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Rumours, Myths and Misconceptions in ASPIRE:

A Zimbabwean Experience

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Rumours, Myths and Misconceptions in sub-Saharan Africa (SSA)

- Medical practices and research in SSA are often a source of popular rumours about:
 - The deliberate, malicious creation and spread of deadly diseases such as HIV (Pool, Nyanzi & Whitworth, 2001; Stadler, 2003; McNeill 2009)
 - Sterility as a side-effect of various health products (Kaler, 2009),
 - Surreptitious, clandestinely inflicted sterility (Kaler, 2009),
 - Blood theft (Geissler, 2005) and the trade in or theft of body parts (Scheper-Hughes, 1996; Campion-Vincent, 2002).
- The South African experience.
- Malawi blood bank scenario.
- Sierra Leone: Ebola "a way to harvest organs and steal blood."
- 'Satanists' as the end users of blood or body parts. (Comaroff & Comaroff 1999; Nichito et al. 2003).
- These concerns reflect the intensity of spiritual insecurities, spiritual gullibility and growing occult practices in SSA in the modern era.(Ashforth, 2005) (Comaroff & Comaroff, 1999)



Rumours, Myths and Misconceptions in Zimbabwe

Hospital for madical

Satanism scare at city primary school – Two primary school pupils reportedly "turned into baboons" after being given rings and bracelets by their class teacher







The parents had to be ca

"We have been informed

Rumours, Myths and Misconceptions in Zimbabwe

Wednesday, May 22, 2013 Zimbabwe miracle baby that was born after a 3 day pregnancy has

A BABY claimed to have been born after a "three-day pregnancy" following a "miracle" performed by a charismatic preacher, has died, it was reported on Tuesday. The baby boy, who was born on November 18 last year is believed to have died on Sunday.







Rumours, Myths and Misconceptions about the Vaginal Ring (VR)







Rumours, Myths and Misconceptions about the Vaginal Ring (VR) in ASPIRE

VR function/properties

Effect on vagina/ cervix/uterus Effect on sexual function

Used for Satanic rituals

Uterus will rot, corrode, shrink, or develop cancer

Tightens or loosens the vagina

Increases sexual pleasure

Decreases female libido

Absorbs/steals sperm

Leads to erectile dysfunction

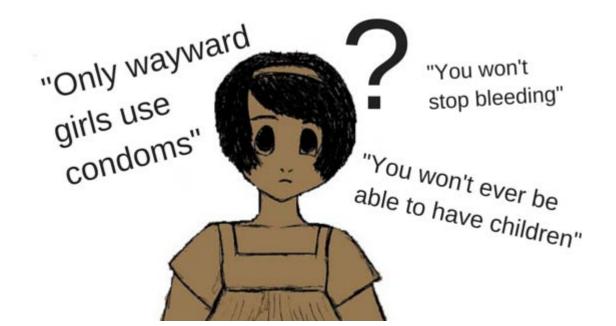
Blocks vagina – poor penile penetration

Causes infertility
Results in miscarriages
or birth defects or
infant death

Blocks menstrual blood flow

Rumours, Myths and Misconceptions about Blood, HIV and Study Participation









Rumours, Myths and Misconceptions about Blood, HIV and Study Participation

Blood collection

Reimbursement

Stigma

Used for Satanic rituals
Sold for a profit

Payment for blood Payment for sex Participants labelled HIV+, using study as "cover" to collect ART Prostitutes

Guinea pigs

Amount drawn –
"buckets of blood,
dangerously high"
(concerns of anaemia)

Too much - coercive Too little - guinea pigs Women are made to have sexual intercourse with HIV infected men so researchers can tell if ring works

When did the Rumours, Myths and Misconceptions Occur?

- The vast majority occurred early on in the study 2013.
- Became less or sporadic as the study progressed.
- Usually took place in the clinic waiting area, with family members at home and in the community at large.
- People likely to raise these rumours were the ineligible women, some partners/significant others, influential community members as well as other participants.
- Earlier on in the study, participants/communities believed these rumours, myths and misconceptions.





Impact of Rumours, Myths and Misconceptions in ASPIRE







Impact: Early Terminations

- Of the 91 early terminations in Zim, 18 (19.8%) were a result of rumours, myths and misconceptions.
- All were allegedly a result of problems related to the VR itself, contraception in ASPIRE, blood draws and study participation or the ring "causing infertility and sexual dissatisfaction."
- All these 18 early terminations were influenced by partners and other significant others





Impact: Social Harms

- One participant reported that her partner regularly put his fingers in her vagina to feel if she was still wearing the ring – this marriage ended up in a divorce.
- She had not fully disclosed details of the study to the partner.
- Another participant was assaulted by partner after he discovered that she had the VR and was failing to get pregnant "due to ring use."





Addressing the Challenge







Participant Engagement

- Between September 2012 and June 2015, we enrolled and followed up 678 participants
- Daily morning discussions / talks.
- One-on-one discussions.
- Adherence workshops/small group participant discussions
 - We conducted a total of 57 such workshops
 - Cumulatively, 620 participants attended these workshops
- We held a total of 6 Retention meetings
 - > 80% attendance of enrolled participants
 - Small group discussions/break out sessions
 - Male break –out sessions
 - Drama group
- Laboratory Tour.
 - Informative laboratory video.



Participant Engagement



Site used creative approaches to engage participants and talk about the study

Motivational activities













- To dispel myths and misconceptions surrounding the handling/processing of bio-specimens in ASPIRE.
- To give an insight of what happens to study bio-specimens from collection, processing, testing, storage and destruction.
- To empower the representatives with the adequate knowledge concerning specimen collection and storage.
- Two participants from each site were randomly selected to take part in the lab tour.
- One CAB member also participated to allow the discussion of bio-specimen management to be continued in the community.





Male Involvement

- A very effective strategy
 - Male involvement meetings with male-based organisations
 - Male break-out sessions
 - Male involvement in community activities
 - Couples counselling and testing.
 - Cumulatively approx. 40% of male partners attended these male-oriented activities



Staff, CAB and male partners - Clean-up campaign





Community Engagement and Education

- Activities ranged from meetings, media sessions to social responsibility activities.
- Social responsibility days a way of giving back to the community health education, free health checks, fun and games, clean-up campaigns and dispelling of rumours, myths and misconceptions.
- Partnered with CAB, stakeholders, civic organizations and government departments
- Our motto MTN: Madzimai Tsvakurudzo Ndeyedu! Ladies, this research is ours!





Conclusion

 In ASPIRE - we employed several and dynamic strategies to address the rumours, myths and misconceptions that arose during study implementation.

Accrual

Initial target was 600, surpassed by 13% to 678

Adherence

- Very good
- Quarterly IoR site metric reports

Retention



Maintained high visit-to-visit retention



Thank you







We are grateful to:

- The 678 study participants and their partners for their participation and dedication.
- The research communities
- CABs
- Ministry of Health and Child Care
- Zimbabwe National Family Council
- Chitungwiza and Harare City Health Departments
- All the study team members at Seke South, Spilhaus, Zengeza CRSs
- UZ-UCSF
- The Protocol Management team and at the MTN Leadership Operations Centre







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School of Medicine

A Study to Prevent Infection

with a Ring for Extended Use



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