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AND TROPICAL DISEASES: to lift women's burden



GENDER AND TROPICAL DISEASES:

Research to lift women's burden

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What does the future hold for her?

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Special Programme for Research and Training in Tropical Diseases (TDR)

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GENDER AND TROPICAL DISEASES

– research to lift women’s burden

Half a billion people are suffering from the “tropical diseases” – malaria, schistosomiasis (bilharzia or “snail fever”), onchocerciasis (“river blindness”), lymphatic filariasis (elephantiasis), African trypanosomiasis (sleeping sickness), Chagas disease (a chronic and fatal disease of Latin America), leishmaniasis (“kala azar” and “oriental sore”) and leprosy.

Both men and women are affected, but in different ways – physically, socially, economically and psychologically.

Little research has been done on these differences, so knowledge of how to protect women from tropical diseases, and how to ensure women get proper care when they are ill, is based on just a few studies supplemented by good judgement and guesswork.

But this situation should change. The United Nations Development Programme/World Bank/World Health Organization Special Programme for Research and Training in Tropical Diseases (TDR) has taken a special initiative to stimulate research on women and tropical diseases, and to disseminate the results of this research to health services, communities, women, men and children.

Preliminary results from TDR-supported and other studies suggest that sex and “gender” (the differences in social role between men and women) can be crucial. If the effects of sex and gender are better understood, it will be easier to improve the quality of health services and ultimately, people’s use of them.



AFRICA: Technology to benefit women is often in the hands of men (fixing a tsetse fly trap, background).



Why focus on women?

While the reproductive health of women in developing countries has been studied for some years, research on broader aspects of women's health has been restricted mainly to developed countries.

Present views on the causes and consequences of tropical diseases may therefore neglect the important concerns of half the community.

For example, onchocerciasis, prevalent in western African countries, is referred to as "river blindness", because over time, and with a sufficient burden of onchocercal worms (the tiny "microfilariae" that invade the eye and skin), it causes blindness. Disease control programmes have therefore seen blindness as the most important effect of the disease, and concentrated on its reduction.

But in a forested area of rural Nigeria, where the disease causes less blindness, adolescent girls and young women say that the rough, leathery skin the disease causes is of great concern to them. This so-called "leopard skin" seriously hinders a girl's prospects of marriage, and if she is married, the stability of her marriage, and therefore jeopardizes her future happiness. Women in this part of Nigeria need treatment for onchocerciasis to improve their lives, rather than to reduce blindness.

TDR's focus on women is thus an attempt to see tropical diseases from a woman's point of view, which may reveal previously unappreciated problems.

"Onchodermatitis affects the marriage chances of a young lady because a man wants a pretty girl for marriage. Moreover, it is commonly believed here that whatever has happened to a mother will happen to a child, so [the diseases] can be transmitted to the offspring at birth." (Mother from the Etteh community, Nigeria; Amazigo and Obikeze, 1992)

Diseases that disfigure

More than men, women may depend on their physical appearance for their *self esteem*. Women are frequently economically dependent, and physical defects caused by diseases may seriously harm their prospects for marriage and survival. Women suffering from leprosy, for example, are more readily evicted from their families than men.

Schistosomiasis, leishmaniasis, leprosy, lymphatic filariasis and onchocerciasis – these diseases all disfigure the body. But the nature and extent of disfigurement differs between men and women. And, for cultural reasons, there has been little research into disfigurement from tropical diseases in women's genital organs.

“As a teenager, Mrs Saraswaty, who migrated from Sri Lanka to a poor district of Madras in India, developed a slight temperature and a swelling in her leg. Work, poverty and family obligations prevented her from seeking medical help. Consequently, she struggled through the bouts of fever that accompany her disease [elephantiasis] and watched her leg enlarge, the skin turn leathery and the flesh grow hard, black and knobbly. At 42, she could no longer walk or do housework...” (UNDP, 1990)

▲ AFRICA: Onchocerciasis can impose a social burden on women of all ages...

◀ ... as well as causing physical damage that can ruin marriage prospects.



AFRICA/ASIA: Leishmaniasis (above) and lymphatic filariasis (elephantiasis) (below) cause anguish to many women.



Sexual health

Some tropical diseases involve the urogenital organs. In women, this can involve disfigurement of external genital organs, as well as chronic infection of the pelvic organs, reduced fertility and even complete infertility.

For example, the social significance of blood in the urine – the result of urinary schistosomiasis – is utterly different for men and women. In men, it is often taken to signify virility; in women, a sexually transmitted disease. So women may hide their symptoms to avoid punishment by their husbands for sexual misconduct.

“Infections of the female genital system in schistosomiasis are by no means rare and impose a distinct burden on the health and well-being of women... Genital organs appear more frequently involved in Schistosoma haematobium infections [urinary schistosomiasis, found mainly in Africa] than in those caused by S. mansoni [Africa and Latin America] or S. japonicum [Asia]... In S. haematobium infections, the external organs such as the vagina, vulva, and cervix are more frequently infected than internal genitalia... Disease of the female genital tract may result in chronic back and abdominal pain, disturbed menstruation, menorrhagia, salpingitis, endometritis, endometriosis, oophoritis and papillomas of the vulva, vagina, and cervix.” (Michelson, 1992)

AFRICA : Some diseases can severely damage skin, internal and external sexual organs.

Pregnancy

While women have better resistance to some infectious diseases than men, pregnancy can alter that resistance. In certain diseases pregnancy reduces the effect of infection, followed by deterioration after delivery; while other infections, such as leprosy, tend to become overt and to progress rapidly during pregnancy, especially in the last trimester and immediately after birth.

Schistosomiasis, in particular, may induce ectopic pregnancy (the development of an embryo outside the womb), as a result of schistosome egg-induced granuloma in the fallopian tubes. The granulomas interfere with the movement of the fertilized human eggs to the uterus, and cause acute bleeding in the peritoneum. The frequency and distribution of such complications and their impact on the unborn child have never been systematically studied.

“The importance of health education of women with leprosy of child bearing age cannot be overstressed... there should be increased surveillance during pregnancy and lactation. Women who are not already receiving multidrug therapy [MDT, the treatment for leprosy infections] should do so as soon as pregnancy is confirmed... This would aim to prevent the emergence of leprosy resistant to dapsone [one of the components of MDT]...” (Duncan, 1992)



ASIA: These women are queuing for multidrug therapy (MDT) to cure their leprosy. The disease can progress rapidly during pregnancy and after giving birth.



Anaemia

Infection is closely linked with anaemia. Infections cause or aggravate anaemia, and anaemia predisposes people to infections such as malaria. Women, for biological reasons, are more prone to anaemia than men, and anaemia can have especially serious consequences during pregnancy and delivery.

“The continued preference for large numbers of children in Zimbabwe’s rural areas means that there are more women who are at risk of malaria infection and anaemia during pregnancy. The total fertility rate is six [nationally, women have on average six children], and [the rate] is likely to be higher among rural women. Multiple pregnancies mean more physiological stress on the woman’s reproductive system, and increased risk to various parasitic infections, particularly malaria. The preference for large families also means that women have to spend more resources on caring for the family, and less money is left for seeking health care...” (Vundule, 1992)

“Haematuria [blood in the urine] is the most common sign of urinary schistosomiasis... individuals lose [up to] 126 ml [about a glassful] of blood a day. It is not surprising that anaemia occurs twice as frequently in female as in male schistosomiasis patients... [The disease must exacerbate] iron and other mineral deficiencies in women from the menarche to menopause, and thus have a considerable impact on women’s physical well-being, working capacity and resistance to infection.” (Feldmeier & Kranz, 1992).

▲ AFRICA: Anaemia threatens women more than men, posing significant dangers during pregnancy and delivery.

◀ AFRICA : Blood in the urine: iron loss lowers resistance to infection.

Psychological effects

Sadly, communities often stigmatize people suffering from disfiguring tropical diseases. Because of their lower status in many societies, women with these diseases may be more vulnerable to condemnation than men, and may tend to internalize the rejection they experience.

In most societies women are the principal caregivers in the family. They feel guilty when they themselves fall ill, because their role is to nurse, not to be nursed. These feelings, coupled with fears concerning the consequences of detection, partly explain why women in many endemic areas wait longer than men before reporting their illnesses.

“Women responsible for their families said that if they had malaria, they were unable to carry out their domestic tasks (washing, cooking, cleaning the house), nor to attend to their children and husband adequately. This was their major preoccupation with their disease. Given that much of her domestic work cannot be done by others, a woman with malaria was obliged to postpone for as long as possible taking time off to recover... In some cases, when the woman was unable to get help, she continued with her housework until she was gravely ill, and when she finally rested, she did not do so completely, but as soon as she would feel a little better, she would get up and do a little work.” (Bonilla, 1991; translated from Spanish)

LATIN AMERICA: Women often feel guilty when they fall ill... ▲

AFRICA: ... yet sick women carry on with arduous tasks. ►





AFRICA: Women's work often takes them to water, which is linked with many tropical diseases.

AFRICA: Exhaustion lowers the ability to fight off infection.

To be poor and a woman is hard

Tropical diseases have as much to do with poverty as with climate. Women are generally not only poorer than men, but suffer special economic impacts of the diseases as a result of their social position (their gender). Women who suffer from a tropical disease may have a reduced value as wives, and this can have a detrimental effect on their ability to provide for themselves economically.

"... not surprisingly young men avoid marriages with girls from areas that are notorious for filariasis. [In villages that are a focus of the disease] even girls as young as 15 years of age will show signs of foot deformity. When women from endemic and nonendemic villages intermingle in a market, feet do not pass unnoticed." (Hunter, 1992)

Men's and women's lives differ greatly with regard to their control over resources — such as money, food, land and time. And their working conditions are different, leading to different risk factors for disease and different strategies for coping when disease arrives.

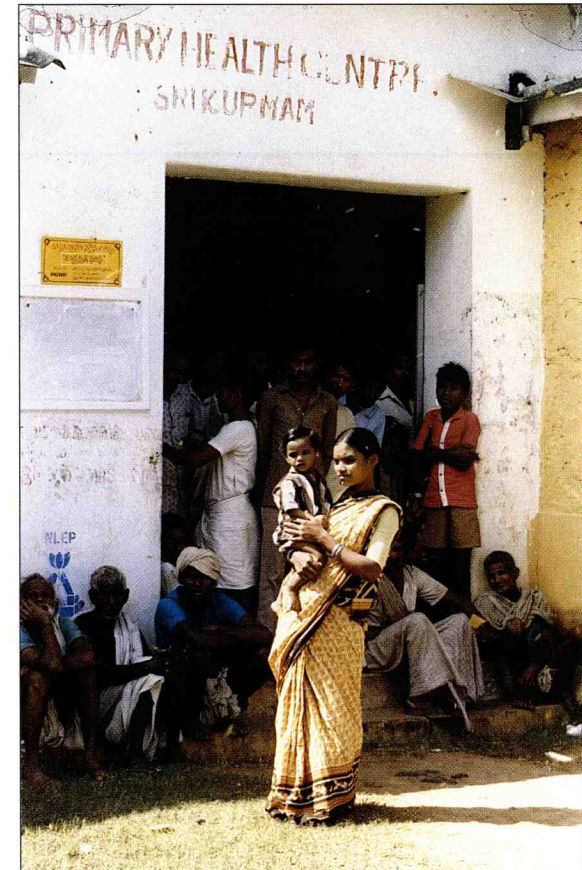
"Of the maternal functions, self-care was the most likely to be neglected as the mothers [suffering from guinea worm infection] did not like to ask for help, even if it was available. They did not wash themselves and their clothes, if this meant asking someone to fetch water for them. They often ate sparingly, either because they were nauseated by the guinea worm, or because they did not want to spend their limited money on food for themselves. Also, some of the more disabled women were reluctant to eat and drink, as they did not want to go out into the bush to defecate." (Watts et al., 1989; observations from rural Nigeria)

Women in developing countries seek out a wide variety of health care — but formal health services are often a “last resort”.

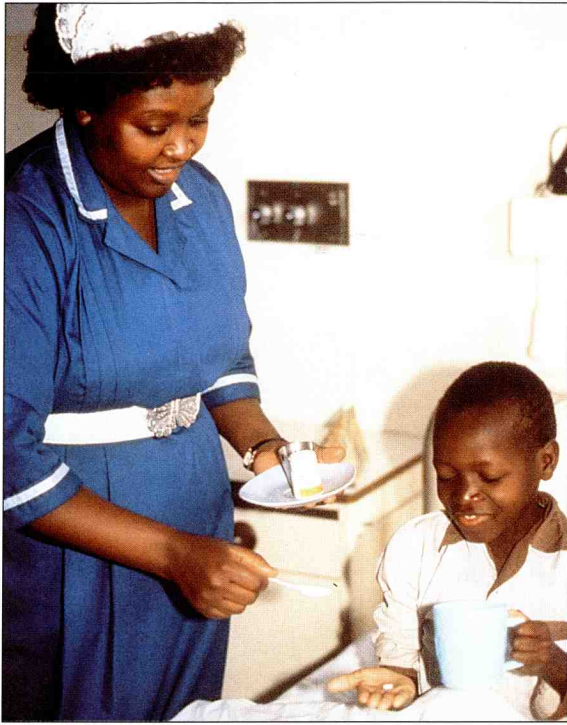
Some studies have found that female patients are given inferior treatment at health services or receive unsatisfactory or incomplete explanations concerning their illnesses. By contrast, women frequently put up with considerable inconvenience and personal hardship in order to bring their children for treatment.

“A woman with a balloon leg and a large lichenified elephant’s foot carries her sick baby into the clinic for an anti-malaria injection. This is done, and the mother leaves without either nurse or patient making reference to the advanced lymphatic disease. It is as if, by collusion, the disease does not exist.” (Hunter, 1992)

For their own care, women in developing countries use the formal services less than men, while women in developed countries visit the health services more than men. Since statistics on disease prevalence rely largely on data from health services, the relative underutilization of services by women can lead to under-reporting of their infection with tropical diseases.



ASIA: Formal health care facilities in developing regions can be unwelcoming to women.



AFRICA: Women are care-givers, whether in institutions...
... or in the family.

Women – the caretakers

The transmission of tropical disease from one person to another is not just a matter for health professionals. Disease transmission has deep cultural and moral implications, and has generated a wide array of beliefs, concepts and practices. Many of these beliefs aim to give explanations that satisfy social and psychological needs.

As women are the main caretakers of the sick all over the globe, it is a part of women's culture to have knowledge about diseases, and skills to care for the sick. Closer dialogue is needed between health services and women to improve knowledge and appreciation of the skills of both groups.

“When my son Segundo was sick he wouldn't eat or sleep, and he cried all the time. I made a (medicinal) tea and brought a pill for his cough, but it didn't help. My mother-in-law told me to see what the doctor could do. I didn't want to do this because everyone would know I couldn't care for my son, but I went. The doctor gave me a prescription for some pills and injections. My son recovered some, but the doctor said I had made him ill with my teas. How could this be? How could a mother make her own son ill?” (Finerman, 1989; observations from rural Ecuador)

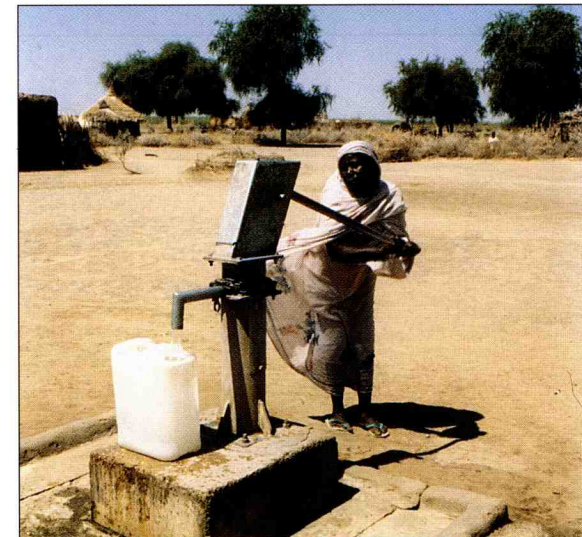
AFRICA: Women should have access to medical attention when they present their children for treatment. ▲

AFRICA: Development projects can have a profound, but mixed, impact on women's health. ►

How can research help?

Already, research has shown that:

- Women know very little about tropical diseases and how to prevent and treat them. *Therefore*, health education about tropical disease should be incorporated into school curricula.
- Mothers visit health services more for the care of their children than for their own problems. *Therefore*, providing counselling on women's health in places women go, such as maternal-child health services or women's clubs could improve their knowledge and demand for health services.
- Pregnant women and infants are at greatest risk of death from malaria. *Therefore*, women should be encouraged to use antimalarials during pregnancy and taught to recognize dangerous signs and symptoms of malaria in their children.
- Women are often given inferior treatment at health services. *Therefore*, ways should be found to improve communication between women and health workers, such as involving women in the choice of local health workers, or adapting working hours to women's needs.
- Economic development projects such as irrigation schemes frequently have adverse effects on health, exacerbating diseases such as malaria and schistosomiasis. Women, as caregivers, experience the greatest burden as a result of ill health in their families. *Therefore*, the impact of economic development projects on women should be given special attention in the planning and implementation of economic development projects.
- Reporting and presentation of national and subnational data on health are frequently not broken down by sex, making it difficult to determine the scale and kind of women's health problems. *Therefore*, health data should be collected and reported by sex.





*LATIN AMERICA: Whether researching into the use of antigens in the diagnosis of Chagas disease...
... or collecting data on socioeconomic issues...*

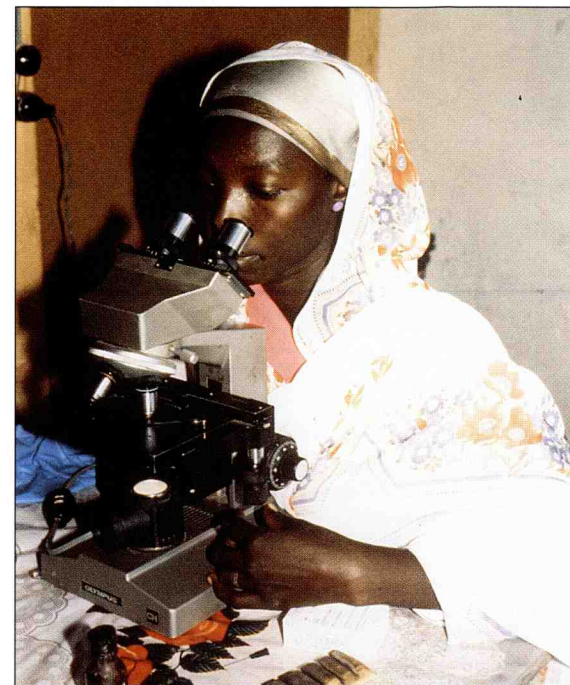
Recommendations for research

Some high priority topics for research on women and tropical diseases were identified at a Symposium on Women and Tropical Diseases, held in Oslo, Norway, in 1992.

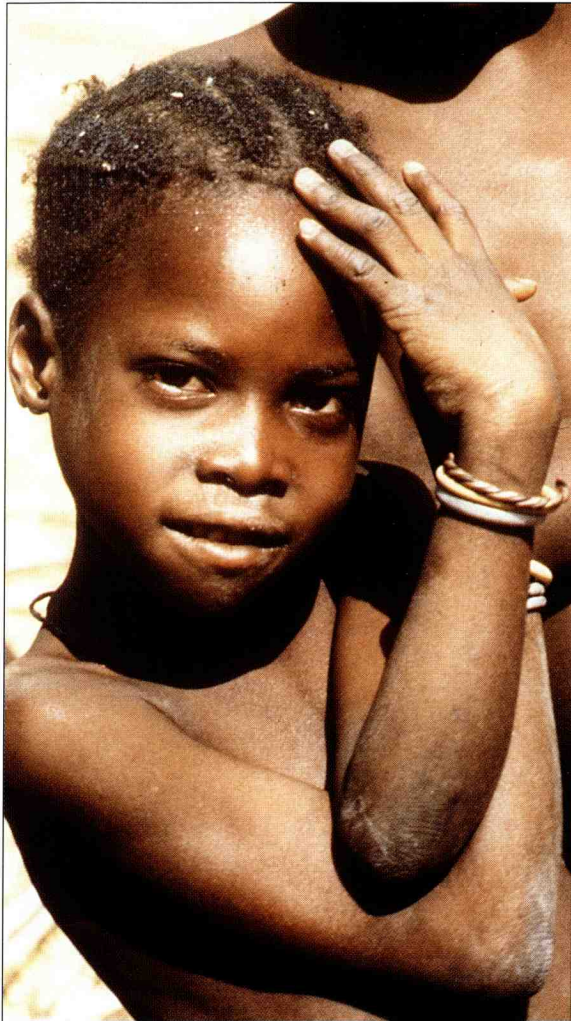
To help women facing tropical disease, we need to know more, the Symposium concluded, about:

- Factors affecting women's use of community health services including: the sex of health staff; the perceived quality of treatment; cultural constraints, such as fear of detection of stigmatizing diseases; and the costs of services.
- The effect of mothers' health beliefs and domestic practices on the causes and effects of tropical diseases.
- The reasons for different gender patterns in health-seeking behaviour between developed and developing countries.
- Self-medication practices, especially of women. When is self-medication used? For whom is it used? For themselves, for male or female children, or for adult male or female family members? Why is it used, and with what perceived effectiveness?
- The different impact of economic structural adjustment policies on the causes and effects of tropical diseases on men and women.
- The different effects in men and women of the chemotherapy (pharmaceuticals) used against tropical diseases, with special emphasis on female hormonal status, and possible interactions with oral contraceptives. Schistosomiasis, leprosy and African trypanosomiasis require special attention.

- Sex differences in the clinical manifestations of diseases, and the associated morbidity, in onchocerciasis, lymphatic filariasis and leishmaniasis, and gender differences in coping strategies in these diseases.
 - The effects of urinary schistosomiasis on females, particularly genital complications and blood in the urine (haematuria), and the interactions of schistosomiasis with other problems such as anaemia, sterility and cancer of the genital tract.
 - The effects on *children* born to mothers with leishmaniasis, schistosomiasis, African trypanosomiasis and leprosy. Little is known about congenital transmission to offspring.
 - The interaction of leishmaniasis and HIV (the AIDS virus) in pregnant women, and the extent to which HIV infection impedes the development of immunity to leishmaniasis in the offspring of women with both infections.
- Some more general policy recommendations were also made in Oslo for the World Health Organization and other international agencies concerned with promoting health and well-being for women:
- Health services should be made more relevant, responsive and accessible to women.
 - Attention should be paid to the impact of tropical diseases on women of all ages, as well as on women during the ages of reproduction.
 - More women should be trained in the biomedical and social sciences, especially those involving field research.
 - Women should have greater representation in health care delivery, management and planning, at all levels of responsibility.
 - Tropical disease education in endemic countries should be integrated into informal and formal educational systems.



... or examining specimens in field conditions...
 ... or gathering data during treatment, women have a major role to play.



Call for research proposals

SER grant application forms and guidelines are available from:
Dr Carol Vlassoff, Secretary,
Steering Committee for Social and Economic Research (SER)
UNDP/World Bank/WHO Programme for Research and Training in
Tropical Diseases (TDR)
World Health Organization
20, avenue Appia
CH-1211 Geneva 27
Switzerland

A brochure giving more information on how to apply for SER grants is also available at the above address. A background paper and bibliography of articles related to gender and tropical health is also available.

In judging applications, preference will be given to proposals for the evaluation of practical interventions to improve women's access to and use of disease control measures, both preventive and curative.

Can her future burden in life be eased?



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