Why taking pills is so different to eating sweets

Rebecca Hodes, Ivy Nonceba Ngonyama, Naomi Fourie and the Mzantsi Wakho research team
PATA 2017 Continental Summit, 25 October 2017
Who takes tablets or uses medicines everyday?
Do you always take them when you are supposed to?
If you do not take them exactly as proscribed, why not?

Hey?

WHY NOT?????
GLOBAL ‘TREATMENT TRIUMPHALISM’

Decreasing AIDS mortality.
Ambitious targets: ‘90-90-90’.
In South Africa, test-and-treat.

... BUT

• Since 2000, adolescent deaths from AIDS have tripled (WHO, 2015)
• AIDS leading cause of death among adolescents (aged 10 – 19) in Southern & Eastern Africa.
WHAT DID WE WANT TO KNOW?

1. What are the risk and protective factors for ART adherence and access to sexual and reproductive health services?
2. What are the lived experiences of HIV+ teens?
3. What can policy and programming learn from this?
RESEARCH DESIGN: MIXED METHODS

• Qualitative research (HODES, GITTINGS)
  - N=80 youth, 30 healthcare providers, 30 caregivers
  - 36 months of community observations
  - Over 1000 hours of clinic observations (ART, family planning, trauma)
  - Participatory research, focus groups and workshops

• Quantitative longitudinal panel study (CLUVER, TOSKA)
  - N=1,526 adolescents, 1060 HIV+, 467 HIV-
  - Every adolescent ever initiated ART in a health district: 53 health facilities
  - Community-tracing, 3-year longitudinal tracking

• Policy influence
  - Teen-led
  - SA’s Adolescent and Health Health Policy

**Quantitative sample**
- Interviewed 90%
- refused 4%
- excluded 1%
- severe cognitive delay 1%
- unable to trace 4%

**HIV-**

**HIV+**
STUDY SETTING: EASTERN CAPE

- Urban, peri-urban, rural settlements.
- Transition from ‘bantustan care’ to ‘healthcare for all’.
- Provincial HIV prevalence 11.6% (HSRC, 2014).
- ART: Primarily nurse-managed.
- Mzantsi Wakho study: community-based.
- Participatory research with teens = PRIMARY
QUANTITATIVE SURVEY: TABLET-BASED QUESTIONNAIRE
NON-ADHERENCE (n=1060 HIV+ adolescents)

Past-week non-adherence to ART: 36% (self-report)

- Non-adherent: 36%
- Adherent: 64%

Past-weekend non-adherence to ART: 25% (self-report)

- Non-adherent: 25%
- Adherent: 75%

Past-year non-adherence to ART: 52% (self-report)

- Non-adherent: 52%
- Adherent: 48%

Detectable VL (>75 copies/ml: clinic records)

- Detectable: 33%
- Undetectable: 67%
GOOD ADHERENCE

Triumvirate of care: healthcare workers, caregivers, teens.

Multiple levels: structural, community, interpersonal, individual.
GOOD ADHERENCE: CLINICAL FACTORS
GOOD ADHERENCE: EXPERIENTIAL FACTORS
‘YUMMY OR CRUMMY’: MZANTSi WAKHO MASTERCHEF

Yummy or Crummy?

Test and Taste
Station 2: Colour

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Station 3: Size & Shape

Please circle the one you like more and explain why

1)  
Explanation:

2)  
Explanation:

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Explanation:

Please circle the one you like more and explain why

1)  
Explanation:

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Explanation:

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Explanation:
‘YUMMY OR CRUMMY’: METHODS
‘YUMMY OR CRUMMY’: FINDINGS (1/2)

**Emotions**
Preferences contingent on previous experiences of illness and disease, both individual and familial

**‘Knowability’**
medicines which they could easily identify, based on their colour, size, smell, taste and ‘scoring’.

**Socio-economic factors**
dependable supply of running water
‘YUMMY OR CRUMMY’: FINDINGS (2/2)

Discretion
Medicines that conferred confidentiality, were easy to swallow, transport and conceal, were the most highly valued.

Gendered significance
Colours, tastes, consistencies and delivery mechanisms

Generational identities
Children and young people had particular needs for the smell, taste and delivery mechanism of medicines.
SO WHAT DO YOU THINK?

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www.mzantsiwakho.org.za
THANK YOU: MZANTSİ WAKHO FUNDERS AND PARTNERS