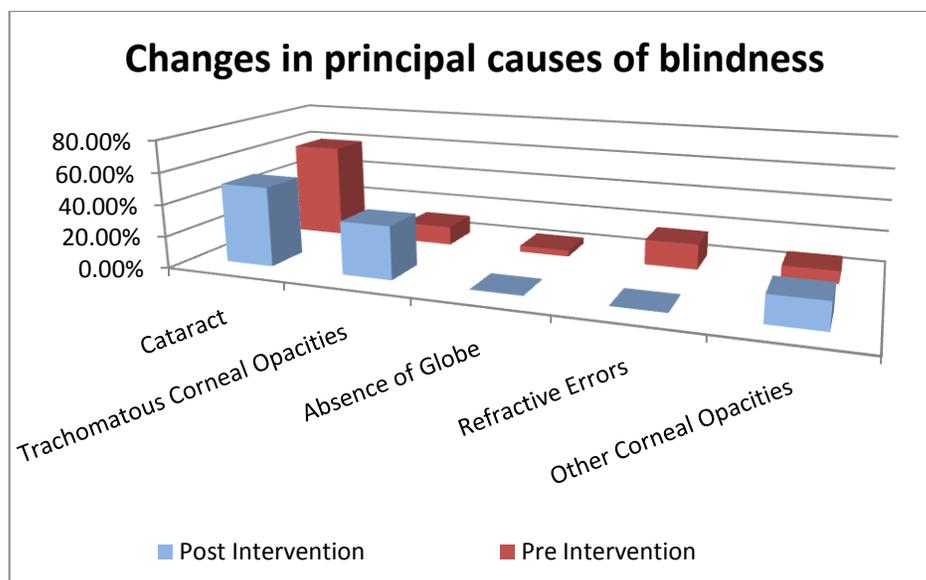


Figure 4.4 Comparing pre and post intervention major causes of blindness

4.8 Change in prevalence of the two main targeted diseases of avoidable blindness

The prevalence of operable cataract (among the population 40+) in intervention villages was 30.8% at baseline with a higher prevalence among females (35.6%) compared to males (23.6%). Overall, operable cataract dropped to 14.5 % after the intervention, a statistically significant reduction of 16.3 %, (95% CI [9.34 - 23.26], $p < 0.0001$). The prevalence among males dropped by 13.2 % (from 23.6 % to 10.4 %, 95% CI (3.24 - 23.16), $p = 0.0175$) while the prevalence among females decreased by 18.4 %, (95% CI [8.99 - 27.81], $p = 0.0003$) from 35.6 % to 17.2%. In the non-intervention villages, there was also a reduction from 31.3% to 24.4%, a 6.9 % difference however that was not statistically significant (95% CI [-.075 - 14.55], $p = 0.0956$). Reductions in the non-intervention villages were similar for men and women.

4.8.1 Change in the prevalence of cataract

Table 4.12 Comparison of pre and post intervention prevalence of cataract

Pre Intervention				Post Intervention		
Cataract	Male*	Female*	Total**	Male*	Female*	Total**
Intervention Villages						
	NO. (%)	NO. (%)	Total	NO. (%)	NO. (%)	
Unilateral	9	14	23	2	7	9
Bilateral	16	43	59	9	21	30
Total	25 (23.6)	57 (35.6)	82 (30.8)	11 (10.4)	28 (17.2)	39 (14.5)

Pre Intervention				Post Intervention		
Cataract	Male*	Female*	Total**	Male*	Female*	Total**
Non-intervention villages						
Unilateral	7	20	27	5	15	20
Bilateral	17	37	54	14	31	45
Total	24 (24.5)	57 (35.4)	81 (31.3)	19 (18.10)	46 (28.6)	65 (24.4)

4.8.2 Change in prevalence of trichomatous trichiasis

There was a significant reduction of 5.7 % in the prevalence of trichomatous trichiasis in intervention villages from 9.4% to 3.7% (95% CI [1.53 - 9.87], $p = 0.013$) while in the non-intervention villages the reduction was 1.74%, from 10.04 % to 8.3%, (95% CI [-3.198 - 6.678], $p = 0.58$). The prevalence of trichiasis among men decreased from 5.7% to 3.8%, a decrease of 1.9% (95 % CI: [-3.82 - 7.62], $p = 0.74$) while there was a 8.2% significant decrease in the prevalence of trichiasis among women, from 11.9% to 3.7% (95% CI [2.41 - 13.99], $p = 0.011$). In intervention villages, of the total 5.7% reduction in trichiasis women accounted for 86.7%.

Table 4.13 Comparison of pre and post intervention prevalence of trichiasis

Pre intervention				Post intervention		
TT	Male*	Female*	Total**	Male*	Female*	Total**
Intervention Villages						
	NO. (%)	NO. (%)	Total	NO. (%)	NO. (%)	
Unilateral	2	5	7	2	2	4
Bilateral	4	14	18	2	4	6
Total	6 (5.7)	19 (11.9)	25 (9.4)	4 (3.8)	6 (3.7)	10 (3.7)
Non-intervention Villages						
Unilateral	1	8	9	2	7	9
Bilateral	4	13	17	2	11	13
Total	5 (5.1)	21 (13.0)	26 (10.0)	4 (3.8)	18 (11.2)	22 (8.3)

4.9 Change in determinants of visual impairment among the population of the intervention sector

Socioeconomic and demographic characteristics are the primary factors associated with visual impairment and blindness. Identifying the key determinants would help our understanding of the amenable causes of visual impairment and blindness in order to plan effective interventions and evaluate such interventions.

Measured characteristics

To measure the contribution of determinants, we linked all household characteristics (from the household form) to the medical exam form through a database query. The linked characteristics or potential risk factors are as follows:

- **Personal characteristics**
 - Age.
 - Sex (Male, Female).
 - Marital Status (Single, Married, Divorced, Widowed).
 - Occupation (Farmer, Worker, Trader, Regular Employee, Temporarily Hired, Student, Unemployed, Others).
 - Education: (Illiterate, Read & Write, Primary, Preparatory, Secondary, Diploma, University, Post Graduate).
- **Household characteristics**
 - Household Head Age.
 - Household Head Sex.
 - Number of children within the household.
 - Children sleep on the same pillow (Yes/No).
 - Constructing Material (Mud, Wood, Stone, Block, Tin, Cement, Others).
 - Number of rooms.
 - Existence of a Separate Kitchen (Cooking in living room).
 - Washroom (Separate door, Toilet covered, Tap inside).
 - Main source of water (General network, Well, Pump, General village tap, Canal, Water seller, Others).
 - Method of sanitation (General network, Latrine inside, Latrine outside, No method of sanitation), and Frequency of tank evacuation.
 - Existence of animals (In-house, Outside kraal, Existence of animal dirt inside, or outside house).
 - Method of getting rid of garbage (Collecting car, Collector, Throw out in street, Burn, Bury, Use as fertilizer or fuel, Dump).
 - Main Source of Income (Own land, Self employed, Regularly hired, Irregularly hired, No source of income).

Results of binary logistic regression analysis for pre intervention determinants

In running the binary logistic regression, our unit of analysis was person with visual impairment and blindness (all people with a vision <6/18). The dependant variable was vision (1 = impaired vision, 0 = normal vision). All variables in the survey were considered as independent variables. Our major aim was (besides knowing the direction and magnitude of the effect size) to detect the major demographic and socioeconomic determinants or risk factors (of non medical or biological nature) associated with having decreased vision.

Multivariate analysis revealed a large number of characteristics associated with vision loss. Age, sex, occupation (farmer and unemployed), and literacy (being illiterate) were significant individual risk factors with having vision loss. Analysis of the characteristics of the household head revealed that; age and main source of income (being temporarily hired) were associated with vision loss. In terms of household characteristics, the number of children per household, having poor water source (well, pump), absence of any sanitation system, having an inside latrine, and need to evacuate every 6 months or less were significantly associated with vision loss. Washroom characteristics associated with vision loss included; having no separate door for washroom and having an uncovered latrine. Poor methods of getting rid of garbage (burning and throwing out), presence of a kraal within or nearby and presence of animals inside the house, and poor construction material (mud, wood, and stone) were also associated with vision loss (Table 4.14).

Table 4.14 Adjusted odds ratios (logistic regression) of vision loss for pre intervention determinants (all males and females)

Characteristic	Category	Adjusted (OR)	<i>p</i> value	95% CI
Age		1.08	< 0.0001	(1.05 - 1.13)
Sex	Female	2.5	<0.0001	(1.57 - 4.26)
Marital Status	Widowed	14.37	<0.0001	(3.78 - 54.64)
Occupation	Farmer	1.7	0.008	(1.25 - 5.34)
	Unemployed	1.8	0.009	(1.06 - 8.33)
Education	Illiterate	3.75	0.009	(1.9 - 7.5)
Household Head	Age	1.03	0.0005	(1.01 - 1.05)
Number of Children per household		1.14	0.006	(1.09 - 1.34)
Water Source	Pump	4.87	0.0028	(1.35 - 17.54)
	Well	3.78	0.015	(1.58 - 9.05)
Method of Sanitation	Tank Inside	3.83	0.013	(1.32 - 11.09)
	No Sanitation	7.39	0.005	(1.81 - 30.26)
Latrine	Evacuate < 6 m	1.02	0.033	(1.01 - 1.04)

Characteristic	Category	Adjusted (OR)	p value	95% CI
Washroom	Washroom no door	2.9	<0.0001	(1.17 - 7.18)
Method of Getting rid of Garbage	Toilet not covered	2.23	0.025	(1.10 - 4.51)
	Burn Garbage	3.37	0.021	(1.19 - 9.51)
	Throw Out Garbage	12.39	<0.0001	(4.61 - 33.31)
Presence of Animals Household Constructing Material	Presence of Kraal	7.65	0.0005	(2.31 - 12.17)
	Mud	5.03	0.0003	(2.48 - 7.19)
	Wood	2.04	0.0021	(1.64 - 7.28)
	Stone	1.86	0.0033	(1.38 - 2.63)
Main Source of Income	Temporarily hired	4.78	0.021	(1.26 - 18.14)

**This table shows only variables and categories that showed significant change in intervention villages.*

Repeating this model on post intervention determinants showed some changes in the pattern; some variables continued to be significantly associated with vision loss after the intervention, while others ceased to contribute. In addition, a few variables (not associated pre-intervention) were associated with vision loss post-intervention. (Table 4.15) Of particular interest, variables that became no longer effective due to intervention which are mainly either related to increased awareness or to broken down barriers.

Table 4.15 Changes in pre and post intervention risk factors

Variables associated both pre- and post-intervention	Variables not associated pre-intervention but associated post-intervention	Variables no longer associated with vision loss (post-intervention)
Age, Sex, Main source of water (pump & well), Sanitation method (inside tank or latrine), Toilet (uncovered), Household constructing material (Mud), and Main source of income (temporarily hired)	Children sleeping on the same pillow (Yes), having bathroom tap (No), and having a separate kitchen (No, i.e. cooking in same living and / or sleeping room).	Marital Status (Widowed), Occupation (Farmer & Unemployed), Education (Illiterate), Head of Household (Age), Number of children per household, Latrine evacuation frequency (< 6 months), Washroom door (No), Getting rid of garbage (Burn and Throw out), Presence of animals at home (Presence of Kraal), Constructing material (Wood & Stone)

Results of logistic regression model for pre intervention female specific determinants

As we detected differences in vision loss between men and women we also sought to assess female specific risk factors with vision loss and a logistic regression model was conducted including females only. This was carried out pre-intervention and post-intervention. Pre-intervention the primary factors associated with vision loss included; marital status, occupation, literacy, age and sex of household head, and number of children in addition to number of children sleeping on the same pillow). The characteristics of the household environment (water, sanitation, kraal, construction) were similar to the combined analysis.

Table 4.16 Results from logistic regression on pre intervention female specific determinants

Characteristic	Category	Adjusted (OR)	p value	95% CI
Marital Status	Widowed	16.15	<0.0001	(2.51 - 52.73)
	Single	3.05	0.0229	(1.89 - 11.41)
Occupation	Farmer	13.8	<0.0001	(7.21 - 18.65)
	Unemployed	1.45	<0.0001	(1.16 - 1.76)
Education	Illiterate	2.15	0.0003	(1.03 - 3.69)
	Read & Write	1.58	0.0008	(1.01 - 1.93)
	Primary School	1.25	0.0013	(1.21 - 1.68)
	Prep School	1.23	0.0239	(1.14 - 1.84)
Household Head	age	1.33	0.0067	(1.18 - 5.01)
	sex	6.09	0.0003	(2.26 - 16.37)
Number of Children per household	Children No.	3.48	<0.0001	(1.82 - 6.42)
Children sleeping on same pillow	No Separate Pillow	2.15	0.0007	(1.21 - 4.35)
Water Source	Pump	7.5	<0.0001	(1.27 - 14.56)
	Well	5.6	<0.0001	(2.71 - 7.85)
	General Village Tap	1.9	<0.0001	(1.23 - 5.32)
Sanitation Method	Tank Inside	2.89	0.0001	(1.69 - 7.48)
	No Sanitation	5.08	0.001	(2.18 - 9.49)
Washroom	Covered Toilet	1.51	0.0006	(1.16 - 4.15)
	Bathroom no tap	3.37	0.005	(1.87 - 21.11)
Getting rid of Garbage	Burn Garbage	3.13	<0.0001	(2.71 - 9.21)
	Garbage Fertilizer	4.38	0.004	(2.28 - 13.57)
	Garbage Throw Out	4.77	0.0054	(2.09 - 8.38)
Existence of Separate Kitchen	Kitchen No	6.57	<0.0001	(1.61 - 9.42)

Characteristic	Category	Adjusted (OR)	p value	95% CI
Presence of Animals	Presence of Kraal	9.65	<0.0001	(3.76 - 15.21)
	Cattle dirtiness	9.13	<0.0001	(4.48 - 14.74)
Household Constructing Material	Mud	5.8	0.008	(3.73 - 9.92)
	Wood	1.9	0.017	(1.16 - 5.31)
	Stone	3.6	0.009	(1.89 - 7.15)
Source of income	No source of income	15.14	0.004	(2.82 - 29.24)

**This table shows only variables and categories that showed significant change in intervention villages.*

From these results, key risk factors of vision loss for women are highlighted in table 4.17.

Table 4.17 Post intervention female specific risk factors

Characteristic	Category	Adjusted (OR)	p value	95% CI
Marital Status	Single	3.05	0.0229	(1.89 - 11.41)
Education	Read & Write	1.58	0.0008	(1.01 - 1.93)
	Primary School	1.25	0.0013	(1.21 - 1.68)
	Prep School	1.23	0.0239	(1.14 - 1.84)
Household Head	Sex	6.09	0.0003	(2.26 - 16.37)
Children sleeping on same pillow	No Separate Pillow	2.15	0.0007	(1.21 - 4.35)
Water Source	General Village Tap	1.9	<0.0001	(1.23 - 5.32)
Washroom	Bathroom no tap	3.37	0.005	(1.87 - 21.11)
Getting rid of Garbage	Garbage Fertilizer	4.38	0.004	(2.28 - 13.57)
Existence of Separate Kitchen	Kitchen No	6.57	<0.0001	(1.61 - 9.42)
Presence of Animals	Cattle dirtiness	9.13	<0.0001	(4.48 - 14.74)
Source of income	No source of income	15.14	0.004	(2.82 - 29.24)

**This table shows only variables and categories that showed significant change in intervention villages.*

Repeating this model post intervention female specific determinants that persisted to be significant included children sleeping on the same pillow, main source of water (pump), washroom (toilet uncovered and no tap in bathroom), having no separate kitchen, presence of animals (existence of kraal, and having animal dirt), and household construction material (mud). Only one characteristic: source of income (temporarily hired) became significant, while 23 (79.4 %) of the characteristics were no longer significant.

Table 4.18 Comparing pre and post intervention female specific characteristics

Variables associated both pre- and post-intervention	Variables not associated pre-intervention but associated post-intervention	Variables no longer associated with vision loss (post-intervention)
Children Sleeping on same pillow, Main source of water (Pump), Washroom (Toilet is uncovered, No tap in bathroom), No separate kitchen, Presence of animals (Existence of kraal, Cattle dirt inside the house), Household constructing material (Mud).	Main source of income (Temporarily hired)	Marital status (Widowed, Single), Occupation (Farmer, Unemployed), Education (Illiterate, Read & Write, Primary school, Preparatory school), Head of household (Age, Sex), Number of children within the household, Water source (Well, General village tap), Sanitation method (Latrine / Tank inside, No sanitation), Getting rid of garbage (Burn garbage, Use as fertilizer, Throw garbage out), Household constructing material (Wood, Stone), No source of income.

Table 4.18 shows that; similar to the overall persistent determinants, factors related to water source and sanitation are the major persisting factors as they weren't targeted by the model and generally speaking not easy to modify. Although the health education component and the barriers-related component managed to neutralize factors such as level of education and some behaviors related factors there is still some effect of factors like presence of animals and their dirt in the house.

4.10 Barriers to eye care service utilization

Based on the pre-intervention phase, ten selected barriers to eye care services were selected to be included in the barriers questionnaire which was applied both pre and post intervention. These barriers are listed below (Table 4.19) they can be categorized into; patient, health system, and family/community related issues.

Table 4.19 Different types of studied barriers and their main domains

Expressed Question	Related to
I didn't feel a problem	patient
Fear of Surgery	patient
Fear of Surgical Outcome	patient
I am too Old	patient
Fear of Bad treatment at hospital	patient

Expressed Question	Related to
Distance to hospital is too long	Health system
Expenses of surgery are too much	Health system
No one to accompany me to hospital	Family/community
I couldn't quit work to go	Family/community
No one to take care of family and children	Family/community

Change in prevalence of barriers between pre and post intervention

Table 4.20 shows that although females had higher magnitudes of barriers than males in many categories, there were no significant differences in prevalence of barriers between males and females in the pre-intervention phase, as none of the apparent differences was found to be statistically significant.

Table 4.20 Comparing male to female barriers in the pre intervention phase

S.	Barrier	Reported Yes No (%).		Difference	95% CI	p
		Male	Female			
1	I didn't feel a problem	19 (90.5)	58 (86.6)	3.90%	-11.06 to 18.86	0.9255
2	Fear of Surgery	18 (90)	60 (90.9)	0.90%	-13.97 to 15.77	0.7506
3	Fear of Surgical Outcome	16 (80)	62 (93.9)	13.90%	-4.56 to 32.36	0.1518
4	I am too Old	19 (95)	56 (84.8)	10.20%	-2.69 to 23.09	0.4160
5	Fear of Bad treatment at hospital	20 (64.5)	39 (70.9)	6.40%	-14.28 to 27.08	0.7099
6	Distance to hospital is too long	14 (70)	48 (73.8)	3.80%	-18.95 to 26.55	0.9627
7	Expenses of surgery are too much	16 (84.2)	60 (90.9)	6.70%	-11.11 to 24.51	0.6795
8	No one to accompany me to hospital	12 (63.2)	35 (53.8)	9.40%	-15.44 to 34.24	0.6431
9	I couldn't quit work to go	7 (36.8)	29 (43.9)	7.10%	-17.67 to 31.87	0.7730
10	No one to take care of family and children	7 (36.8)	25 (37.9)	1.10%	-23.54 to 25.74	0.8560

**Respondents were allowed to report all applicable barriers.*

Tables 4.21 to 4.23 show the pre and post intervention questionnaire results for the intervention villages (Appendix I; Questionnaires) first overall then disaggregated by sex. In the pre-intervention phase; most of the listed barriers were already high in magnitude (more or less around 80 %, Table 4.21) 'Knowledge and personal willingness'

barriers (#1-4) were the most prevalent. There is an overall decrease in the magnitude of most of the barriers, with large decreases in all categories except family and community support (#7-10). Furthermore, Disaggregating data by gender, the following two tables (4.21 –4.22) demonstrate the change in both male and female specific barriers separately.

Table 4.21 Differences in prevalence of barriers between pre and post intervention

S.	Barrier	No (%). reported		Difference	95% CI	p
		Yes				
		Pre	Post			
1	I didn't feel a problem	77 (87.5)	104 (70.7)	16.80%	(6.71 - 26.89)	0.0051
2	Fear of surgery	78 (90.7)	97 (66.4)	24.30%	(14.48 - 34.12)	0.0001
3	Fear of surgical Outcome	78 (90.7)	83 (63.8)	26.90%	(16.61 - 37.19)	< 0.0001
4	I am too old	75 (87.2)	59 (51.8)	35.40%	(23.82 - 46.98)	< 0.0001
5	Fear of bad treatment at hospital	59 (68.6)	44 (41.1)	27.50%	(13.97 - 41.03)	0.0003
6	Distance to hospital is too long	62 (72.9)	52 (48.1)	24.80%	(11.46 - 38.14)	0.0009
7	Expenses of surgery are too much	76 (89.4)	66 (54.5)	34.90%	(23.87 - 45.93)	< 0.0001
8	No one to accompany me to hospital	47 (56)	42 (40)	16.00%	(1.8 - 30.2)	0.041
9	I couldn't quit work to go	36 (42.4)	44 (42.3)	0.10%	(-14.06 - 14.26)	0.8933
10	No one to take care of family and children	32 (37.6)	25 (30.1)	7.50%	(-6.76 to 21.76)	0.3877

*Respondents were allowed to report all applicable barriers.

Table 4.22 Differences in prevalence of **male specific** barriers between pre and post intervention phases

S.	Barrier	Reported Yes, No (%).		Difference	95% CI	p
		Pre	Post			
1	I didn't feel a problem	19 (90.5)	35 (76.1)	14.40%	-3.18 to 31.98	0.2937
2	Fear of Surgery	18 (90)	32 (71.1)	18.90%	0.24 to 37.56	0.177
3	Fear of surgical outcome	16 (80)	26 (72.2)	7.80%	-15.04 to 30.64	0.7461
4	I am too old	19 (95)	20 (62.5)	32.50%	13.20 to 51.80	0.0212
5	Fear of bad treatment at hospital	20 (64.5)	12 (48)	16.50%	-9.33 to 42.33	0.3327
6	Distance to hospital is too long	14 (70)	14 (51.9)	18.10%	-9.44 to 45.64	0.3423
7	Expenses of surgery is too much	16 (84.2)	23 (67.6)	16.60%	-6.13 to 39.33	0.3225
8	No one to accompany me to hospital	12 (63.2)	13 (56.5)	6.70%	-22.98 to 36.38	0.9009

S.	Barrier	Reported Yes, No (%).		Difference	95% CI	p
		Pre	Post			
9	I couldn't quit work to go	7 (36.8)	15 (53.6)	16.80%	-11.69 to 45.29	0.4038
10	No one to take care of family and children	7 (36.8)	9 (40.9)	4.10%	-25.77 to 33.97	0.9580

**Respondents were allowed to report all applicable barriers.*

Table 4.23 Differences in prevalence of **female specific** barriers between pre and post intervention phases

S.	Barrier	Reported Yes, No (%)		Difference	95% CI	p
		Pre	Post			
1	I didn't feel a problem	58 (86.6)	69 (68.3)	17.60%	5.44 to 29.76	0.015
2	Fear of surgery	60 (90.9)	65 (64.4)	26.50%	14.87 to 38.13	0.0002
3	Fear of Surgical Outcome	62 (93.9)	57 (60.6)	33.30%	21.86 to 44.74	< 0.0001
4	I am too old	56 (84.8)	39 (47.6)	37.20%	23.35 to 51.05	< 0.0001
5	Fear of Bad treatment at hospital	39 (70.9)	32 (39)	31.90%	15.91 to 47.89	0.0005
6	Distance to hospital is too long	48 (73.8)	38 (46.9)	26.90%	11.66 to 42.14	0.0018
7	Expenses of surgery is too much	60 (90.9)	43 (49.4)	41.50%	28.91 to 54.09	< 0.0001
8	No one to accompany me to hospital	35 (53.8)	29 (35.4)	18.40%	2.46 to 34.34	0.0387
9	I couldn't quit work to go	29 (43.9)	29 (38.2)	5.70%	-10.51 to 21.91	0.6044
10	No one to take care of family and children	25 (37.9)	16 (26.2)	11.70%	-4.39 to 27.79	0.2228

**Respondents were allowed to report all applicable barriers.*

Table 4.22 shows that; among males, the only barrier that showed a significant decrease (32.5%) was feeling "*too old for surgery*". On the other hand, in Table 4.23, among females 8 out of 10 barriers have a significant reduction in magnitude. These include; knowledge, all fear barriers, feeling too old, distance, cost of surgery and accompany. Only the last two barriers (work and family related barriers) didn't show any change in magnitude.

Despite that the previous set of tables have provided detailed picture of different assessed barriers, the following table (Table 4.24) compares barriers assessed by

quantitative to qualitative methods (questionnaires to interviews). This comparison is necessary to constitute a clear idea about the implicitly and explicitly expressed barriers.

Table 4.24 Comparing barriers results from questionnaires and interviews

Barrier	Questionnaires		Interviews	
	Male	Female	Male	Female
	Rank (Magnitude %*)	Rank (Magnitude %)	Rank (Magnitude %)	Rank (Magnitude %)
Expenses (Cost)	4 (10.8)	2 (17.2)	1 (43.8)	1 (33.3)
Low quality of service	1 (13.1)	1 (13.1)	2 (12.5)	2 (13.3)
No one to accompany	6 (8.1)	7 (7.4)	2 (12.5)	3 (6.7)
Distance	5 (9.5)	5 (10.2)	3 (6.3)	2 (13.3)
Fear	3 (12.2)	2 (12.7)	3 (6.3)	3 (6.7)
Feeling no pain	2 (12.8)	3 (12.3)	3 (6.3)	3 (6.7)

Table 4.24 compares the results from the interviews with the relevant results from the barriers questionnaires. In the questionnaires, quality of service was the highest barrier, while “*expenses*” was ranked as one of the four highest together with “*quality*”, “*fear*” and “*no pain*”. In the interviews, it is triple the nearest barrier which is “*quality of service*” which was previously ranked as “1” in the questionnaire results. Moreover, females who previously reported “*cost*” as a great barrier almost two times more than males. In the interview they reported “*expenses*” less than males; however, it became their 1st barrier, which indicates that they didn’t want to explicitly state that in the questionnaire. Likewise, they reported; “*no one to accompany*” as their last barrier in the questionnaire, however, in the interview it turned to be one of their three major barriers. Another very interesting example is “*fear of surgery*”, females who had “*fear of surgery*” more than males in the quantitative questionnaire, have equally reported the same barrier as males did in the qualitative interview.

A part of that, a set of barriers showed consistency in its results between both techniques. Those barriers were similar in having low ranks in both types of analysis. Moreover, there weren’t any significant differences between cataract and TT patients in the quantitative results, whereas the differences became quite clear when we looked at the qualitative results.

4.11 Eye care service utilization

To describe eye care service utilization in terms of quantity, and pattern, two different sources of information were utilized. First, we assessed patients who received cataract or trichiasis surgery in relation to those in need for surgery. This information was abstracted from eye exam, cataract, and trichiasis forms collected by the health educators. Secondly, an aggregated analysis of surgical registration data at both local hospitals (Menia and Samalout) was carried out.

Patients who have had surgical services

Prior to intervention 21.1% of eyes that underwent cataract surgery did not have insertion of an IOL; this persisted post intervention with 22.5% of eyes have non-IOL cataract surgery. Overall, the increase in service uptake (both cataract and trichiasis) was highest among women. Recurrence of trichiasis reduced from 53.3% pre intervention to 14.3% post intervention (Table 4.25). However, some of the cases still performing cataract without IOL insertion, this may be due to one of two reasons, either for performing such surgeries in some private settings that still use that technique or because some of the villagers can not afford to buy the IOL as requested by hospital.

Table 4.25 Numbers of eyes which had surgeries pre and post intervention

Surgical Intervention	Pre Intervention			post intervention		
	Male	Female	Total	Male	Female	Total
Cataract (No IOL)	3	1	4	3	6	9
Cataract + IOL	10	5	15	17	23	40
Total Cataract	13 (68.4%)	6 (31.6%)	19	20 (40.8%)	29 (59.2%)	49
TT Surgery	7 (46.7%)	8 (53.3%)	15	14 (40%)	21 (60%)	35
TT Recurrence	3	5	8	2	3	5
total avoidable blindness (Cataract + TT)	20 (58.8%)	14 (41.2%)	34	34 (40.5%)	50 (59.5%)	84

Cataract surgical coverage (CSC) and trichiasis surgical coverage (TSC) are two important indices of surgical uptake. The surgical coverage is defined as the number of cases that had surgery / number of cases that had surgeries + those who are still currently in need for surgery. Total and female specific pre and post intervention surgical coverage rates are compared in Table 4.26. Both cataract surgical coverage and trichiasis surgical coverage improved between pre and post intervention. Furthermore, the gap between men and women decreased with equity achieved in terms of trichiasis surgical coverage, while in cataract the male specific rate is still exceeding the female's rate.

Table 4.26 Cataract and TT Surgical coverage rates pre and post intervention

Surgical Coverage		Pre Intervention (Rate [95% CI])	Post Intervention (Rate [95% CI])
<i>Cataract surgical coverage (CSC)</i>		18.8% [11.19 – 26.43]	55.7% [45.3 – 66.06]
Gender Specific CSC	Male	34.2% [19.13 – 49.29]	64.5% [47.76 – 81.36]
	Female	9.5% [2.28 – 16.77]	50.9% [37.9 – 63.86]
<i>Trichiasis surgical coverage (TSC)</i>		37.5% [22.5 – 52.5]	77.8% [65.63 – 89.92]
Gender Specific TSC	Male	53.8% [26.75 – 80.95]	77.8% [58.57 – 96.98]
	Female	29.6% [12.41 – 46.85]	77.8% [62.10 – 93.46]

Patients' selected service providers

Prior to intervention the first choice of patients in terms of service providers was private practice (41.2%). While only 10.5% of cataract patients went to government hospitals, one third of trichiasis patients used this option. Post intervention, utilization of the local hospital increased markedly; the local hospital became the first choice for service for both cataract (46.9%) and trichiasis (48.6%) patients.

Table 4.27 Cataract and TT surgeries per patient's preference

Service Provider	Pre intervention			Post intervention		
	Cataract No. (%)	TT No. (%)	Total No. (%)	Cataract No. (%)	TT No. (%)	Total No. (%)
Local Hospital	3 (15.8)	2 (13.3)	5 (14.7)	23 (46.9)	17 (48.6)	40 (47.6)
Governmental Hospital ¹	2 (10.5)	5 (33.3)	7 (20.6)	8 (16.3)	6 (17.1)	14 (16.7)
University Hospital	2 (10.5)	3 (20)	5 (14.7)	6 (12.2)	3 (8.6)	9 (10.7)
Private Clinic / Center	10 (52.6)	4 (26.7)	14 (41.2)	9 (18.4)	7 (20)	16 (19)
Outside Menia	2 (10.5)	1 (6.7)	3 (8.8)	3 (6.1)	2 (5.7)	5 (6)
Total	19 (100)	15 (100)	34 (100)	49 (100)	35 (100)	84 (100)

Trend and pattern of service utilization at both local hospitals

To understand the changes in trend and pattern of service utilization at both Samalout and Menia eye hospitals, we collected data from 6 years (2002 - 2008) including our intervention-affected years (last quarter 2006 – first quarter 2008). There was a marked increase in the numbers seeking eye care services at the outpatient's clinics during the program implementation years at both hospitals. Additionally, the gender disparity in service utilization reduced, particularly at Samalout eye hospital. (Table 4.28)

Table 4.28 Trends and patterns of outpatient service utilization in Samalout and Menia eye hospitals

Year	Samalout Eye Hospital			Menia Eye Hospital			Total (Two Hospitals [% gender])		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
2002	23,432	9,113	32,545	66,214	38,887	105,101	89,646 (65.1)	48,000 (34.9)	137,646
2003	22,868	10,762	33,630	68,408	40,522	108,930	91,276 (64)	51,284 (36)	142,560
2004	26,396	11,694	38,090	76,628	36,895	113,523	103,024 (68)	48,589 (32)	151,613
2005	29,276	11,727	41,003	82,073	38,297	120,370	111,349 (69)	50,024 (31)	161,373
2006	29,764	14,071	43,835	78,581	46,150	124,731	108,345 (64.3)	60,222 (35.7)	168,566
Intervention started last quarter 2006									

¹ Governmental hospital means the main ophthalmology hospital that's usually in the capital of the governorate and serves all districts as a referral hospital.

Year	Samalout Eye Hospital			Menia Eye Hospital			Total (Two Hospitals [% gender])		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
2007	31,851	21,234	53,085	96,235	53,897	150,132	128,086 (63)	75,131 (37)	203,217
2008	33,469	23,354	56,823	99,455	55,944	155,399	132,924 (62.6)	79,298 (37.4)	212,222

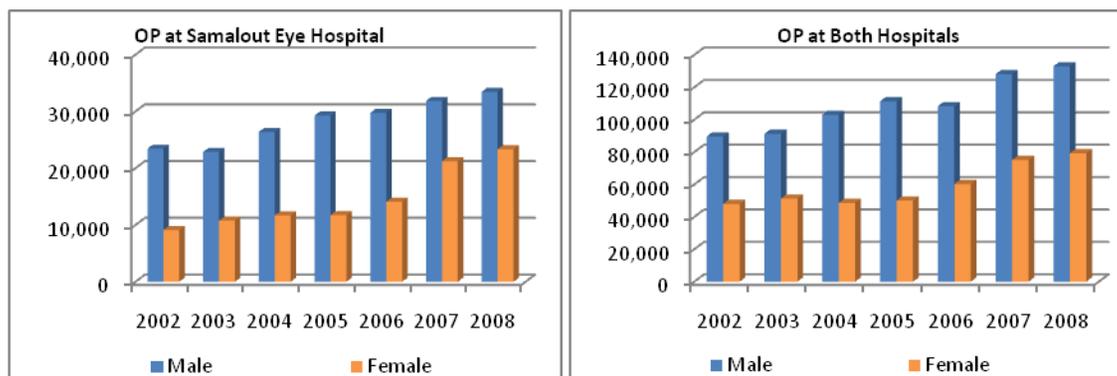


Fig. 4.5 Trend and pattern in outpatient volume in local hospitals

Likewise, there was a large increase in the number of surgeries during the last two years; the number of cataract surgeries almost doubled. However, the number of surgeries among men continued to exceed the number of surgeries among women. (Table 4.29)

Table 4.29 Trends and patterns of cataract surgery uptake in samalout and menia eye hospitals

Cataract Surgery									
Year	Samalout			Menia			Total both hospitals		
	Male	Female (%)	Total	Male	Female (%)	Total	Male	Female (%)	Total
2002	16	7 (28.7)	23	71	35 (33)	106	87	42 (32.2)	129
2003	25	11 (31)	36	87	42 (32.9)	129	111	54 (32.5)	165
2004	36	18 (33)	54	108	55 (34)	163	144	73 (33.8)	217
2005	39	20 (33.2)	59	115	62 (35)	177	154	82 (34.6)	236
2006	51	24 (32.4)	75	134	79 (37)	213	185	103 (35.8)	288
2007	131	67 (33.6)	198	311	182 (37)	493	442	249 (36)	691

Cataract Surgery									
Year	Samalout			Menia			Total both hospitals		
	2008	144	74 (33.9)	218	335	198 (37.2)	533	479	272 (36.2)

Similar to the cataract figures, there was a large increase in the number of trichiasis surgeries, at both hospitals, during the last two years. Consistent with the cataract uptake data, gender equity was not achieved in terms of trichiasis surgery; men still outnumbered women. (Table 4.30)

Table 4.30 Trends and patterns of TT surgery uptake in samalout and menia eye hospitals

TT Surgery									
Year	Samalout			Menia			Total both hospitals		
	Male	Female (%)	Total	Male	Female (%)	Total	Male	Female (%)	Total
2002	10	4 (30.7)	14	38	22 (37)	60	48	26 (35.4)	74
2003	31	14 (30.9)	45	80	48 (37.2)	128	111	62 (35.7)	173
2004	34	15 (31.2)	49	86	48 (35.9)	134	120	63 (34.5)	183
2005	37	17 (32.1)	54	98	59 (37.7)	157	134	76 (36.1)	210
2006	39	18 (31.3)	57	109	69 (38.9)	178	148	87 (37)	235
2007	111	52 (32.2)	163	224	136 (37.7)	360	335	188 (36)	523
2008	125	62 (33)	187	256	149 (36.8)	405	381	211 (35.6)	592

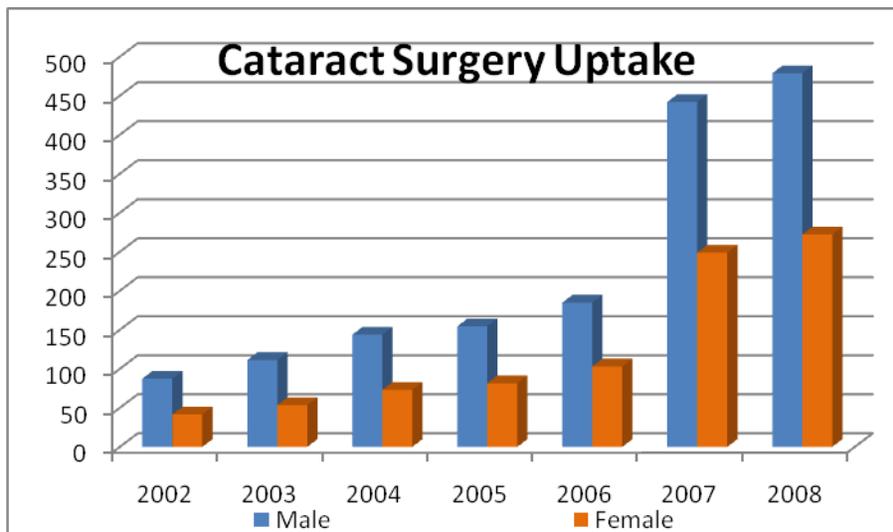


Fig. 4.6 Cataract surgery uptake in both hospitals by gender

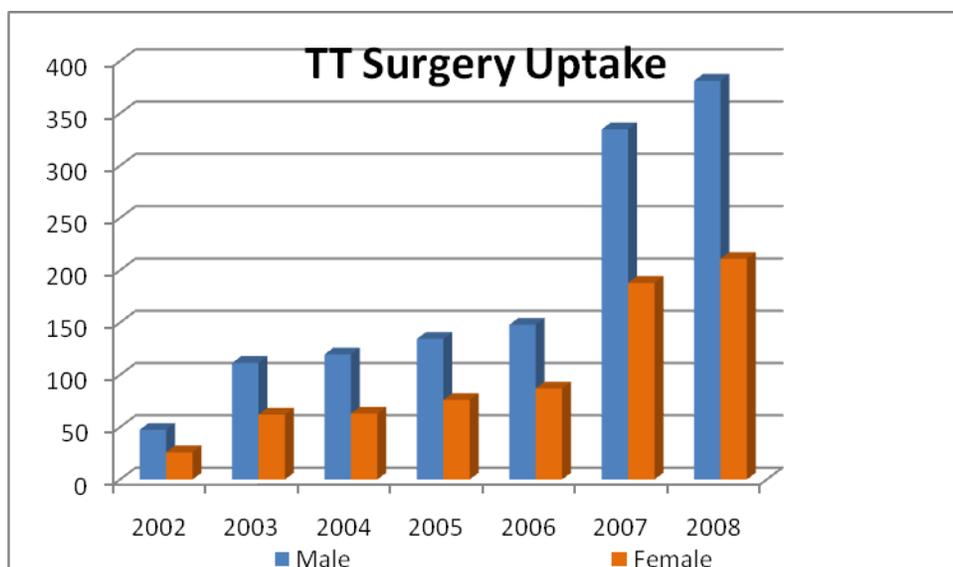


Fig. 4.7 TT surgery uptakes in both hospitals by gender

One of the important indicators on service is to compare surgical uptake to outpatient volume (surgical win-rate). The surgical win-rate shows a significant increase in 2007 after introduction of the interventions. Moreover, surgical win rates were almost similar for men and women. (Table 4.31)

Table 4.31 Change in surgical win rates from 2002 - 2008

Surgical Win rate (per thousand Outpatient clients)				
Year	Male	Female	Total	Rate of annual increase*
2002	1.505	1.418	1.475	-
2003	2.442	2.245	2.371	60.8%
2004	2.556	2.812	2.638	11.3%
2005	2.595	3.160	2.770	5.0%
2006	3.072	3.158	3.103	12.0%
2007	6.065	5.818	5.974	92.5%
2008	6.470	6.090	6.328	5.9%

*Rate of annual increase = $[(N_2 - N_1)/N_1]\%$.

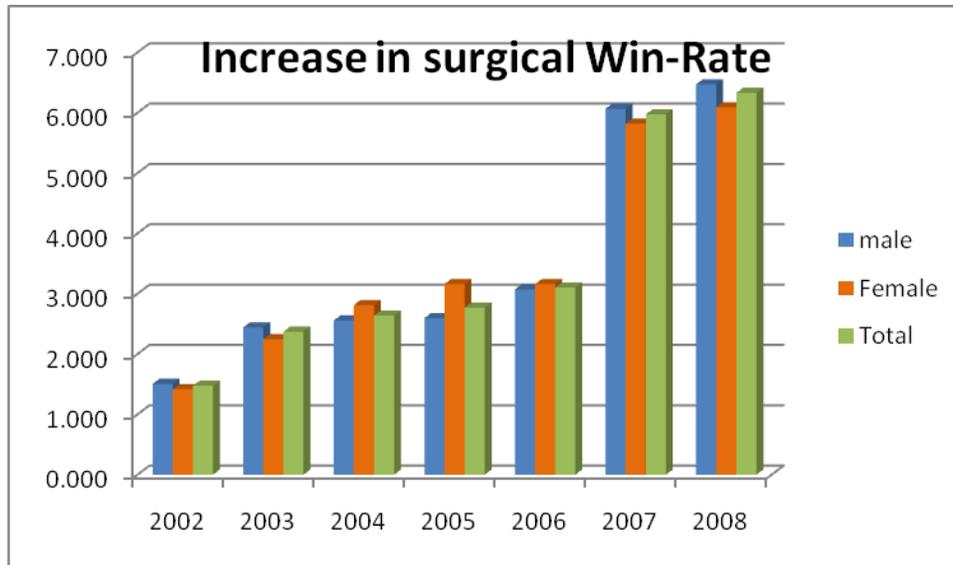


Fig. 4.8 Increase in surgical win-rate over the last 7 years.

4.12 Change in quality of visual life after surgery as a surrogate to service improvement

The widely accepted VF-14, an assessment of visual function¹ was modified and validated to suit African countries² and used to evaluate quality of visual life of those who had surgeries (before or after intervention). Comparing VF mean scores of cataract patients showed that; the mean (\pm SD) VF improved from 19.3 (\pm 21.1) to 28.3 (\pm 25.9), with a mean difference of 8.9, (95% CI: [1.743 – 16.124]), $T = 2.45$, p value = 0.015 (Student's T test).

There were also improvements in the mean VF score among trichiasis patients with pre intervention VF of 18.2 (\pm 19.4) increasing to post-intervention VF of 27.5 (\pm 29.7). However, the 9.3 difference was not statistically significant (95% CI: [-5.707 – 24.299]), $T = 1.3$, p value = $p = 0.217$ (Student's T test).

¹ Steinberg EP, Tielsch JM, Schein OD, Javitt JC, Sharkey P, Cassard SD, et al. The VF-14. An index of functional impairment in patients with cataract. ArchOphthalmol. 1994 May;112(5):630-8. Earl P.

² Van Dijk K, Lewallen S, Chirambo M, Gardiner J, Hoar B, Lindley J, et al. Creation and testing of a practical visual function assessment for use in Africa: correlation with visual acuity, contrast sensitivity, and near vision in Malawian adults. Br J Ophthalmol. 1999 Jul;83(7):792-5.

4.13 Change in patient satisfaction with surgery results

For both cataract and trichiasis patients who had surgery, we compared the pre and post levels of satisfaction. Among cataract patients, the percentage of people who needed glasses after surgery reduced from 37.5 % to 12.5 %. The percentage of those who continued to wear glasses also reduced from 77.8 % to 33.3 %. Meanwhile, the percentage of those who expressed their self reported satisfaction with surgery increased from 66.7% to 83.3 %, an increase of 16.6%. Those who reported being unsatisfied with their surgery results had two main reasons: lack of improvement of their vision (62.5%), and deterioration of their vision (37.5%). The percentage of patients that are willing to recommend surgery to other patients increased from 66.7 % to 83.3 %. Those who refused to advise other patients to go for surgery had three main reasons: their feeling that the *"surgery is not useful"* (50 %), *"surgery is painful"* (25 %) and *"surgery is unnecessary"* (25 %).

Among trichiasis patients; satisfaction improved from 66.7 % to 77.8 %, an increase of 11.1 %. Those who were unsatisfied had four major reasons in the pre intervention assessment: *"No improvement in visual acuity"* (33.3%), *"deterioration of vision"* (22.2%), *"Painful experience with surgery"* (22.2%), and having *"Recurrence of trichiasis"* (22.2%). In the post intervention assessment, reasons for non-satisfaction were limited to two causes; *"Non improvement of vision"* (50 %), and *"Pain of surgery"* (50%). The number of patients who were willing to recommend surgery uptake to others increased from 61.5% in the pre intervention assessment to 77.8% in the post intervention assessment. The three self reported causes for non recommending surgery to others in pre intervention were; *"Surgery is not useful"* (40%), *"Surgery is so painful"* (40%), and *"Surgery has many side effects"* (20%) respectively. These pre intervention causes were limited to two main causes in the post intervention; *"Surgery is so painful"* 75 %, and *"Surgery is unnecessary"* (25 %).

4.14 Second focus group meeting with community leaders

- The second meeting was held near the end of the project, the community leaders were satisfied with the achieved results, and were ambitious to maintain these results through a sustainable mechanism.
- They discussed different scenarios for maintaining the acquired success including training more health visitors, or performing annual orientation sessions to the household inhabitants. Other interventions included adding a prevention of blindness curriculum at the primary schools, and including prevention of blindness activities within the routine primary health care activities (at the village health unit).
- The leaders concluded that the model can be simulated, adapted and applied to solve other health problems using the same concept and techniques.

- The community leaders also investigated whether the project can be extended to other district villages. They offered to help by communicating with community leaders in these villages.
- There was a constructive discussion about the impact of integrated approaches to prevent blindness and combat other endemic diseases; where it is necessary to improve water and sanitation systems, and control environmental factors that play a major role in the spread of disease.
- The leaders reported another success story in the light of their experience where they developed a garbage and rubbish collection project. The most common way, was that villagers throw their garbage on a pile, and every one or two weeks the local authorities bring a huge truck that drains this pile. Their model implied developing a system where they hired a small truck to pass by the village every other day and collect the garbage from houses where every house is to pay a very minute share (around 3 L.E. per month, less than one dollar) to cover the expenses.

Chapter 5: Discussion and limitations

5.1 Creation of a new model

The current study designed and implemented an integrated model to work in rural areas that is cost effective and replicable. We utilized the program logic model technique as a tool for linking and identifying phases as well as enabling accurate monitoring for implementation and overall evaluation of outcomes. The implementation of the model followed a well prepared plan involving policy makers, health authorities and community leaders. It merged new health education messages with screening and referral activities in order to bridge the gap between local providers and the community. It identified and then actively worked to break down individual, family, and community specific barriers to utilization of eye care services.

The study included pre and post intervention assessments to evaluate the effect of the proposed intervention and relied on the hierarchical constitution of staff to provide a tool for monitoring such activities based on the program logic model. This monitoring system not only came through the implementation team but also relied on vital discussions with stakeholders and community leaders to share viewpoints and empower their capabilities to take over at the end of the program.

5.2 Importance of communications and advocacy

Preliminary communication with all possible stakeholders occurred before starting the fieldwork activities. This helped to open the gate to the community on both political and community based levels¹. Advocating to policy makers and health authorities required special effort because these officials deal with multiple health, social and economic problems. The importance of convincing governments to support prevention of blindness programs was studied by two distinguished scientists in the field (H. Faal and C. Gilbert 2007)². Policy makers were reluctant and needed to be convinced about the cost effectiveness and cost utility benefits. Policy makers like to see the problem in one hand and the solution in the other, in which minimal efforts will lead to large benefits. On the other hand, health authorities do not like to see serious problems in their governed areas. If present, they are likely to blame the issue on limited resources involving everything from human to financial resources including equipment. In Egypt, as in most of the developing countries especially in Africa and Asia, endemic diseases are prevalent. Although being overwhelmed with health problems, they are always criticized by civil

¹ Report of the IAPB/WHO workshop on national committees for the prevention of blindness. Bensheim: World Health Organization; 1994 Nov. Report No.: WHO/PBL/95.46

² Faal H, Gilbert C. Convincing governments to act: VISION 2020 and the Millennium Development Goals. *Community Eye Health*. 2007 Dec;20(64):62-4.

societies instead of lending support. The deputy ministers of health in rural upper Egyptian governorates usually encounter problems such as polio, hepatitis, and other serious diseases that may lead to death. In this case they may look at blindness as a lower rank of danger and hence prefer to allocate more time and efforts to fatal endemic diseases. To overcome this obstacle, we highlighted social, economic, and other consequences of blindness. During advocacy meetings, we clarified that the intervention is here to support the political authorities and not just to highlight this problem. The required support was made clear with political approval that the program will build the capacity of the service providers in rural areas. Meanwhile, borderlines of political ambition were delineated as limited by the program ceiling. Questions about what the program was giving back to the local hospitals were addressed. At times, policy makers may not always be happy with providing training, and / or health education, or dissolving barriers. To them, this may lead to an increase in demand and overload the capacity of the system which is already insufficient. Great efforts were made to convince the authorities that the program is going to develop the provider rather than increase the demand. Having provided such explanations, they welcomed the idea that their area will be a pioneer model for other areas in terms of being disease free. Therefore, our advocacy plan was based on educating authorities about the positive components of the intervention and to highlight that minimal contribution from their side will lead to huge benefits at the end of the day.

Although community leaders were eager to reap benefits for their communities, it was clear that they were tired of previous theoretical advices given by local NGOs. Those leaders needed to be convinced that actual and applicable steps are going to be taken by the intervention plan which will lead to concrete results. Community leaders are the real keys for the community. In rural areas, local community leaders such as the mayor or heads of distinguished families are trusted by the community. When these leaders were convinced, they played a major role in increasing compliance to program activities and hence positively contributed in its success. We worked to involve them in the planning process. They were instrumental in providing us with an understanding about the community and in convincing villagers to change their behaviours. It was also planned to prepare them to take over management of these programs once established into the community.

5.3 Classification of the model

In our study we classified the model into three phases -pre intervention, intervention, and post intervention. This approach was very successful in terms of focusing the interventional phases, building on successive steps, and monitoring different activities. Training and preparation of the implementation team was a crucial component during the pre intervention phase. Appropriate training of health educators permitted accurate collection of data, accurate screening of individuals that reduced the amount of false

positives, and ensured best utilization of resources. It was also important to build confidence among the health educators who delivered the message and dealt with barriers. It was through their efforts that the community would need to be convinced to be compliant and enthusiastic about service uptake. Moreover, prioritization of low vision and blinding diseases to reduce, control, and / or prevent blindness is a difficult task. The consensus is that the most prevalent avoidable causes of blindness in developing countries are Cataract and Trachomatous Trichiasis. Glaucoma and Diabetic retinopathy are felt to comprise the third and fourth most common cause. In developed countries the pattern of such causes is different. For example, age related macular degeneration and long surgical waiting lists are the most significant factors. In situations of limited resources, there is a need to focus only on easily avoidable causes that can result in a remarkable reduction of such burden if tackled with existing resources. In developing countries these avoidable causes are mainly cataract and trachomatous trichiasis. This is true in rural Egypt where *Chlamydia Trachomatis* is still persistent, and both cataract and trachoma are responsible for an estimated 67% of the problem. Targeting these two diseases will yield a drastic reduction in the prevalence of blindness. Despite we weren't able to conduct messages or activities to control cataract, including a trachoma prevention component will lead to future decrease in trichiasis as one of its complications. Measuring the impact of such component would require a separate longitudinal cohort study. It should be noted here that this idea is susceptible to changes and modifications per other countries and settings.

Blindness determinants, associated risk factors, and specific barriers play important non medical roles in constituting the magnitude of blindness. Therefore, we sought to estimate the effect size of these factors. By doing this it helped to prioritize which barriers would be most needed to be addressed by the model later on. Our findings supported the hypothesis that identifying these issues at the beginning would increase the probability of the model success. To our knowledge, most of the available literature either focus on causes and the determinants or conduct pre and post intervention assessments of disease prevalence to evaluate the outcome of their interventions. In our study we merged both approaches by including determination of the associated factors with assessment of the prevalence of disease in both pre and post intervention phases. Thus, we were able to achieve two goals in one study. First, we managed to evaluate the model through the change in prevalence of disease; second, we were able to determine the associated factors and the barriers that guided us while implementing the model. Moreover, we decided to keep the assessment of determinants and barriers included in the post assessment to investigate whether the model managed to change its magnitude and pattern.

5.4 Community perceptions and the knowledge, attitude, and practice gap

Knowledge is the capacity to acquire, retain and use information. *Attitude* refers to reacting in a certain way to certain situations. “*Practice* is the application of rules and knowledge that lead to action”¹. “*Awareness* is the state or ability to perceive, to feel, or to be conscious of events”². “*Perception* is the process of attaining awareness or understanding of sensory information”³. “*Barriers* are any conditions that make it difficult to make progress or to achieve an objective”⁴. Thus, in community health research, *knowledge* means understanding diseases in terms of manifestations, methods of transmission or occurrence, and impact. *Awareness* means the ability to detect these manifestations and distinguish them. *Attitude* means willingness to seek service for diagnosis and cure of such diseases. *Practice* means taking the necessary actions needed to cure such disease. *Barrier* means any obstacle that may hinder such practice.

It is clear from the previous definitions that there are a series of associations and interactions between these different domains. Such associations and interactions can be clarified in the following diagram.

¹ Badran IG. Knowledge, attitude and practice the three pillars of excellence and wisdom: a place in the medical profession. East Mediterr Health J. 1995;1(1):8-16.

² Wikipedia the free encyclopedia. [Internet]. San Francisco: Wikimedia Foundation Inc.; 2009. Awareness; [cited 2009 Nov 7]. Available from: <http://en.wikipedia.org/wiki/Awareness>

³ Wikipedia the free encyclopedia. [Internet]. San Francisco: Wikimedia Foundation Inc.; 2009. Perception; [cited 2009 Nov 7]. Available from: <http://en.wikipedia.org/wiki/Perception>

⁴ WordNet dictionary. [Internet]. New Jersey: Princeton University; 2010. Barrier; [cited 2009 Nov 7]. Available from: <http://wordnetweb.princeton.edu/perl/webwn?s=barrier>

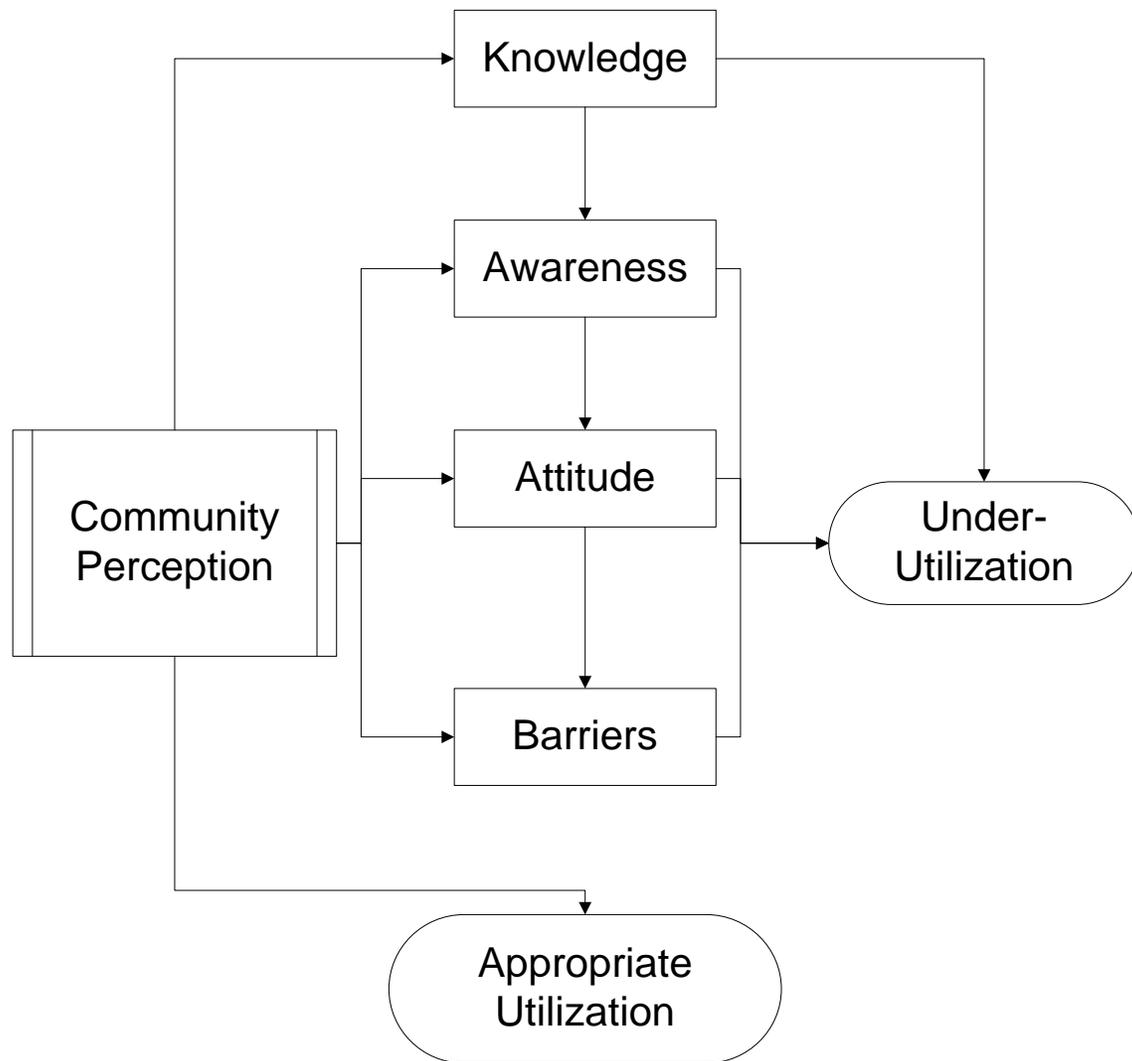


Figure 5.1 Relationships among different domains affecting service utilization

One reason for failure in prevention of blindness is developing intervention models that mainly focus on the medical aspects of the problem and ignore other non medical issues. As a result, it was found that improvement in medical aspects only lead to partial success in reduction of blindness burden¹. Brilliant et al (1985)² were the first to look at other (non-medical) determinants by comparing the characteristics of those who accept to those who reject cataract surgery in Nepal. Brilliant noted that access, and less education are the most common barriers to receiving surgery in addition to a number of geographic,

¹ Kaplan-Myrth N. Blindness Prevention in Mali:Are Improvements in Sight? Disability Studies Quarterly. 2001;21(3).

² Brilliant et al (1985), op. cit.

socioeconomic, and logistical conditions. Brilliant study also highlighted gender bias by identifying that females are more affected than males and have lower surgical rates.

In the current study, we employed qualitative techniques to determine the level of understanding by people about cataract and TT. We gained information about how they behave if they have such problem and how they see their local providers. In addition, we could also clarify the actual picture about specific concepts, beliefs, cultures, customs, and traditions of this community. Our interview results were similar to Brilliant's study in terms of knowledge and access. Roughly 30% of respondents had not even heard of the diseases. The remaining 70% believed that it could be cured and understood that cleanliness is a major risk factor and that the diseases can lead to blindness. Despite this healthcare was not sought. Brilliant and her colleagues thought of community health education as a potential solution to increase the awareness and encourage villagers to seek services. Later she conducted another study to evaluate the effectiveness of community health education on increasing cataract surgical uptake in India (Brilliant et al, 1991)¹. The study compared eight different interventional approaches based on four health educational methods alternatively combined with two economic components. Results of this study suggested that health education should be combined with economic incentives like offering free or subsidized surgeries, and supporting transportation and accommodation expenses. It also recommended employing local people to conduct health education within their villages and merge this with screening and referral activities for increasing surgical uptake.

In light of these studies, we sought to establish the correct knowledge and increase awareness of our group using the most understandable and appropriate approach. For example in our study, we removed the vulgar eye pictures that have been widely used by the WHO programs in Africa. From this viewpoint, we also worked to develop a health educational message that addresses the misconception about eye diseases in terms of causes, manifestations, undesired complications and the existence of plausible solutions. However, the health education message and its delivery is one part of an integrated plan that initially aims to achieve behavioural change outputs. Changing behaviours of a certain communities is very complex and requires an intervention that takes all possible factors into consideration^{2,3}.

¹ Brilliant et al (1991), op. cit.

² Gove DJ, Shahani AK, Meacock SE, Van der Hoorn HH, Bailey R, Ward ME, et al., editors. *Operatioanl Models for the Prevention of Blindness In: Models for Infectious Human Diseases Their Structure and Relation to Data*. 1st ed. Cambridge: Press Syndicate of the University of Cambridge; 1996. ; p.402-6.

³ Arseneault R. Blindness in the world: nursing experience in Nepal. *J Ophthalmic Nurs Technol*. 1992 Nov-Dec;11(6):241-6.

We incorporated some pictures from the intervention villages itself. This helped in accepting and understanding the message. Also, the idea of using the year calendar to post these messages was successful as opposed to other developmental organizations working in Upper Egypt that used posters about maternal health. These were found not to last very long in the households.

In terms of blindness determinants and groups at high risk, our results also showed similar findings to Brilliant's results. Education, occupation, family size, water source, sanitation, and garbage collection were all found to be significant risk factors. Moreover, females were found to be more affected by such factors than males. This supported our hypothesis that the determinants of and the factors associated with blindness are almost the same in most of the investigated developing countries¹⁻³. These findings would also support the conclusion that well developed models can be modified and utilized in different regions provided that an assessment to detect specific determinants of each community is conducted. Both community-specific determinants and barriers should be considered while tailoring the health educational message and designing the model. Tackling these issues increases the probability of model success in local and regional levels.

Consequently, our interventional model succeeded in changing the pattern and minimizing the effect of the majority of these determinants. Our results supported the hypothesis that focusing on health educational components significantly decreases the impact of determinates like education, occupation, source of income and family size. Additionally, there were improvements in personal attitudes towards hygienic behaviours and increased awareness of disease risk factors. However, factors related to general water supply and sanitation systems were still persistent. This is mainly because more sophisticated and governmental based actions are required and cannot be manipulated through community based interventional models.

Within the same context (Snellingen et al, 1998)⁴ introduced screening and referral as components of an interventional model to reduce cataract blindness in Nepal. The study also attempted to measure possible reasons for non acceptance of surgery and tried to compare these results to results from India. The impact of visual disability on psychiatric

¹ Schemann JF. [Is the analysis of blindness in developing countries at the occasion of a national census of interest to public health?]. *Rev Int Trach Pathol Ocul Trop Subtrop Sante Publique*. 1990;67:153-61. [Bibliography.enl Page 4](#)

² Gharebaghi R. Social determinants in ocular diseases. *Clinical Optometry* 2010;2:119–20.

³ Rabi MM. Ecological determinants of blindness in Nigeria: The Nigeria National Blindness and Visual Impairment Survey. *S Afr Med J* 2011;101:53-8.

⁴ Snellingen et al (1998), op. cit.

status, quality of life, ability for socialization, and covering self care needs were also explored by this study. Moreover, differences in concept between patients and doctors about surgery and understanding the decision to go for surgery as a family decision were critical issues that were comprehensively raised by this study. The study went for interviewing, not only the patients, but also their guardians (relatives/neighbours) as decision sharers.

In our study we found that the screening and referral component was highly effective. It worked to decrease the gap between gaining knowledge and seeking services where a lot of decrements and drop outs tend to occur. Screening and referral create the commitment to practice and help to decrease the in-between gaps. Proper training is required to correctly identify eligible cases and minimize misdiagnoses which will negatively affect the program credibility. Model developers should pay more attention to this point as it may result in more frustration among the community and hence yield a reversed impact. In our study, despite training of health workers to diagnose cataract and TT, the confirmation rate for eligible cases for cataract surgery (by senior consultant and hospital based investigations) was around 50%, which is considered low. However, we consider this low rate as a high success rate as many patients acquire knowledge and therefore adapt a positive attitude towards acceptance of surgery if needed in the future. The KAP gap is highly related to both perceptions and barriers where there are specific barriers for each phase. In our study, after confirmation of eligible cases, we achieved a 70% acceptance rate of surgery. This is similar to outreach programs in Egypt and other developing countries¹. Thus, one of the advantages of this model was to link screening and referral to service uptake through the health visitors' team. The prepared lists of patients who were accompanied to the hospital and supported during proceedings decreased the number of decrements, drop outs, and missed appointments. This reduction was due to encouraging people to get service, increasing ease of access to service, and by breaking down many barriers². Brilliant pioneer study (1985) also found that even among those who were aware of their illness, one third still did not seek service because of barriers like visual disability or the need for accompaniment. This is why it is crucial in the model to link people in need to the available local service providers. However, this requires two major issues. First, there must be an increase in trust through capacity building of the local provider, and second, barriers need to be broke down. Breaking down barriers needs a comprehensive understanding of these barriers. In our study we

¹ Kessy JP, Lewallen S. Poverty as a barrier to accessing cataract surgery: a study from Tanzania. *Br J Ophthalmol.* 2007 Sep;91(9):1114-6. [Bibliography.enl Page 3](#)

² Silva JC, Bateman JB, Contreras F. Eye disease and care in Latin America and the Caribbean. *Surv Ophthalmol.* 2002 May-Jun;47(3):267-74.

assessed barriers with both quantitative questionnaires and qualitative interviews and utilized this knowledge in prioritizing and breaking down such barriers.

5.5 Barriers to eye care service utilization

Our results show that barriers related to knowledge and attitude like (*Feeling no problem*, and *Feeling too old*), barriers related to eye care provider like (*Fear of surgery*, *Fear of surgical outcome*, *Fear of bad treatment at hospital*), barriers related to capability like (*Distance to hospital is too long*, and *No one to accompany me to the hospital*), and barriers related to economic status like (*Expenses of surgery are too much*) were significantly reduced. This reflects the effectiveness of the corresponding components of our model such as the health educational message, improvement of provided services and supporting people to receive service at the local hospital. However, the persistence of barriers like; *couldn't take time off work*, or *need for someone to take care of children* may reflect the need for additional components that can deal with such barriers. Nevertheless, it should be understood that any model will never be able to overcome all existent barriers. Therefore, one useful ways to analyze barriers is to arrange them in a ranked list of priorities where the model can focus not only on those of high priority, high magnitude, and high effect size but also on those which can be manipulated and dealt with. Also, another important consideration is to disaggregate barriers by groups at high risk. Looking at specific barriers of a high risk group will yield a remarkable decrease in the overall barriers' effect and will consequently result in a remarkable increase in service uptake. In our study we looked at female specific barriers which not only resulted in paying attention to factors that prevent females from seeking service, but also provided an interpretation for why females use eye care services less than males. This question would not be answered if we looked at barriers collectively.

Qualitative assessment of barriers added a lot of information that cannot be captured through questioning. this was very helpful in: (1) adding specific barriers that characterizes the targeted community; (2) providing clarification as to why certain people seek services while others do not in presence of “*equal exposure*” situations i.e., fixing other determinants like awareness, knowledge, and financial issues; (3) abstracting actual reasons behind non seeking services (people tend to report common or plausible barriers regardless of their subjective barriers; (4) prioritizing barriers in relation to actual effect size (in absence of options and lists, people usually mention the first ranked barriers that immediately come to mind). It is also useful to compare barriers measured by both methods to each others. Our results indicated some clear examples that may support this hypothesis. For example, females report cost barrier three folds greater than males (plausible, convenient, and common barrier) in quantitative questionnaire. Conversely, state there is no one to accompany them and that they have fear of surgery (relatively realistic to rural females) as the main barriers in the qualitative interviews.

The question why some people report fake barriers or hide the actual barrier they feel most affect them is a subjective issue. A general trend in humans is to report common

barriers to avoid debate or hide a barrier that may be embarrassing. For example, in our study we found that some people may prefer reporting “*low quality of service*” rather than “*we don’t have enough money to afford for eye care*”. This stigmatic feeling may also be accompanied by the notion that they may be badly treated at the hospital because of their poverty and low socioeconomic class. “*My grandson had an eye problem before, his eyes were swelling, I took him to the hospital, the doctor said, look how his face and his hands are dirty? Also, his clothes? You should keep all this clean if you want his eyes to be cured. How can I prevent him from playing with his friends, dust and dirt are everywhere, since then, I never went back to the hospital again, I didn’t even give him the medications they gave me, my neighbor came in the evening, she grilled an onion and squeezed it in his eyes and he was cured, and till now his eyes are very well*” [Manquateen: female, 75 years, a TT patient]. Although the doctor’s advice was 100% correct, the way he communicated it was offensive. This leads to negative feedback to the point that this lady did not even use the medication and threw it away. Although the perfect resolution for this issue is to establish a medication reconciliation process at hospitals, this should be taken as phase two when the increase in outpatients flow is well established. Likewise, some other TT patients – specifically women - may refuse to disclose that they have TT because of the common perception they are unclean. “*Females here don’t want to mention that they have TT because other women would say that these women are unclean in their houses. I’ve also heard them saying that one should be careful when she shakes hands with them. These poor women become so ashamed of themselves and very sensitive to attend social events*”. [Ibrahim Basha: male, 81 years, TT patient]. There is a common link between poverty and eye diseases among rural communities¹. Despite being true to some extent, however, this much increases the stigmatization process specifically among females with TT. “*Those females who have TT in their eyes are usually ashamed to mention that they have TT to hide their poverty, and to keep respect to their husbands and male sons*” [Ibrahim Basha: male, 48 years, not a TT patient, and household characteristic are good].

Regardless of the stigma, perception about trachoma transmission and TT causes can be utilized to develop strategies towards prevention and control². On the other hand, there was no negative perception regarding risk factors for cataract. Knowledge about exposure to cataract may need more advanced level of awareness. However, this awareness may not be practical in community intervention programs that are mainly

¹ Gilbert CE, Shah SP, Jadoon MZ, Bourne R, Dineen B, Khan MA, et al. Poverty and blindness in Pakistan: results from the Pakistan national blindness and visual impairment survey. *BMJ*. 2008 Jan 5;336(7634):29-32.

² Burton MJ. Trachoma: an overview. *Br Med Bull*. 2007;84:99-116.

aiming to decrease the blindness burden. Nevertheless, some advanced studies have included similar items and it was quite successful¹.

This rearrangement of priorities does not diminish interest in other important barriers like cost. Cost is a global barrier to eye care service utilization in developing countries. It can be classified into direct and indirect costs (Mulluken Melese et al, 2004)². The Melese study found that direct hospital costs may constitute a partial magnitude of the total cost barrier. It concluded that indirect costs such as transportation, food and beverage, accompaniment, and lodging expenses may also be highly effective especially for poor people. This result was also supported by findings from other studies in India, Nepal, and Uganda^{3,4} where some villagers had a two day round trip walk to the hospital to get service and were accompanied by a guiding or supportive person. This barrier also interacts with the opportunity cost barrier of leaving work, especially for farmers and other professions who need to be at work every day where an absence becomes problematic. In our study, we could not accurately quantify indirect costs, however it can be estimated from support given by local NGOs' staff to referred cases, it was approximately equal to direct (subsidized) hospital costs.

Although the previous studies deal with cataract and / or trichiasis diseases either separately or as one unit, Melese's study found a significant difference between cataract and TT patients in terms of the pattern of seeking service. As a result they suggested that these diseases should be dealt with separately. Our results confirmed this concept where disaggregating barriers per disease (disease specific barriers) revealed that cataract patients are more worried about quality of surgery in terms of vision restoration in addition to hospital related barriers. TT patients were also concerned about outcome but more so in terms of disease recurrence and pain (during surgery, and relief after surgery). These differences suggest that barriers should be looked at from disease specific points of view. This approach can be quite helpful if translated into arranged priorities for intervention. i.e., specific barriers related to a disease with higher magnitude and more contribution to the overall blindness burden should be prioritized for overcoming more than barriers related to disease of lower impact.

¹ Agte V, Tarwadi K. The importance of nutrition in the prevention of ocular disease with special reference to cataract. *Ophthalmic Res.* 2010;44(3):166-72.

² Melese M. et al (2004), op. cit.

³ Thulasiraj RD. Social Marketing for Effective Eye Care Delivery [Internet]. 1995 [updated 1999; cited 2010 Apr 7]. Available from: http://www.who.int/ncd/vision2020_actionplan/documents/Socialmarketing.PDF

⁴ Kyndt M. Importance of affordable eye care. *Community Eye Health.* 2001;14(37):1-3.

Breaking down barriers would be of no value unless capacity building of the local provider takes place. Two major components considered by any model should aim at increasing service utilization. First, community service improvements should occur with local providers. Second, the gap between the provider and recipient should be bridged. This gap may encompass provider related barriers (ignorance, quality, etc.), difference in concepts between doctors and patients (disease and need for intervention), and community misconceptions about eye care providers. In our study we asked the health visitors to highlight the message that the local providers have been improved in terms of capacity and systems and that they have been informed about the impending new case referrals and have been instructed to efficiently deal with them.

5.6 Capacity building of local providers

Capacity building of local providers makes sure they have quality improvement in their services. This would guarantee the means to increase surgical uptake occurring as a result of an increase in demand. Our results showed evidence of improvements in the provided services as measured by the increase in number of provided intraocular cataract surgeries (with IOL insertion) and entropion TT surgeries using the new techniques (Small Incision and Tarsal Rotation respectively). Additionally, there was an improvement in the visual functioning score of cataract patients as measured by the verified VF 14 tool. Capacity building of local providers was also had an effect on gender pattern, where the recurrence rates (or need for re-intervention), which was higher in females, had balanced out considerably in cataract surgery, and totally balanced in TT surgeries.

Assessing patient satisfaction with provided services adds value to the model. Satisfaction assessment would indicate whether patients were happy with locally provided services. In our model we measured satisfaction at both pre and post intervention to monitor for any change. Patient satisfaction is considered a sensitive and valid indicator, but this data should be looked at cautiously in community based studies. There are several reasons for this. Poor and deprived communities they may be: (1) keen to show appreciation of free or subsidized services - this was clear in some of our interviews; (2) Very sensitive to minimal improvements in quality of the provided services; (3) Willing to accept any service even if of poor quality. Studies that measured patient satisfaction after cataract surgeries in outreach programs have showed high satisfaction rates that may be misleading in some poorly designed programs; (4) Incapable of efficiently evaluating the provided services because of minimal or no experience with other providers. This concept was clear among some of the respondents to our semi-structured interviews, where it was found that patients were still appreciative of accommodations and hospitality despite having prolonged hospitalization stays.

Robin Haynes et al (2000) compared satisfaction with cataract surgical outcome and other related factors in England. All measured indices in this study showed higher satisfaction among outreach versus walk in patients. However, the study was conducted in England, a developed country, in which patients attending outreach programs were

“typically of poor health and faced barriers in accessing eye care”¹. Our results are in parallel with Haynes; therefore, using qualitative methods to measure satisfaction may be more reliable and valid than using quantitative methods. Also, satisfaction with available diagnostic equipment, medical treatment, and minor interventions should be looked separately from satisfaction with major surgical interventions. The latter implies multiple factors including surgical outcomes, accommodation, waiting time, hospital proceedings, complications, and paramedical services. Model developers should be aware they are not only evaluating surgical outcomes, but rather the evaluation also includes the service as a package including surgical procedure as one component. However, different components should try to be looked at separately. This point is critical. For example, a hospital may be famous for its reputable surgeons but patients do not like it because of other issues related to the general status of the hospital like, cleanliness, patient care, complicated proceedings, staff ignorance, corruption, etc. So, it is a wide scope of health systems / health services aspects.

One aspect of improving services at the provider’s side is to enable more economical levels of service. Our model did not tackle this issue due to its complexity and need for input by higher levels of political leaders. However, research can find cheaper resolutions to prove cost effectiveness of provided services without the need for major changes in policies. Successful international models for similar achievements are already available to simulate². Nonetheless, model developers may need to compromise between different certain components in order to increase the model effectiveness. Xn et al (2002)³ compared the effect size of screening and referral to decreasing surgical fees in rural China which is famous for its high prevalence of cataract. The study adopted a community interventional study design and found that merging both components together exceeded the mathematical sum of the effect size of both components. This study emphasized that a model consisting of multiple components aimed at tackling various barriers would be cost effective and more efficient.

Contribution of community leaders and civil society may improve performance of the model. Its effectiveness can be increased when model developers assign specific roles to the local communities and NGOs. Sayed Masud et al (2003)⁴ tried to measure the impact of NGOs on the difference between poor vision poor populations, and males vs. females in seeking health services in Bangladesh. However, Masud hypothesized that implementing health interventions with NGOs activities to improve the economic status

¹ Haynes R, Gale S, Mugford M, Davies P. Cataract surgery in a community hospital outreach clinic: patients' costs and satisfaction. *Soc Sci Med.* 2001Dec;53(12):1631-40.

² Thulasiraj RD, Sivakumar AK. Cost containment in eye care. *Community Eye Health.* 2001;14(37):4-6.

³ Xn et al (2002), op. cit.

⁴ Masud S. et al (2003), op. cit.

and empower females would result in increasing health services uptake. Rejecting this hypothesis, Masud results showed that there was no significant impact on service uptake. These results indicate that local and international NGOs activities should be focusing either on health components or that a health educational component should be intentionally embedded within their activities in order to increase service uptake. In our study better allocation of NGOs resources was effective to increase the model success. We limited the role of the two participating NGOs to provide trained staff, share in health education activities, organizing meetings and logistics related to case referrals. The major advantage of using the NGO trained staff was their previous experience with the target villages. Most were from the same community which also facilitated better interactions with local people and permitted better conduction of sensitive tasks like the semi-structured interviews and accompanying them to hospitals. This was particularly true with when dealing with the elderly ladies. Thus, we believe that through well identified roles, tasks, and responsibilities of a multidisciplinary team, better results can be achieved.

Not only that, but also because the problem of scarcity of manpower and human resources always encounter any proposed interventional program in terms of the need for trained cadres to do field work activities like screening, referral, and delivering health educational messages. Thus, there is always a need to train and utilize local people to perform these tasks which may be also considered as capacity building of the community. This idea was evaluated in several studies (Lind Forst et al, 2004)¹. Forst study pointed to a review of literature where 140 national community health worker's programs in the United States attempted to tackle this issue. The review has also found that 275 citations focused on 20 studies of which 8 were clinical trials. Frost study, attempted to evaluate the effectiveness of community health workers in promoting eye safety of farm workers found that well trained community health workers can be used in training of other trainers (TOT) and trainees in order to promote the message on a wider scale. In addition, co-workers are the best message transmitters to their own colleagues. This knowledge can be applied to other peer groups such as farmers to farmers, teachers to teachers, neighbour to neighbour, etc. One major concern by this study was how to achieve sustainability of these successful programs. Therefore, training local people would increase the effect duration rather than using external staff to conduct the messages and perform screening and referral tasks. It is common in community interventional studies that the prevalence of the target disease would slowly increase after the end of the project because people may lose interest due to absence of motivators. In our study, we utilized local NGO's staff, provided additional training and included other cadres like school teachers and village health unit staff. The approach resulted in better program sustainability.

¹ Forst L. et al (2004), op. cit.

5.7 Traditional healing

When the demand for service is high, service is inaccessible, of low quality, or in presence of highly effective barriers, people may seek other solutions such as traditional healings. This type of service is not uncommon in African and Asian countries. It is typically centred around customs and traditions within the developing countries. This issue needs to be addressed along with constituting a clear idea about the community perceptions and culture. This is extremely important as some traditional healing methods are in fact harmful to eyes^{1,2}. It was found that collaboration with traditional healers and providing them with adequate training can contribute to decreasing the blindness burden³⁻⁵.

Our study found traditional healing techniques that were relatively unknown by the scientific community prior to our study. This included using mother's milk, donkey's urine, and a swab made from the powder of certain smashed stones. However, the major difference between our findings and the literature is that these techniques were used in absence of actual traditional healers. None of our respondents reported visiting any traditional healer, but rather adopted these techniques from their ancestors. To deal with this situation, we included additional health educational messages to clarify that although some of these methods were felt to benefit in some regards, there could still be yet unknown potential side effects. We emphasized the concept that some herbs and natural stones may contain the effective substance, however, a manufactured drug is always safe because of sterilization and pharmaceutical abstraction techniques and that the doctor and the pharmacists are the only experts about medication issues. Our findings also highlighted that females are more likely to use traditional healing because they are more

¹ Lewallen S, Courtright P. Peripheral corneal ulcers associated with use of African traditional eye medicines. *Br J Ophthalmol*. 1995 Apr;79(4):343-6.

² Courtright P, Lewallen S, Kanjaloti S, Divala DJ. Traditional eye medicine use among patients with corneal disease in rural Malawi. *Br J Ophthalmol*. 1994 Nov;78(11):810-2.

³ Courtright P, Lewallen S, Kanjaloti S. Changing patterns of corneal disease and associated vision loss at a rural African hospital following a training programme for traditional healers. *Br J Ophthalmol*. 1996 Aug;80(8):694-7.

⁴ Leonard KL. African traditional healers and outcome-contingent contracts in health care. *Journal of Development Economics* 2003;71:1-22.

⁵ Poudyal AK, Jimba M, Poudyal BK, Wakai S. Traditional healers' roles on eye care services in Nepal. *Br J Ophthalmol*. 2005 Oct;89(10):1250-3.

likely to be affected by barriers than males. This is consistent with findings in similar studies¹.

5.8 The concept of integrated models

Within the context of developing integrated models that work on both reduction of the prevalence of avoidable blinding diseases and decrease the effect of the associated factors, many endeavours by local and international teams were done to produce such models. One well established model is the Surgery, Antibiotic, Face washing, and Environmental improvements, commonly known as ‘SAFE strategy’. The SAFE strategy, known in some African countries as “SAFI”, is widely accepted in many developing countries and internationally adopted by the WHO - Vision 2020 program, the International Agency for Prevention of Blindness (IAPB) and the International Trachoma Initiative (ITI)². The SAFE strategy was tested in many African and Asian countries where it had showed a lot of success but also faced a lot of challenges. One major challenge was that the “A” component can prove to be too expensive to be adopted by governorates (i.e. on national levels due to the price of Azithromycin[®]). Another challenge is that application of “E” requires costly national plans to extend pure water and safe sanitation networks to the whole country including rural areas. This is often not possible or needs to be incorporated in long term plans. Successful pilot studies have been supported by Pfizer inc[®] as a donor of the antibiotic and other collaborative international NGOs or UN bodies like UNICEF to support pilot “E” component on smaller scales. However, success in these implementations means that the model is successful in terms of evaluation of its efficacy, but doesn’t necessarily mean that it is generalizable. Some countries who sought to benefit from the capacity of this model have adapted its application to implement some of its components. Community health education components can also be added to increase the capacity of a partially applied SAFE model (Tansy Edwards et al, 2006). Edwards’ study tried to incorporate four different health educational models (using radio broadcasting, videos, NGOs activities and distribution of printed materials) with two different combinations of SAFE components (S,A,F in one arm and A,F,E in another arm) and evaluated the outcome of each model by comparing results to a control arm. Study findings showed that although knowledge and awareness improved significantly, there was no significant difference in reduction of trachoma across all arms. Moreover, this increase in both knowledge and awareness was not accompanied by behavioural changes as all the undesired behaviours that increase the risk of getting a trachoma infection were still the same. This reflects two important issues. First, partial application of the model does not yield a remarkable achievement. Second, health education alone is not enough to achieve improvement in behaviours unless other supportive actions are in place. The insignificant difference

¹ Shaikh A. GENDER AND BLINDNESS: Initiatives to address inequity [Internet]. 2008 [updated 2008 Aug; cited 2009 Aug 6]. Available from: http://www.seva.org/publications/SevaCanada_GenderandBlindness.pdf

² Emerson PM, Burton M, Solomon AW, Bailey R, Mabey D. The SAFE strategy for trachoma control: using operational research for policy, planning and implementation. Geneva: Bulletin of the World Health Organization; 2006 Aug. Report No.: 84(8).

across arms was most probably due to the strong effect of the antibiotic which dramatically, although temporarily, reduced the prevalence of active trachoma. The prevalence soon increased after the dose response of the antibiotic ended¹. Although the SAFE strategy is a good model, it is from our point of view, not an applicable solution to the prevention of trachoma. Besides, it only focuses on trachoma which may be the leading preventable cause of blindness (responsible for an estimated 7%) per se, but it is not the leading avoidable cause (like cataract for example which is responsible for more than 50%). There is increasing evidence that any proposed model has to have a health education component to increase both knowledge and awareness. This is an essential step to initiate the demand for service uptake. However, behavioural change interventions, breaking down barriers and linking 'most in need' cases to service providers are crucial to achieve success which can be sustainable in prevention of blindness. Our results showed a significant increase in service utilization as measured by the increase in outpatient numbers at the local hospital. We also found a decrease in the prevalence of low vision and blindness and a decrease in the prevalence of cataract and TT as the major contributing avoidable causes. This decrease was also supported by improvement in community hygienic behaviours, decrease in the effect of major barriers, and an increase in acceptance of surgical intervention and satisfaction with results. These achievements are expected to be long lasting relative to the short term impact of antibiotic components. Gender wise, our results showed that at baseline there were substantial differences in knowledge, attitude, and practice, where women were markedly less aware than men. However, women were found to be more willing to change their behaviors, overcome their barriers, be more compliant to treatment options and more apt to accept surgery than men. Being the group at higher risk, that contributes two thirds of the burden, this is a very positive point that can be added to increase the reliability of gender sensitive interventions (that focuses on women) towards reduction of the overall low vision and blindness burden.

5.9 Limitations

During the current study there were a number of constraints that obstructed ideal implementation of our original plans. These constraints reduced our desired outputs or in collecting some specific data and / or properly interpreting it. Limitations also hindered achieving perfect results or providing concrete evidence on some hypotheses. We are also unable to explore potential associations that if enabled would have provided more knowledge. However, we don't think encountered limitations have resulted in fatal flaws in the study design, in the analysis, or with the interpretation of our major results. The limitations and constraints of this study can be separated into two categories, those that hindered, delayed, or complicated execution of some tasks and general research related limitations. These constraints and limitations can be briefed in the following points.

¹ West SK, Munoz B, Mkocho H, Gaydos C, Quinn T. Trachoma and ocular Chlamydia trachomatis were not eliminated three years after two rounds of mass treatment in a trachoma hyperendemic village. *Invest Ophthalmol Vis Sci.* 2007 Apr;48(4):1492-7.

5.9.1 Constraints

- The need for many formal proceedings and multiple approvals required from the Ministry of health, its local undersecretary offices, and the local political authorities. This proved to be very time consuming resulting in delayed implementation of the intervention activities and required some minimal modifications. However, efforts done in advocacy and gaining political support were useful.
- Reluctance of the local authorities to facilitate some logistic tasks and to allocate time and efforts to promote blindness as one of the priorities was another negative factor. Nevertheless, convenient discussions and explanations managed to convince the local authority that the efforts of the NGOs and civil society can be an additional support to their developmental efforts.
- The need for periodical travelling, and stay at the fieldwork site was also an impact factor at the beginning of the implementation phase. However, conduction of training and arranging a hierarchy of program fieldwork team secured a smooth flow of implementation.
- Lack of well-trained human resources in rural areas (who can perform tasks like data collection, delivering of health educational messages to the community, conduct screening, etc.) was a dilatory issue. Nevertheless, although this was a big issue in the beginning, conduction of appropriate training to local people positively contributed in capacity building of the local community.
- Lack of equipment, in adequate systems, and skilled personnel at the local eye hospitals was one of the major retardant issues. Equipping these hospitals, staff training on medical & surgical skills, and suggesting some resolutions for improving the provided services was not the core area of intervention. For example developing and implementing some system improvement tasks were not accepted by both the medical and administrative staff until approved by the local health authorities. Thus, inflexible bureaucratic bylaws were the main obstacles. In many situations requested changes even required approvals from the MoH headquarters. Also, it was extremely difficult to allocate an appropriate budget and required efforts to adequately assess the overall needs related to equipment and training as it would get the model out of the track and decrease its cost effectiveness. In our study we tried to limit contribution in this area to the necessary needs to fulfill avoidable blindness tasks. Health system / service improvement can be a huge separate withstanding project.
- Community expectations greatly exceeded the capacity of the model. Whereas there was a community feeling that the intervention can easily overcome any constraints that may emerge and provide readymade magic and immediate solutions.

5.9.2 Limitations

During implementation phase

- There was difficulty correcting previously ingrained concepts, beliefs, and perceptions about eye diseases and its treatment among the community. This required providing concrete evidence on the appropriate knowledge and attitudes.
- Mistrust of local eye care providers and free or subsidized eye care due to bad experiences in the past were major barriers in bridging the gap between receivers and providers.
- Established barriers to eye care utilization created a high dam against behavioural and attitude changes with regards to seeking available services. Meanwhile, the dignity feeling which is a characteristic of upper Egyptians prevented many from seeking help from others.
- Inflexibility in local eye care provider systems and inability to absorb the increase in demand (for example giving incentives, re-allocation of space and / or resources, change in job tasks & working hours of some staff) was another limitation to implement change.

During assessment, analysis, and interpretation phase

- Despite training of local health visitors on screening, there was a considerable percentage of error realized during confirmation of referred cases as evident in the high number of false positives.
- Absence of accurate data about the local eye care provider's capacity and capabilities (for example some of the registered ophthalmologists were on unpaid leave, and still registered with the MoH as manpower within the hospitals). This required actual assessment of these providers through multiple field visits.
- Incomplete medical filing system disabled accurate calculation of the increase in service uptake and disaggregating it by gender, residence, etc.
- Absence of a disease registry, outcome monitoring and evaluation systems have also disabled accurate assessment of the quality improvement in provided services (for example registry of detailed surgical outcomes, complications, etc.). To overcome the last two points, the research team had to follow up with results and do quantitative estimations in the form of percentages of success rates.
- Following up with the referred cases showed the acceptance rate was low in the first phase. The second tracking phase, the overall acceptance rate still did not achieve the planned target. However, we expected that many cases will seek services after being motivated by outcomes of the done surgeries.
- Comparing the pre and post intervention indices showed a percentage of error in attributing the exact reduction of low vision and blindness to reduction in

prevalence of avoidable blindness. To fulfil this attribution, there was a need to screen the entire intervention village both pre and post intervention. The current study used random walk sampling procedure to proximately measure the overall decrease that would reflect the overall reduction in the community as a unit of analysis rather than calculation of the exact figures through pre to post intervention comparisons on the same group.

- Similarly, there was inability to compare the exact effect size of different components of the model on reduction of low vision and blindness. This would require complicated path and factor analyses techniques that may be beyond the scope of this study. However, it may be quite useful to understand the exact effect size of each component solely at any further study.
- There was an inability to measure the exact effect size of the model on age and gender specific prevalence of low vision and blindness. We had four comparable groups in terms of age and sex which would also require further sophisticated analysis. However, we measured the reduction in prevalence and contributing diseases on females as the targeted group (being at high risk).
- In continuity with the previous point, we were unable to attribute the exact reduction in avoidable blindness to the corresponding increase in female service utilization and surgical uptake. If this could be achieved, very useful information would have been gained. This may be an important topic to pursue in future research projects.
- Another important point was to measure the magnitude and directions of interaction between different risk factors and barriers on service uptake, especially for women. There were an inability to measure exactly these different interactions as it would require a separate series of analyses and interpretations. The advantage of understanding this interaction can be directly reflected by arranging intervention priorities for the future.
- It was quite difficult to accurately relate the increase in service utilization, particularly to the intervention villages due to weak registry (manual) systems at the hospital. Nevertheless, we were more or less able to track most patients through our prepared lists of referrals. However, there was a need to subtract those patients who walked to the hospital from the intervention villages and those who travelled sough to the hospital from other surrounding villages. This limitation was applicable to both outpatient and surgical services. If this information would have been established, we could have calculated the exact effect size of improving provided services without any health education intervention.
- Accurate win rates, acceptance rates, rejection or postponements, no show rates, and consequently surgical coverage rates were also difficult to determine due to the nature and availability of data at community based levels. However,

comparison of pre and post indices approximately estimated the increase / change in these rates on macro level.

- While conducting supportive outreach caravans, some people may have joined in from the surrounding villages. However, we do not think this resulted in much contamination between the intervention and control villages.
- Due to scarcity of resources, and focusing on avoidable causes, other diseases could have been easily served. For example, a convenient component could have been included to fix refractive errors with glasses. This alone may have affected the overall rate of decreased vision.
- Other diseases like corneal opacities, diabetic retinopathy, glaucoma, or retinal detachment were not addressed as outcomes tend to be poor and our focus was on avoidable causes to achieve reduction in blindness rates.
- There was some uncertainty related to some of the qualitative investigations. This included issues such as satisfaction, stigmatic feeling, change in behaviour and preference in selecting service provider. Typical utilization of qualitative investigations requires a long process of testing-retesting, validation, etc. to assure high levels of reliability and validity. However, the utilized tools were designed and tested in the light of previous utilization of similar tools in Africa and Asia which are well documented in the literature. We believe that minimal changes to suit local language and circumstances did not reduce reliability and validity.

Chapter 6: Summary, conclusions and recommendations

6.1 Conclusion

The current study is a community based trial investigating the effectiveness of a health education intervention (focused on women) on the prevalence of low vision and blindness in rural upper Egyptian villages, particularly among women. The secondary outcomes include: 1) increasing awareness of eye problems, and breaking down barriers to service utilization, and 2) increasing the quality and capacity of local eye care providers. Menia governorate was selected for the study because the author had previously conducted a baseline blindness survey there. Moreover, Menia governorate has good communications, cooperative local partners, and it is representative of the majority of rural Egyptians in terms of population characteristics, eye problems and eye care utilization.

Priorities for intervention

In designing this study, two major axes were explored to understand the background prevalence of eye disease in Menia: 1) Risk factors for the targeted diseases and 2) the group of people at high risk for the disease. Guided by the literature, and the baseline prevalence study it was noted that the group at highest risk of being blind are women and girls primarily due to a low pattern of service utilization. Women were therefore prioritized as the target for the interventional model.

In order to design an effective intervention to increase service utilization, three main axes were considered; (1) diseases to be prevented or controlled, (2) social and cultural determinants of, risk factors for and barriers to service utilization and (3) how to target the groups at high risk. The relationships between these three different axes are highly interactive and dynamic and are illustrated in the following diagram.

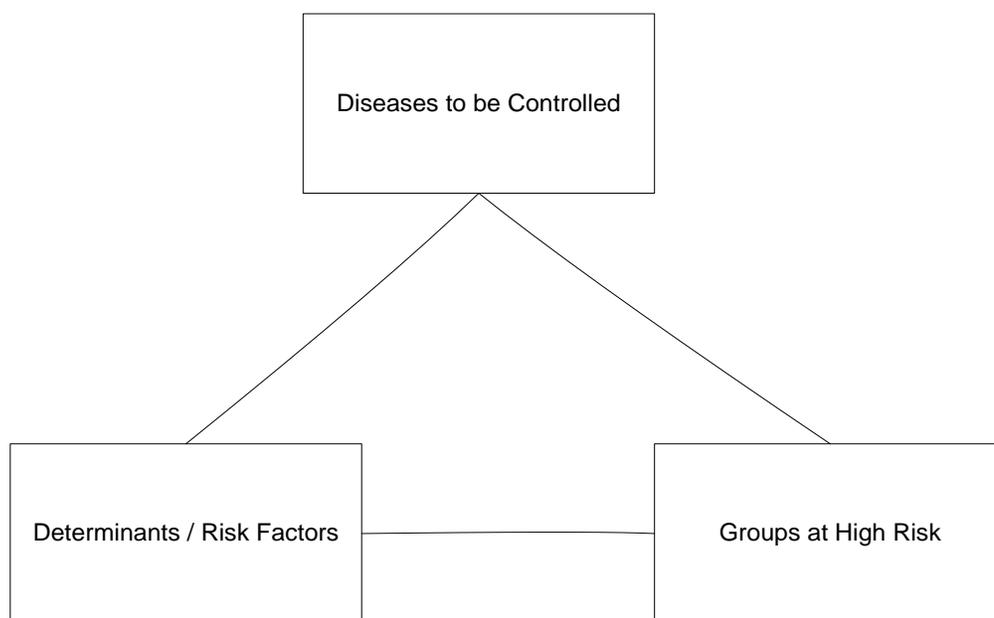


Figure 6.1 Major axes for prevention of blindness

Each item of this triangle is further categorized into a number of components, which were arranged in order of priority within an overall interventional model.

Methods for message delivery, eye disease screening and referral

This study focused on delivering of an educational model primarily to village women. It adopted a from door to door approach to deliver such message in addition to distribution of year calendars to remind the villagers with the delivered messages. The study revealed that face to face meetings are the most suitable approach to people living in rural communities of Egypt. The messengers included school teachers and village volunteers in addition to village unit staff (health workers) and medical staff. The recruited messengers were trained female health visitors from the same village / setting. We found that recruiting female visitors is more appropriate for these tasks where they can easily penetrate to the households (according to customs and traditions in rural Upper Egypt) and hence increase the compliance rate to treatment.

Training of those community health workers was extended to screen for the targeted eye diseases which was found to have an acceptable level of accuracy. Training the village health unit staff and school teachers to screen for eye diseases built up the local capacity for early detection and referral. When this primary eye care role was performed, there was a sustainable reduction in blinding eye diseases within these rural villages.

Screening and referral were essential components of this study's interventional model, as was accompaniment of patients to receive eye care services at the nearest local hospital. Our approach therefore went far beyond simply delivering the educational

message and inviting people to seek service at the local hospital. The disadvantage of the latest method is that only knowledgeable, self motivated and barrier free people will seek service. Therefore, our method – in our opinion – resulted in far more true positive cases that went on to receive surgery. We found that the overall increase in service utilization by intervention villages was around 30 to 40% compared to minimal insignificant change in the control villages. Furthermore, most common residual reason for not utilizing services were problems in the referral process to actually attend the available eye care service

Bridging the knowledge, attitude and practice gap

To develop an effective and enduring community intervention model we addressed five mechanisms: (1) Increasing knowledge, (2) Emphasizing positive attitudes, (3) Breaking down barriers, (4) Assuring good practice, and (5) Linking the community to the local service providers. This comprehensive package is what we consider unique about our proposed model. Moreover, in depth understanding of the target community, its concepts, culture, barriers, and perceptions about the local providers was critical for implementing these mechanisms.

Additionally, we assessed and addressed the health providers' service capacity and quality. This meant conducting a needs assessment of the local eye care providers and addressing urgent and essential provider's needs. Including the upgrade of eye care providers in our model is also considered one of its strengths. Most community intervention models either worked on community side or on provider's side, not both

Enhancement of the model and achieving sustainability

Holding discussion sessions with the executive teams and the community leaders both a priori and during implementation of the program was quite constructive. Discussion meetings at the baseline helped to modify the model (including the key messages) to suit more with specifications of the targeted community. Moreover, holding such sessions during implementation gave useful feedbacks about; (1) How does the community look at the delivered messages and what are the responses? (2) What are the problems facing the intervention team, and what are the possible resolutions? and (3) What are the additionally required modifications (either in the model or in the implementation approach) that can be done to enhance the performance and maximize the benefit? Meetings that held nearby the end of the implementation phase have also added a lot of value in terms of overall evaluating the intervention from a stakeholders' viewpoint, in addition to discussing proposed methods of sustaining the achievements.

One of the major successes of this project was to leave in place real developmental progress at the end of its duration. The intervention established self sustainability of the local eye care providers and methods to routinely increase awareness of eye diseases in the community. Getting the community deeply involved in different parts of the model

especially in planning and implementation phases seemed to create ownership which led to smooth and successful continuation of the changes the model introduced.

Overall achievements

The community intervention model improved the community knowledge and enhanced its attitudes and practice which consequently enabled rural people to overcome barriers to eye care service utilization. As a result, service utilization at the local hospitals was increased by 20.6 % (24.8% female specific) in the outpatient clinics, cataract surgical rate was increased by 36.9% (40.3% female specific), while the TT surgical coverage rate was increased by 41.4% (48.2% female specific). These improvements were also accompanied by improvement in the local provider's performance as the surgical outcome was improved by 8.9 % as measured by enhanced visual functioning after cataract surgery and increase of satisfaction by 16.6% among cataract patients and by 11.1% among TT patients. Selection of local provider as first choice to seek service was also increased by 31.1%. Consequently, the prevalence of cataract was reduced by 16.3% (18.4% female specific), and TT prevalence by 5.7 % (8.2% female specific). These results ultimately led to overall decrease in the prevalence of visual impairment by 13.3 % (14.1% female specific) and blindness by 7.2% (9% female specific).

Model limitations

The provided community intervention model achieved a considerable increase in service utilization, and a decrease in the burden of low vision and blindness. However, the model itself should not necessarily be seen as a standard for prevention and control of blindness. Instead, far more important are the principles of its development that involve extensive community involvement in formulating, conducting, and modifying the intervention activities. Therefore any replication of the model in different settings should emphasise flexibility to add, remove or modify any part according to the pre-assessed circumstances of the targeted community.

This research project does provide a number of learned lessons that should be highlighted for any researcher who is interested in building interventional models for prevention / control of low vision and blindness. The most important lesson is that any community intervention model needs to be very flexible and dynamic to reflect changes over time. Implementation teams, community leaders and other stakeholders are the best candidates to be involved in this process.

6.2 Recommendations and potential areas for future research

Results of the current study and its interpretation have yielded some recommendations for future implementation of similar interventional models. Moreover, there were some areas that may need to be further explored or enhanced and may be valid

points worth for doing further research to integrate knowledge and achieve more success rates. These recommendations and areas for improvement can be listed as follows:

6.2.1 Recommendations

- Interventional programs to reduce low vision and blindness should be designed in an integrated way that tackles the major associated determinants, risk factors of blindness, and barriers to service utilization.
- Interventional models should work on the causative and utilization triangle: groups at high risk, available services, and barriers. Those three dimensions are also known as; people (patients & at risk), facility (hospitals and primary eye care), and constraints & limitations.
- Each community needs to be well understood before implementation of the intervention. One of the best tools to understand the targeted community is to collect qualitative data that would enable in depth understanding of the community perceptions, cultures, existence and use of traditional healing, customs and believes.
- Community health education as the major component of such models is highly effective in terms of prevention / control of diseases and in increasing service utilization. However, there should be a linking component that bridges the gap between the communities unmet needs and the providers' capacity. It may be useful at the beginning to emphasize people to seek services even by accompanying them to services.
- One of the useful tools is to conduct both pre and post intervention assessments that enable measuring the intervention outcomes accurately. These assessments should go beyond measuring the magnitude of the diseases to include the change in its patterns in subpopulations and to understand the characteristics, reasons, and rationales of those who sought services and those who did not.
- Designing and utilization a program logic model is quite helpful to understanding the relationships between the activities and follow up tasks. It can also support keeping on scheduled time, organizing the process and conducting mid and final term evaluations.
- Capacity building of local providers should be carefully conducted in order to compromise between prioritized needs - that would have a direct feed back on the community (within model objectives) - and actual needs of the local providers. A needs assessment is a useful tool before conduction of this capacity building process.
- Achieved improvements of the system should be maintained in a way that guarantees its continuity in community practice.

- It is important to emphasise training of local people on all aspects of the intervention, starting from data collection and screening teams, to recognizing the importance of increasing knowledge and skills of medical & paramedical staff.
- Well designed and implemented advocacy to policy makers and health authorities is a must before implementing any interventional program. Policy makers and health authorities should be aware of and involved during planning for and application of any activity.
- More advocacies should be conducted at the end of the intervention program. A final (non academic) report including list of priorities and recommendations should be disseminated to both political and health authorities. This report should highlight areas of success and failure of the model in addition to limitations and constraints. This would help policy makers to consider these results while planning for the future and emphasize them to generalize or adopt successful models on wider scales.
- Participatory development approach should be adopted through involving all related stakeholders. This implies; local NGOs, civil society associations, community leaders, and grass roots. It is necessary to look for and identify community key persons who can increase compliance of local communities to intervention tasks (for example sheikhs and saints in religious communities, mayors, schools headmasters, parliament members, senators, and heads of big families).
- Creation of local task forces to monitor and maintain outcomes would help in achieving sustainability of results.
- Good organization between hospitals and patients is quite crucial at least at the beginning. Defects / failures in linking the first referred cohort of service seekers with the local providers can threaten the continuity of increase in service utilization.
- Gender sensitive interventions that include focusing on women and consider their specific determinants, needs and barriers can easily and quickly reduce the prevalence of blindness. Moreover, it contributes in reduction of the disease prevalence among children and the rest of the household inhabitants.

6.2.2 Areas for future research and / or enhancement of the provided model

- Seeking collaboration of national and international bodies working in development would magnify and maintain the achieved results. In particular, including associations and foundations that are of multidisciplinary interest in different aspects of development would synergize the power towards comprehensive achievements. For example, involving international NGOs that work in the area of ecological and environmental changes (water source and

sanitation systems, economic improvements, empowering women, etc.) may significantly increase the effectiveness of the program.

- Collaboration with other local ministries like ministry of education (to imply informative components in curriculum) and ministry of housing (to arrange for improved hygienic and infrastructure aspects) is quite useful in achieving the overall goals of the program.
- Incorporation of prevention of blindness activities and efforts in other successful programs that are being conducted since a long time on macro or national level would - for sure - build on the capacity of these programs and benefit from its well established infrastructure. For example, in Egypt, family planning and maternal health programs are being implemented since the 1970's and can incorporate more activities due to its national wide capacity and resources.
- Future studies should pay more attention to conduction of adequate and sophisticated training (as much as possible) that would increase the precision of the model activities which may require specific skills.
- Due to the limitation of attributing reduction of low vision and blindness to specific model components, it may be more useful to use compact segmented cluster approach instead of random walk methods in pre and post assessments. We believe that segmented clusters would give more reliable results in terms of adequate comparison of indices.
- It may be more helpful to design a future study that adopts clinical trial study design with multiple arms where in each arm, partial models can be implemented. With this approach, exact effect size of each component can be accurately estimated.
- Future wise, models should design the health education to be target-focused, i.e. conducted to effective key persons like; relatives, guardians, friends, and neighbors together with the patient. This may also require conduction of the message in group wise settings rather than per single household.
- Primary eye care is a major role player in the process of prevention of blindness. An effective mechanism of early detection and referral should be one of its routine activities. This may require providing more training and equipping activities to the village health unit.
- Pure qualitative separate studies are more needed to understand the targeted community. These qualitative studies should be phase one before the quantitative

assessments whereas all further activities should be planned in the light of its results.

- More sophisticated analyses as regards service providers are required to monitor the outcomes of the provided services and its impact on the increase in service utilization pattern.
- Implementation of the model requires a lot of harmony within and across different teams and organizations as it is more or less built up on several successive and some parallel phases like a group of mechanical gears that should work in parallel and successive way. Therefore, there is a need for evaluation research to be designed within the context of such implementation programs.
- It may be useful also to generate an integrated research project that can be adopted by one of the reputable universities where a committee of experts and academic professors can break it down into different reasonable withstanding research points. Such research points can be then tackled by researchers and graduate students in different specialties like; epidemiology, community ophthalmology, social sciences, humanity studies, ethnography, anthropology, etc. this project can provide further detailed understanding about areas that limited the interpretations of some of the current study results. For example, interaction between different determinants, barriers, and the exact effect size of different model components.
- In addition to that, there may be a need to design a separate health systems/services study for assessing, and improving the performance of eye care providers in a cost effective/self sustainable way. This study can be also recommended to countries which are planning for conduction of their national surveys for blindness and the associated determinants whereas it can be done as phase two of the survey on a minor scale or selected representative areas of the country. We believe that this can be a good start for an effective third phase of intervention to eliminate avoidable blinding diseases.

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Appendix 1: Pre and post intervention assessment questionnaires

1. Village form

Village name: District:.....
Visit Date: / / Intervention Control
Total population size: Total area:.....
Distance to district capital: Distance to governorate capital:

1. Are there any hamlets or satellites following this village? Yes No

If the answer is Yes;

- a. How many?
- b. What is the total population size of these satellites?
- c. Do they share the same village health unit? Yes No

If the answer is No;

- i. If the answer is no, what is the nearest health unit?
- ii. What is the distance to this health unit?.....

2. Who are formal authorities and community leaders of this village?

Name	Position
-----	-----
-----	-----
-----	-----

3. What is the nearest health facility?

- Village Health Unit Central Hospital General Hospital
- University Hospital Private Hospital/Clinic

4. What is the distance to the nearest health facility?

Distance:..... Common Transportation Method:..... Average Time:.....

5. What is the availability of this transportation?

All the time Sometime Rarely Needs previous arrangement

6. What is the nearest eye care facility?

Village Health Unit Central Hospital General Hospital

University Hospital Private Hospital/Clinic

7. What is the distance to the nearest health facility?

Distance:..... Common Transportation Method:..... Average Time:.....

8. What is the availability of this transportation?

All the time Sometime Rarely Needs previous arrangement

9. Do this facility provide Cataract and Trichiasis surgery?

Yes No Don't Know

a. If No, what is the nearest facility providing these services?

Facility: Distance:.....

10. Is there a pharmacy or more in this village? Yes No

If Yes,

a. How many? (No.:.....)

b. What are the working hours of this pharmacy? ...From: am topm

11. If no, what is the nearest pharmacy?..... Distance:

12. How many schools are there in the village? And what level?

Primary..... Preparatory..... Secondary.....

Others:..... Type:..... No.:.....

Interviewer:

Reviewer:

2. A. Household form

Date: / / Village:..... District:.....

Sector No.:..... Household No.:..... Person ID:.....

Household head Name:..... Age:..... Sex: Male Female

1. No. of children \leq 15 years No. of Rooms:

2. Every child has a separate Pillow? Yes No Inapplicable

3. Main source of water:

General Network Pump Well General Tap

River/Canal Water Seller Other:.....

4. Sanitation Method:

General Network In house Latrine Outside Latrine

No Sanitation Other Methods:.....

In case of sanitation, what is the frequency of evacuation:

5. Washroom:

a. With separate door? Yes No

b. Toilette is covered? Yes No

c. Washroom Tap Inside Outside Absent

6. Method of getting rid of garbage:

Collecting car Manually Collected Dump

Burning/burying Used as fuel/fertilizer Throw away

Other Method:.....

7. Kitchen: Separate Kitchen Cooking in living room

8. Kraal: Inside House Outside House Absent

9. Animal waste: Inside House Outside House Absent

10. Household Constructing Material:

- Mud Wood Stone Brick
- Cement Tin Others:.....

11. Main source of income:

- Own land or private business and hire others.
- Work for himself & don't hire others. Regular Employee.
- Irregular Employee. Unemployed.
-

2. B. List of household inhabitants in the age 40+

Serial	Name	Age	Sex	Marital Status	Education	Occupation
Total No. of household inhabitants (40+ of age):						

Education Code:

Occupation Code:

-
- (1) Illiterate
 - (2) Read and Write
 - (3) Primary School
 - (4) Preparatory School
 - (5) Secondary School
 - (6) Diploma
 - (7) Bachelor
 - (8) Post Graduate

-
- (1) Farmer
 - (2) Worker
 - (3) Trader
 - (4) Employee
 - (5) Student
 - (6) Unemployed

Interviewer:.....

Reviewer:.....

3. Eye Exam form

Village: District:
Name: Date: / /
Sector No.: Household No.: Person ID:
Age: Sex: Male Female
Occupation: Education:
Address: Tel:

Visual acuity evaluation

With Glasses

Without glasses

OD

OS

$\geq 6/18$

6/24 – 5/60

6/60 – $>3/60$

$\leq 3/60$

.....Notes

External examination

OS	OD	Examination
<input type="checkbox"/>	<input type="checkbox"/>	Interned lashes
<input type="checkbox"/>	<input type="checkbox"/>	Corneal Opacity
	<input type="checkbox"/>	Central
	<input type="checkbox"/>	Peripheral
		Lens
	<input type="checkbox"/>	Clear
	<input type="checkbox"/>	Obvious Opacity
	<input type="checkbox"/>	Aphakia
	<input type="checkbox"/>	Pseudo-Aphakia
		Trachoma
	<input type="checkbox"/>	No Sign
	<input type="checkbox"/>	TT
	<input type="checkbox"/>	TF
	<input type="checkbox"/>	TI
	<input type="checkbox"/>	TCO

Previous services

OS	OD	Service
<input type="checkbox"/>	<input type="checkbox"/>	TT Surgery
<input type="checkbox"/>	<input type="checkbox"/>	No.
		Cataract Surgery
<input type="checkbox"/>	<input type="checkbox"/>	Aphakia
<input type="checkbox"/>	<input type="checkbox"/>	Pseudo
<input type="checkbox"/>	<input type="checkbox"/>	Aphakia
.....	Other Surgeries
		Mention

Major cause of low vision / blindness

OS	OD	Cause
<input type="checkbox"/>	<input type="checkbox"/>	Absent Globe
<input type="checkbox"/>	<input type="checkbox"/>	Refractive Error
<input type="checkbox"/>	<input type="checkbox"/>	TCO
<input type="checkbox"/>	<input type="checkbox"/>	Other Corneal Opacity
<input type="checkbox"/>	<input type="checkbox"/>	Cataract
.....	Others (Mention)

Reviewer:

.....

Examiner:

.....

4. Cataract form (A)

Cataract patient who didn't seek service

Date: / / Village:..... District:.....

Sector No.:..... Household No.:..... Person ID:.....

Name:

1. Can cataract be cured? Yes No Don't Know

If yes, how? Treatment Surgery Other:.....

2. Do you know anyone who had cataract surgery? Yes No

If yes, was this person Male Female Both

Was the patient satisfied with surgical outcome? Yes No Don't Know

3. Did anyone advice you to get cataract surgery before? Yes No

If yes, who advised you to get cataract surgery?

One of the village unit health workers. Doctor / Ophthalmologist.

A relative/Friend. Others:.....

4. Do people need to wear glasses after cataract surgery to improve vision?

Yes No Don't know

5. Why didn't you seek cataract surgery? (*please list all possible causes*)

Didn't have a problem with vision. Fear to have an eye surgery.

Worried about the outcome of surgery. Too old to benefit from surgery.

Worried to be badly treated at the hospital. Distance to hospital is too long.

Surgery is very expensive. No one to accompany.

Couldn't leave work. No one to take care of children.

Interviewer:.....

Reviewer:.....

4. Cataract form (B)

Cataract patient who had surgery

Date: / / Village:..... District:.....

Sector No.:..... Household No.:..... Person ID:.....

Name:

1. Where did you have surgery?

- Local hospital Central governmental hospital University hospital
 Private hospital/clinic facility outside Menia governorate Other:.....

2. Since when did you have your surgery? Years.

3. Were you advised to wear glasses after surgery? Yes No

If yes, do you still use them? Yes No

4. Are you satisfied with your surgery outcomes? Yes No

If no, why?

- Vision didn't improve Vision got worse Other:.....

5. Do you advice other patients to get surgery? Yes No

If no, why?

- It is not necessary It has no benefit it is so painful

Other:.....

Interviewer:.....

Reviewer:.....

5. Trichiasis form (A)

Trichiasis patient who didn't seek service

Date: / / Village:..... District:.....

Sector No.:..... Household No.:..... Person ID:.....

Name:

1. Do you feel any problems because of your eyelashes? Yes No

If yes, to what extent?

Mild problem Moderate problem Severe problem

2. Did you ever epilate your eyelashes? Yes No

If yes, how frequent?

Few times Several times I always do

3. Are you aware of surgery to cure your disease? Yes No

4. Do you know anyone who had this surgery? Yes No

If yes,

a. Was this person a male or female? Male Female Both

b. Was this person satisfied with outcomes of his surgery?

Yes No Don't know

5. Were you advised before to have surgery? Yes No

If yes, who advised you?

One of the village unit health workers. Doctor / Ophthalmologist.

A relative/Friend. Others:.....

6. Why didn't you seek cataract surgery? (*please list all possible causes*)

Didn't have a problem with vision. Fear to have an eye surgery.

Worried about the outcome of surgery. Too old to benefit from surgery.

Worried to be badly treated at the hospital.

Surgery is very expensive.

Couldn't leave work.

Distance to hospital is too long.

No one to accompany.

No one to take care of children.

Interviewer:.....

Reviewer:.....

5. Trichiasis form (B)

Trichiasis patient who had surgery

Date: / / Village:..... District:.....

Sector No.:..... Household No.:..... Person ID:.....

Name:

1. Where did you have surgery?

- Local hospital Central governmental hospital University hospital
 Private hospital/clinic facility outside Menia governorate Other:.....

2. Since when did you have your surgery? Years.

3. How many times did you have trichiasis surgery? OD:..... OS:.....

4. Are you satisfied with your surgery outcome? Yes No

If no, why?

- Vision didn't improve Vision got worse Surgery was painful
 Surgery resulted in disfiguring It recurred Other:.....

5. Do you advice other patients to get surgery? Yes No

If no, why?

- It is not necessary It has no benefit It is so painful
 It has a lot of complications Other:.....

Interviewer:.....

Reviewer:.....

6. Visual functioning form

Date: / / Village:..... District:.....

Sector No.:..... Household No.:..... Person ID:.....

Name:

Age:..... Sex: Male Female

Vision group: Normal vision Low vision

Use glasses: Yes No

1. Do you find any difficulty reading large prints such as street advertisements?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

2. Do you find any difficulty in reading regular prints such as newspapers?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

3. Do you find any difficulty in reading small prints such as medicine labels?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

4. Do you find any difficulty in writing a document or signing a check?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

5. Do you find any difficulty in recognition of faces or watching TVs?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

6. Do you find any difficulty in participation in social events because of your vision?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

7. Do you find any difficulty in moving around at night because of your vision?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

8. Do you find any difficulty in avoiding obstacles such as stones or trees?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

9. Do you find any difficulty in cooking, or pouring water because of your vision?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

10. Do you find any difficulty in sorting stones, preparing or having food?

Yes No Inapplicable

If yes, to what extent?

Little Moderate Great deal Unable to do activity

11. Do you find any difficulty in recognizing your hand watch or counting money?

- Yes No Inapplicable

If yes, to what extent?

- Little Moderate Great deal Unable to do activity

12. Do you find any difficulty in performing your daily job tasks?

- Yes No Inapplicable

If yes, to what extent?

- Little Moderate Great deal Unable to do activity

13. Do you need accompany while doing your tasks that needs travelling?

- Yes No Inapplicable

If yes, to what extent?

- Little Moderate Great deal Unable to do activity

14. Do you find any difficulty in doing your personal day activities?

- Yes No Inapplicable

If yes, to what extent?

- Little Moderate Great deal Unable to do activity

Interviewer:.....

Reviewer:.....

Appendix 2: Semi structured interview guidelines

Introduction:

The proposed interview has different objectives that would meet with the project overall goal and specific objectives, it will be also used as a tool for better understanding of the community perception and hence contributes in improvement of the project performance.

As the current project is generally aiming at community sensitization towards eye care service uptake with a special focusing on reduction of the gender gap, this interview will be targeting twelve household heads in six different groups following two main categories (T1 to T4 and C1 to C2) of household heads.

Criteria of selection will be as follows

Trachoma (T)

(T1) Have Trachomatous Trichiasis (**TT**) and suffering **Bad** Household Conditions.

(T2) Have Trachomatous Trichiasis (**TT**) and enjoying **Good** Household Conditions.

(T3) Doesn't Have Disease (**No TT**) and suffering **Bad** Household Conditions.

(T4) Doesn't Have Disease (**No TT**) and enjoying **Good** Household Conditions.

Cataract (C)

(C1) **Have Cataract** (currently) and **never sought service** before.

(C2) **Had Cataract** and **sought service** before.

The rationale behind the criteria of selection for group (T) is to achieve an in depth understanding of the relationship among presence of disease, household condition and the

household conditions. Trachoma and its consequences are suitable for this type of investigation as it is much related to household conditions. While the rationale behind the criteria of selection in the (C) group is to plot the pattern of service utilization, and investigate the positive and negative factors affecting this process as well as the KAP gap. Cataract patients are the ideal candidates for this type of understanding as they are in more urgency to seek service because of the direct impact of cataract on visual impairment.

In each of the above (6) groups one house headed by a male and one household headed by a female will be interviewed to reflect the gender gap this will give us a total of 12 households.

Answers will be linked to the household, eye exam and village forms for matching, integration of information, and understanding of the related barriers & quality of life of the respondents.

General guidelines:

A semi-structured interview is different from both structured questionnaire forms that's mainly designed for quantitative data collection purposes where we exactly know which information we are looking for, and open-ended interviews where the respondents are given much space to express their own ideas and usually used when we know very little about the phenomena. It is on the half way between each where we need to get a better understanding of a certain phenomena we already know about, and we need to control and focus the amount of information we are looking for.

The degree of success of a semi structured interview is based upon the presence of comfort-ability and trust feeling between the interviewer and the interviewee. It also relies much on the communicability skills of the interviewer and his/her ability to listen and gave the impression of interest in what he/she listens to. You shouldn't show any sign of agreement / disagreement to whatever answers you get. You also shouldn't express any impression that may lead to direct the speech in any direction or encourage the respondent to go on any track.

Your role here is not to give any correct information, counseling, or health education to the community. As much as you will keep neutral, we will better understand people's perception that may help us and the communities to change their behavior, health educate them, improve the provided services and advocate the policy makers. Hence enhance the overall situation of eye care.

Please start by:

- Making sure that you have your name tag on place.
- Introducing yourself and the project purposes and formal collaboration with the governorate and MoHP.
- Seek oral consent of the patient for conduction of interview.
- Seek approval to use the recorders (better if you start by re-seek of consent on the tape).
- Mention confidentiality and anonymity in data analysis.
- Start by familiarizing yourself with the respondent in a decent and warm manner.
- Express the need for understanding of the respondent's perception and its great benefit to improve eye care profile in the governorate.

Then:

- Use your eyes and body language to show your attention and interest even when you are silent.
- Rephrase or reformulate the question in the language you feel more close to the respondent understanding or feel free to clarify what you are refereeing to (be aware not to suggest a direction of answer).
- Show signs of comprehension of the respondent's opinion without agreement / disagreement.
- Use simulation scenarios (some people said..., some people did...)

Please note that:

- You should conduct such interview with your colleague (coupe team), where only one would take the (lead) and the other should remain quite with negative interference.
- You should select a quite setting for conduction of the interview, and you can ask the respondent friendly where you can set to do this.
- Try to avoid any interruption and / or interference that may be created by anyone in the nearby who may try to affect the respondent or direct his / her speech, you can gently draw his/her attention to the necessity of listening to the respondents view points.
- This interview was designed to be conducted in an average time of one complete hour, spending 90 minutes may mean that you open ended the respondent's replies which may lead to weakening and distraction of the

analysis. Meanwhile, a 20 minutes interview may mean that you received very short and brief answers that may lead to less understanding of the under-investigation perceptions. You should know where to give the respondent a space to talk and where to keep him/her on track.

- Always take short notes (keep a notepad close) to take points on improving your performance in next interview.
- Use both self and peer evaluation for your / your colleague interview, and suggest methods for improvement.

Interview guiding questions:

(T) Group

1. What are the most common eye diseases in your village?
2. What do you know about such diseases? How do they occur? What do you think their causes are?
3. Did you ever have a problem in your eye before?
4. What do you usually do when you have such problem? Where do you go?
5. Did you hear about trachoma before? (If yes, Continue, if No go to "11")
6. What do you think its causes are? Why in your opinion some people get diseased while others don't? Do you think that this disease is age or gender related?
7. Do you think that it is an infective disease?
8. Who do you think the most affected group would be? And why?
9. Do you think that it can be cured?
10. Do you think it can lead to a complication (If yes, Like what?) (Go To 14)
11. What do you think trachoma is?
12. Which part of the body / eye does it affect?
13. What would you do if you suspected such a disease? For whom would you go first?
14. Did you hear about trichiasis?
15. What do you think it comes from?
16. Did you hear of / had someone in your family or the village had trachoma or trichiasis before? If yes, what did he/she do then?
17. Have you ever do epilating to your eye lashes? Why?
18. How do you find eye-care services usually in your village? Markaz and the governorate in general?
19. Are there any traditional healers or a person that people may ask his/her help in these cases (other than medical personnel).
20. Why in your opinion some people would seek service while others don't.
21. What do you think is the best approach to prevent trachoma and reduce the burden of trichiasis in your village?
22. What would you like to add or comment on in addition to the previous conversation?

(C) Group

1. What are the most common eye diseases in your village?
2. What do you know about such diseases? How do they occur? What do you think their causes are?
3. Did you ever have a problem in your eye before?
4. What do you usually do when you have such problem? Where do you go?
5. Did you hear about cataract before? (If yes, Continue, if No go to "11")
6. What do you think its causes are? Why in your opinion some people get diseased while others don't? Do you think that this disease is age or gender related?
7. Do you think that it is an infective disease?
8. Who do you think the most affected group would be? And why?
9. Do you think that it can be cured?
10. Do you think it can lead to a complication (If yes, Like what?) (Go To 14)
11. What do you think cataract is?
12. Which part of the body / eye does it affect?
13. What would you do if you suspected such a disease? For whom would you go first?
14. Did you seek surgical service before? (If yes continue, if no go to 18)
15. Who first advised you to get surgery?
16. Where did you go then?
17. Are you satisfied with the service? Why? Or why not?
18. Why didn't you seek service before?
19. Did you hear of / had someone in your family or the village had cataract surgery before? If yes, what did he/she do then?
20. How do you find eye-care services usually in your village? Markaz and the governorate in general?
21. Are there any traditional healers or a person that people may ask his/her help in these cases (other than medical personnel)?
22. Why in your opinion some people would seek service while others don't.
23. What do you think is the best approach to avoid vision loss due to cataract and in your village?
24. What would you like to add or comment on in addition to the previous conversation?

Appendix 3: Additionally collected data from control villages:

1. How many cataract and TT surgeries (approximately) are usually done annually in the village?
2. What are the (estimated) direct and indirect costs associated with cataract and TT surgeries respectively?
3. What usually happens when a villager face an eye health problem, how does he act? Especially in case of cataract and TT?
4. What are the different therapeutic itineraries of patients with TT or cataract? Which therapeutic itineraries are more common for men and women?
5. Where does he/she usually go first?
6. What are the nearest healthcare and the nearest eye care facilities to the village (eye care means where eye surgeries can be done)?
7. How far are these facilities? Do they need a mean of transportation? If yes, what is the cost of transportation?
8. What is the examination cost (fees), and how much does cataract and TT surgery cost?
9. Do villagers usually start by visiting the village health unit which then refers them to specialized eye care or do they just go there?
10. Are there any traditional healers in the village? And if yes, do people still go to them?

11. Are there any local traditions or customs regarding the treatment of eye care illnesses?

12. What is the overall impression of the villagers about the local eye hospital (Samalout Eye Hospital) regarding the quality of the services provided, satisfaction with visual outcome, interactions with staff (attitude, friendliness)...

13. What are the overall concepts / perceptions among villagers regarding eye care, prevention, and treatment? And what is the estimated level of knowledge about eye diseases?

14. What are the major barriers to eye care service utilization at the village level and in Samalout and Menia in general?

15. What is the estimated number of cataract and TT surgeries done during the period from April 1st 2006 to March 31st 2007? Do you think that it is increasing or decreasing?

16. Where were such surgeries done and what were its results?