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Neglected Tropical Diseases: Alleviating the suffering of poor and vulnerable
women and children in affected countries

As a partner of the Canadian Steering Group on Neglected Tropical Diseases (NTDs) and a researcher in the field of gender and infectious diseases for more than two decades, I wish to draw your attention to an important, but frequently overlooked, obstacle to global development - the suffering of poor and vulnerable women and children from debilitating tropical diseases. I would also like to highlight the potential for greater Canadian involvement in addressing this suffering.

Background

In 2012, inspired by the World Health Organization's 2020 Roadmap on NTDs, a group of partners from the NGO and the private and public sectors signed what is known as "the London Declaration on NTDs", with a commitment "to control, eliminate or eradicate 10 NTDs by the end of the decade". These diseases included *lymphatic filariasis (elephantiasis)*, a disease causing severe disfigurement and disability due to abnormal enlargement of body parts; *onchocerciasis (river blindness)*, a parasitic worm infection causing severe itching, skin disfigurement and blindness; *trachoma*, the leading infectious cause of blindness globally; *schistosomiasis*, a snail-borne, parasitic worm disease that causes intestinal problems and mental debilitation, especially in children; *soil-transmitted helminths* causing malnutrition and physical and mental impairment; *Guinea worm disease*, causing severe pain; *visceral leishmaniasis*, a parasitic infection causing disfiguring lesions and death; *Chagas disease*, a parasitic infection associated with heart damage, digestive and neurological problems; *leprosy*, a bacterial infection causing disfigurement and organ damage; and *African trypanosomiasis*, a parasitic disease associated with mental debilitation and death.

Efforts to address these NTDs have been ongoing for many decades, spearheaded by the World Health Organization's Special Programme for Research and Training in Tropical Diseases (TDR). However, the London Declaration greatly enhanced and galvanized efforts to accelerate progress, and progress has indeed resulted. The drivers of success include large drug

donations from the pharmaceutical industry; better tools, from mapping to diagnosis; expanding treatment through mass drug distribution; and country commitment, demonstrated by increased domestic contributions. Ongoing challenges remain, however, including reaching the most vulnerable, among whom women and children are a top priority; the need for additional investment; advancing innovation; and improving financial risk protection.

The effort to improve the reach of control programs involves practical, targeted research on how to better reach poor and vulnerable women and children, a need that was recently highlighted in a meeting of stakeholders in London in July, 2016. The results are summarized in a brochure entitled, "Neglected Tropical Diseases: Women and Girls in Focus".*

Having co-authored (with a fellow Canadian, Dr. Eva Rathgeber) a seminal paper on gender and tropical diseases in 1993**, I am delighted by the increasing momentum to understand and address gender inequities in the impact of these diseases. I also feel that Canada has a unique opportunity to join and accelerate the global effort through federally funded health research and action.

*Impact of NTDs on Women and Children: What the Research Shows****

NTDs continue to affect over a billion of the world's most impoverished, marginalized and remote communities, and they thrive where access to clean water, hygiene and health care are limited. They are harmful to people of all genders in affected areas, women and children are disproportionately affected in various ways, due to biological factors, as well as sociocultural and economic circumstances. A few examples (below) demonstrate how each of these factors differentially affects women and/or children, based on research findings to date.

Biological factors

Biological factors place women in a particularly vulnerable position with respect to the impact of NTDs in several respects. In general, pregnancy and childbirth may permit more rapid disease progression of NTDs due to women's reduced immunity during this period. Further, treatment during mass treatment campaigns or other treatment opportunities may exclude women simply by virtue of the fact that they are pregnant or lactating, even when very little evidence exists to justify this exclusion.

Recent research has highlighted a heavy burden for adolescent girls and women from female genital schistosomiasis (FGS) infection in schistosomiasis-endemic areas. Suffering from FGS is caused by pain, resulting from egg deposits (from infected snails) and lesions in the genital area, suspected infertility, and depression. Health workers in endemic areas are frequently unfamiliar with FGS because women often fail to report it due to fear and shame associated with genital infections. Moreover, women with FGS are considerably more likely to contract HIV and other sexually transmitted infections, with which FGS is sometimes confused by health workers. Recent research suggests that infection with FGS increased the risk for HIV infection by three times, making it a potentially important

contributor to the rise of HIV among adolescent girls in sub-Saharan Africa, where schistosomiasis is endemic. The coexistence and higher burden of FGS and HIV in tropical countries results in exacerbated morbidity from both types of infection. Schistosomiasis can be treated with a donated drug, Praziquantel. However, access to this free treatment remains challenging in many sub-Saharan African contexts for many women and girls. Research in this area is limited, and numerous questions remain regarding the biological links between FGS and HIV, how the severity of morbidity is related to treatment for one or both diseases and interactions between treatments. Further, the relationships between contraceptive use, pregnancy and infection with FGS and HIV remain unexplored.

Sociocultural factors

Sociocultural factors, often grounded in gender relations that enforce women's subordinate status, influence women's access to health services and interventions, including freedom to travel, competing domestic duties, and the need, in some settings, for women to be accompanied by a male. Even when men are willing to accompany their wives or children, they may be constrained by their own work responsibilities, and the often inconvenient opening hours of health centers or the timing of mass drug administration (MDA) programs. More research, of an applied, operational nature, is needed to understand and address gender-specific constraints such as these, so that the inclusion of women and children (as appropriate) in programs of NTD health information, prevention and treatment can have a more complete and lasting impact.

Some NTDs, such as lymphatic filariasis, leishmaniasis, and leprosy, lead to significant visible disfigurement, especially at later stages of the disease. Women are at considerably greater risk of social stigma and isolation as a result, limiting their marriageability and social wellbeing. For example, women with elephantiasis have fewer opportunities for marriage, and those with leprosy experience "double jeopardy" as a result of both their gender and their disease. Even girls and women who are not affected directly by NTDs may have to forgo schooling and educational opportunities to care for family members who suffer from severe NTD illness.

Economic factors

Economic factors negatively associated with NTDs include reduced or lost productivity, cost of some drugs, and expenditures associated with health seeking for individual workers and their employers. Economic activities place men and women at different risk of exposure, but women seem to be even more impacted than men, at least for several diseases. For example, women perform two-thirds of water collection in endemic areas, putting them at greater risk of schistosomiasis and other water-borne vectors. Women's responsibilities place them at greater exposure to Chagas disease in households and domestic surroundings in rural Latin American settings, where the insect that transmits this disease is found. Social stigma and suffering from NTDs also limits women's employment opportunities and economic survival. However, the economic impact of NTDs at the household level, including the cost of labour substitution by other household members

when members are ill, lost days of schooling for children, lost productivity in the performance of household duties, and lost leisure time, remain poorly understood, and cannot be calculated in purely monetary terms. Moreover, because caring for others during times of family illness is part of the traditional role expectation of women, their additional efforts mostly go unmeasured in terms of economic costs.

Enhancing Canada's Contribution

Canada, as a Member State of WHO and its regional branch for the Americas, AMRO/PAHO, has already made a significant contribution to NTD control. Many individual Canadians, too, have been involved in efforts to control NTDs, including in research, international committees and conferences, NGO activities, and country missions for capacity building, monitoring and evaluation. Therefore, joining the accelerated global movement, possibly through the window of improving women and children's health, is a timely opportunity for Canada to showcase work already done by Canadians, as well as to support future targeted research in this field.

A focus on NTDs is in very much in line with Canada's international development strategies - for example, by reducing the inequalities that stand in the way of economic growth and transformation, and by enhancing the impact of Canada's existing maternal and health programs globally. Moreover, the control, elimination and eradication of NTDs will make a direct impact on the Sustainable Development Goals (especially Goals 1, 3 and 5), and on the goal of Universal Health Coverage, to which Canada is deeply committed.

I therefore urge the Standing Committee on Health to consider increasing Canadian commitment and contributions to research and development work in the important field of NTDs in general, and on their impact on women and children in particular, thus addressing a critical need within the significant global efforts currently underway.

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*Uniting to Combat (2016) Neglected Tropical Diseases, Women and Girls in Focus, London.

**Rathgeber, E. and Vlassoff, C. (1993) Gender and Tropical Diseases: A New Research Focus, *Social Science and Medicine* 37(4):513-520.

***Research mentioned in this section is cited in the above-mentioned Uniting to Combat document.