

Performing compliance in a PrEP Trial

Jonathan Stadler
VOICE-C Co-chair
Wits RHI,
Johannesburg
MTN Regional Meeting, Cape Town



Background


- Results of PrEP trials - varied
- Poor adherence ...low or no effectiveness
 - FEM-PrEP
 - VOICE

Study	Population	Drug	N	Results
CAPRISA 004	Women	TFV gel (peri-coital use)	889	39%
iPrEx	MSM	TRU	2499	44%
TDF2 Study	Men and Women	TRU	1200	62%
Partners PreP	Serodiscordant couples	TFV TRU	4758	67% TFV 75% TRU
FEM-PrEP	Hi-Risk Women	TRU	1950	TRU not effective
VOICE	Women	TFV gel TFV/TRU	5029	TFV gel not effective TFV not effective TRU not effective
Bangkok Study	IDU	TFV	2400	49% TFV
FACTS-001	Women	TFV gel peri-coital use)	2900	Enrolling



Conflicting Results

- In VOICE - plasma drug levels revealed pervasive product non-use, but high reported use (Marrazzo et al. 2013)
- ... inconsistent with...
 - High retention rates
 - Women 'liked' the trial (Magazi et al 2013)
- So, ... why misrepresent adherence?



Theories – ‘the lie’ in medical settings

- Social desirability bias ...
- Politeness
- The social meaning of ‘the lie’
 - Secrecy – medical secrets
 - – what discursive ‘work’ does lying do?
- An articulation of power relations
 - Resistance to biomedical authority (weapons of the weak)
 - Exertion of biomedical authority
 - But ... resistance is paradoxical
- A performance of selfhood
 - The ‘social drama’
 - The theatre of the lie



Evidence?

- IDI, EI and FGD with 102 women
- Coded texts
- Scripted responses:
 - Faultless compliers
 - Embodied adherence
 - Imperfect others

Script 1: Faultless compliance

'I used to wait for Generations [a television soapy] (...) now I am using the alarm because some days I won't be watching television'.

Interviewer: So, tell me, if there is no electricity and your phone is off and you cannot watch Generations at ten o'clock, what do you do?

Respondent: I have to take a bath and when I take a bath I have to take my clothes out of the wardrobe, immediately when I take my clothes out I notice the tablets so I will take them.

Interviewer: But what if you take a bath at twelve or at one o'clock or you bath at different times?

Respondent: I wash my face in the morning when I wake up. That one is a must, I cannot bath my face at eleven or... when I wake up in the morning I brush my teeth and wash my face and I keep my toiletries in the wardrobe.

Respondent: In that way I remember to take the tablets.



Script 1: Faultless compliance (cont.)

Interviewer: I would be lazy to get out of bed and drink cold water at nine in the night

Respondent: I will never be lazy as long as there is an alarm.

Interviewer: I know the alarm will remind you but will you be able to get out of bed when it is cold and drink cold water?

Respondent: Do you imply that to take a few seconds and drink water would be an issue? No, I don't think so and I'll go back to bed, it's not a problem.

Script 2: 'Imperfect others'

*reported speech from the waiting
room*

When they ask you about other things you will find that...if you are not using the gel you will lie, you will just say whatever you normally hear people saying

'I don't use it; I just take the gel and put it there. I take the money and go home'.

Script 2: 'Imperfect others' (cont.)

'I heard somebody saying, "no I didn't tell them at the interview that I didn't use the gel and I also lied in the ACASI because I want to be perfect"'

'Others were just saying that they are using the gel when they were not doing so'.

'I discovered that other participants are very naughty. They are not honest'



Script 3: Embodied adherence...

‘If it is the time for me to insert the gel I could feel it’.

‘it has become ingrained in my mind that each and every day when I wake up I must take these tablets’.

‘if I do not take the tablets I can feel it. My body has adapted to the tablets. I *have* to take them every day’ (emphasis added).

And the loss of agency ...



Resisting biomedical authority?

- If this is resistance, what is being resisted?
- Willingness to join the trial
- Good participation ... poor adherence

Formation of new subjectivities?

- Trials create opportunities for the creation of novel forms of sociality
- Bio-citizenship / Bio-sociality? (Paul Rabinow, Vin Kim Nguyen, Susan Reynolds-Whyte)
 - Medical technologies - new diagnostic techniques, therapeutic technologies, form the basis for new social groupings – new forms of citizenship
 - Do clinical trials of HIV prevention technologies do the same?
 - Formation of new social identities and the preservation of these new forms of selfhood

VOICE participants misrepresented their adherence behaviour, not only to continue to benefit from the trial, but also to sustain their new found identities as HIV negative, healthy and empowered. Admitting to being faulty with regard to adherence threatened to undermine these subjectivities.



Trials that transform

‘[for] once in [my] lifetime, I was dedicated to something ... yeah I was very happy, hmm’.

Repeated testing for HIV at monthly intervals made her partner afraid to cheat on her, as this would cause him great embarrassment.

Frequent testing helped her to ‘love myself’ because she knew that the clinic staff would be able to detect ‘if I have done something dirty’.

Volunteers in a redistributive economy

- Trial participation – represents an investment in **hope**
 - As volunteers trials represents a hopeful future ... for HIV prevention but also ...
 - ... a way out of poverty and hopelessness
- Access to the ‘redistributive economy’ of SA
 - A substitute for formal employment



Acknowledgments

- VOICE C research team at RTI, FHI, DAIDS, and Wits RHI
- MTN 003C study participants
- Microbicides Trials Network (MTN)

MTN is funded by NIAID (5UM1AI068633), NICHD and NIMH, all of the U.S. National Institutes of Health