

# *Acting* for Health

Schistosomiasis (Bilharzia) Project  
March 2018  
Uganda

In Uganda in March 2018, Acting for Health ran a pilot programme in a fishing community heavily affected by the parasitic worm infection schistosomiasis (Bugoto Village in Mayuge District on the north shore of Lake Victoria). The project was commissioned by the University of Glasgow 'Schisto Persist Program', led by Dr. Poppy Lamberton, who has been conducting research in this community for 14 years, and run in collaboration with Uganda's Vector Control Division.

## **BACKGROUND**

---

Schistosomiasis is a parasitic disease caused by flatworms which affects over 250 million people worldwide. Due to this parasite's complex life-cycle which involves aquatic snails, populations living near contaminated water sources and with inadequate infrastructure are most at risk – many individuals in poorer communities are at a high risk of contracting schistosomiasis, particularly when living near and using infested water for fishing, washing, bathing...

A proven treatment exists and the drug praziquantel is routinely administered to large parts of vulnerable communities to treat the disease as well as break transmission cycles. In areas such as Bugato Village, despite repeated and community-wide treatment with praziquantel and the existence of some communal pit latrines, levels of infection can remain very high. Although effective in eliminating current infection, praziquantel doesn't protect against future re-infection. In addition, it appears that reinfection is facilitated by the persistence of two main behaviors that contribute to the cycle of disease: open defecation (worms eggs are carried in human faeces) and contact with infested water (the 'cercaria' stage of the worm enters human skin) – in this case the water of the lake shore.

## **AIMS**

---

The intention of our project was to work with a small group of local people who represented various strata of the population: teachers, parents, fisherfolk, children, health workers etc, and, using a neutral theatre forum, enable the participants to explore, in a manner that is most relevant to them, the issue of schistosomiasis in order to:

- uncover attitudes to the disease and treatment
- uncover misunderstandings around the disease and treatment
- establish the level of priority the disease is given in the community
- explore problems caused by the disease
- explore behaviours that lead to infection / re-infection
- explore potential solutions
- uncover resistors / barriers to treatment / solutions
- present these findings to other villagers in the form of a performance of scenes

- create 'community champions' / advocates
- explore the value of methodologies of the science of acting & theatre of the oppressed in this context

## METHODOLOGY

---

The Acting for Health interventions are designed to use theatre as a *lingua franca* to engage and give a voice to groups affected by specific public health issues, no matter how complex, in order to trigger effective, appropriate and sustainable solutions to public health challenges.

During the Uganda project, the Acting for Health intervention brought together a varied group of participants including from the local community, research project and government; held a series of hands on activities and workshops to draw out some of the main barriers to schistosomiasis control; developed a tailored theatre production and communication tools to raise awareness and solutions to ongoing schistosomiasis infections.

In more detail, the Acting for Health (AFH) team first spent a day meeting with local stakeholders (local school teachers, health workers, fishermen, District Commissioners office, District Vector Control Program office, District Education office, ...) to inform them of the project and to enroll villagers to be participants in the workshops.

From this AFH built a cohort of 18 participants that included 7 fishermen, a local council member, 2 teachers, 3 local health workers, the Assistant to the head of the National Vector Control Programme, the District Health team coordinator, 1 child, local young self-employed man.

AFH then held 5 days of meetings for three hours each day, from 2pm-5pm. Each meeting was highly interactive and included exercises to improve communication skills; understanding of own self, behaviours, motivations and community; collaboration within a group; skills to develop four sketches or mini 'plays' and narratives; a final theatre production aimed at a broad audience from the local community and neighbouring villages.

On the 5<sup>th</sup> day, which was market day in the village, AFH and the participants presented the scenes we had been working on to the other villages. This half hour performance was preceded by a performance of traditional singing & dancing by girls from the local school.

Some key points raised / brought to light by this project:

- Schistosomiasis is to some extent a 'hidden' illness in that many symptoms take many years to be noticeable, and can be misdiagnosed
- Local beliefs in 'Cidada' (witchcraft) have an impact in transmission and treatment (for example a belief that if women use the toilet they will not conceive)
- There is inadequate infrastructure, for example not enough toilets or access to alternative water sources
- These may not be used even if present
- The transient and/or non-integrated nature of the fishermen population means that rounds of community-wide treatment (Mass Drug Administration or MDAs) can miss them out
- Fishermen are scared to take the MDA because of misconception of side effects meant that they thought they would not be able to work and provide for the families if sick
- Fishermen think the drug Praziquantel will make them impotent
- Youngsters don't like to go in latrines without shoes (which many of them do not have)
- Fishermen fear they will drown if they fall into the lake wearing wading-boots
- Subsistence living makes engaging with solutions to the disease a 'luxury'

- Villagers want regular theatre forum to use to explore potentially risqué topics and themes
- Villagers need and are ready for local champions
- There is a disconnect between the Community Health Worker to the Village Health Worker and actual patient cohort

## CONCLUSIONS

---

The Acting for Health intervention in Bugato Village, Mayuge District, Uganda in April 2018 resulted in a community oriented theatre production where the story-line and the acting was done by the community, for the community and using imagery and language that was adapted to the local audience and priorities. This play was performed on market day to members of several villages. Through the process of developing the performance, Acting for Health was able to:

- identify and bring together **key individuals** in terms of schistosomiasis infection and control (including, local primary healthcare providers, regional healthcare directors, members of the village, teachers, Ministry of Health figures)
- understand from the communities themselves their **specific and main barriers to schistosomiasis control**; the behaviours in the way of successful control or which perpetrate infection; the wrong beliefs about infections and disease
- **develop language and imagery relevant to specific communities** to share knowledge about the disease
- **transmit important public health information** about treatment options and where to access this as well as further information
- identify and empower specific **figures of trust** in the community with strong impact on their peers
- **encourage treatment uptake** and empower individuals to take action to address their health as well as the health of the entire community
- **document and record the process and progress** in terms of developing the play but also **monitoring for changes in behaviour and treatment uptake**

Further conclusions derived from the Acting for Health methodology and intervention include the following:

- In the absence of a vaccine or eradication of the worm and its intermediate host (water-snails), treatment of schistosomiasis will depend on ending behaviours that facilitate the disease cycle
- Theatre is an excellent tool for uncovering authentic, 'lived-experience' attitudes, beliefs and issues around disease, transmission, behaviour and treatment
- Theatre provides a 'neutral' setting for breaking down entrenched and limiting hierarchical structures and personal inhibitions that prevent expression and communication
- Engagement with this process develops individual self-esteem, confidence, communication and team-work skills, and creates healthy communication between individuals and groups in the community
- There is a huge untapped potential for creating advocates / community champions
- There is a very ready tendency and talent for performance and story-telling that provides a perfect vehicle for health messaging and inspiration to action
- There is huge appetite for engagement and training in the community

- There is some level of dependency or expectation on outsiders to solve the problem
- Common beliefs that are resistors to behaviour change and/or engagement with solutions to schistosomiasis persist in the community
- Community members are very willing to engage with and support this kind of project (e.g. local community radio made announcement about the performance) and there is great enthusiasm for live performance