Harvard Global Health Institute

Organizational Change: Positive Deviance

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I have no conflicts of interest to declare

Outline

- Objective: Understand how to design and lead systems changes to achieve quality improvement within a heath care ~~organization~~ delivery program
- Review the concept of positive deviance
- Focus on adherence to antiretroviral therapy (ART)
- Present my experience in sub-Saharan Africa

Holy Grail of quality improvement

- Is there an innovative approach that can promote and sustain behavioral or cultural change that is
  - More people-driven
  - More sustainable
  - Less resource-intensive?

Positive Deviance

- Behavior and social change strategy
- Based on the observations of nutrition professor Marian Zeitlin
- There are well-nourished kids even among the poorest communities: "positive deviants"
- Identify what these families are doing right and amplify it rather than fixing what's wrong with the community

Positive Deviance

- Save the Children's Jerry and Monique Sternin operationalized the concept as a tool to promote behavior and social change
- Problem: >65% of Vietnamese children are malnourished
- Traditional supplemental feeding programs unable to sustain weight gains after the programs ended

Positive Deviance

- Sternins sat with families to learn from them through discussions and observations
- Process
  - Enabled the community to define the problem
  - Uncovered current attitudes and feeding behaviors

Positive Deviance

- Villagers created their own growth charts and "discovered" well-nourished kids among them
- Parents kept these kids well-fed through "unusual" behaviors:
  - Went out to rice paddies every morning to gather fresh water shrimp, crabs and sweet potato greens
  - These foods were abundant but misconceived by the community to be inappropriate for young children

Positive Deviance

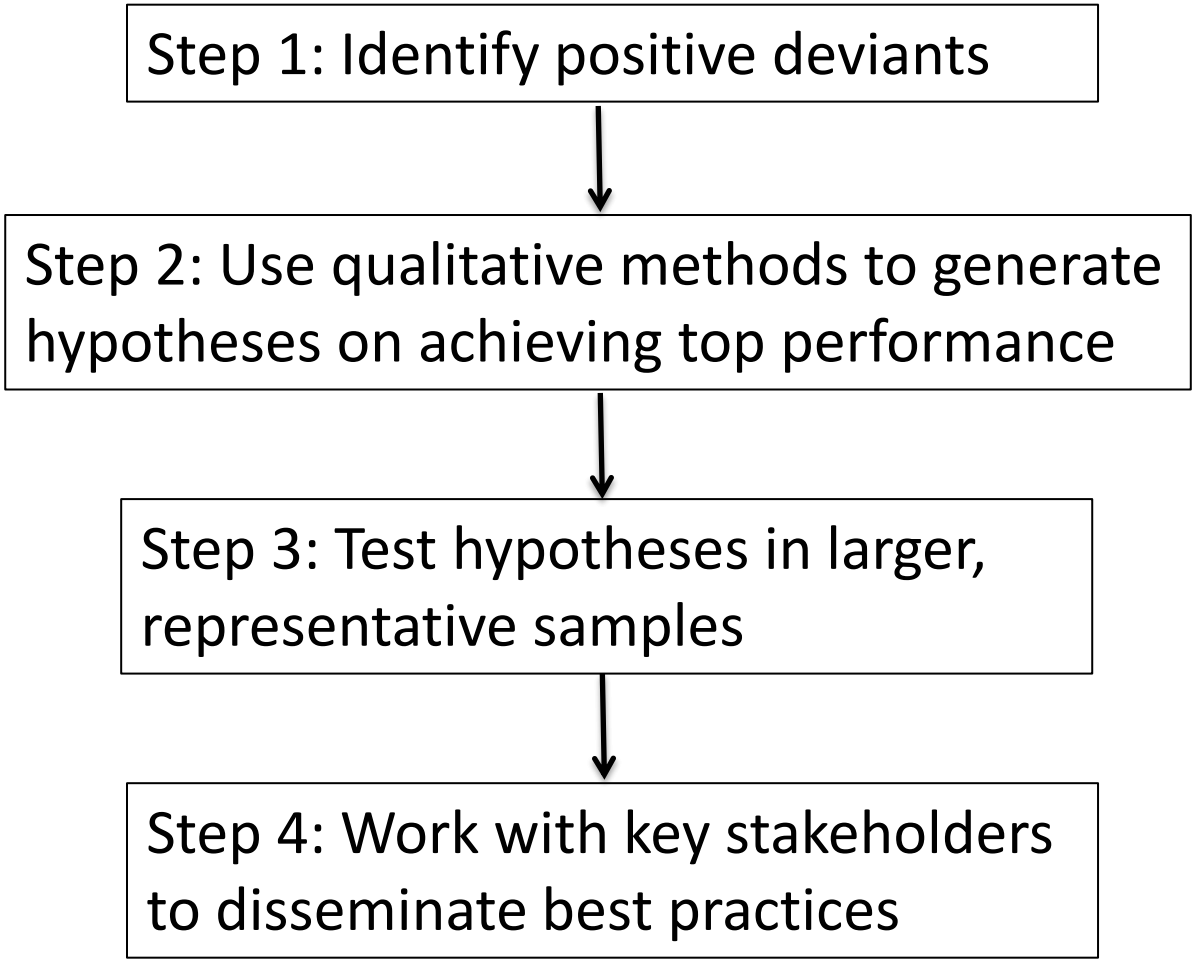
- Sternins encouraged villagers to *design* a plan to enable families with malnourished kids to learn the new practices
- Learning and resource families went to rice paddies, prepared meals and fed their kids together

"It is easier to act your way to a new way of thinking than to think your way to a new way of acting."

Positive Deviance

- Sustained 65-80% reduction in childhood malnutrition in Vietnamese communities
- Increase in primary school student retention in Missiones, Argentina
- Reduction in girl trafficking in East Java, Indonesia
- Decrease in neonatal deaths and sickness in Pashtun, Pakistan
- VA Pittsburgh Healthcare System to scale initiative to reduce MRSA

Positive Deviance



Bradley et al, Implementation Science, 2009

Adherence to ART

- HIV can be fully suppressed with highly active antiretroviral therapy (3-drug regimen)
- Lapses in adherence may allow the virus to start replicating again
- In the presence of sub-therapeutic levels of drug, drug resistance and ultimately treatment failure will develop
- Good adherence is therefore really important

Fears of poor adherence

- *Will widespread, unregulated access to antiretroviral drugs in sub-Saharan Africa, lead to the rapid emergence of drug resistant viral strains, spelling doom for the individual, curtailing future treatment options, and [leading] to transmission of resistant virus?"*

Harries et al, Lancet, 2001

- *[In sub-Saharan Africa]….the potential short term gains from reducing individual morbidity and mortality may be far outweighed by the potential for the long term spread of drug resistance…. In Africa, a higher proportion of patients are likely to fall into the category of potential poor adherers unless resource intensive adherence programmes are available.*

Stevens et al, BMJ, 2004

More fear… and prejudice?

Africans "don't know what Western time is,"and "do not know what you are talking about," when asked to take drugs at specific times.

Andrew Natsios, USAID Administrator, 2001

Adherence to ART in the US

San Francisco *Bangsberg, AIDS, 2000*	67%
Pittsburgh *Paterson, Annals Int Med, 2000*	74%
Los Angeles *Liu, Annals Int Med, 2001*	63%
New York City *Arnsten, CID, 2001*	57%
Hartford *McNabb, CID, 2001*	53%
Philadelphia *Gross, AIDS, 2001*	79%

Adherence in patients purchasing generic ART in Uganda

(N=36)

MEMS	Unannounced pill count	Self-report
93% (SD 16%)	92% (SD 16%)	94% (SD 16%)

Oyugi et al, JAIDS, 2004

Meta-analysis of barriers to adherence in developed and developing settings

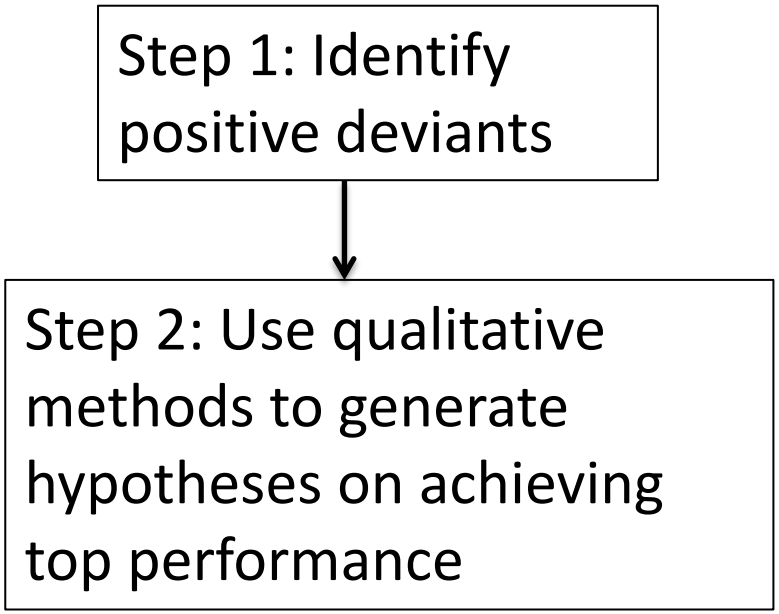
- Systematic review of adherence
  - 28,689 patients in 228 studies
    - North America
    - Brazil, Uganda, Cote d'Ivoire, South Africa, Malawi, Botswana, Costa Rica, Romania
  - Achieved >95% adherence
    - Developed countries: 55% (95% CI: 48-61%)
    - Developing countries: 77% (95% CI: 67%-86%)

Mills et al, JAMA, 2006

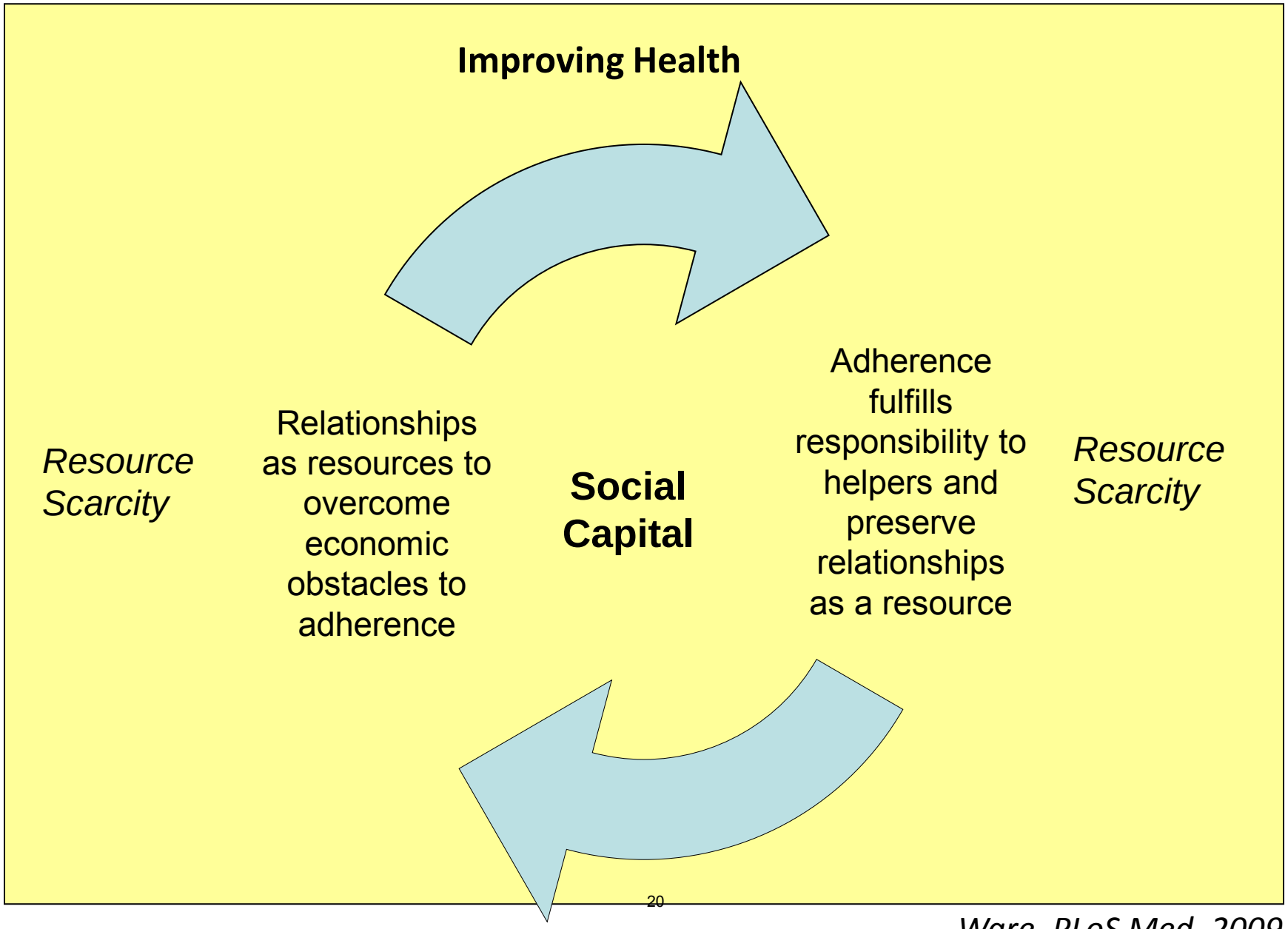
Adherence over 12 months on free ART in Mbarara, Uganda (N=274)

Graph removed due to copyright restrictions. Results show ~95% medication adherence over a 12-month period, but self-reports show 100% adherence.

Bangsberg, CROI, 2008



A social model of adherence for sub-Saharan Africa



Ware, PLoS Med, 2009

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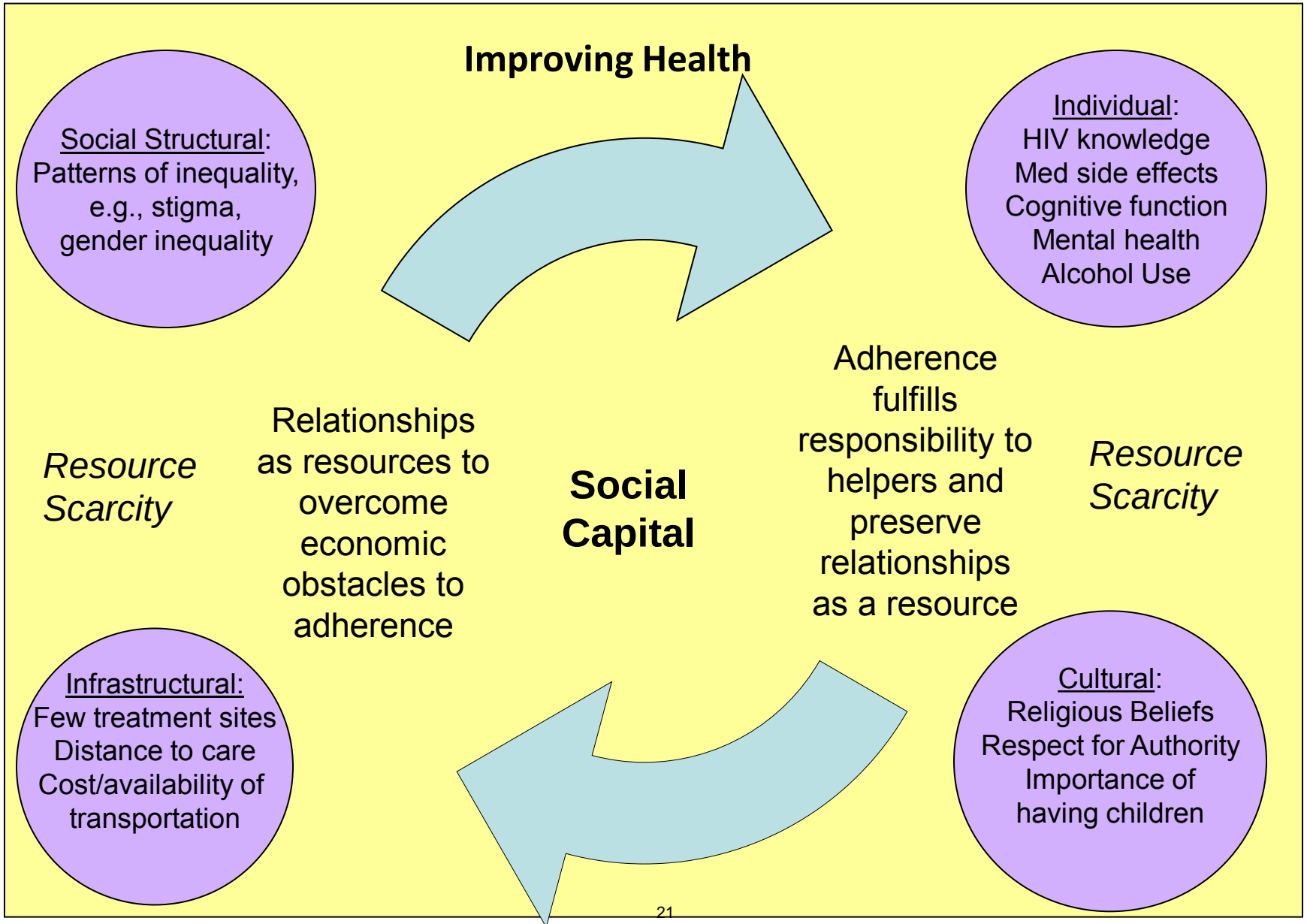


Ware, PLoS Med, 2009

Triomune

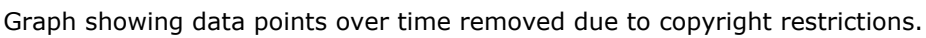
D4T/3TC/Nevirapine
$17 USD per month

How to take ART on time in rural Uganda without a watch: John's adherence story

- No education
- Works as a farmer
- Lives with his brother, sister-in-law, and 3 nieces in a 3 room mud-walled house without electricity
- Owns a lantern, bed, sofa, bike, and a radio, but no watch.
- HIV in April 2005 and started generic ART (Triomune) after disseminated herpes zoster and Kaposi's sarcoma
- CD4 count of 151

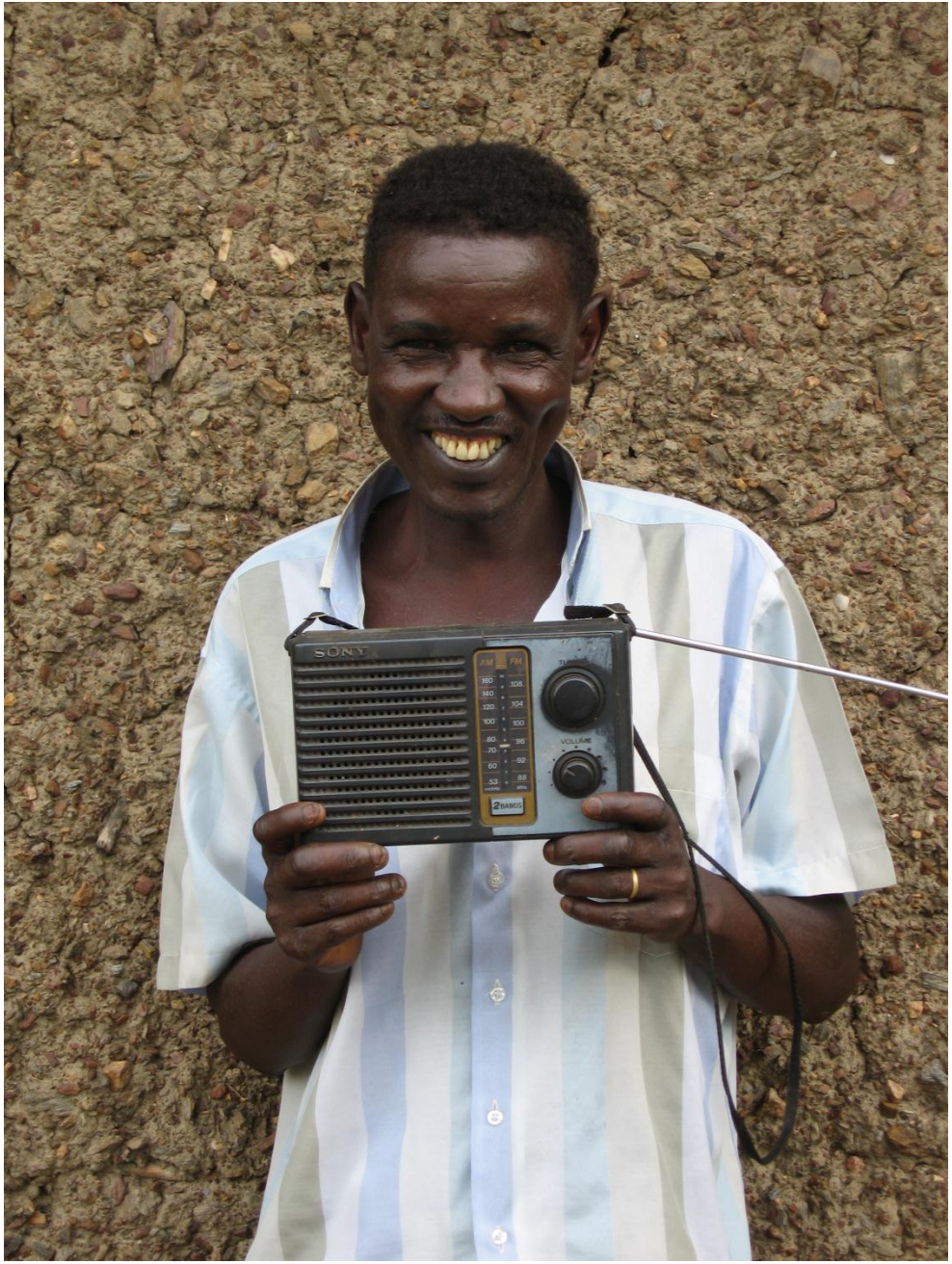
Maier, PLOS, 2006

Electronic medication monitor record (MEMS) of bottle openings for AM and PM doses



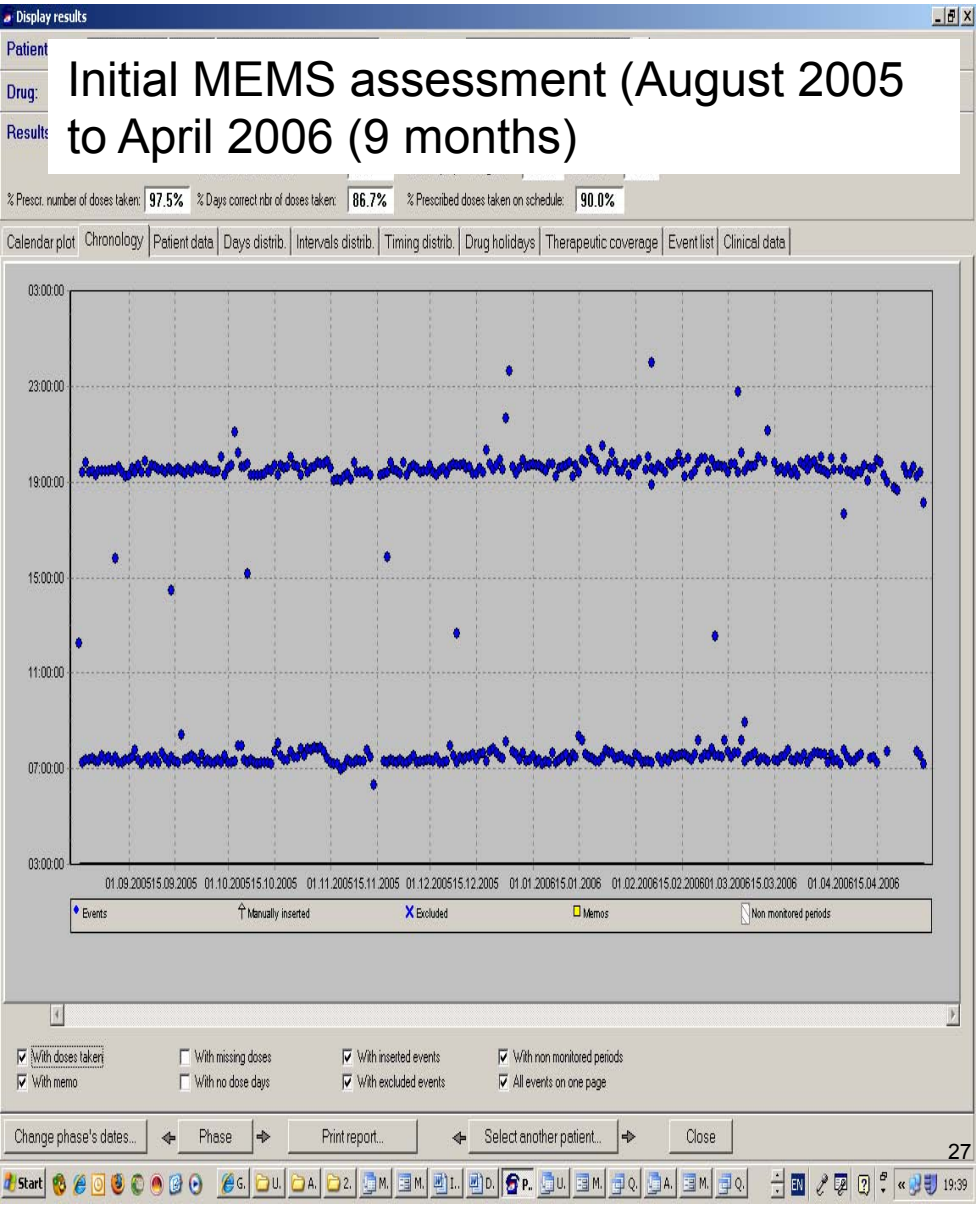
John’s adherence

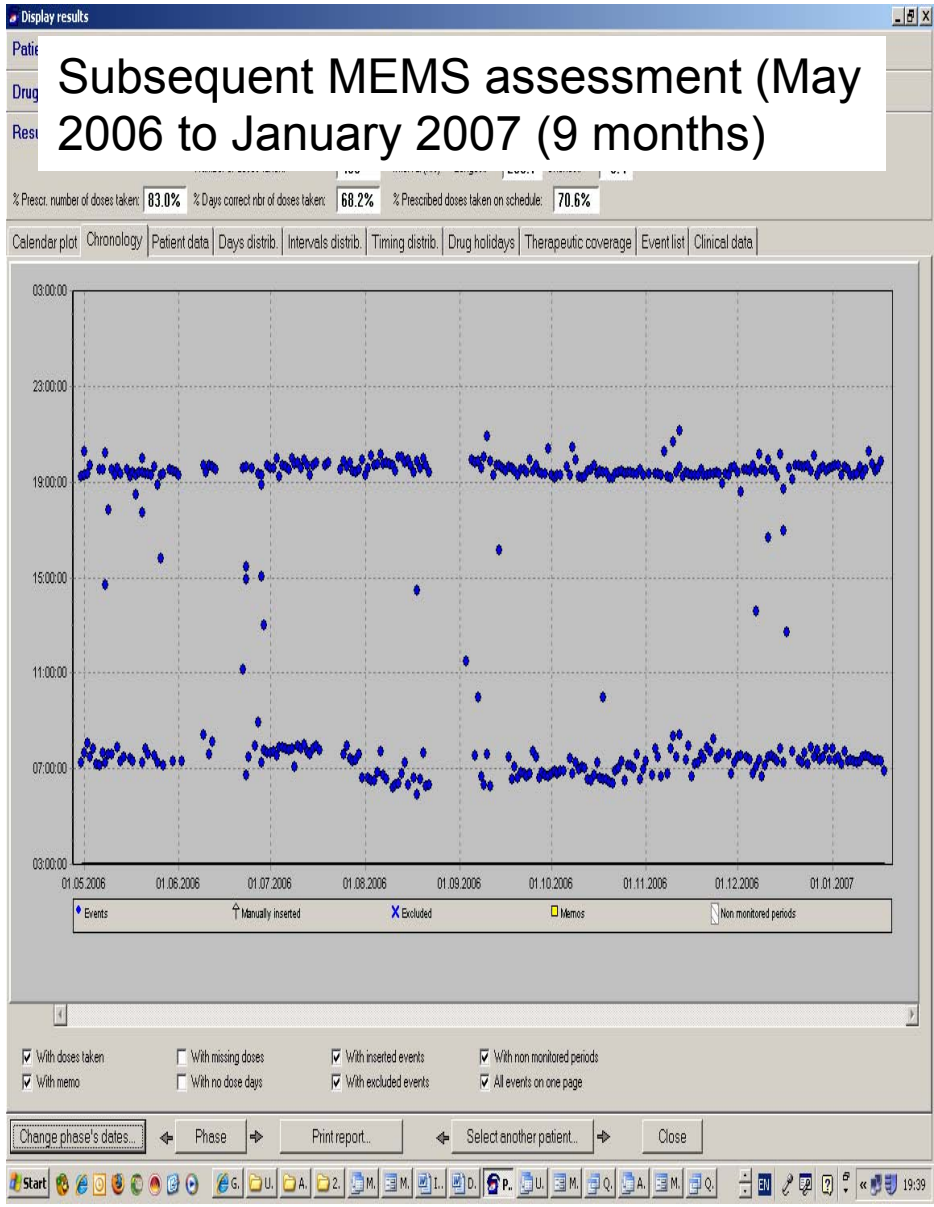
- 90% of doses within 10 minutes of 7:20 pm
- 90% of doses within 17 minutes of 7:20 pm
- Overall adherence: 99%



Maier, et al. "How to Take HIV Antiretroviral Medications on Time without a Watch in Rural Uganda." *PLoS Medicine* 3(3) (2006).

John's Adherence: 0-9 and 10-18 months



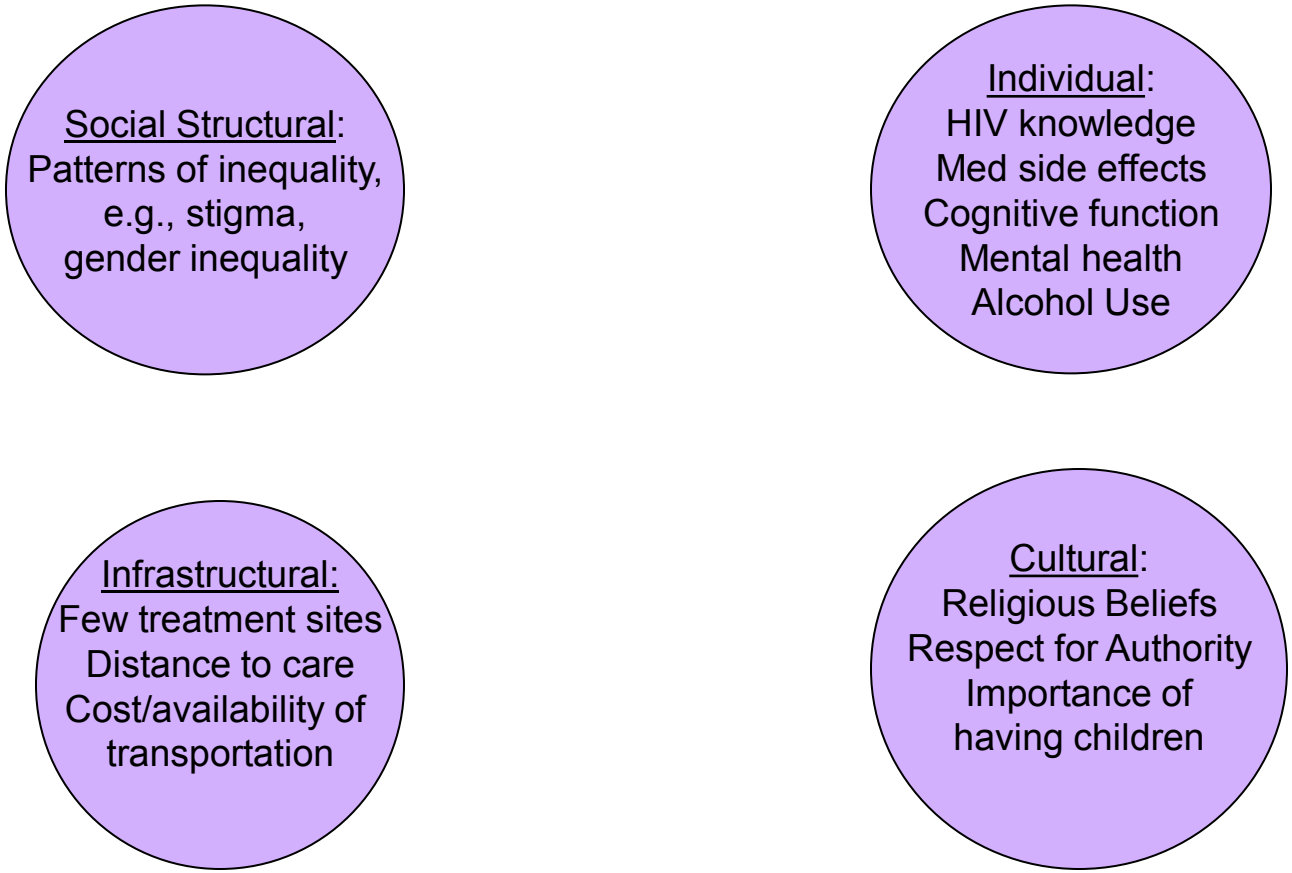


Deceptively good adherence

- Median adherence levels may mask transient adherence lapses
- Cohort of children taking ART in rural Uganda
  - Median adherence: 94-100% by multiple measures
  - Percent with viral suppression: 47%
- Transient adherence lapses may result in drug resistance to 1-2 drugs that will eventually result in treatment failure

Haberer et al, in preparation, 2011

Key barriers to good adherence



How to extend good adherence

- Identify those people with adherence problems and intervene before the clinical consequences develop
- The window of opportunity is short, as viral replication likely begins within 48 hours of an adherence lapse
- Real-time adherence monitoring and intervention is needed…

enter technology!

Types of adherence monitoring

- Subjective
  - Structured patient interview (a.k.a. self-report)
  - Various recall periods (e.g. last 7 days)
  - Number of doses missed/taken, rating, frequency
  - Visual analog scales

    0%----------50%----------100%
  - In person, by audio computer assisted self-interview (ACASI)
  - Quick, easy, and cheap, but tend to overestimate true adherence

Types of adherence monitoring

- Objective
  - Clinic and home-based pill counts
  - Pharmacy refill
  - Electronic monitors (e.g. MEMS caps)
  - Drug levels (blood, hair, urine)
  - More likely to be accurate, but
    more expensive and still imperfect

Methods for self-report by mobile phones

- Types
  - Live calls: flexible for detailed data collection
  - Interactive voice response (IVR): great for low literacy
  - Text messaging (SMS): popular and convenient
- Key features
  - Involves 2-way communication (i.e. not just reminders)
  - Data source may be the patient or a community health worker

Limitations

- Subject to network availability
- Patients may share phones, change numbers, turn off or not power their phones
- Requires some technology infrastructure and expense
- Dependent on patient understanding and motivation

Data from rural Uganda

Map showing locations of Kampala and Mbarara in Uganda removed due to copyright restrictions.

- 49 adults, 46 caregivers of children 2-10 yrs
- Weekly adherence queries
- Expected response: PIN -> # HIV meds missed
- Multiple attempts per week
- Participants given phones, received training with "just in time" support

Adherence measure	N weekly attempts	100% adherence	"Don't know"	Other response	Median adherence for other response (IQR)	Failed (e.g. incorrect PIN, no response)
Adults						
IVR	1624	571 (32.0%)	182 (11.2%)	117 (7.2%)	92.9% (82.9%-96.7%)	754 (46.4%)
SMS	129	73 (56.6%)	20 (15.5%)	4 (3.1%)	98.3% (97.5%-98.3%)	32 (24.8%)
Caregivers						
IVR	788	374 (47.5%)	50 (6.3%)	33 (4.2%)	96.7% (85.7%-97.5%)	331 (42.0%)
SMS	305	183 (60.0%)	55 (18.0%)	19 (6.2%)	95.6% (92.9%-98.3%)	48 (15.7%)

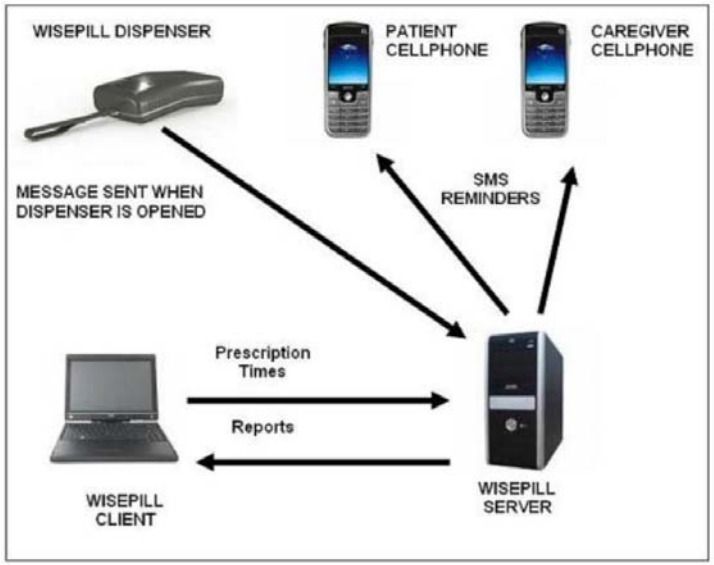
The participant's experience

- *"At first those questions confused me. They would ask you for your year. You would still be trying to respond and the call goes off. Then, they say that we shall try to call you back. Yet, the person who had trained me had repeated for me and told me what to do. It really greatly disturbed me. They were hard."*

- *"Well, for the first time I had forgotten what to do, and when trying to click yes the call went off. They came and trained me again and I learnt that when the call comes and you respond, you don't first erase, because when I would try doing so the call would go off."*

Wireless pill containers

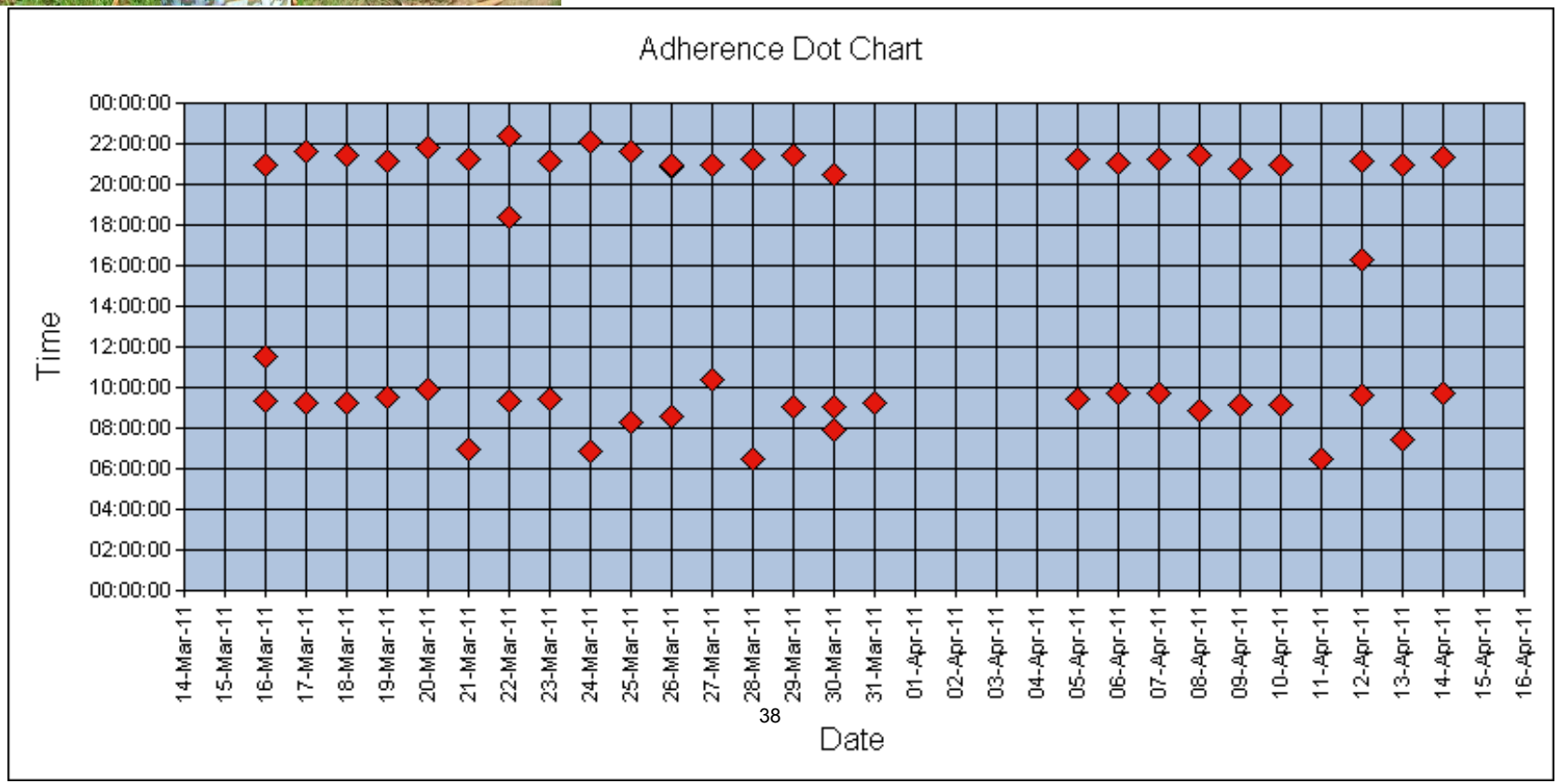
Wisepill™



- Signal sent over cellular network when device opened
- Daily signal to confirm battery and device functionality
- Flash memory to send signals if travel out of network
- Data transmitted to a server by general packet radio service (GPRS) with back up SMS

Data from rural Uganda

- 49 adults and 46 children aged 2-10
- 48+ hour adherence interruptions assessed by interview
- HIV RNA determined every 3 months and during interruptions



Results

- High acceptability
- Adults: median adherence 92% (IQR 83%-97%) with 45 interruptions
- Children: median adherence 97% (IQR 89%-100%) with 19 interruptions
- Causes of 48+ hour interruptions:
  - 17 due to forgot doses, intentional non-dosing, pocket doses, hospitalizations, unexpected travel, new caregivers
  - 42 interruptions had no clear cause (likely behavioral)
- Wisepill data correlated with HIV RNA suppression (r=0.44, p=0.01)
- New viral rebound detected in 15% of interruptions

Step 3: Test hypotheses in larger, representative samples

- We are currently expanding this pilot work in a cohort of ~500 adults
  - Looking at social support, stigma
  - Data will be used to design real-time adherence interventions
  - Experience with cell phones will be used to automate linkages to enhanced support

Other ongoing studies in Mbarara

- Examination of social capital for propagation of adherence behavior, treatment of depression (*Christakis, Rosenquist*)
- Role of food security (*Weiser*)
- Role of transportation cash transfers (*Emenyonu, Bangsberg*)
- Factors of fertility desire (*Matthews, Kaida*)

SMS reminders improve ART adherence and viral suppression (N=538)

- RCT of weekly SMS reminders vs controls in Kenya
- Adherence by self-report
  - Relative risk of non-adherence: 0.81 (95% CI 0.69-0.94; p=0·006)
  - # Needed to treat >95% adherence: 9 (95% CI 5.0-29.5)
- Virologic failure
  - Relative risk: 0.84 (95% CI 0.71-0.99; p=0·04)
  - # Needed to treat: 11 (95% CI 5.8-227.3)

Lester, Lancet, 2010

Type of SMS reminder matters (N=431)

- RCT of daily vs weekly SMS reminders vs controls in Kenya
  - >90% adherence by MEMS: 53% of participants receiving weekly SMS vs 40% in the control group (p = 0.03)
  - 48+ hour interruptions: 81% of participants receiving weekly SMS vs 90% in the control group (p = 0.03)
  - Significance seen with weekly, not daily, SMS

Pop-Eleches, AIDS, 2011

Step 4: Work with key stakeholders to disseminate best practices

- Potential implementation partners
  - Ministry of Health
  - Presidential Emergency Plan for AIDS Relief (PEPFAR)
  - US AID
  - NGOs (e.g. Millennium Villages Project, Médecins Sans Frontières)

Summary

- Most, but not all, Africans adhere well to ART
- Careful, observational research has identified key factors to explain why
- Ongoing studies are developing means to intervene in those individuals unable to achieve this high level of adherence
- Developed countries could learn a lot from the experience in sub-Saharan Africa
- Implementation is the next challenge

Acknowledgments

- National Institute of Mental Health
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- Gerald Begumisa (Yo! Voice Solutions)
- Lloyd Marshall (Wisepill)
- Study participants and research team in Mbarara, Uganda

Questions for Discussion:

- What is positive deviance as it relates to improving health care?
- What are the pros and cons of positive deviance for research geared towards improving quality of care?
- How might you follow the steps outline in the Bradley et al. article about positive deviance within an health-care organization (or health care delivery) and apply them to a model that can be used in a developing country?

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