



Transitioning through Adolescence with HIV: Supporting Families through **Disclosure** of HIV Status, Medication **Adherence**, and Overcoming HIV-Related **Stigma**



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East Africa IeDEA

Children with HIV

- 3.2 million children under 15 years living with HIV
- Only 32% of children accessing treatment*
- 2 million adolescents (10-19) with HIV**
- 4.3 million young adults (15-24) with HIV***
- HIV/AIDS is #2 cause of death among adolescents globally — #1 cause of death for adolescents in sub-Saharan Africa****

* UNAIDS, Global AIDS Update, 31 May 2016.

** UNICEF, Sixth stocktaking report, Nov 2013.

*** UNAIDS, How AIDS changed everything and 2014 HIV estimates, July 2015.

****Global Burden of Disease Study, 2013

If you want to walk far,
WALK TOGETHER



WALKING TOGETHER



Adherence

Disclosure

Stigma

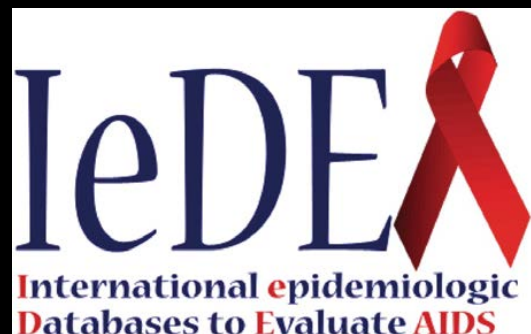
WALKING TOGETHER

Adherence



Adherence in East Africa

- 3,165 children, 52.4% male, less than 13 years
 - Enrolled in care for median 850 days
 - Median age at ART initiation 5.4 years ([IQR] 2.9-8.4 years)
 - On ART for median of 638 days ([IQR] 610-663 days)
- Self-reported good adherence was extremely high, remaining on average above 90% throughout all years of follow-up
- Longer time on ART associated with higher adherence
- Older age and orphanhood associated with lower adherence
- Significant variance in reported adherence was associated with site

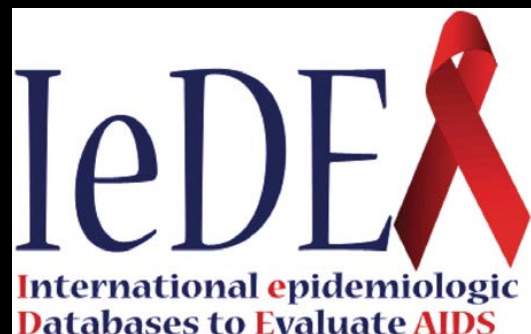


Global Adherence

- 2015 adherence survey
- Clinical staff from 180 pediatric sites in 45 countries
- Most sites manage both adults and children (82%)

Region	Sites	Children
Asia	16	4,357
Central & South America	7	1,746
Central Africa	18	906
East Africa	33	12,218
Southern Africa	95	45,641
West Africa	11	8,932

“Adherence measurement and support services for HIV-infected children and adolescents followed in global sites of the international epidemiologic databases to evaluate AIDS (IeDEA)” to be presented at AIDS 2016, Durban, South Africa.



Global Adherence Measurement

MEASURE	% Sites Using
Clinician adherence assessment	87%
Pharmacy refills	86%
Structured recall items (one recall item, any report time period)	77%
Targeted HIV viral loads	75%
Instruments with multiple adherence question items	61%
Pill counts	40%
Drug levels	7%
Electronic dose monitoring	2%
Routine viral load monitoring	13-79%



“Monitoring adherence is necessary to assess the effect of interventions and also to inform providers of the need to implement interventions.”

Thompson MA, Mugavero MJ, Amico KR, Cargill VA, Chang LW, Gross R, et al. Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel. *Ann Intern Med*. 2012;156(11):817–33.



Academic Model Providing Access to Healthcare (AMPATH)

AMPATH is a collaboration between Moi University School of Medicine, Moi Teaching and Referral Hospital, and a consortium of North American academic medical centers led by Indiana University School of Medicine. AMPATH provides comprehensive HIV care, as well as chronic disease and primary healthcare services, through a network of 65 government healthcare facilities in 19 districts across western Kenya. AMPATH has significant clinical, research, and community-based infrastructure to deliver high-quality and comprehensive HIV care and related services to western Kenya.

AMPATH by the numbers March 2015

Adults

Enrolled in Care	142,670
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Receiving ART	102,407
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Children

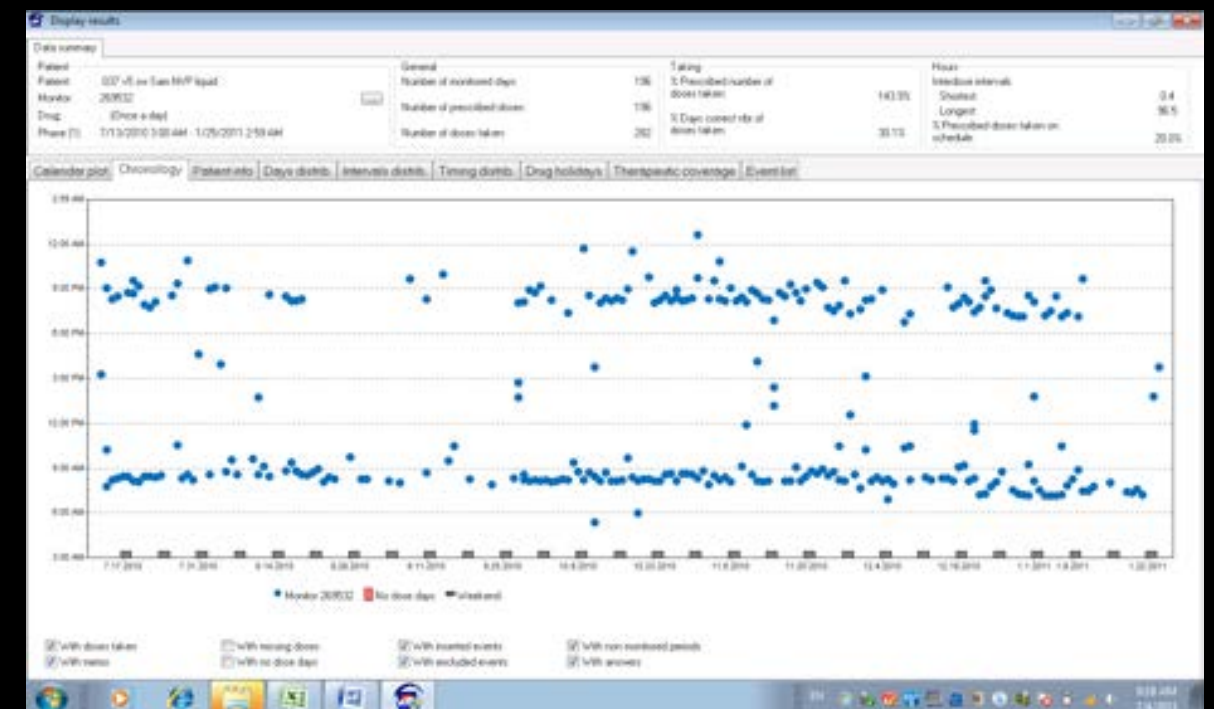
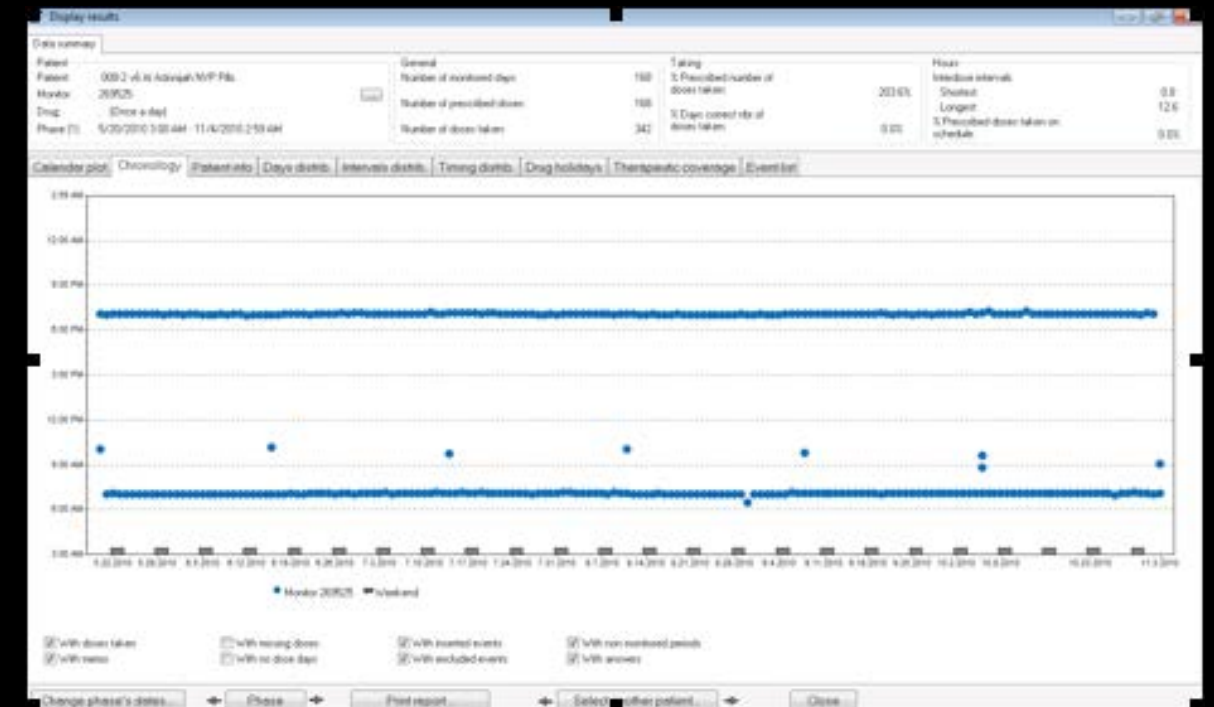
Enrolled in Care	44,173
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Receiving ART	19,649
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DEVELOP AND VALIDATE MEASUREMENT INSTRUMENT TO ASSESS PEDIATRIC ADHERENCE

- Culturally grounded model of pediatric ART adherence in this context through qualitative research
- Prospective adherence evaluations in Kenya with 191 children ages 0-14 and their caregivers, followed 6 months
- Medication Event Monitoring Systems® (MEMS, MWW/AARDEX Ltd, Switzerland) and plasma drug concentrations as external criterion
- Analysis: Variable selection using LASSO technique with logistic regression to identify items best correlated with dichotomized MEMS adherence ($\geq 90\%$ or $< 90\%$ doses taken)



DEVELOP AND VALIDATE MEASUREMENT INSTRUMENT TO ASSESS PEDIATRIC ADHERENCE

- Median adherence: 93% by MEMS over 6 months
- Adherence improved over course of study:
 - 51% of children had $\geq 90\%$ MEMS adherence at month 1
 - 64% achieved $\geq 90\%$ MEMS at month 2
 - 67-68% for following months
 - Only 29% maintained $\geq 90\%$ MEMS adherence all 6 months
- MEMS treatment interruptions common:
 - 49.5% had at least one treatment interruption of ≥ 48 hours
 - Median 3 treatment interruptions per child (range 0 to 17, IQR 0-6)

MEASURING PEDIATRIC ADHERENCE (SHORT-FORM)

- Ever have problems keeping time with the medicines?
- Ever have problems getting child to take medicines?
- How many doses of medicine has child missed in last month?
- Child-level factors make it difficult to give medicines
- Caregiver-level factors make it difficult to give medicines
- Currently enrolled in AMPATH nutrition program?
- Number of days missed at least one dose in past week
- Number of days dose given more than one hour late in past week
- Number of extra doses in past week

ICAMP STUDY – Adherence Questionnaire for Children/Adolescents

Filled by Research Assistant

Study ID:

Date of Encounter:

Filled by Clinician/Nurse/Provider

Patient Initials:

Patient Age (yrs):

Patient Sex: ☐ Male ☐ Female

Relationship of person accompanying child to clinic (please describe):

Child disclosure status: ☐ Disclosed ☐ Not disclosed
☐ Disclosure ongoing ☐ Don't know

☐ No one accompanying child

Is the child enrolled in a nutrition support program? ☐ Yes ☐ No

ADHERENCE QUESTIONNAIRE

1. Who gives you your medicines? (tick all that apply) ☐ Mother ☐ Father ☐ Grandparent ☐ Auntie/Uncle ☐ Guardian ☐ Relative who lives in home ☐ Relative who lives outside of home ☐ Neighbor ☐ Sibling ☐ House help ☐ Child takes meds themselves ☐ Other (specify) _____

2. Do you know why you are taking these medicines?
☐ Yes ☐ No ☐ Don't Know

3. How many people in your household also take these medicines? _____ ☐ Don't know

4. Do you ever have problems keeping time with the medicines?
☐ Yes ☐ No
When? ☐ Mornings ☐ Evenings ☐ Weekends
☐ Weekdays ☐ Other:

5. Do you ever have problems with taking the medicines?
☐ Yes ☐ No
What problems does child raise? (explain)

6. There are many reasons why people do not like to take medicines. We know that many people miss taking their medicines at times. Have you missed your medicines for any of these reasons:
☐ I did not know why I was taking the medicines or I had questions about the medicines
☐ I forgot to take medicine
☐ I was playing or at school or work
☐ I have a problem taking either the tablets or liquids
☐ I can't take without food
☐ Other (specify): _____
☐ I felt ill or was vomiting
☐ I just did not want to take the medicines
☐ I find the medicines too bitter
☐ None of the above

7. Sometimes, a child does not take their medicine every day or at the same time every day because of difficulties for the caregiver, parent, or guardian. I am going to read a list of issues that may be problems for your caregiver, parent, or guardian. Tell me when you hear a problem mentioned that applies to you or your caregiver. My caregiver or I:
☐ Was away from home (work, field, etc.)
☐ Was not always around with the child
☐ Did not want others to see
☐ None of the above
☐ Had difficulty with the instructions for the medicines
☐ Was too busy and forgot
☐ Had trouble with timing or giving the doses on time
☐ Other (specify) _____

8. Sometimes, problems at the clinic make it difficult for you to take these medicines every day. Have any of these things been a problem for you:
☐ There was no money to purchase medicine (if not offered at AMPATH)
☐ The medicine was not available in the pharmacy.
☐ I finished or ran out of the medicines
☐ None of the above
Which medicine? ☐ ARVs ☐ Septrin ☐ Other (include abx)
☐ Other (specify) _____

9. In the past week,
a. On how many days did you miss at least one dose? ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Don't know
b. On how many days did you take a dose more than an hour late? ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Don't know
c. How many extra doses or syringes of medicine did you take? ☐ Don't know

10. How many doses of medicine did you miss in the last month? _____ ☐ Don't know

Vreeman RC, Nyandiko WM, Liu H, Tu W, Scanlon ML, Slaven JE, Ayaya SO, Inui TS. Comprehensive Evaluation of Caregiver-Reported Antiretroviral Therapy Adherence for HIV-Infected Children. AIDS and Behavior. 2015 Apr;19(4):626-34.

LS: _____
LS: _____
sit: _____

WALKING TOGETHER



Adherence

Disclosure

Pediatric Disclosure by Age

- Random sample
- HIV-infected children, 6-14 years, at 4 large HIV clinics in western Kenya
- Clinician administers questionnaire to parents and children individually

Age	Number	Disclosed
6	106	10.4%
7	103	8.7%
8	106	17.9%
9	104	9.6%
10	85	32.9%
11	84	39.3%
12	65	41.5%
13	57	56.1%
14	38	55.3%
Total	748	25.7% (N=192)



Vreeman RC, Scanlon ML, Marete I, Mwangi A, Inui TS, McAteer CI, Nyandiko WM. Characteristics of HIV-infected adolescents enrolled in a disclosure intervention trial in western Kenya. *AIDS Care*. 2015 Dec; 27(Suppl 1): 6-17.

Vreeman RC, Scanlon ML, Inui TS, McAteer CI, Fischer LJ, McHenry MS, Marete I, Nyandiko WM. 'Why did you not tell me?': perspectives of caregivers and children on the social environment surrounding child HIV disclosure in Kenya. *AIDS*. 2015 Jun;29(1): 47-55.

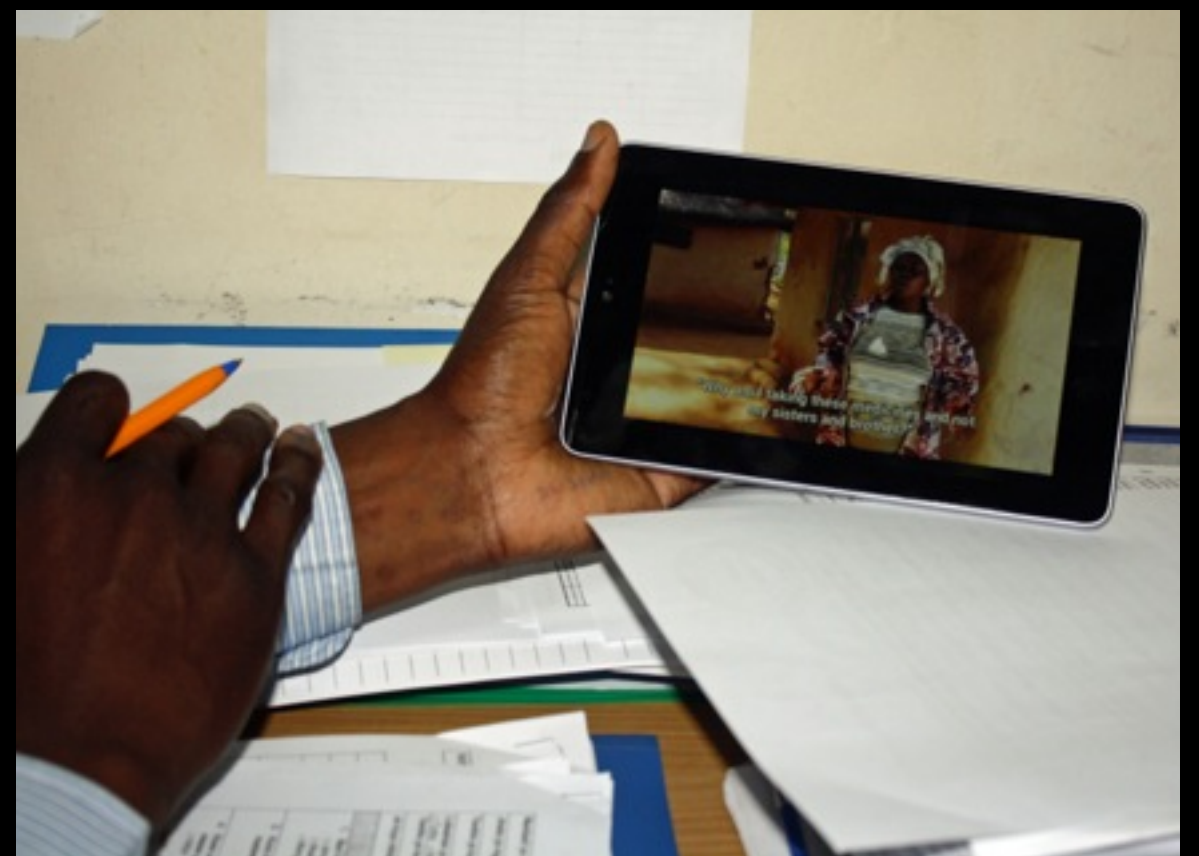
NIH/NIMH 1R01MH099747-01 (Vreeman)

- Cluster-randomized trial to assess effect of patient-centered intervention guiding disclosure to HIV-infected Kenyan children
- Curriculum for disclosure and adherence counseling: video-taped narratives and animated, tablet-based educational modules
- Counseling
- Peer support groups

JAMES

LIVES POSITIVELY







Intervention Trial

- 285 caregiver-child dyads enrolled
 - Mean age of children: 12.3 years
 - On ART for average of 4.4 years
 - Almost half orphans
- At baseline, 43% of children knew HIV status per caregiver or child report
- Mean age at disclosure: 10.1 years (range: 6 to 14)
- 7 (2.5%) died during the course of 2-year study



Intervention Trial

	6 Months	12 Months	18 Months	24 Months
Cumulative Rate of Disclosure - Intervention	38%	52%	65%	79%
Cumulative Rate of Disclosure - Control	22%	44%	52%	71%
HR for disclosure among those not disclosed	1.77	0.79	1.84	1.00
CI for HR	(1.04, 3.01)	0.39, 1.60)	(0.72, 4.72)	(0.50, 2.00)



Depression

- PHQ-9 at Baseline
 - No depression (0-4): 227 (80%)
 - Minimal Symptoms (5-9): 41 (15%)
 - Mild Major Depression (10-14): 7 (3%)
 - Major Depression (>20): 6 (2%)



Other Measures

- Adherence: Questionnaire and MEMS
- Stigma Questionnaire
- Strengths and Difficulties Questionnaire
- PACTG General Health Assessment for Children (GHAC) Quality of Life Questionnaire

WALKING TOGETHER



Adherence

Disclosure

Stigma

Figure 1: Mechanisms of Stigma and Illustrative Quotes

Enacted Stigma

"I was supposed to be in St. Theresa's school but because my mum told the principal of my health, the principal wrote a letter that I am not supposed to be in a boarding school and so I couldn't manage fare to and from school. So I was taken to St. Patrick's."

"For me, there is a neighbor who used to tell my son, I don't want to see you playing with my children. Let me not see you because I will beat you. So this child started avoiding that lady's children."

"I was affected because when looking for a job, I was told we don't want anyone who is infected."

"Like my sister that I am staying with, she used to live with the uncle, and the uncle's children discriminated her telling her that you will soon die. She would become gloomy and would come and ask me, 'They are saying that I will die, is that true?' I told her, 'It's not true. You will live and you will heal.' For now, she is not that stressed"

Perceived Stigma

"...there are parents who warn their teens not to play around those who are infected with HIV. Even if they were friends, they will separate because of that."

"Some people will no longer come to your homes. Others who have little information will say, I won't go to that family because I will be infected. So they start discriminating you."

"When your husband gets to know that you have gone for testing, you will not have peace anymore. You can get tested and lose your marriage."

"The other thing is when people hear you have HIV, they won't eat with you on a single plate. For instance, you cannot share ugali on one plate neither do they accept you to use the same cup."

"Maybe your parents died and left you a house. When your relatives know that you are HIV positive, they will come and take your house from you leaving you with nothing."

"When they know that you have HIV, they will look down upon you. If you borrow from them, they will never give you."

Courtesy Stigma

"You know the assumption is...that for you to take care of an HIV positive (individual), you also have to be HIV positive just the same way it is known that anyone working in AMPATH is positive. You see that is the scenario outside here. So you just have to that way. The same thing to the caregivers. They ask if you are not sick then why did you accept to take care of the child. So, that is the situation"

"If you ask them why they don't take him to the clinic, they say that people may also say that they are infected. So when I usually come with this child to the clinic, they do say that I am also sick, my family included-my husband and children."

Internalized Stigma

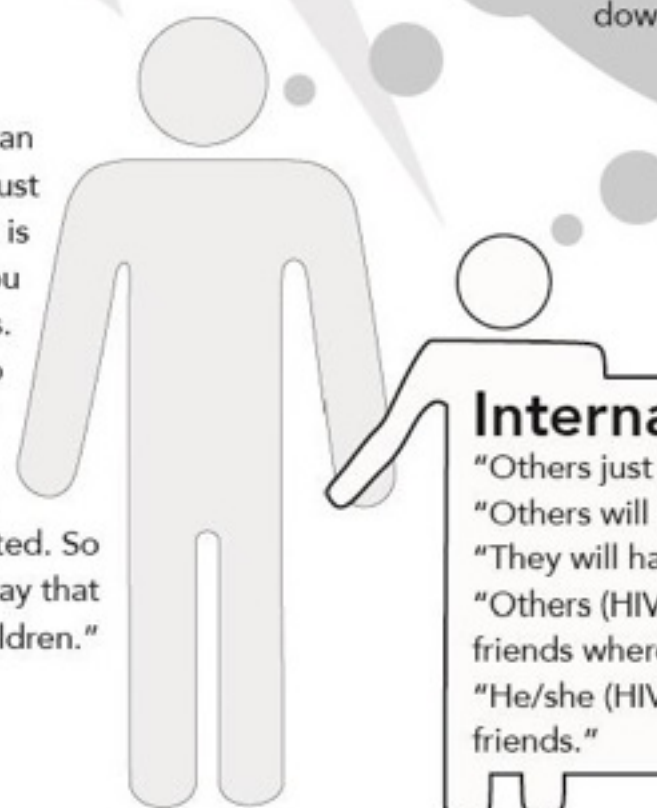
"Others just feel shame of being infected with HIV."

"Others will insult themselves in their hearts."

"They will hate themselves."

"Others (HIV-infected individuals) will fear sitting next to their friends wherever they have sat."

"He/she (HIV-infected individuals) will fear walking with his/her friends."



HIV-negative

HIV-infected

Stigma Measurement: Caregivers

- 285 caregivers, 6 months of assessment
 - Negatively judged: 11.9%
 - Isolated / avoided: 9.1%
 - Called names / insulted: 12.4%
 - Lost financial support or work: 5.9%
 - Lost social support: 6.8%
 - Stressed or anxious: 12.3%
 - Depressed or saddened: 13.5%
 - Restrict child's play or travel due to stigma: 4%

Stigma Measurement: Children

- 285 children, 10-15 years of age
 - Lost friends: 6.4%
 - Called names, bullied, insulted: 7.1%
 - Lose financial support or work: 3.2%
 - Feel stressed / anxious: 8.7%
 - Feel depressed / saddened: 7.1%
 - Chose not to play or go places: 3.2%
 - Important to keep HIV status secret: 57.1%
 - Caregiver feels important to keep secret: 56.5%
 - Delayed taking medicine so others do not see: 13.5%

Stigma and Adherence

- On multiple items, experiences of stigma were associated with a child being less adherent (90% cut-off on MEMS, repeated measures logistic regression)

Item	OR (95% CI)
Caregiver Questions	
Caregiver experienced stigma in clinic	1.60 (1.18, 2.16)
Caregiver experienced stigma in other places	0.81 (0.73, 0.90)
Caregiver lost financial support/work	0.83 (0.71, 0.98)
Child Questions	
Child experienced stigma in neighborhood	0.78 (0.62, 0.97)
Child experienced stigma in church	0.84 (0.81, 0.87)
Child experienced stigma in other places	0.50 (0.48, 0.52)
Child lost financial support/work	0.71 (0.56, 0.89)
Child lost social support	0.65 (0.45, 0.95)

