Rural research

From the ivory tower to advanced and practical research on Female Genital Schistosomiasis (FGS)

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Figure 10. Sandy patches appearing as grains and homogenous, yellow areas of the vaginal wall.
Known about schistosomiasis

- It could be a risk factor for HIV
- Morbidity in 261 million people
- Mass-treatment can prevent morbidity
- Genital lesions were irreversible in adults
- People don’t know how to diagnose genital schisto

Grainy sandy patches on the vaginal wall.
Why hasn’t more been done on genital schistosomiasis?

- Traumatised patients – by whites, by rapes, by stressed ‘bully’ nurses, by husbands
- Ethical mine field – private parts, pain, dominant husbands, low diagnostic yield, what do you do with the cases you cannot handle – chronic dyspareunia, chronic STD-symptoms, infertility, referral-mission-impossible
- Logistic ‘impossibility’ – autoclave, electricity, freezers, patient transport, untrained staff, referral institutions don’t work, high-tech
Target group

• Treatment did not work in adults
• Is it feasible to work in children and teenagers
NOT known about schistosomiasis

• Can genital schistosomiasis be cured in young women - or when is the best time to treat?
• Will treatment of FGS prevent HIV transmission?
• How should health professionals diagnose genital schisto
Can people be rescued from lifelong disease?

• Will Female Genital Schistosomiasis (FGS) be reversible if teenagers are treated?

• Can HIV transmission be prevented by the treatment of FGS?
Preparatory investigations
Permissions

• Institutional review board (IRB)
• Provincial DoH /DoE etc
• District level
• Chiefs
Get hold of money
Get hold of staff

• Expensive to take staff “from town”
  – Subsistence
  – Fussy about living conditions
  – Speak different dialects
  – Don’t know who’s who/ what’s where

• Local staff
  – Please do not steal our nurses (internal brain drain)
  – The ones that did not make it, poor English, gloves, biological waste, autoclave, confidentiality : massive training job
What is needed to do this research

• Good light, autoclave where there is no electricity
• Patients where females are under someone’s command
• Handle diseases where there is no one to refer to and where patients cannot afford to go
Schisto research suffers from:

- the control group likely also has schisto
- confounders
- herd immunity
- not-representative studies
  - sampling by convenience
  - randomisation is provocative – ‘unfair’
- participants and their families are desperate
  - you will not be able to work unless you relate to that
  - lack of capacity to handle all the parallel clinical dilemmas
Permissions

- Institutional review board (IRB)
- Provincial DoH /DoE etc
- District level
- All those who think you are working in their “territory”
  - Ward managers, school circuit managers
  - Heads of school, principals, teachers, employers
  - Local clinic nurses
  - Fathers, mothers, grandmothers – a 19-year old is “still a child”
  - Boyfriends and husbands “she is mine now”
Ugu district

– 530 schools, 5 hospitals,

– Clinics run by nurses = primary health care

– 230 m² research station: interview rooms, blood tests, laboratory, -80 freezers, generators, , autoclave, waiting rooms (movies, games), investigation rooms, colposcopes, centrifuges
• Community liaison persons
  – Car
  – Extinguish fires
• School experts (our own staff)
• Immediate report back of rumours / adverse events / local conflicts
Figure 21. Malignant looking lesion.
Basic medicine

Clinical research

Operational research

Beyond shelves
Basic medicine

Clinical research

Operational research

Beyond shelves

Small cross-sectional and prospective case-control studies
Basic medicine

- Flow cytometry, cytokines, immunochemistry

Clinical research

- HIV incidence, effects of treatment, diagnostics
  - Regression of clinical manifestations

Operational research

- Effects of realistic (stakeholder) implementation, learning by doing

Beyond shelves

- Inform authorities directly
- Encourage and advise policy

Cluster Randomised Controlled Study recruiting in rural schools – high-tech investigations

Small cross-sectional and prospective case-control studies
Basic medicine

Small cross-sectional and prospective case-control studies

Clinical research

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Operational research

Cluster Randomised Controlled and Large cross-sectional work (> 10,000 participants)

Beyond shelves

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Beyond shelves

Meetings, writing policy together, pull slowly, media, advocacy, participate in others’ initiatives
Status 2010 - now

- Pocket atlas – still needing distribution & training, evaluation
- 40 medical students have participated – many publish
- 6 PhD students -
- 200 months of Marie Curie Research Fellows exchange
- 45 publications to date
- 25-50 staff
Status 2010 - now

- 2 clinics
- Accommodation
- Vehicles, drivers, security
- Almost 3000 gynae invest
- Almost 4000 interviews
- Collaborations
Fieldwork

Always
- Life-changing experience
- Crowded
- Multicultural
- Full of tricky choices
- Insects
- Fear
- Hunger
- Exhaustion
Always
- Uncomfortable
- Muddy, wet
- Stories to tell
- Friends to make
- Emotionally taxing
- Worries – money, time
- Change the plan

A test of your flexibility and kindness
Thanks for listening
Figure 23. Nabothian cyst.
Sandy patches appearing as single grains and homogenous, yellow areas surrounded by abnormal blood vessels.

http://127.0.0.1:8081/plosntds/article?id=info:doi/10.1371/journal.pntd.0003229
Figure 18. Histological correlate of a rubbery papule to Figures 17 and 18.