

**Outcomes of Transition
to Adult HIV Care
in Perinatally HIV-infected (PHIV) Young Adults
in Miami, Florida**

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- ❖ **Study participants**
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Outline

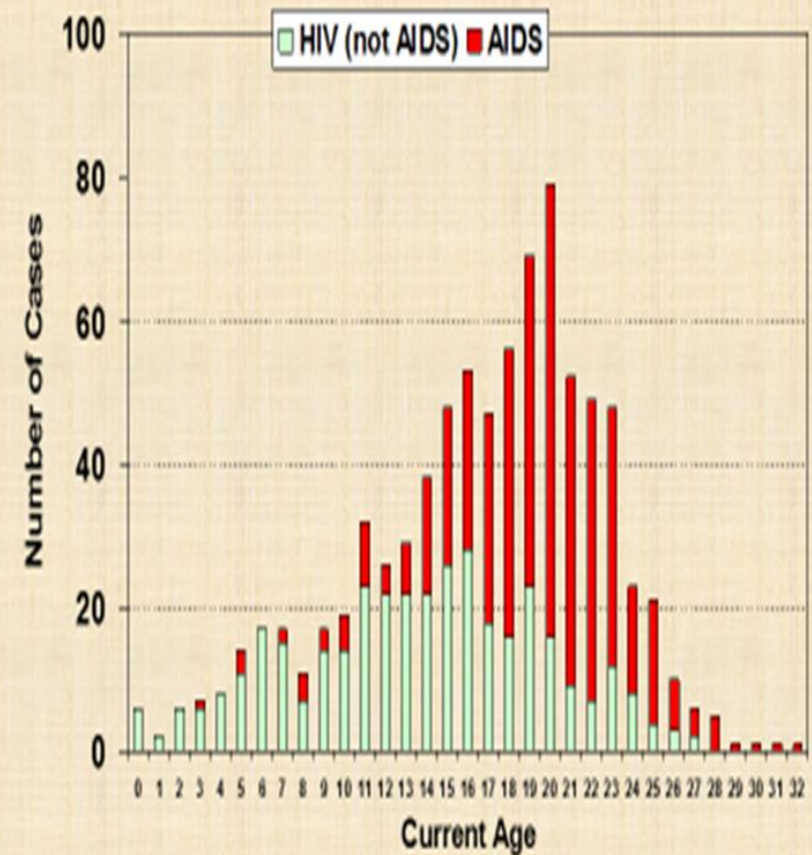
- ❖ Background of perinatal HIV Infection
- ❖ Introduction to the research
- ❖ Presentation of studies to examine:
 1. Post-Transition Mortality
 2. Post-Transition Engagement in adult HIV care
 3. Post-Transition Experiences
- ❖ Summary & Program Recommendations



Epidemiological Changes

- ❖ **Medical advances** reduced vertical transmission and increased survival to adulthood in PHIV children.
- ❖ **Current PHIV population in the US:**
 - About 10,000
 - “Aging” cohort which will have to transition from pediatric to adult HIV care before 25 y/o
 - In most young adults HIV disease has progressed to AIDS

Living PHIV cases in Florida through 2012 (n=819)



Treatment Challenges in PHIV Children, Youth, and Young Adults

From fatal to chronic disease : Lifelong treatment to control viral replication, prevent immune and clinical deterioration and transmission of HIV

- ❖ **Clinical:** most PHIV young adults are in advanced stage of HIV disease with complex medical histories.
- ❖ **Long-term complications of HIV disease:** metabolic disorders & mild neurocognitive impairments.
- ❖ **Compliance issues:** adherence to medical appointments and HIV medication tends to decrease in adolescence through young adulthood.
- ❖ **Psychosocial:** living with chronic illness, loss of parent(s), HIV/AIDS stigma; most are members of racial/ethnic minority communities with high levels of poverty.

Transition from Pediatric to Adult HIV Care

System differences between pediatric & adult HIV care

Pediatric HIV care

- Comprehensive “one-stop shop” care in a small clinic
- Longtime bond with providers
- Accessible hours and supportive services by multidisciplinary staff

Adult HIV care

- Fragmented care, with multiple locations and providers for various services
- Much higher (>20-fold) patient - provider ratio
- Requires patients to navigate and coordinate care independently

Concerns that transitioned patients may discontinue treatment or become marginally engaged in adult HIV care.

Transition services became a key component of pediatric HIV care

“Outcomes of Transition to Adult HIV Care in Perinatally HIV-infected (PHIV) Young Adults in Miami, Florida.”

- ❖ Research conducted at the pediatric HIV clinic at UM
- ❖ “Aging” population of PHIV patients who transition to adult HIV care by age 25 y/o
- ❖ In 2008, the clinic implemented a comprehensive transition program to support transitioning patients.



The Comprehensive Transition Program: Conceptual Model

Aim:	To prepare and support patients to independently navigate adult HIV care
Program components address:	Services made available:
<i>To prepare patients for independent living</i>	Educational and psychosocial support; help to access housing, employment services, financial assistance & medical insurance
<i>Lack of continuity of HIV care between pediatric and adult HIV care</i>	Transition plan discussion & linkage to adult services, and pre-and post “transition clinic.” Participants were seen by an adult provider at the pediatric clinic and could be seen by the same –now familiar– provider at the adult clinic (Jackson) who had more time for the visit.
<i>Lack of self-management skills</i>	“Life skills” training, support groups, and one-year post-transition follow-up by pediatric transition social worker to teach patients to solve problems encountered in adult care.

Research Questions

1. How did transitioned PHIV young adults do in adult HIV care?

- Mortality
- Attendance of scheduled appointments
- (Post)-transition experiences.

2. Did the transition program help them to transition?

- Did outcomes differ significantly by transition program exposure?

3. How can the transition program be improved?

- What recommendations can be made based on the study results?

Methods

- ❖ **Study Design:** Single-center, retrospective cohort study to:
 - **Assess:** 1) post-transition mortality and 2) engagement in HIV care using *de-identified quantitative data abstracted from medical records*.
 - **Explore:** 3) (post)transition experiences, using *de-identified quantitative & qualitative data* from a computer-assisted survey and debriefing interviews.
- ❖ **IRB approval:** FIU & UM Institutional Review Boards
- ❖ **Eligibility criteria:** Patients of the Miami pediatric clinic who transitioned to adult HIV care between January 2003 and September 2012
- ❖ **Exclusion criteria:** 1) substantive cognitive disability; (2) incarceration, or (3) relocation outside of S. Fl.

Methods

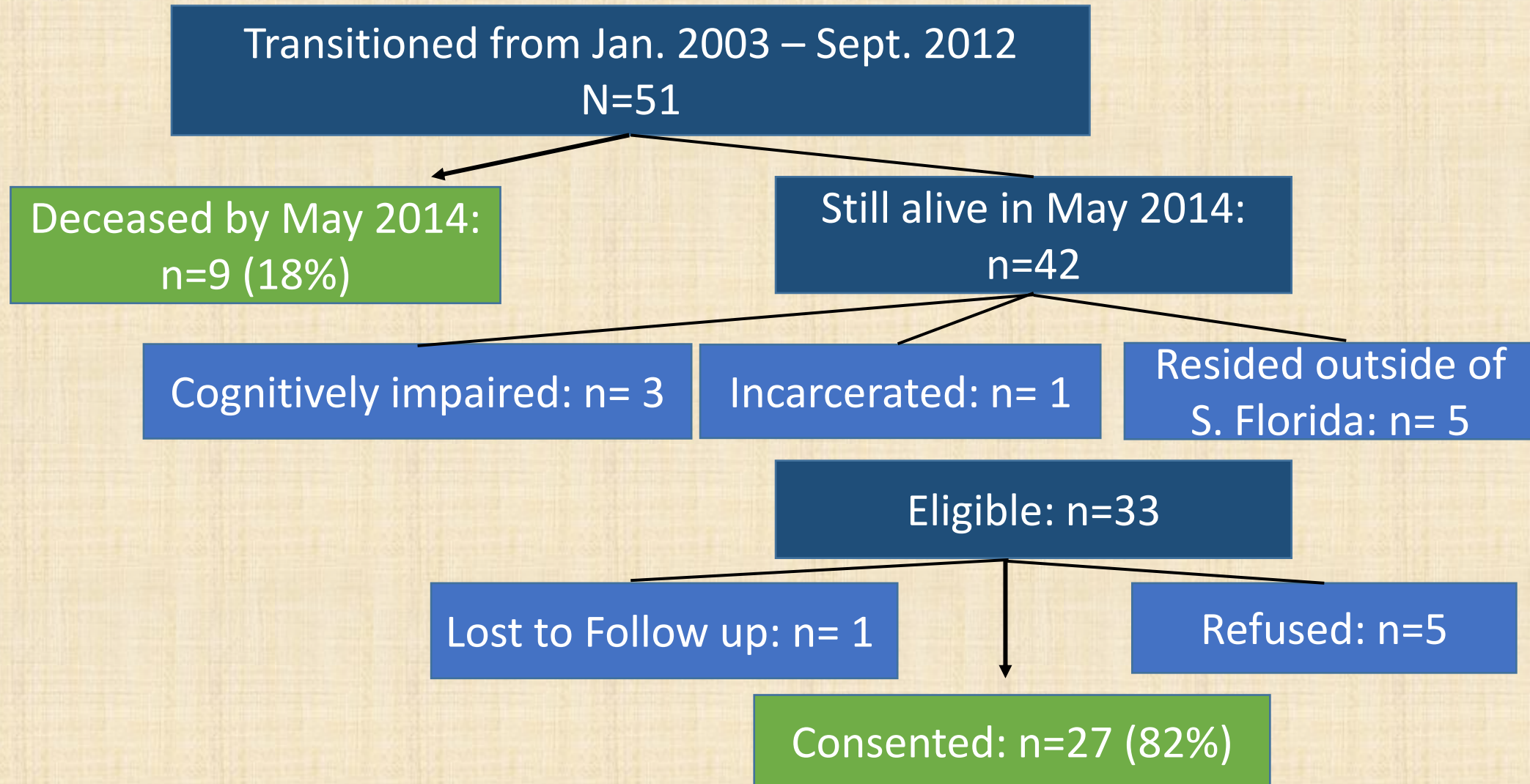
❖ Recruitment of Participants:

- The pediatric clinic coordinator contacted eligible (former) patients.
- Extra efforts to contact “hard to reach” patients.
- Independent researcher set up appointments at the pediatric clinic
- Participants:
 - signed informed consent, HIPAA Authorization and 3rd Party Disclosure Forms
 - completed computer-assisted survey and debriefing interview
 - received \$20 and travel reimbursement
 - were offered assistance by pediatric staff to access adult services.



Dr. Ana Garcia at the healing tree with messages and photos of children born with HIV but who did not survive.

Results: Flow Chart of the Study Population



Study 1

Purpose: Assess post-transition mortality and clinical and socio-demographic factors, including exposure to the transition program, that might affect mortality risk.

Methods

Measures:

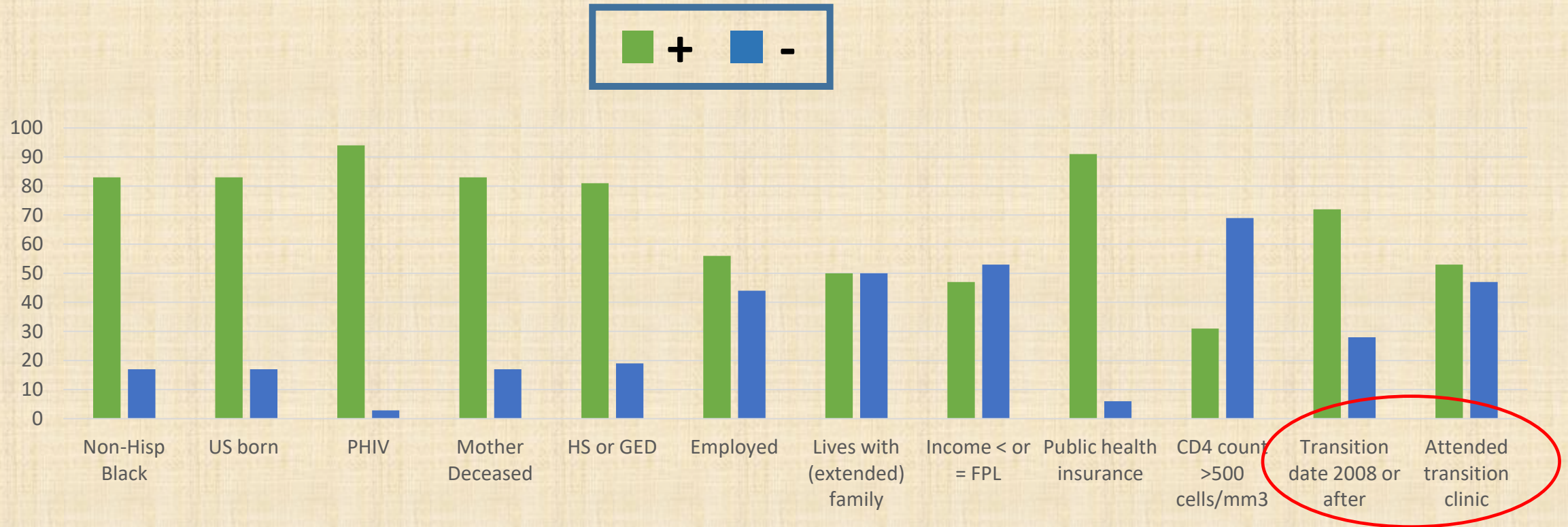
- ❖ **Outcome variable:** Death after transition (by May 2014)
- ❖ ***Independent variables:***
 - sociodemographic and clinical factors at transition abstracted from pt. records
 - exposure to the transition program:
 - (1) transition date (before vs after 2008) and;
 - (2) transition clinic attendance (kept ≥ 1 appointment in pre-or post-transition clinic)

Statistical Analysis:

- ❖ Univariate analysis to describe study population characteristics
- ❖ Fisher exact or Kruskal-Wallis tests for significance testing ($\alpha = 0.05$)
- ❖ Risk ratios (RRs) to assess strength of associations; 95% CIs to calculate RR precision
- ❖ Stratified analysis to control for confounding

Sociodemographic and Clinical Characteristics at Transition

(N=36, aged 18-26 [mean=23] years)



Post-transition Mortality

- ❖ Post-transition mortality: 18% (nine out of 51 patients who transitioned between January 2003 and September 2012).
- ❖ All 9 participants had died of HIV-related causes.
- ❖ Five out of nine (56%) died within one year of their last pediatric visit.
- ❖ Median post-transition survival time was 195 days (range 13-2,142 days).

Characteristics of PHIV young adults at transition who died post-transition

#	Gender	Race/ Ethnicity	Transition year	Transition age (years)	CD4 Count (cells/ μ l)	Viral load (copies/ ml)	Hospital stay pre-trans. year (days/times)	Survival time (days)	Pediatric clinical notes
1	Female	Haitian	2004	18	143	83,800	unavailable	2,142	"Unwilling to take meds. Does not want to discuss it."
2	Female	Hispanic	2007	19	<20	500,000	63 (6)	152	"Multi-drug use." "Extremely non-compliant."
3	Male	Haitian	2008	23	<20	33,400	5 (1)	1,167	"Does not keep his appointments."
4	Female	A.A.	2010	24	157	1,613	12 (2)	1,614	"Could not understand viral loads and explain it."
5	Female	A.A.	2010	22	157	210,812	86 (13)	83	"Multi-drug use." "Does not keep appointments."
6	Male	A.A.	2011	23	<20	15,416	49 (5)	13	"Huge compliance issues."
7	Male	A.A.	2012	23	<20	4,870,720	142 (15)	195	"Chronic non-compliance."
8	Male	A.A.	2012	23	<20	11,437	15 (2)	180	"Patient is not motivated to get any treatment."
9	Male	Haitian	2012	24	<20	238,581	32 (3)	413	"Does not believe he has the virus."

Factors NOT Significantly Associated with Post-Transition Death

Characteristics at time of transition	Died # (%)	Total	Risk ratio (95% C.I.)	P value
Male Gender	5 (28)	18	1.25	>0.99
Female Gender	4 (22)	18	(0.40-3.91)	
Non-Hispanic Black	8 (27)	30	1.6	>0.99
Hispanic	1 (17)	6	(0.24-10.54)	
Foreign-born	1 (17)	6	0.63	>0.99
US-born	8 (27)	30	(0.09-4.12)	
Married/in relationship	4 (27)	15	1.12	>0.99
Single	5 (24)	21	(0.36-3.49)	
Mother deceased	6 (20)	30	0.4	0.30
Mother alive	3 (50)	6	(0.14-1.17)	
Household income below FPL	6 (35)	17	2.2	0.34
At or above FPL	3 (16)	19	(0.66-7.58)	
Medicaid insured	8 (32)	25	3.5	0.30
Not Medicaid insured	1 (9)	11	(0.50-24.84)	

Factors Associated with Death (n=9) after Transition to Adult HIV Care (N=36)

Characteristics at time of transition	Died # (%)	Total	Risk ratio (95% C.I.)	P value
Viral load >1000 copies/ml	9 (43)	21	-----	.006
≤1000 copies/ml	0	15		
CD4 count <100 cells/μL	6 (67)	9	6.0 (1.9-19.2)	.005
≥100 cells/μL	3 (11)	27		
Employed (<i>adjusted for CD4 Count</i>)	1 (5)	20	0.2 (0.04-0.88)	.02*
Unemployed	8 (50)	16		
< High School/GED (<i>adjusted for CD4 Count</i>)	4 (57)	7	3.0 (1.4-6.4)	0.07*
High school/GED	5 (17)	29		
<i>Transition Year Before 2008</i>	2 (20)	10	0.7 (0.18-2.99)	>0.99
<i>During or after 2008</i>	7 (27)	26		
<i>Attended Transition Clinic</i>	6 (32)	19	1.8 (0.53-6.07)	0.56
<i>Did not Attend</i>	3 (18)	17		

*Mantel-Haenszel Chi-Square

No (Real) Association between Transition Clinic Attendance and Mortality (Stratified Analysis)

- ❖ All (9) who died were severely immunosuppressed (6) or extremely poor (3).
- ❖ These participants were more likely to attend the transition clinic.
- ❖ When analysis was stratified by CD4 count and poverty, mortality risk was identical in attenders and non-attenders (42.9% vs 42.9%).

A) CD4+ T-lymphocyte count <100 cells per μL or living in poverty

Characteristic	# died (%)	RR (95% CI)	P-value
Attended transition clinic	6/14 (42.9)	1.0 (.35,2.9)	>0.99
Non-attender	3/7 (42.9)		

B) CD4+ T-lymphocyte count \geq 100 cells per μL and not living in poverty

Characteristic	# died (%)	RR (95% CI)	P-value
Attended transition clinic	0/5 (0)	-----	----
Non-attender	0/10 (0)		

Study 2.

**Purpose: Assess changes in engagement in
adult HIV care compared to pediatric care
&
examine the effectiveness
of a comprehensive transition program**

Methods

- ❖ **Participants:** eligible & consenting transitioned patients from the Miami pediatric clinic (n=27) and patients who had died ≥ 1 year post-transition (n=4)
- ❖ **Measures obtained from patient medical records included:**
 - Outcome variables:* Kept appointments with HIV provider in 3 observation periods:
 - pre-transition year
 - year 1 post-transition
 - year 2 post-transition
 - Two retention measures:
 - number of kept visits in 12-month period
 - visit constancy (at least one kept visit every 3 months)
 - Independent variables:* sociodemographic and clinical factors, and transition program exposure
- ❖ **Statistical analysis:** similar to mortality study

Number of Kept HIV Appointments during Health Care Transition (3 Observation Periods)

Period	N	Median Number of Kept Appointments (Interquartile Range)	Median Difference (Interquartile Range)	P
Last Pre-transition year (Pediatrics) 1 st Year Post-Transition	25	5.0 (4.0- 6.0) 2.0 (1.0-10.0)	3.0 (0-4.0)	.002
1 st Year Post-Transition 2 nd Year Post-Transition	20	2.0 (1.0-4.0) 3.0 (1.0-4.0)	1.0 (0-1.0)	.78

Factors NOT Significantly Associated with Regular Engagement in Adult HIV Care, One Year Post-Transition

Characteristic at time of transition	N	Regular: ≥ 1 kept visit in 3 or 4 quarters (%)	P-value
Male Sex			
yes	14	2 (14)	.12
no	12	6 (50)	
Married/in relationship			
yes	14	6 (43)	.31
no	12	2 (17)	
Completed high school/GED			
yes	4	1 (25)	>.99
no	22	7 (32)	
Employed			
yes	16	6 (38)	.62
no	10	2 (20)	

Characteristic at time of transition	N	Regular: ≥ 1 kept visit in 3 or 4 quarters (%)	P-value
Lived with extended family	10	4 (40)	.70
Not living with family	16	4 (25)	
Medicaid insured			
yes	18	7 (39)	.38
no	8	1 (13)	
CD4 T-cell count <200 (cells/mm ³)			
yes	9	2 (22)	.83
no	17	6 (35)	
Viral load			
≥ 1000 copies/ml	14	2 (14)	.12
< 1000 copies/ml	12	6 (50)	

Factors Associated with Regular Engagement in Adult HIV Care, One Year Post-Transition

Characteristic at time of transition	N	Regular: ≥1 kept appointment(s) in 3 or 4 quarters (n (%))	P-value
Black non-Hispanic			
yes	21	4 (19)	.04
no	5	4 (80)	
Income ≤ FPL			
yes	12	1 (8)	.06
no	14	7 (50)	
Attended transition clinic			
yes	15	2 (13)	.07
no	11	6 (55)	
Transitioned after Jan. 2008			
yes	21	7 (33)	>.99
no	5	1 (20)	

No Association between Transition Clinic Attendance and Post-Transition Engagement in Care, when Controlled for Poverty

- Participants who attended the transition clinic were more likely to have a higher viral load ≥ 1000 copies/ml (92%) or to live in extreme poverty (100%) compared to non-attenders (40%; $p=.02$, 42%; $p=.005$, respectively)
- When stratified by severe poverty (Income \leq FPL) association no longer approached stat. significance.

Household Income \leq FPL

Characteristic	Regular (≥ 1 Kept Appt. in 3-4 Quarters)	P-value
Attended transition clinic	1/10 (10%)	>.99
Non-attender	0/2 (0%)	

Household Income $>$ FPL

Characteristic	Regular (≥ 1 Kept Appt. in 3-4 Quarters)	P-value
Attended transition clinic	1/5 (20.0%)	.27
Non-attender	6/9 (66.7%)	

Crude Prevalence Ratio (PR)=.24 95%CI=.06-.99; $p=.07$. Adjusted PR=.38 (.07-2.1); $p=.39$

Study 3

**Mixed-methods study of post-transition experiences
to assist with:**

**interpretation of quantitative findings (WHY?) &
formulation of transition program recommendations
(WHICH changes?)**

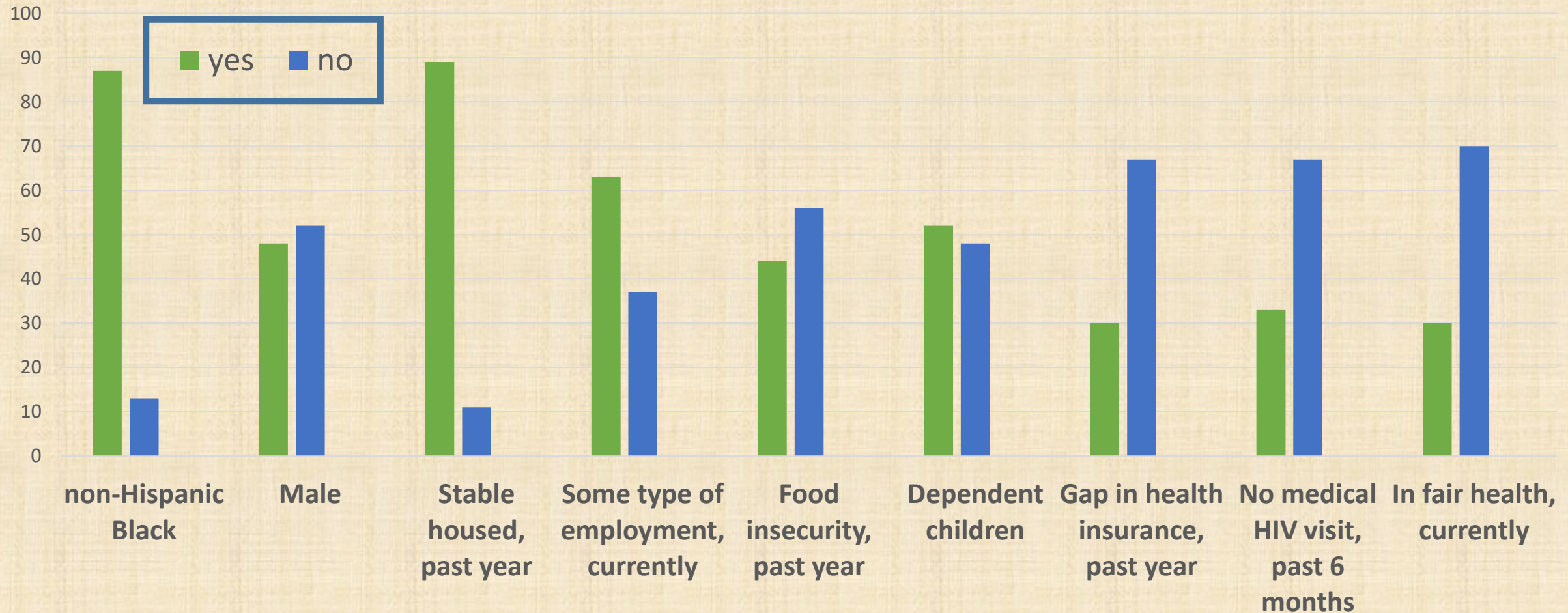
Methods

- ❖ **Research Design:** Mixed-methods explanatory (concurrent) research design
- ❖ **Research Instruments:**
 - Pretested computer-assisted survey, with close and open-ended questions. The survey was administered at the pediatric clinic, and was followed by:
 - Short debriefing interview. Notes and verbatim quotes were written down during or soon after the interview.
- ❖ **Measurements:**
 - *How are transitioned patients doing?*
Sociodemographic information including: family composition, income (with food insecurity as a proxy measure of current poverty), housing, employment, health status, and gaps in medical insurance in the past 12 months.
 - *What were their transition experiences?*
Questions to assess and explore transition experiences and experiences in adult HIV care.

Qualitative Analysis

- ❖ **Thematic Analysis** to systematically analyze qualitative data.
- ❖ **Validation:**
 - Multiple coding by different researchers.
 - Coding was conducted by two researchers with HIV-related experience (but not with PHIV young adults) to minimize preconceived notions and expand on alternative explanations.
 - Third researcher (with clinical and research experience with PHIV adolescents) reviewed the analysis and helped to explore associations between core findings, established literature and theoretical perspectives.
 - De-briefing interviews

Sociodemographic and Clinical Characteristics of Transitioned PHIV Young Adults (*N=27, aged 25-34 [mean=27] years*)



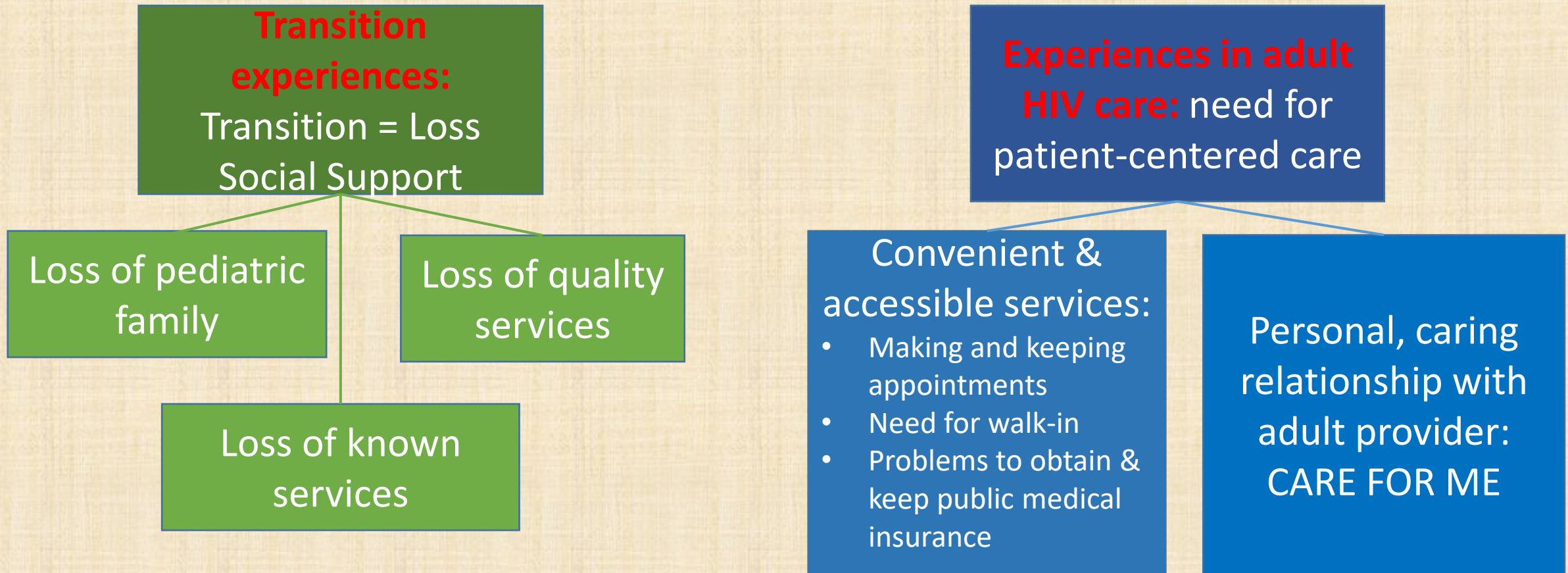
Problems Post-transition (N=27)

Although most participants (23 out of 27 [85%]) reported pediatric clinic staff had been very helpful in preparing them for transition and had discussed a transition plan with them, transition was more difficult than anticipated for many (11 out of 27 [41%]). Only 47% of transition clinic attendants felt this intervention was helpful.

Problems post-transition	N (%)
It has been difficult for me to do well in adult HIV care	16 (59)
Problems finding HIV provider	8 (30)
More difficulties to take meds as prescribed	12 (44)

Problems post-transition	N (%)
More medical needs or complications	11 (41)
Problems with medical insurance	11 (41)
Difficulties finding supportive services	10 (37)

Transition Experiences & Experiences in Adult HIV Care: Themes based on participant's descriptions



Transition Experiences:

Transition = Loss

Loss of (pediatric) family

*“You practically raised here. They have become like family.”
(Hispanic male, transitioned 8 years ago)*

*“Now I ‘m basically alone but I guess I am getting older.”
(Haitian male, transitioned 1 year ago)*

*Transition was easy “because of the support system I had with my family.”
(A.A. female, transitioned 1 year ago)*

Loss of supportive, quality care

“They are here for you. They help us a lot more.” (A.A. male, transitioned 1 year ago)

Loss of known, familiar care

*“I really did not think it would be so different. Until it hits you. I was not coping too much. Its like going from high school to college.”
(A.A. male, transitioned 3 years ago).*

Experiences in Adult HIV Care: Needs for Convenient and Accessible services.

Problems with making and keeping medical appointments

“Need help to remind me of appointments with the doctor cause I tend to forget”
(Haitian male, transitioned 2 years ago)

“I did not know how to do it. Now they make them [appointments] for me.”
(A.A. female, transitioned 4 years ago)

“Amazing doctor, took amazing care of me. Problem was to get into her office to see her. She did not pick up the phone” *(Hispanic male, transitioned 2 years ago).*

Need for easy access/walk in

“In the adult clinic you were just a number. You cannot just show up.”
(A.A. male, transitioned 4 years ago)

“ I can call him [adult provider] whenever, he calls me back, puts me on the list when I need to see him. He is personal.” *(A.A. female, transitioned 10 years ago)*

Experiences in Adult HIV Care: Need for Accessible Public Medical Insurance

Problems in navigating (public) medical insurance

“Ryan White is a nightmare over here. It’s much easier in Broward. I tell everyone to move.” *(Haitian female, transitioned 3 years ago)*“

“They [Medicaid] made it very difficult for me to enroll again.”
(A.A. male, transitioned 4 years ago)

“ It wasn’t too bad for me because I had private health insurance through my job and was able to choose a really good doctor. I have heard some of the experiences other people had and they were not good experiences so I am glad I was able to avoid that.”
(Haitian female, transitioned 3 years ago)

Experiences in Adult HIV Care: Unmet Need for Personal, Caring, Relationship with Adult Physician.

Relationship with adult HIV Provider (“care for me”)

“I need someone who takes time for me. AIDS is not just a disease, but it influences everything. My doctor now understands that. ...He is interested in me.” (Haitian female, transitioned 8 years ago).

*“Now we are adults they do not care anymore”
(A.A. female, transitioned 3 years ago).*

“ They do not care for you [in adult care]. You just lose interest in that part of your life.” (A.A. male, transitioned 3 years ago)

*“They just went through the motions. If they care you will take better care of yourself also.”
(A.A. female, transitioned 10 years ago)*

Qualitative Analysis of Experiences with Transition and in Adult HIV Care

Themes	Participant's experiences are influenced by environmental & personal determinants	Theoretical and program implications
Transition = Loss of social support	<ul style="list-style-type: none"> ❑ Poverty & living in impoverished neighborhoods with limited resources ❑ HIV/AIDS stigma is barrier to social support. PHIV youth are hidden, socially isolated population ❑ No continuity between pediatric & adult HIV care, and fragmented adult services 	<p>1. Narrow focus on self-management and transition preparation leads to limited attention for other factors that may influence behavior. <i>Or: it's not just the patient!</i></p>
Need for patient-centered adult HIV care	<ul style="list-style-type: none"> ❑ Inadequate funding to address needs of low-income patients with complex medical & social needs ❑ Systemic barriers prevent access and service utilization ❑ High provider-patient ratio with disease focused "impersonal" relationship ❑ High levels of self-management skills assumed & required. 	<p>2. Instead: <u>multilevel theory</u> and <u>systematic planning model</u> to address barriers to access and consistent use of adult HIV services.</p>

Answers to the Research Questions

❖ What were the outcomes of transitioned PHIV young adults?

Our research suggested that transitioned PHIV young adults are at risk for poor health outcomes. We observed:

- High post-transition mortality (18%), particularly in participants who were in poor health, unemployed, or uneducated at time of transition
- Engagement in HIV care was significantly higher in the comprehensive pediatric clinic than in adult HIV clinics, but no changes between 1st and 2nd post-transition years.
- The first post-transition year seemed to be crucial to establish care engagement behavior for PHIV young adults, and may be predictive of subsequent care engagement.

Answers to the Research Questions

❖ What were the effects of the transition program?

- Patients in poor health at transition, non-Hispanic black or very low-income patients may be at greater need of transition support.
- This research did not find evidence that the transition program affected mortality or engagement in adult HIV care.

Limitations

- ❖ Preliminary, explorative study.
- ❖ Single site limits generalizability; small sample size reduced power.
- ❖ Ineligibility and non-participation of 15 living patients.
- ❖ Retrospective study design:
 - measures of association (and not causation)
 - use of existing data came with risk of missing information on potential relevant factors (f.e. depression, substance use)
 - participants' descriptions may have been influenced by recall bias.

Program Recommendations

❖ How can the transition program be improved?

1. Use planning models to systematically develop theory-based, multi-level programs.
2. Do not isolate transitioning patients. Prepare & transition patients in cohorts, with group-level interventions to allow for mutual support and empowerment
3. Continue groups and support in the 1st post-transition year; co-manage with pediatric and adult staff.
4. Increase capacity of adult HIV services to facilitate transitioned patients. Explore strategies to increase:
 - continuity between pediatric and adult HIV care. Examine models to offer pediatric and adult care at the same site, with shared comprehensive services; create a network of adult providers willing to meet the needs of transitioned PHIV young adults
 - capacity of the adult care system to deliver patient-centered, comprehensive care for low-income patients with complex medical and social needs.

Thank You

**I welcome your questions
and comments**

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