



Symposium: "Improving Women's Eye Health: Strategies to address the greater burden of blindness in women"

November 7, 2003, Harvard Club of Boston

**Organized by: The Women's Eye Health Task Force,
based at: The Schepens Eye Research Institute**

Lay Summary

In every part of the world, women have twice the risk as men of losing their vision. On November 7, 2003, the Boston-based Women's Eye Health Task Force hosted a symposium at the Harvard Club, on the topic "Improving women's eye health: Strategies to address the greater burden of blindness in women." The goals of this meeting were to understand the reasons why women have a greater burden of blindness, and to find remedies to begin to change this situation. Internationally recognized leaders in eye diseases, women's health, and public health policy were invited to speak at the symposium and to take part in the lively discussions that followed each presentation.

The reasons for the large gender disparity in blindness depend partly upon the geographic regions of the world, partly upon biological differences between the sexes, and largely upon cultural, demographic, sociological, economic, and environmental factors. There is much that can be done right now to improve women's eye health. We already have most of the required knowledge, and there is no need for any "medical breakthroughs."

Dr. Paul Courtright, who runs the Kilimanjaro Centre for Community Ophthalmology in Tanzania, gave the audience insight into why women in developing parts of the world have more than their share of blindness. The main causes of blindness are cataract (an opacity in the lens of the eye) and repeated eye infections; these conditions, with proper treatment, should not lead to blindness. Cataract can be cured by a simple, safe operation, and infectious diseases like trachoma (which destroys the cornea), by antibiotics. However, in developing countries, women have far from equal access to the medical care that would be required to prevent blindness from these conditions. Women do not control the money in their families and they are last in line for medical care, behind husbands (first) and then children. Further research is needed to develop strategies to overcome economic, cultural, religious, and environmental factors that render eye health for women so poor in developing parts of the world.

In developed nations, such as the United States, part (but not all) of women's increased risk of blindness is due to the fact that, on average, women live longer than men here. At ages over 90, there are five times as many women alive as men. Therefore, women have a greater chance of getting the serious, aging-related eye diseases—macular degeneration, cataract, and glaucoma. But there's more to the story. For largely unknown reasons, probably rooted in gender differences in hormones, women constitute 80 percent of the 8.5 million Americans with autoimmune diseases, such as multiple sclerosis, lupus, rheumatoid arthritis, and Sjögren's syndrome, which all can have serious consequences for the eye. Dry eye disease and uveitis (inflammation of the eye) are also much more common in women. And furthermore, even in America, women tend to under-utilize health-care services, including visits to eye doctors. The reasons for this may be that many women feel they are too busy, as their families' chief caretakers, to find time for themselves, and that women are less knowledgeable, and hence more fearful, of medical procedures.

The risk factors that lead to premature death (due to heart disease, stroke, diabetes, and some cancers) in developed nations are virtually the same as those that lead to vision loss—smoking, obesity, physical inactivity, "fast food" diet, and high blood pressure. For example, smoking is responsible for an estimated 30 percent of age-related macular degeneration, a blinding eye disease for which there is no good cure. These negative life-style factors not only promote premature death, but they also degrade the quality of a person's life. Loss of vision is a major factor in poor quality of life.

Over the past 50 years, medicine has focused so much on risk factors that promote early death that it has given short shrift to the issues of quality of life that are now coming forward, as premature death recedes as an important human concern in industrialized parts of the world. Among the quality-of-life issues, good vision is

paramount. Visual impairment, which is more common than people realize, significantly decreases the ability to live independently and to function socially.

The keynote speaker of the symposium was Dr. Hugh Taylor of the University of Melbourne in Australia. His talk, "Translating research into public health action," can be summarized simply: Save your sight; get tested! This means you should learn which eye diseases you may be prone to, because of heredity (glaucoma), diabetes (retinopathy), or age (maculopathy), get tested for them, and get treated. Refractive errors and cataracts are particularly easy to treat. Even with no history of disease, everyone over age 50 should get regular eye examinations. Dr. Taylor estimated that half of visual impairment is correctable, and that one quarter of it is preventable.

A major conclusion gathered from the meeting is that an important public health message needs to be generated and disseminated: women must pay attention to the known risk factors for premature death, as these are the same risk factors that degrade their quality of life—including their ability to see.

Contributed by Alice Adler, Ph.D, Advisory Board member and science writer for the Women's Eye Health Task Force.

General Summary

Women have twice the risk as men—at all ages—of losing their vision. The reasons depend in part upon the geographic region of the world, and upon cultural, sociological, economic, and environmental factors.

In developed nations, the difference in risk gets progressively greater as the population ages and the much greater preponderance of visual impairment in women in developed nations is due largely, but not exclusively, to the fact that men die younger than women, and this difference is magnified at each decade of life—so that by 90+ there are almost 5-6 times as many women alive as men.

The risk factors that lead to premature death in developed nations are virtually the same risk factors that lead to vision loss: obesity, smoking, lack of exercise, poor "fast food" diet. These factors not only promote premature death, but they degrade the quality of life. Loss of vision is a major factor in degrading the quality of life. As our population ages, fear of death is being replaced by fear of degraded quality of life. For this reason, loss of vision ranks as the second most feared affliction by Americans and others living in developed nations, and women will realize this outcome far greater than men as the boomer generation "comes of age."

There are two risk factors that increase the risk of vision loss in women compared to man at any age—even in developed nations. The first is the propensity of women to develop autoimmune diseases (the ratio is something like 4:1, women: men who get these diseases). Autoimmunity and inflammation of the uveal tract of the eye (iris, retina, choroid plexus, etc.) is a cause of vision loss in about 10% of cases—and the majority of these individuals are women. The second may be related to the first and is the waves of hormonal changes that women experience monthly, combined with the hormonal changes necessary to maintain successful pregnancy. The data aren't in, but it is reasonable to suggest that hormonal changes of this type may place women at higher risk of autoimmune disease—and therefore, for blindness from inflammation of the eye (uveitis).

A similar argument can be made for dry eye syndrome where the very best evidence indicates that women are at least 5 times more likely to be affected than men.

Additional research in the causes and cures of blinding diseases, especially those that afflict the aged, is needed to reduce the impending epidemic of vision loss in our population over the next 5 decades. Additional epidemiologic research is necessary to identify additional risk factors that place the aged at special disadvantage for vision health.

In developing nations, the difference in risk of vision loss between women and men is evident at the beginning of the reproductive years and is maintained through life. Among the factors that contribute are:

Women care for the children, and repeated infections of the eye because of touching children, etc. is an important cause of trachoma (a blinding infectious disease of the cornea).

Women do not control the money and they are last in line for medical care—behind husbands (first), children (next). Lack of medical attention is an important cause of vision loss, especially for cataracts and glaucoma where medical care is needed to reverse vision loss.

Women in many countries avoid wearing glasses because of the social stigma, and this is a significant cause of visual impairment.

Additional research, especially epidemiologic, is necessary in order to identify additional factors, and their root causes, that prevent women in developing nations from seeking and obtaining good eye health care. Further research is needed to develop strategies to overcome economic, cultural, religious, and environmental factors that render eye health for women so poor in developing countries.

A big message that I took away from the meeting is that medicine in general, and epidemiology in particular, have focused so much over the past 50 years on risk factors that promote early death that they have given short shrift to the issues of quality of life that are now coming forward as premature death recedes as an important human concern. Among the quality of life issues, good vision is paramount. Therefore, additional research, especially in epidemiology, is needed to define what factors contribute most to maintaining a high quality of life.

Another message—the fact that women are much more at risk for being visually impaired than men—is important medically and sociologically. Where this situation arises from differing abilities to age, or from cultural factors, the public health and economic issues are the same. Something must be done to reduce the loss of visual function in women, especially that which renders them more likely to lose sight than men.

A final message: A public health message needs to be generated and disseminated that women need to pay attention to the known risk factors for premature death, since these are the same risk factors that degrade their quality of life—including their ability to see.

Contributed by: Wayne Streilein, M.D., President of Schepens Eye Research Institute, Member of the Advisory Board, Women’s Eye Health Task Force

Summaries of Presentations and Discussions

Presentation #1: Gender & Blindness, Eye Disease, & Use of Eye Care Services

Speaker: Paul Courtright, DrPH, Kilimanjaro Centre for Community Ophthalmology, Moshi, Tanzania

Presentation notes:

- Burden of blindness in the population: Women 64%; Men 36%
- Global blindness: currently—50+ million; estimated by 2020—75 million
- 80% global blindness is in developing countries, particularly Africa
 - Longer life expectancy for women and blindness associated with increasing age
 - (But age-specific rates show greater numbers of blind in most age groups)
 - Different, gender-related risk factors for acquiring eye diseases
 - Unequal utilization of eye care services
- 60-70% of total cataract blind are women in developing countries
(Despite this, corrective surgery is performed consistently more often on males than females)
- Medical anthropology: lack of access, particularly in developing countries, but same trends in the United States (IG)
 - Women don’t have money
 - Men exercise financial control
 - There is a lack of knowledge about treatments
 - PC gave examples of programs in Moshi, Tanzania to bring people to services
- Recommendations:
 - Build a gender focus in WHO 2020 plan
 - Expand programs into other countries
 - Build gender-sensitive data in monitoring systems

- Expand network of gender researchers/program personnel

Discussants: Debra A. Schaumberg, ScD, OD, MPH; Brigham & Women's Hospital, Harvard Medical School, Boston, MA
Richard D. Semba, MD; Johns Hopkins University, School of Medicine, Baltimore, MD
Janine A. Smith, MD; The National Eye Institute of the National Institutes of Health, Bethesda, MD

Discussion Points:

- In developing countries:
 - A major problem is trachoma.
 - We need to work with traditional healers, combine Western with traditional medicine.
 - In China, an increased standard of living was much more beneficial to men than to women.
 - In Tanzania, a lot of ophthalmologists are under utilized, so the issues of culture biases and travel/access to clinics, particularly for women, need to be addressed.
- In developing countries:
 - A second major problem is cataract.
 - We need to analyze the data we already have to learn the reasons for the gender disparity in vision problems; perhaps studies looking at smaller age ranges are needed.
- What can the WEHTF do?
 - They have made a good first step in their awareness efforts.
 - They need to collaborate with other outreach agencies

Presentation #2: Major Concerns in Women's Health

Speaker: Julie E. Buring, DSC, Brigham & Women's Hospital, Harvard Medical School, Boston, MA

Presentation notes:

- Our increasing life expectancy is leading to a rapidly aging population, with increasing numbers of older women.
 - Population of older people will be unprecedented by 2050—more older people than younger people
- As we are living longer, there is an increasing focus on quality of life, as well as recognition of the critical importance of prevention.
 - For women in the 20th century, reproductive and gynecologic health were main issues.
 - For women in the 21st century, physical, mental and social health are the big issues.
- Age-related chronic diseases (such as CVD and cancer) and age-related causes of blindness (such as cataract and AMD) share a number of modifiable risk factors: smoking, diabetes, physical inactivity, obesity, hypertension, hormones, nutrition.
 - Smoking, obesity, and lack of physical activity is greater in U.S. adolescents now than when their parents were in that age range.
- What we urgently need are innovative strategies to raise awareness of the importance and impact of these risk factors (education/screening) and effective strategies to modify these risk factors (compliance).
- More research documenting the effect of risk factors is not needed.
- What is needed are innovative strategies to raise awareness and modify risk factors.
- Take an aspirin everyday, but before you swallow it, take it for a five-mile walk!

Discussants: Judyann Bigby, MD; Brigham & Hospital, Harvard Medical School, Boston, MA
Paula A. Johnson, MD; Brigham & Women's Hospital, Harvard Medical School, Boston, MA
Mara Lorenzi, MD, Schepens Eye Research Institute, Harvard Medical School, Boston, MA

Discussion Points:

This discussion took the form of comments on the barriers to health care for women.

- There are many ophthalmologists in the Boston area, one for every 25,000 people; however, many women don't have access, or are afraid because they aren't knowledgeable about the treatments. Women's doctors often have to send them to a different practice to have even a simple eye exam, and often the patient does not follow up.

- Both eye problems and women's health issues have been marginalized in the health-care system. Vision problems are not on the "radar screen" because they are not lethal.
- Quality of life (Q of L) is the issue here, not just life or death; Q of L messages should be crafted for doctors and for the public. Tables are needed for years of Q of L, including vision, as well as for years of life.
- Eye care providers tend not to talk to other MDs or to attend general medical meetings. Most clinicians don't know about eye health; if primary care doctors (and cardiologists, etc.) were educated, they could pass this knowledge on to their patients. Vision problems (except for those associated with diabetes) are not even in the source books used by doctors.
- Physical activity is known to be an important factor in prevention of diabetes. Yet most women are inactive due to largely cultural factors. There is the critical issue of time commitments to women's families. Time to exercise has to be made. Children have less physical education in school than they had in the past, do not play as much outdoors, and are dependent on cars.
- What is needed is a good, positive message about prevention of eye disease—not scares, but rather, how to improve life.

Presentation #3: Sex Steroid Hormones and Eye Disease

Speaker: Debra A. Schaumberg, ScD, OD, MPH; Brigham & Women's Hospital, Harvard Medical School, Boston, MA

Presentation notes:

- Women will spend an average of 30 years in peri/post menopause.
- Women are two-to-three times more likely to develop dry eye than men.
 - Dry eye estimated to affect >3.2 million women in US aged 50 and older.
- There are no major sex differences in cases of ARM (AMD).
- Sex difference in age-related cataract from 65 years on.
 - Increased risk of cortical cataract in women.
- HRT is a risk factor for dry eye
 - (70% increased risk among women who use estrogen alone versus 30% among women using a combination of estrogen plus progesterone/progestins.
- Possibility that acute loss of estrogen at menopause may increase risk of ARM or cataract among women not strongly supported by currently available data
- Effect of HRT on ARM and cataract are highly speculative
 - Even if protective effect could be proved, benefit would not outweigh other risks of HRT demonstrated in Women's Health Initiative

Discussants: Dimitri T. Azar, MD; Massachusetts Eye & Ear Infirmary, Harvard Medical School, Boston, MA
Kathryn M. Rexrode, MD; Brigham & Women's Hospital, Harvard Medical School, Boston, MA
David A. Sullivan, PhD; Schepens Eye Research Institute, Harvard Medical School, Boston, MA

Discussion points:

- Doctors still treat dry eye syndrome (DES) with hormone replacement therapy (HRT), in spite of the evidence. The relation between hormones and DES isn't simple: The emphasis has thus far been on estrogen. There are several types of estrogen and androgen receptors, and it isn't known which are in the eye. Androgen imbalances in women should be more closely studied. Funding of clinical studies in DES has been difficult to obtain.
- Inflammation is probably involved in the etiology of DES. Women generally have higher levels of C reactive protein (CRP), and HRT increases CRP levels.
- Intake of omega-3 fatty acids, found in fish, may help prevent DES.
- Quality of life needs to be a factor in assessing efficacy of treatments of dry eye.

Presentation #4: Nutritional Factors and Eye Disease

Speaker: Richard D. Semba, MD, The Johns Hopkins University School of Medicine, Baltimore, MD

Presentation notes:

- Micronutrient deficiencies are common in older community-dwelling women.
- Nutritional supplementation may help reduce age-related macular degeneration.

- Further studies needed to evaluate lutein and zeaxanthin supplementation in large controlled clinical trials.
- Relationship between nutritional status and cataract still inconclusive; trials to date are disappointing.
- Women of childbearing age in developing countries are at risk of vitamin A deficiency and associated morbidity.
- Time for a paradigm shift: focus on needs of high-risk women in developing countries.

Discussants: Alice Adler, PhD; Schepens Eye Research Institute, Harvard Medical School, Boston, MA
Paul F. Jacques, ScD; Tufts University, Boston, MA
Johanna M. Seddon, MD; Massachusetts Eye & Ear Infirmary, Harvard Medical School, Boston, MA
Allen Taylor, PhD; Tufts University, Boston, MA

Discussion points:

- There is no clear message with respect to specific nutrients, for women in developed countries. Beyond general advice to eat a balanced diet, this approach may not be as fruitful as maintenance of a healthy weight (through exercise and proper diet) to prevent diabetes and subsequent retinopathy.
- Is the study of frail, elderly women in this country continuing? A. No; the cohort in the study is dying off.
- On supplementation with lutein/zeaxanthin: Studies need to be continued for at least 5 – 10 years to see any effect on AMD. The small amounts of L and Z in over-the-counter supplements are much too small to be effective.
- Public health measures take time. It was known for 50 years that smoking was associated with disease before large segments of the population stopped smoking. But public health efforts to stop the rise in obesity are not well enough funded. For example, money for education through the Mass. Dept. of Public Health, which was successful against smoking, was eliminated.
- It always comes back to the same thing: maintain a healthy weight, exercise and don't smoke! A boring message perhaps, but there is no "quick fix."

Presentation #5: Autoimmunity in Ocular Diseases

Speaker: Janine A. Smith, MD, National Eye Institute of the National Institutes of Health, Bethesda, MD

Presentation notes:

- Women represent 80% of the 8.5 million Americans with autoimmune disease
- Peak onset in reproductive years: 15-45 years.
- Lifelong variability of hormones: menarche, pregnancy, post-partum and menopause, may play a role in the pathogenesis of autoimmune disease in women.
- Autoimmune diseases often have eye disease component.
- Etiologies essentially unknown.
- Pregnancy ameliorates some and exacerbates other immune-mediated diseases.
- Autoimmune ocular disease is an important cause of vision loss in women during their working years and can significantly diminish quality of life for affected women.

Discussants: Kathryn A. Colby, MD, PhD; Massachusetts Eye & Ear Infirmary, Harvard Medical School, Boston, MA
Deborah S. Jacobs, MD; Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA
J. Wayne Streilein, MD; Schepens Eye Research Institute, Harvard Medical School, Boston, MA

Discussion points:

- On communication: Although uveitis is relatively uncommon, it strikes working-age people. As it is often the presenting symptom of systemic disease, these patients should be well screened. The ophthalmologists who specialize in uveitis and in ocular manifestations of autoimmune disease are very good about talking to the other doctors involved in the patients' care; this is often not the case with other ophthalmologists.
- On hormones: Balance is the key. Testosterone deficiency in women is an under-recognized and under-treated disorder. Distortion of hormone levels make pregnancy possible; the fetus is not attacked. Do women with reproductive failures, who have difficulty with immune regulation (which might give rise to inflammation) tend to have eye disease?

Presentation #6 (Keynote): Translating Research into Public Health Action

Speaker: Hugh R. Taylor, MD, Univ. of Melbourne, East Melbourne, Victoria, Australia

Presentation notes:

- Poor vision is bad for you.
 - Visual Impairment significantly reduces:
 - The quality and length of life
 - Independent living
 - Healthy aging
 - Consequence of Visual Impairment:
 - Increased social isolation
 - Difficulties with daily living increased two-fold
 - Ease of social functioning reduced by half
 - Religious participation reduced by half
 - Community services increased 12% per line of vision lost
 - Admission to a nursing home three years earlier
 - Increased morbidity:
 - Risk of falls two times higher
 - Risk of depression three times higher
 - Risk of hip fractures four times higher
 - Increased mortality
 - Risk of death two times higher
- Poor vision is much more common than you realize.
 - Half of visual impairment is correctable and one quarter is preventable
 - Barriers to use:
 - “I don’t have a problem”
 - “Services are not meant for me”
 - “I can’t get there”
 - Referral process “nothing further can be done”
 - Refractive Error:
 - Solutions:
 - Have all people over 50 years test their vision on a regular basis (every 5 years)
 - Have all elderly tested for vision as part of aged care assessment
 - Establish appropriate referral pathways for those detected with poor vision
 - Improve access to spectacles for the poor
 - Cataract:
 - Solutions:
 - Promote protective behavior:
 - Stop smoking
 - Reduce ocular UV exposure (sunglasses)
 - Detect those with unoperated cataract with simple aged care vision tests
 - Improve efficiency and capacity of cataract surgery services
 - Diabetic Eye Disease:
 - Solutions:
 - Promote awareness of the need for regular eye examinations to those with diabetes
 - Involve all those who care for diabetics promote regular eye examinations
 - Train professionals so that management follows clinical practice guidelines
 - Develop sustainable local models of screening
 - People with diabetes are 25 times more likely to have visual impairment, but almost all of this is preventable
 - Glaucoma:
 - Solutions:
 - Promote awareness about the family links of glaucoma
 - Regular eye exams for those with a family history and those over the age of 50
 - Effective community-based screening for glaucoma
 - See better ways of treating glaucoma and promoting clinical practice guidelines
 - Macular Degeneration
 - Present situation:
 - Two out of three people will develop AMD

- One person in four will lose sight because of AMD
- For most cases there is no effective prevention or treatment
- A family history of AMD increase the risk 4 times
- 30% of AMD is due to smoking
- Solutions:
 - Encourage cessation of smoking
 - Confirm the genetic basis for AMD
 - Develop and evaluate new treatment strategies
 - Support access to optimal rehabilitation for all those with vision loss
- Community Messages
- Relay a simple message that can be adopted easily. In Australia, this is the message:
 - Got Diabetes? Get Tested
 - People with diabetes need to have their eyes examined at least every 2 years
 - Family history of Glaucoma? Get Tested
 - A family history (1st degree relative) increases the risk of glaucoma 4 times
 - Noticed a change in vision? Get Tested
 - People with a change in vision should have an exam without delay
 - Over 50? Get Tested
 - People over 50 should have an eye exam every 5 years,
 - People with diabetes need to have their eyes examined at least every 2 years
- Protect your eyes
- SAVE YOUR SIGHT...GET TESTED!

Discussants: Graham A. Colditz, MD, DrPH; Brigham & Women's Hospital, Harvard Medical School, Boston, MA
Ilene K. Gipson, PhD; Schepens Eye Research Institute, Harvard Medical School, Boston, MA
Eleanor G. Shore, MD; Harvard Medical School, Boston, MA

Discussion points:

The discussion centered around obstacles to better eye-health care.

- Women's health issues in general, and women's eye health in particular, are under-represented in medical education. For example, there is no eye health at all in the current Harvard Medical School case-based curriculum. The WEHTF should work towards rectifying this.
- We must get women's vision (and other health issues) out with others' outreach materials. Partnerships are crucial.
- We have the knowledge to prevent much blindness. A social strategy is needed for better education for both the public and their health providers; this is largely a matter of politics. For example, the Australian government (unlike in the US) paid for eye-health ads.
- Partnerships should be developed among state health departments, the CDC, universities, and volunteer organizations like the Lions. There also have to be changes at the primary health-care provider level; this will not be simple to accomplish.
- It's primarily the GPs, the doctors out in the communities, who should be trained to get the message across and who should make referrals to eye doctors. The ophthalmologists (hospital staff) need only to be trained in their specialties, such as glaucoma management, and to be good at their jobs. Ophthalmic residents want to hear about new methods and about procedures they can charge for, not about talking to patients.
- The health-care system is antagonistic and hard to buck; its rules are sometimes not in the best interest of patients.
- To prioritize limited resources, the goal should be to educate everyone older than 40, plus diabetics. There is no point trying to reach anyone else.
- We need to use a multi-pronged approach. Rather than one group trying to do it all, each should concentrate on their own patch of the patchwork quilt.

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