

Overview

TRACHOMA: A Women's Health Issue

***Trachoma is a women's health issue
whose time has come.***

Although few women's health advocates are familiar with this painful, disfiguring and ultimately blinding disease, and most women's health advocates do not think of trachoma as a women's health issue, the epidemiological data are compelling.

***Trachoma disfigures and blinds three
times as many women as men.***

Trachoma is a disease that is both preventable and treatable, yet trachoma is the second leading cause of blindness in the world, responsible *for blinding at least five million people, three fourths of whom are women.*

This paper examines trachoma and women's health by reviewing and addressing the trachoma literature from a women's health perspective; the burden of disease associated with trachoma, the social and economic implications of blindness for women; the relative importance of trachoma in women's health; and the various interventions for controlling trachoma and how they might link programmatically with programs and services in the trachoma-endemic world.



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Concepts of Women's Health

“Women’s health” is a concept that conjures up many meanings and agendas in different regions of the world among many different strata of women. Yet these differences do not discourage women from espousing and supporting women’s health; nor is there much of an interest on the part of women advocates for reducing the number of concerns. Generally speaking *women’s health is conceptually pragmatic -- that is, women’s health is generally thought to include all conditions, diseases, care and research that affects women either disproportionately or differently from men.*⁸⁸

In other words, women’s health is all-encompassing and all-inclusive, relying for its internal logic on widely-shared beliefs that have mostly been confirmed:

- *Women’s health, until perhaps the later part of the 1990’s, has been under-attended, under-serviced and under-financed in nearly all countries of the world.*
- *As a result of this lack of concern, women have suffered and continue to suffer needlessly.*²⁵

There are multiple rationales used to justify investing in women’s health. They assert that women’s health must be attended to because:

- (1) *health is a human right;*
 - (2) women’s health is central to the *empowerment of women;*
 - (3) women’s empowerment is central to *development;*
 - (4) that health care research, services and investment must be governed by principles of *equity* and *equality.*²⁴

Another fundamental and shared belief among proponents of women’s health, which has also been largely confirmed, is that although the majority of women in most countries live longer than men, they live most of their lives with more disease, infirmity and disability than do men.

Based on these broad, pluralistic perspectives and based on the epidemiological data discussed below, there is no question that trachoma is a women’s health concern.

Trachoma From a Women's Health Perspective



Tanzania

photo by Dr. Joseph Cook

The rate of trachoma and risk of blindness from trachoma is 3 to 4 times higher in women than in men.

Worldwide estimates of people affected by or at immediate risk for developing blindness from trachoma range from 5.2 - 9 million.⁵ Approximately 500-540 million people, or 10% of the world's population, are affected or are at immediate risk for developing the disease.^{79,92} Ninety-eight percent of trachoma is found in developing countries, primarily in Sub-Saharan Africa and the Middle East, with substantial pockets of endemicity in Asia, Mexico and Latin America, and Australia.⁴² Research indicates that the rate of trachoma and risk of blindness is 3-4 times higher in women than in men.^{10, 19, 41}

Trachoma begins in childhood with an acute infection of *Chlamydia trachomatis*, and progresses over the years with repeated infections. Scarring and irritation caused by chronic inflammation of the *conjunctiva*, (the inner eyelid) cause the eyelid to shrink and the eyelashes to turn inward, scraping the cornea. If left untreated, this condition, *trichiasis*, may lead to corneal opacity and eventual blindness.⁵ **Trachomatous blindness most frequently occurs in women in mid-life and beyond.**

Special Focus: **Gender Risks**

The essential risk factors for trachoma are related to gender. Because of the progression of the disease, blindness can occur at any time in a woman's life, and interventions may be introduced at most stages of her lifecycle.²⁶

1. *Caring for children* has been identified as a risk factor for active trachoma and for the progression to trichiasis and blindness. Many studies indicate children are the major reservoir for chlamydial infection and have high rates of inflammatory trachoma.⁶⁸ Women are more likely to have higher rates of trachoma because they are the primary caregivers of children, and thus in greatest contact with them.

2. *Water: Accessibility and Use.*

A. Inaccessibility of water is a major risk factor for a number of infectious diseases, including trachoma. When water is not easily accessible, face-washing declines. Communities may be reluctant to use precious water for hygienic purposes which reduces water for more basic sustenance activities. However, field testing has demonstrated

that face-washing, even with a small amount of water, is an effective trachoma prevention strategy.^{17, 67}

B. Studies of the relationship between trachoma and distance to water are inconclusive. In the Gambia, no relationship was found between the prevalence of active disease and distance to the nearest water supply,³ whereas the prevalence of trachoma in Southern Malawi was strongly associated with the time it took to walk to the nearest water supply.

India

UN Photo/Doranne Jacobson



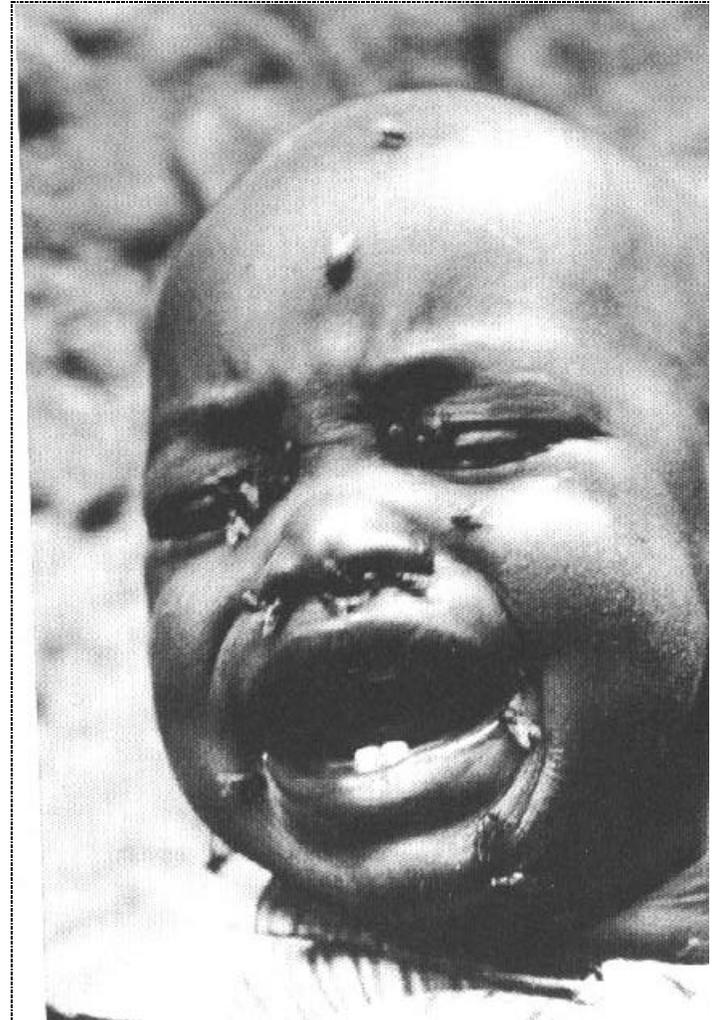
For Trachoma

3. Women's socioeconomic status (SES). Studies have found an inverse relationship between SES and the risk of trachoma.⁴⁵ Poverty and other economic factors affecting women have created a vulnerability relating to health knowledge and education, so that poor women do not have the necessary information to care adequately for their children. Accordingly, as the mother's education level rises, the risk of trachoma to her children declines.⁶⁸

4. Flies and cattle have been implicated as risk factors for the disease, but again, results have been inconclusive.¹⁵ One study in the Dodoma region of Tanzania revealed that neither the ownership of cattle, nor their presence in the village was as important to disease risk as the proximity of the cattle corral to the living quarters.⁸²

5. Household environment is another risk factor for trachoma. Women cooking in poorly ventilated rooms or sleeping in a room with a cooking fire may be at higher risk for the disease, since eye irritants may aggravate the conjunctiva, causing it to be more susceptible to infection.^{40,55}

The risk factors listed here, -- **child caregiving, low SES, inadequate water supply, and poor hygiene** -- increase the frequency and severity of trachomatous infection, and are tightly interwoven with gender roles assigned by culture.²⁷



Morocco photo courtesy of Pfizer, Inc

Women and the Burden of Trachoma

Trachoma is first and foremost a disease of morbidity, reflecting suffering and disability, in contrast with mortality, which reflects the rate of death. The burden of disease is an effective framework for discussing trachoma since it takes into account the effects of morbidity and mortality on the ability to fulfill societal roles. The burden of disease looks beyond the prevalence of a disease; that is, it attempts to measure the impact of disease based on its distribution by sex and age.

The demographic changes within populations, especially in developing regions, are projected to occur at a rate of three and a half times from 1980 to 2020, causing a rapid increase in the over-60 population. With more people living longer, the burden of unnecessary blindness from trachoma among older people is estimated to be very high. And, of the projected 50 million blind people living in low-income societies by the year 2020, roughly 38 million will be women.*

Disability-Adjusted Life Years attributed to Trachoma, 1990*

GEOGRAPHIC AREA DALYs**	TOTAL	MEN	WOMEN
Established Market Economies	-	-	-
Former Socialist Economies of Europe	-	-	-
India	309	112	197
China	472	115	357
Other Asia and Islands	931	235	695
Sub-Saharan Africa	901	210	690
Latin America and the Caribbean	110	38	72
Middle Eastern Crescent	576	218	358
Total	3298	928	2370

*Adapted from *Global Comparative Assessments in the Health Sector*. C. Murray and A. Lopez, Eds. 1994. WHO, Geneva.

Social and Economic Implications of Blindness for Women

Blinding trachoma undermines women's non-wage work, such as caregiving, water collecting, and meal preparation. The community and family lose this productive labor, and the women lose status.



Women cooking in poorly ventilated rooms may increase their risk of eye infection.

Nepal

UN Photo/Ray Witlin

Similarly, in societies where women are engaged in waged or money-based enterprise, trachoma diminishes their economic capacity.

In addition, trachomatous blindness is an unnecessary sensory loss, which results in substantial pain and suffering. In aging women, trachomatous blinding may be compounded by a variety of disabilities, such as arthritis. But unlike arthritis, trachomatous blinding is easily preventable.³⁵

Trachoma can be treated in its early stages and subsequent blindness prevented, but in order to accomplish this, it must be identified and reported.

The Impact of Blindness on the Family

Trachoma has an impact on the entire family, and the mother's blinding trachoma appears to have the greatest impact on the daughter.



A young girl in Kathmandu, Nepal.

UN Photo/J.K. Isaac

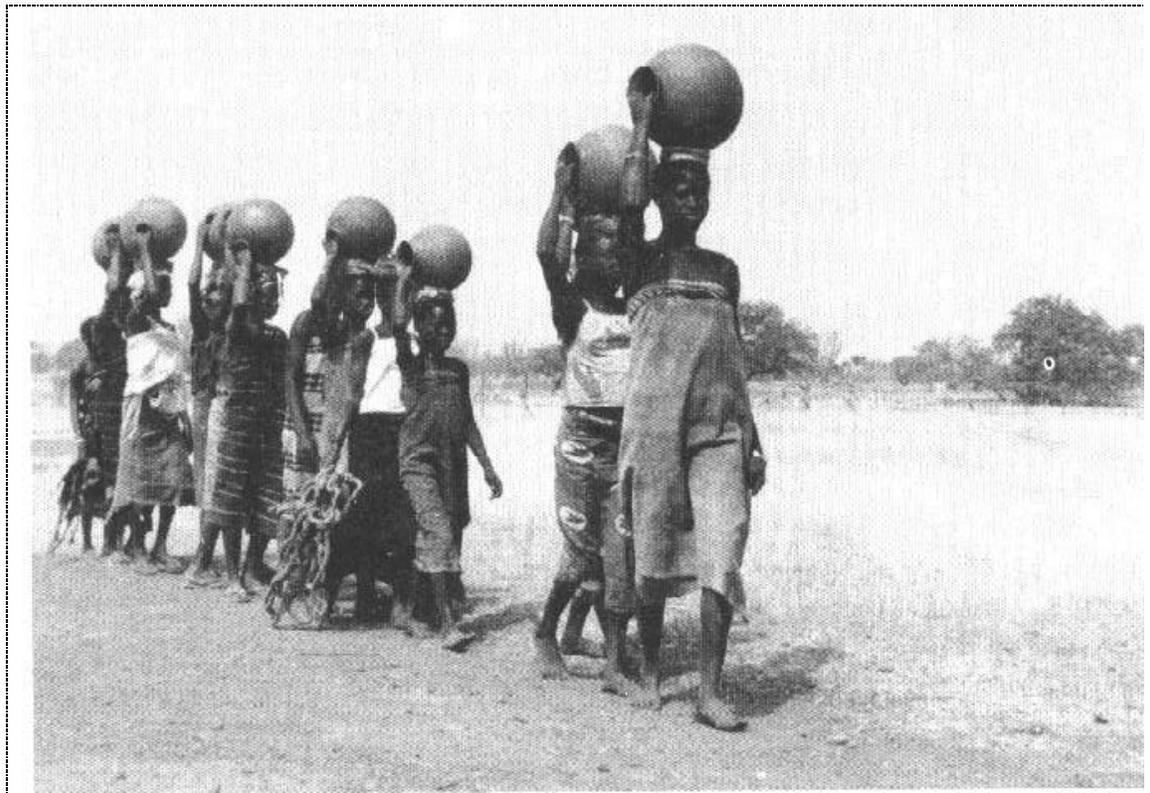
Trachoma has an impact on the entire family, but the mother's blinding trachoma appears to have the greatest impact on the daughter. The girl-child may have to take on household responsibilities to the detriment of her education when the mother is blind. A daughter's dowry may be undervalued if it is perceived that her disabled family members will need care in the coming years.

The balance of the household may be upset in numerous ways, potentially leading to eventual impoverishment. Changes in work routine reverberate within the family by causing further displacement. *When women in their 40s and 50s, and even as young as their 20s, are increasingly unable to carry out the activities required of them due to trachomatous vision loss, the informal arrangements of the family are undermined.*

Impact of Gender and Culture on Treatment of Trachoma in Women

The prevalence of trachoma may be as much as 10-fold greater than hospital records suggest.

Traditionally patriarchal societies that require women to be stoic and uncomplaining about ill health may result in the underreporting of vision loss.⁷⁶



These women in Burkina Faso have to go to a distant well to get water.

UN Photo/Ray Witlin

In some societies, women must be careful about reporting illness because they may be perceived as being lazy and selfish by their peers and husbands.⁷⁶ Women who spend time addressing their own health problems may fear that they are neglecting their primary duties of caregiving and meal preparation. Fear of defying social norms may be

an obstacle to the implementation of face-washing prevention programs and other interventions.

Varying beliefs about disease etiology may also serve to minimize the prevalence of trachoma. Beliefs about the causes of disease range from blindness caused by old age to illness induced by the glance of an envious person. Cultural beliefs in an Egyptian Delta hamlet discourage the discussion of trachoma since villagers believe trichiasis can be spread by word of mouth, and discussion of the disease is equal to questioning the will of God.³⁴

In one study, villagers' assessments of their quality of vision greatly exceeded evaluations by ophthalmologists.³⁵ In addition to the danger of underreporting, ignoring symptoms may lead to the greatly increased risk of trachoma progressing to blindness.

Existing data from population-based surveys which use cluster-sampling may underestimate trachoma prevalence since the disease is generally concentrated in foci. Children and their parents may not complain about inflammatory trachoma, and primary health care workers often do not examine patients' eyes unless requested. *Many people are often unaware that their condition is preventable and that treatment can halt the progression toward irreversible damage.* The prevalence of trachoma may be as much as 10-fold greater than hospital records suggest.¹⁷



China
UN Photo

Strategies to Eliminate Trachoma

A wide range of cost-effective intervention strategies can be implemented to combat trachoma both in its early, inflammatory stages and in its advanced stages in order to help alleviate present suffering and prevent impending blindness. The **SAFE** strategy consists of the curative approaches of surgery and antibiotics, and preventive approaches of face-washing and environmental change.⁹⁶ It is the combination of interventions that is most likely to bring about successful and long-lasting change.

TRACHOMA SIMPLE GRADING SYSTEM

Thylefors B, Dawson CR, Jones BR, West SK, Taylor HR. A simple system for the assessment of trachoma and its complications. Bull WHO 1987;65:477-483.



Photo: Murray McGavin

Normal everted upper lid. (The area to be examined for inflammatory changes is outlined).



Photo: John DC Anderson

TF = Trachomatous Inflammation - Follicular: the presence of 5 or more follicles, each of which must be at least 0.5mm in diameter, on the flat surface of the upper tarsal conjunctiva.



Photo: Allen Foster

TI = Trachomatous Inflammation - Intense : marked inflammatory thickening of the upper tarsal conjunctiva that obscures more than half of the normal deep tarsal vessels.



Photo: Hugh Taylor

TS = Trachomatous Scarring: the presence of scarring of the tarsal conjunctiva.



Photo: John DC Anderson

TT = Trachomatous Trichiasis: evidence of one or more eyelashes rubbing on the eyeball. If one eyelash or a number of eyelashes have recently been removed, then the patient's trachoma should also be graded as trachomatous trichiasis.



Photo: John DC Anderson

CO = Corneal Opacity: corneal scarring due to trachoma where the scarring is central and sufficiently dense to obscure part of the pupil margin.

Success at eliminating trachoma as a public health hazard over the preceding centuries has been attributed to general economic improvement and improved standard of living.⁶⁴ It is perhaps tempting, therefore, to believe that where trachoma is currently endemic, the disease will be eliminated when a country's general economic development improves.

Although development will improve the conditions for children and future generations, people who have already suffered from repeated infections will not benefit and will continue to be at high risk for blinding complications unless they are treated with antibiotics and surgery.

Surgery

Surgery is the most appropriate intervention for trichiasis. However, in order for surgery to be an option for women with trichiasis, it must be affordable, accessible, and in traditional societies, women must have the cooperation of husbands or other male heads of household.

Hundreds of thousands of people suffer from trichiasis, the stage of trachoma in which the deformed eyelid has already caused the eyelashes to turn inward. These people need immediate surgical intervention in order to save their remaining sight. In order for surgery to be an option for women with trichiasis, however, it must be affordable, and accessible. In traditional societies, women must also have the cooperation of their husbands or other male heads of household.

Access to surgery is further limited because such services are costly. Surgery must be performed by trained health care workers; moreover, access to such skilled intervention is not yet widely available to people in remote villages. Surgery may challenge cultural norms and even though women are blinded by trachoma at a rate 3-4 times higher than men, women are far less likely than men to undergo surgery.

Health Promotion : Research suggests that in promoting surgical intervention, both men and women should be targeted:

1. Men and community elders should be educated and their approval obtained for the implementation of all trachoma prevention and intervention efforts.
2. Women should also be educated about trachoma prevention and treatment. Their special skills at disseminating health information through existing peer networks should be encouraged.⁷⁵

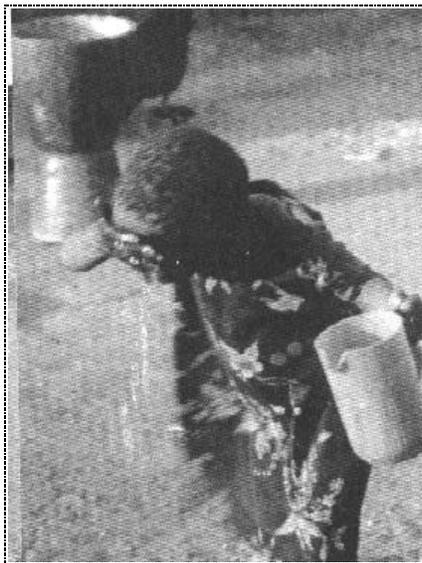
Antibiotics

Antibiotics are another component of the **SAFE** strategy. Preventing re-infection of the Chlamydial bacteria is necessary to halt the progression of trachoma. Tetracycline eye ointment has been used to treat inflammatory trachoma in young children by applying the ointment directly to the eyes 2 times a day for 6 weeks.⁸³ This topical antibiotic is effective in reducing inflammation caused by the bacterial infection, but re-infection rates remain high after treatment.⁸³

Researchers have been using azithromycin, a macrolide oral antibiotic, as an alternative approach. There is good evidence suggesting that annual or biannual mass treatments may reduce the intensity and persistence of infection and reduce the progression of trachoma to trichiasis and blindness. Clinical trials in Morocco, the Gambia, and Tanzania have been conducted with promising preliminary results. Antibiotics are an important part of the **SAFE** strategy, and trachoma prevention advocates hope to link an annual treatment for trachoma with existing treatment programs for infectious diseases in children.

Research scientists are studying the immune response to look for ways to interfere with disease progression from inflammation to scarring to trichiasis with the knowledge that each individual's immune system responds differently to infection. In one study, strains of the chlamydia bacteria were found in ocular specimens of several children, yet none of the children developed clinical trachoma.⁶³ Different strains of the bacterium have been found in different geographic regions,^{2,62} and continuing research on geographic differences is important as researchers identify ways to combat this microorganism.

Face-Washing



Tanzania

photos by Joanne Edgar

The association between face-washing and trachoma was first quantified by Dr. Hugh Taylor in the highlands of southern Mexico in 1985. The striking correlation led to further research and to confirmations that *keeping children's faces clean reduces the risk of trachoma.*³⁵ Face-washing, an integral component of the **SAFE** strategy, is one of the most effective methods of prevention available.

A study in Tanzania examined the major hurdles to changes in water use patterns.⁴⁰ Perceptions of the amount of water available and household priorities for use of water, as opposed to the amount of water in the home, were the primary determinants of the cleanliness of children's faces.⁴¹ Water availability influences water-use patterns and is affected by seasonal variations during the year. However, even with extreme seasonal variation of water availability, enough water is generally available for the small amount needed for face-washing. The key to successful implementation of face-washing programs is overcoming the perception that a large amount of water is necessary to wash a child's face.

Community Context:

A community effort is key to ensuring that face-washing actually prevents the transmission of the pathogen which causes trachoma. Women in the study stated that it was meaningless to wash their children's faces if other mothers did not do the same.

Women are responsible for washing children's faces and for their general health and hygiene, but the legitimacy and authority for changes in water use in rural communities is dependent on the support of the community and, of men specifically.

Education and Prevention:

The experiment in Tanzania included classes teaching the importance of face washing and techniques to reduce the amount of wasted water. These classes included men and women, school children, traditional healers, and village social groups. The breadth of participation explicitly recognized the need to include men in order to legitimize the changes in water use.

Additional interventions included neighborhood level meetings, and reinforcement strategies that linked face-washing to villagers' everyday lives. Young girls who participated in the Tanzania program were affiliated with a school where children created songs and poems about face-washing and prevention of blinding trachoma. The experiment was a success, face-washing increased from 9% to 33% within one year.⁴⁰



Nepal

UN Photo/J.K. Isaac

Environmental Change

Environmental changes that are costly may be the most difficult to put in place. Nevertheless, universal access to safe water and community sanitation is critical to eliminating trachoma in the long term. In the short term, however, community based health promotion and education on the uses of water and sanitation may successfully limit the spread of the disease while community based education for eyelid surgery may help stem the blinding progression of the disease for thousands of women and men already infected.

Concepts and Strategies for Institutional Linkages

In order to link trachoma elimination and control with women's health, there must be an investment in basic informational health promotion. This promotion should be directed across a number of groups and issues without regard to the historically divisive women's health concerns. To be effective, the outreach must go beyond grassroots, national, and international NGOs engaged in operations, and should extend to NGOs engaged in advocacy. The advocacy NGOs provide the policy and political infrastructure that is necessary to sustain program initiatives.

Partnerships

Several potential partnerships might be forged with intergovernmental agencies already involved in various aspects of women's health. These include the World Health Organization, UNICEF and UNFPA with the interagency coalitions currently underway concerning "Safe Motherhood" and HIV / AIDS. Studies indicating a strong relationship between the reservoir of infection in infants and young children and the transmission of infection and reinfection to mothers and other caregivers, could be shared among the interagency allies already committed to programs and policies for maternal and child health. Additionally, the SAFE strategy for the prevention and control of trachoma could be promoted with services linked to the interagency "Safe Motherhood Programs."

A number of other conceptual linkages could be developed with the women - centered concern for trachoma. For example, UNICEF's extensive programs for the girl child could be called upon to link with issues related to the increased risk to girl children for repeated re infection because of their responsibilities for caring for younger siblings. Additionally, the impact of trachoma on the school attendance of the girl child also falls within UNICEF's mandate which stresses the need for girls to be educated. Linkages with the World Bank and UNIFEM can be used with virtually the same rationale.

Conceptually, the clinical progression leading to blinding trachoma for women throughout the life span should be of interest to agencies and programs which address the needs of the aging population such as WHO Aging and Health Programme, UNFPA and the UN Population division.

Surgical interventions to stem or prevent the abrasion of the cornea are usually required for women infected with trachoma from young adulthood and beyond. Because eye surgery requires decision making in households in which the allocation of resources is controlled by gender inequality, it is quite plausible to make linkages with the concept of empowerment as it was articulated in the Beijing Platform for Action. This concept is also held by the UN Commission on the Status of Women and its administrative counterpart, the Division for the Advancement of Women, UNIFEM, and the Human Capital Development and Operations Policy division of the World Bank.

The Beijing Declaration and Platform for Action

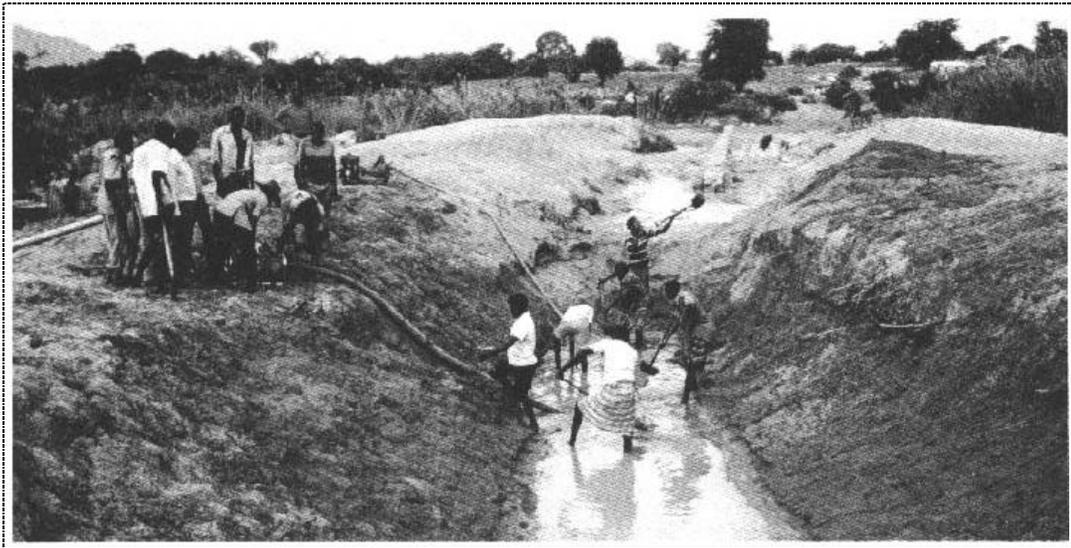
Paragraph:

105. In addressing inequalities in health status and unequal access to and inadequate health-care services between women and men, Governments and other actors should promote an active and visible policy of mainstreaming a gender perspective in all policies and programmes, so that before decisions are taken, an analysis is made of the effects for women and men, respectively.

-Beijing Declaration and Platform for Action. Fourth World Conference on Women, Beijing, China, 4-15 September 1995. Department of Public Information, United Nations, New York, 1996.

Water and Sanitation Programs

Face washing is part of the SAFE strategy for preventing trachoma. The use of water, however, is problematic in many villages because it is not easily accessible. In these areas women spend a large part of each day fetching water. Similarly, waste disposal is also inadequate. Several UN agencies, such as WHO, UNICEF, the World Bank, INSTRAW, and the UN Environment Program, have women's health agendas that include water and sanitation. It is possible that as the disproportionate prevalence of blinding trachoma in women becomes more widely known, these agencies will revitalize their water and sanitation policies and programs.



Tanzania
UN Photo/B. Wolff

The Jakarta Declaration and New Players and New Partners for Health Promotion and Education

There is a natural fit between health promotion and health education efforts initiated by WHO at the intersectoral meetings held in Jakarta, July 1997 and the GET 20/20 (Global Elimination of Trachoma) including the SAFE strategies. This fit could be leveraged not only to the benefit of all the players, but more importantly to the benefit of the recipients—the women who are at risk or who are already blinded by trachoma.

Summary

While it appears that women and girls are not biologically predisposed to trachoma, the heavily skewed prevalence rates support the concept of trachoma as a women's health issue.

All of the parameters -- the etiology, the course of the disease, and the medical / surgical, pharmacological and environmental interventions are either driven or constrained by issues of gender. Millions of women in the trachoma endemic parts of the world suffer disproportionately from this disease because, according to the evidence, their gender-determined roles as unwaged, poorly educated, child caregivers with subordinate decision-making roles in their households and in society, put them at greater risk.

Supporters and proponents of women's health must not minimize the burden of blinding trachoma on the lives of women already infected. Since the disease is both preventable and treatable, it is important to advance strategies an interventions that will bring relief to the millions of women who are either needlessly blinded or at risk of being blinded.

It is also incumbent on women's health supporters throughout the world to advocate for appropriate interventions including surgery, antibiotics, water, and education in trachoma endemic communities. Recent history has demonstrated that women are capable of arousing the conscience of the global community, and recent history has also demonstrated that when men and women, NGOs, governments and intergovernmental agencies work together to eradicate infectious diseases such as polio and smallpox, it can be done. The elimination of trachoma is possible. It requires health promotion and education, political will and effective resource allocation to implement effective interventions throughout the world.

With your help, it can be done.

*Inaccessibility
of water is a
major risk
factor for
trachoma.*



Cote d'Ivoire

photo by Dr. Nina Tanner Robbins

“Women in the village were fortunate because there was actually a well within the village, but it was not mechanical and every drop of water had to be pulled from the well by hand. The woman at the right in the picture dropped her pail into the well, lifted the water to the top with a rope and then poured it into her large white enamel bowl. After she had done this fifteen times and the bowl was full, she strapped her baby back onto her body with a large piece of fabric, two other women helped her lift the bowl on to her head, she picked up a bundle which she carried in front of her, and she walked off down the lane.”

Dr. Nina Tanner Robbins

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