Female Genital Schistosomiasis
- FGS, HIV and the launch of the UNAIDS-WHO report -

DR. MBABAZI, Pamela Sabina, WHO-NTD, HQ

The Schistosomiasis Action Plan: next generation research on the road towards elimination meeting, NOLA 2018

Working to overcome the global impact of neglected tropical diseases
Outline

- FGS - highlights
- Association with HIV
- Opportunities

Next steps:
- Call to action - Concerted, collective, coordinated, collaborations
Female genital schistosomiasis (FGS)

**Defined:** as the presence of schistosomiasis ova in the female reproductive organs or a characteristic clinical pathology (Feldmeier, Krantz, Poggensee, 1995; Kjetland et al., 2005).

- Egg granulomas & subsequent **disease can occur anywhere in the genital tract.**
- The clinical picture a range of signs and symptoms and may affect **external and internal genital organs.**
- **Inflammatory response** produces typical intravaginal lesions and bleeding that result in genital itching and pain, bleeding, dyspareunia, and infertility
- Profound **mental health effects from social stigma**, such as depression and marital discord
Organ involvement according to age

- Post-mortem and histopathological studies show that the vulva and the vagina may be the organs most frequently affected during puberty and adolescence.

- Lesions have been seen to shift to the cervix, the ovaries and the Fallopian tubes with increasing age:
  - Lesions may be present when a girl reaches sexual maturity, and the barrier function of the vagina and the cervical epithelium may already be impaired before sexual debut.

FGS - Cervix lesions

Source: FGS Pocket Atlas
**Female genital schistosomiasis (FGS)**

Sequelae of female genital schistosomiasis have been reported to include:

<table>
<thead>
<tr>
<th>Organ affected</th>
<th>Manifestation</th>
<th>Organ affected</th>
<th>Manifestation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vagina, vulva</td>
<td>Destruction of hymen or clitoris, Vesico-vaginal fistula, Contact bleeding, Spontaneous bleeding, Dyspareunia, Increased susceptibility for sexually transmitted infections</td>
<td>Fallopian tubes</td>
<td>Ectopic pregnancy, Infertility, subfecundity</td>
</tr>
<tr>
<td>Cervix</td>
<td>Genito-pelvic discomfort, Increased susceptibility for HPV and HIV infection*</td>
<td>Ovaries</td>
<td>Delayed puberty, Infertility, subfecundity, Menstrual irregularities</td>
</tr>
<tr>
<td>Uterus</td>
<td>Miscarriage, premature labour</td>
<td>Placenta</td>
<td>Preterm delivery, Small-for-date infant</td>
</tr>
<tr>
<td>Douglas pouch</td>
<td>Haemoperitoneum</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Important implications for clinical care & alleviation of suffering**

- Need to reverse the very low index of clinical suspicion for FGS
a common manifestation of infection with *S. haematobium*, even in lightly infected individuals with few eggs excreted in the urine (Leutscher et al., 1997).

WHO estimates up to 56 million women have FGS, nearly all in Africa alone.

FGS estimates for the upper genital tract do not exist.

- Only a few population-based studies have provided data on the frequency of female genital schistosomiasis of the lower genital tract.

<table>
<thead>
<tr>
<th>Country</th>
<th>Group/study site</th>
<th>Number (N)</th>
<th>Prevalence (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Niger</td>
<td>Community</td>
<td>61</td>
<td>75 (65–87)</td>
</tr>
<tr>
<td>Malawi</td>
<td>Outpatients</td>
<td>51</td>
<td>63 (48–76)</td>
</tr>
<tr>
<td>Madagascar</td>
<td>Community</td>
<td>36</td>
<td>33 (19–51)</td>
</tr>
<tr>
<td>Tanzania</td>
<td>Community</td>
<td>122</td>
<td>43 (39–56)</td>
</tr>
<tr>
<td>Tanzania</td>
<td>Community</td>
<td>263</td>
<td>55 (48–61)</td>
</tr>
</tbody>
</table>

From Renaud et al., 1989; Kjetland et al., 1996; Leutscher et al., 1998; Poggensee et al., 2000; Kjetland et al., 2005
FGS CASE REPORTS 1982-2012

Number of clinical cases in travelers & immigrants reported/published = 65

Need to evaluate effect of FGS atlas
Greatest increase in prevalence in the early phases of the global HIV epidemic occurred in countries with SCH rates of about 70% (Feldmeier H, et al 1994).
Children and adolescents have been observed to have a higher trend of reinfection when compared to the 30-59 years age group, with more than 50% in the 5-19 year age group becoming re-infected within a period of 1 year. (El-Khoby T et al 2000, Svein G et al 1999, Traore et al 1998, Vester U et al 1997, Muthami LN et al 1995).

In rural women the HIV prevalences peak at younger ages (Gouws et al., 2008, UNAIDS 2009).
Why the grave concern: Outcomes of WHO consultation meeting (‘09), literature review

1. Genital schistosomiasis is a **distinct disease entity** and not just part of urinary tract disease (WHO report, 2009) – ie **urogenital schistosomiasis**

2. **Biological consequences of genital schistosomiasis in children** ≥ 9 years.

3. Genital schistosomiasis pathology is possibly linked to, or increases, **HIV transmission** in endemic areas, from earlier studies (‘90s-2006).

4. Noted existing and called for more evidence for **association** and how SCH - HIV co-infection influences **progression to AIDS.**
FGS association with HIV

- follow-up epidemiological studies show that FGS is responsible for up to a 3-4 fold increase in horizontal transmission of HIV/AIDS (Downs JA et al, 2011, Brodish PH et al, 2016).
  - Not much more information on SCH influence on AIDS progression

- regression analysis of prevalence of *S. haematobium* infection and HIV in Sub-Saharan African countries: each *S. haematobium* schistosomiasis infection per 100 individuals resulted in a 3% relative increase in HIV prevalence (Mbah MLN et al, 2013)

---

- *S. haematobium* infection of girls and women (~60-70 million cases)
- Deposition of terminal-spine schistosome eggs in female genital tract (Up to 40-56 million cases)
- Increased susceptibility of horizontal transmission of HIV/AIDS
Opportunity for change

  - unified NTD community around the issue
  - However, efforts to integrate or link schistosomiasis/FGS prevention activities with HIV/AIDS prevention efforts in Africa have not progressed
  - Raised awareness among human rights activists

- UNAIDS recognition that declines in new HIV/AIDS infections remain too slow, especially in young women – in 25 countries, of which 18 in sub-Saharan Africa:
  - UNAIDS launched its Prevention 2020 Road Map calling for innovative combination prevention packages
  - Opened up to dialogue on FGS: UNCW, IAS/UNAIDS
Global advocacy on FGS and HIV, 2018

Call to Action: As Human Rights & Reproductive Health issue

Launched at IAS - UNAIDS 2018

- Increased advocacy for Schistosomiasis treatment of Adolescent girls and women, and more praziquantel to prevent FGS

- Integration of schistosomiasis treatment in HIV prevention package. Use existing health-care delivery systems as a platform to expand FGS prevention, screening and treatment.

- More research to provide evidence and impact of Schistosomiasis preventive chemotherapy on HIV and FGS prevention.

  - multi-disciplinary collaborations: including child health, reproductive health, social scientists etc.
- Urgent action for public health programmes -

1. Increase awareness among health workers & policy makers
   i. **Clinical unawareness is leading to misdiagnosis** and therefore false and ineffective therapy (Sawi B et al, 2006, Britta S et al 2006). **Need to sensitize & re-educate clinicians, especially those working in areas co-endemic for HIV and schistosomiasis.**
   
   ii. Female genital schistosomiasis should be added to the disease burden of **women in all age groups** (Sawi B et al, 2006, Britta S et al 2006).

   iii. **Physicians caring for travellers and immigrants** must become familiar with the signs and symptoms of schistosomiasis (Salvana EM et al 2008).

   iv. Health education models need to **consider social representation and illness experience besides scientific knowledge** in order to increase knowledge of schistosomiasis transmission and prevention. (Gazzinelli MF et al 2006).
Infection is acquired when people come into contact with fresh water infested with the larval forms (cercariae) of parasitic blood flukes (known as schistosomes) during routine agricultural, domestic, occupational, and recreational activities, which expose them to infested water.

Implement complementary interventions: Health education, WASH, Vector control
Action: Prevention and treatment

- **Scale-up and sustain public health approach:**
  - Regular treatment with praziquantel from an early age prevents schistosomiasis from progressing to genital damage and other related complications.
  - Women who have been treated with praziquantel at least once in their lifetime have been found to be 50% less likely to develop FGS later in life.
  - Treatment with praziquantel kills the adult worms and provides relief and regression of some inflammatory lesions.
  - WHO recommends preventive chemotherapy (mass treatment) of entire communities in endemic areas, with a particular focus on school-aged children.

- **Provide clinical treatments**
  - 40m/kg, stat. Cure rates of 65-90% have been described after a single treatment with praziquantel. Treatment may be repeated if deemed necessary.
  - Follow-up symptomatic treatment of gross occlusive pathology if still needed.
  - Praziquantel is safe in pregnancy. Pregnant women can, and should be treated.
  - Gynaecological treatment is not standardized (no grading done yet). Needs improvement.
  - **Note:** Incorrect diagnosis of female genital schistosomiasis lesions frequently leads to debilitating and irreversible operations such as ovariectomy, salpingotomy, hysterectomy.
# Global status of preventive chemotherapy in 2017 – schistosomiasis

<table>
<thead>
<tr>
<th>PC implementation</th>
<th>AFR SAC/Adults</th>
<th>AMR SAC</th>
<th>EMR SAC/Adults</th>
<th>SEAR SAC/Adults</th>
<th>WPR SAC/Adults</th>
<th>GLOBAL SAC/Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of countries requiring PC</td>
<td>41</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>4</td>
<td>52</td>
</tr>
<tr>
<td>Number of people requiring PC</td>
<td>102.9M/88.8M</td>
<td>1.6M</td>
<td>9.8M/6.7M</td>
<td>4K/18K</td>
<td>0.6M/2.2M</td>
<td>115M/97.7M</td>
</tr>
<tr>
<td>Number of countries implemented and reported</td>
<td>29/15</td>
<td>1/1</td>
<td>4/4</td>
<td>1/1</td>
<td>3/3</td>
<td>38/24</td>
</tr>
<tr>
<td>Proportion (%) of districts implemented PC&lt;sup&gt;3&lt;/sup&gt;</td>
<td>82.8</td>
<td>0</td>
<td>64.6</td>
<td>0</td>
<td>53.3</td>
<td>81.6</td>
</tr>
<tr>
<td>Proportion (%) of districts achieving effective coverage&lt;sup&gt;4&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of people treated</td>
<td>73.7M/11.4M</td>
<td>0.1K/3.2K</td>
<td>6.4M/3.4M</td>
<td>1K/5K</td>
<td>0.4M/1.3M</td>
<td>80.5M/16.2M</td>
</tr>
</tbody>
</table>

**Coverage (%)**<sup>5</sup>

<table>
<thead>
<tr>
<th>AFR SAC/Adults</th>
<th>AMR SAC</th>
<th>EMR SAC/Adults</th>
<th>SEAR SAC/Adults</th>
<th>WPR SAC/Adults</th>
<th>GLOBAL SAC/Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>66.9/10.9</td>
<td>&lt;0.1</td>
<td>64.6/48.7</td>
<td>26.8/28.3</td>
<td>66.6/61.1</td>
<td>65.7/14.6</td>
</tr>
</tbody>
</table>

---

1. Number of endemic countries moved to post-treatment surveillance stage is not included in total.
2. Number of countries reporting data on PC implementation. Countries submitting blank reports are not included in total.
3. Proportion of known endemic districts implementing PC for SAC in countries that reported on PC interventions.
4. Proportion of districts implementing PC achieving the defined effective coverage of SAC population for the disease - ≥75% for SCH.
5. Coverage is calculated as the number of people in need of PC and treated out of total population requiring PC.

---

**Regional coverage** is calculated starting from 2010 when new country estimates by age group were published.

- **AFR**
  - 2008: 1.8
  - 2012: 41.0
  - 2017: 58.1

- **AMR**
  - 2010: 58.1
  - 2017: 42.3

- **EMR**
  - 2011: 62.5

- **SEAR**
  - 2009: 1.8
  - 2012: 41.0

- **WPR**
  - 2013: 58.1

- **GLOBAL**
  - 2008: 1.8
  - 2012: 42.3
  - 2017: 65.7

---

AFR – African Region; AMR – Region of the Americas; EMR – Eastern Mediterranean Region; SEAR – South-East Asia Region; WPR – Western Pacific Region

Source: WHO/NTD
THANK YOU