NEGLECTED TROPICAL DISEASES: WOMEN AND GIRLS IN FOCUS

Produced by: Lola Arakaki, Luwam Kidane, Arianna Rubin Means, Tao Sheng Kwan-Gett
For the five NTDs for which mass drug administration (MDA) is the primary intervention (Lymphatic filariasis, onchocerciasis, schistosomiasis, soil transmitted helminths, and trachoma):

- Conducted PubMed searches of the published literature
- Conducted online searches of the gray literature
- Conducted key informant interviews with topic experts
- Identified and modified appropriate gender-focused frameworks to organize data
For each theme presented, we invite your feedback and group discussion on the evidence provided:

1. What are the gaps in the evidence?

2. What are appropriate next steps to address NTD impact on women and girls?
Theme 1

Impact of NTDs on women and girls
Are women and girls disproportionally affected by NTDs?

- **Burden**
  - Across NTDs, does the burden of disease fall disproportionately among women?
  - What are drivers of disproportionately female burdens, and how might we address them?

- **Equity**
  - Do the physical, sociocultural, and socioeconomic implications of NTDs worsen inequity in the lives of women and girls?

- *From a burden lens, when women and girls are disproportionally affected they become a target population for NTD programs and move to the center of the critical path to elimination*
Gender dependent risk factors for NTDs

- Gendered division of labor places women at greater risk of exposure to NTDs

**Schistosomiasis**

2/3 of water collection is performed by women and girls

MICS and DHS surveys from 45 developing countries, 2005-2008

**Soil-Transmitted Helminthes**

Nightsoil exposure increases the risk of hookworm infection among adult women in Vietnam

Van der Hoek et al 2003

**Trachoma**

Primary caretakers’ proximity to infected individuals increases risk of repeated exposure

Congdon et al 2003
Examples of sex-specific NTD morbidities

Female genital schistosomiasis (FGS)

Helminth-associated anemia in pregnancy

Source: Kleppa 2014

Source: k4health.org
### Theme 1: Impact of NTDs on women and girls

Evidence regarding the impact of NTDs on women and girls (N=80)

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**Evidence in Peer-reviewed journals**

- 3 or more articles published in peer-reviewed journals or recognized expert organization
- 2 articles published in peer-reviewed journals or recognized expert organization and/or conflicting studies
- 1 article published in peer-reviewed journals or recognized expert organization
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**Summary of evidence:**
- FGS and development of genital lesions and bleeding associated with higher risk of HIV acquisition
- FGS can occur before sexual debut
- Two case-control studies found association between FGS and HIV

**Limitation of evidence:**
- Need for longitudinal studies to document FGS infection prior to HIV acquisition
- Need to explore emerging evidence for relationship between schistosomiasis and other diseases such as HPV
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Summary of evidence:
- Hookworm-infected women were found to have lower Hb levels compared to non-infected women.
- Among hookworm-infected women, women with greater intensity infections found to have lower Hb levels than lightly infected.

Limitation of evidence:
- Few studies examining Trichuris and anemia measured intensity of infection.
### Theme 1: Impact of NTDs on women and girls

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**Summary of evidence:**
- Women report experiencing isolation, depression, shame, and rejection.
- Women have fewer opportunities for marriage.
- Stigma associated with disfigurement resulted in a delay of treatment and preventable disease progression.

**Limitation of evidence:**
- Limited evidence quantifying the effects of stigma on women and girls.

**Evidence in Peer-reviewed journals**
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### Summary of evidence:

- Amongst women in Tanzania, limitations of visual acuity loss were similar to Trichiasis alone. The combination of the two produced a synergistic effect on the risk of adjusted difference in proportion of tasks completed.
- Trachoma-related blindness is two to four times higher in women compared to men.

### Limitation of evidence:

- Majority of evidence on the socioeconomic impact of Trachoma on women comes from Tanzania.

### Evidence in Peer-reviewed journals

- 3 or more articles published in peer-reviewed journals or recognized expert organization.
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What are the gaps?

- Lack of gender-disaggregated data on burden of disease such as Disability Adjusted Life Years (DALYs), Quality Adjusted Life Years (QALYs)
- Need better data on complications of NTD infection
  - Hookworm anemia in pregnant women – treatment solutions
  - Female Genital Schistosomiasis – irreversible impacts
  - Rigorous studies to establish association between NTD and other diseases
- Need quantitative measures of stigma
- Need data on economic impact, e.g. exacerbated poverty due to loss of work/time/compensation and effects on poverty perpetuation
Questions and Next Steps

- Based on the literature, where is the impact of NTDs on women and girls particularly pronounced?
  - What are the drivers?
  - Are there interventions or solutions that are known?
  - What additional data would be needed to take action?

- Where is evidence more urgently needed? What do we do about it?

- What are cross-cutting physical or socio-economic impacts across NTDs?
  - Do these impacts warrant further exploration or investment?
Theme 2

Delivery of NTD programs by women and impact of women in the workforce
Agents of change

Source: Melaku, USAID 2006
## Theme 2 Data (N=21)

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Coverage and performance of female distributors in the workforce

Examples:

- Where there was a female CDDs in the village, 81.1% of eligible respondents reported receiving ivermectin compared with 78.4% in villages with male CDDs (Males CDDs outnumbered females 2:1)
  - Brieger et al, 2002 CDT Oyo State, Nigeria CDTI

- 44% of female Community Directed Health Workers (CDHW) achieved 90% or more of their annual treatment objectives within 7 days compared to 26% of male CDHW
  - Katabarwa et al, 2002 Rukungiri District, Uganda Kinship CDTI
Coverage and performance of female distributors in the workforce

Summary Findings:

- Women distributors achieve equal or greater coverage, better service and less participant attrition.
- 45% studies report gender statistics of community drug distributors, volunteers and community health workers. Only 11% demonstrate greater proportion of women to men.
- Cultural and political structures influence the selection of women as community-based health volunteers and workers.
- Drain on time and resources
Benefits and barriers to engaging female health workers

**Benefits**

- Female involvement directly addresses SDG 3 and 5
  - Women report a sense of pride and fulfillment in their roles as community health workers and volunteers

**Barriers**

- Female health workers may be underrepresented but over utilized
  - Multiple roles of women limits the extent to which they can participate in especially as volunteers
  - Appropriateness of delivery program
  - Support from partners
Women’s Empowerment Framework (Sara Hlupekile Longwe 1999)

- **Influence** – Evidence demonstrating women are able to not only participate but act as influencers in MDA programs
- **Participation** – Evidence demonstrating equal representation and the ability to make decisions
- **Recognition** – Evidence regarding recognition that gender discrimination creates gender-related inequities and women may themselves contribute to this discrimination
- **Access** – Evidence demonstrating ability to use resources (ex. training) that enable women to perform duties
- **Welfare** – Evidence related to basic needs, material welfare and well-being of women
Theme 2: Delivery of NTD programs by women

Critical gaps in literature of women’s empowerment

**Influence** – Minimal to no evidence of Influence
Key Reference: Katabarwa et al 2002, CDTI Rukungiri, Uganda

**Participation** – Lack of evidence on the performance of women workers. Only 10 in 19 studies documented disaggregated reporting of participation and performance data

**Recognition** – Majority of data come from qualitative interviews documenting community perceptions of MDA

**Access** – Minimal to no evidence of the effects of increased access to resources for women.
Key References: Jenson et al 2014 & Omedo et al 2012

**Welfare** – Lack of evidence regarding effects of uncompensated labor
Questions and Next Steps

- Is there a discernable difference in MDA coverage and performance of women delivering MDA in the workforce as compared to men?
- Do these programs provide some benefit to the volunteers?
- How can the perceived benefits of women in the MDA workforce be leveraged to improve delivery, gender equity and compliance?
Theme 3

Reach of MDA platform and access by women and girls
Importance of reaching women and girls through the MDA platform

- Globally, MDA has the potential to reach an incredibly large number of women and girls
  - Are we optimizing this potential to reach women and girls?
  - Are we/should we be looking for win-win integration opportunities?
- Reaching women and girls is paramount to achieve our goals to eliminate NTDs and promote gender equity.

Source: CDC/ Teresa Roebuck; Alaine Kathryn Knipes, PhD
### Theme 3 Data \((N=16)\)

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MDA coverage in unpublished data

- LF and oncho coverage were significantly different between genders.
- Burkina Faso and the DRC had different schistosomiasis coverage. The same trend was observed in analysis of STH MDA coverage.
MDA coverage in published data

- **Mixed evidence of distribution of MDA coverage by gender**
  - Studies showing higher coverage among females than males
    - Rilkoff 2013: 3 villages in Eastern Uganda in 2011; multi-drug
  - Studies showing little or no difference
    - Adhikari 2015: 3 out of 60 endemic LF districts in Nepal in 2011; LF
    - Worrell 2012: 37 CDC coverage surveys in 8 countries in 2000–2011; various drugs; gender ratio (female/male) was between 0.96 and 1.17
    - Clemmons 2002: 10 CDTI projects (APOC) in Nigeria, Tanzania, and Cameroon in 1998–2000; Onchocerciasis
  - Studies showing lower coverage among females
    - Brieger 2012: 5 projects (APOC) in Nigeria and Cameroon 2003–2005; Onchocerciasis; Higher proportion of males (44.7%) in the high compliance group compared to females (41.1%)
### Barriers to MDA access by gender

#### Target Population Factors
- Knowledge and attitudes towards disease and MDA, literacy, education
- Lack of decision making power in household, lack of control over finances
- Community attitudes towards disease and MDA, employment, housing, governance

#### MDA Delivery System Factors
- Healthcare worker (HCW) gender, education, training
- Patient-HCW communication, trust
- Distribution setting (home, school, employer, central location)

#### Individual
- Healthcare worker (HCW) gender, education, training
- Patient-HCW communication, trust
- Distribution setting (home, school, employer, central location)

#### Interpersonal
- Community attitudes towards disease and MDA, employment, housing, governance

#### Community
- Knowledge and attitudes towards disease and MDA, literacy, education
- Lack of decision making power in household, lack of control over finances
- Community attitudes towards disease and MDA, employment, housing, governance

#### Structural
- Radio/TV/internet access, electricity, school system, local health department

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*Social Ecological Model (CDC)*
Barriers to MDA access by gender

- Women refusing treatment because had not eaten and were fearful of side effects (Rilkoff 2013; Hussain 2014)
- Women unaware of available treatment at health centers (Rilkoff 2013)
- In some communities, rumors of harmful effects of treatment were more pervasive among men (Rilkoff 2013)
- Differences in relationship with MDA – women comply, men adhere (Clemmons 2002)
- Women had lower compliance than men; author attributes lower compliance with having lower literacy (Hussain 2014)

*Social Ecological Model (CDC)
Barriers to MDA access by gender

- Few CMDs had received training on NTDs and gave confusing information on disease transmission and drug distribution to pregnant and lactating women (Rilkoff 2013, Hussain 2014)
- Potential for differential performance by gender of CDDs (Vouking 2015)

*Social Ecological Model (CDC)*
### Barriers to MDA access by gender

#### Target Population Factors
- Knowledge and attitudes towards disease and MDA, literacy, education
- Lack of decision making power in household, lack of control over finances

#### MDA Delivery System Factors
- Healthcare worker (HCW) gender, education, training
- Patient-HCW communication, trust

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**Theme 3: Reach of MDA platform**

- Few individuals received health promotion; lack of info fueled opposition to treatment (Rilkoff 2013)
- Women were unaware of the MDA program or why they were taking medication, though it did not necessarily prevent them from taking the medication (Clemmons 2013)

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*Social Ecological Model (CDC)*
Barriers to MDA access by gender

- Women not included in community meetings about MDA programs (Rilkoff 2013)
- Previous recommendation to exclude pregnant women from treatment may influence subsequent exclusion of pregnant women despite reversal of recommendation (Krental 2014)

*Social Ecological Model (CDC)*
Barriers to MDA access by gender

**POP**

- Men have difficulty accessing treatment with house-to-house method in Uganda (Rilkoff 2013)
- Drugs distributed at school may have greater reach among male students (Hussain 2014)

**MDA**

- Education, training

**FACTORS**

- Healthcare worker (HCW) gender, education, training
- Patient-HCW communication, trust
- Distribution setting (home, school, employer, central location)
- Media channels for promotion, transportation

**Community**

- Community attitudes towards disease and MDA, employment, housing, governance

**Structural**

- Radio/TV/internet access, electricity, school system, local health department

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*Social Ecological Model (CDC)*
What are the gaps: Joint Reporting Forms

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filariose lymphatique | Population traitée pour l'onchocercose |
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Gaps: PCT Databank (WHO) lacks gender-disaggregated data
What are the gaps: Data and Delivery

- Disaggregated data by sex and age (by region)
  - Which delivery method (e.g., central location vs. house-to-house) may be best to reach women and girls?

- Unclear whether populations of girls are entirely missed from denominators and whether coverage of women and girls approximate compliance

- Need for training of CDDs/consensus on treatment for pregnant and lactating women
Conclusion

The Sustainable Development Goals challenge Neglected Tropical Diseases (NTD) programmes to control disease and seek gender equity in both programme design and delivery.

**Goal 3, Target 3.3:** End the epidemics of AIDS, tuberculosis, malaria, and neglected tropical diseases and combat hepatitis, water-borne diseases, and other communicable diseases.

**Goal 5:** Achieve gender equality and empower all women and girls.
Questions and Next Steps

- Working Hypothesis: MDA platform is gender blind and currently reaching women and girls effectively.
  - Does the data support or contradict this hypothesis?
- How might program design address barriers identified in the social ecological model?
- As we think about the legacy of MDA, what are some natural health/development program partners? Where would they see the potential win-win?