Transitioning Youth from Adolescent to Adult HIV Care: Best Practices, Outcomes and the Experiences of Three Programs

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Disclosures

Presenter has no financial interest to disclose.

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Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. To become familiar with the clinical and psychosocial issues of different HIV+ youth populations (perinatally infected vs. behaviorally infected) as they approach the age of transitioning from adolescent/young adult HIV care to adult HIV care
2. To become familiar with the differences in HIV care models between pediatric, adolescent and adult HIV care clinics and how developing bridges between these care models can facilitate effective transitioning processes
3. To address specific strategies HIV care programs can develop with respect to effective transitioning services and programming

Obtaining CME/CE Credit

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University of Miami: Program Demographics

- 1981 - First perinatal pediatric cases seen by Dr. Gwendolyn Scott
- 1986 – SW / Nursing Case Management Model
- 1988 – Pediatric Healthcare Demonstration Project (13)
- 1994 – Ryan White Title IV
- 1994 – UM Division of Adolescent Medicine receives first cases of behaviorally – infected youth

- Currently 112 HIV-infected infants, children and youth in Part D project
- 22 = 0 - 12, 19 = 13 – 17,

  71 = 18 – 24
- Of 71, 16 are pre-transition 23 years of age
- 12 were transitioned at age 24

2003 - 2018

Pregnancies:

- 69 females had 132 pregnancies, 99 live births
- 23 males – of 33 pregnancies, 30 live births
- Three sets of perinatal youth coupled and were married

Transition:

- 2004 – three youth were > age 24 (<u>transferred</u> to adult service)
- 2007 – 2018, 158 youth have been transitioned
- 2013 – 2017 peak years with an average of 20 youth/yr (born between 1989 and 1993)

BEST PRACTICES

How To Develop a Transition Model

- Determine what will be your program's age for transition
- Run the caseload and project how many patients are to be transitioned each year
- How many will be pre-transition age (23 or older)?
- Research the literature and 'pediatric chronic illness' models
- Run focus groups: patient, parent/guardians and program staff
- Assess for transition readiness from all three groups
- Which model is best for your site?

Peds to Adolescent Med to Adult

Peds to Med-Peds to Adult

Peds to Adult

Transition Preparation

	Discussed	Achieved
Help identify appropriate adult HIV provider		
Discuss transfer to case management services		
Discuss linkage to other supportive services, if needed		
Review most important medical history		
Discuss adherence problems and review strategies		
Discuss social support network & ways to seek social support		
(Refer to) counseling to talk about sexual identity (if relevant for client)		
Discuss disclosure, and offer help if wanted.		
Discuss education plan, if needed		

How To Develop a Transition Model

- Begin transitioning conversation early
- Many will need *extra* education and reinforcement (low cognition)
- If the staff are struggling to let go – offer them extra support
- Patient Navigator's role crucial to the process – follow the patient for one year post-transition
- Establish relationships with adult providers who *REALLY* like challenging patients
- Develop transition protocols so everyone is on the same page

EVALUATION

The Pediatric Hand-Off

2012: HRSA Supplemental funding to evaluate pediatric transition

Goals:

- identify the attributes of transitioned patients, including both perinatally and behaviorally HIV-infected young adults
- assess if patients <u>successfully</u> transitioned from pediatric/adolescent to adult care
- describe factors, including but not limited to participation in the transition process, associated with transition outcome

The Pediatric Hand-Off

- Transition period:
  Jan 1, 2003 – September1, 2012
- N= 51 / 104 (deceased, severe cognitive impairment, incarcerated, moved from area, whereabouts unknown, refused)
- Collected: primary care history; socio-demographic data; health status (AIDS dx, ARVs, co-morbidities)

- Methodology:
  - Patient questionnaire - transportation and insurance barriers, obtaining social (support) services, issues related to school, family or employment, housing instability and food insecurity; and b) patient satisfaction with current medical adult HIV-care. Additional (outcome) questions include: participant's self-reported current health status, hospitalozations, frequency of recent medical appointments (past 3 and 6 months), and number of emergency room visits past 12 months;
  - Chart abstraction and focus groups

Outcomes

"Those who do well in Pediatrics, will do well in adult care…most will make it, many won't"

- 9/51 patients expired within a year of last pediatric visit
- The 1st post-transition year seemed to be crucial to establish care engagement behavior, and may be predictive of subsequent care engagement
- Non-Hispanic Black or very low-income patients may be at greater need of transition support, exposure to transition interventions did not appear to be sufficient

"I really did not think it would be so different…until it hits you…"

- Transition = loss of social support
- Loss of pediatric family
- Loss of known & quality services
- Need for patient-centered care

Retention in Care

2017: HRSA Supplemental funding to *improve* retention in adult HIV care and viral load suppression in transitioned youth

- focus groups with transitioned youth (experiences with adult provider?)
- focus groups with key staff involved with transition process (peer educators, patient navigator, care coordinators, nurses, social workers, pediatricians
- team meeting with *four* of *nineteen* adult providers (seven agencies) and their care teams to assess gaps, needs and successes with transitioned patients
- develop a mobile application through which pediatrics can assist with facilitating services with transitioned youth throughout the first year post-transition period
- develop an adolescent-friendly website promoting HIV testing, health education and referral services

Transitioning Data

Viral load and CD4 Count: Last Labs before Transition 2016 – June 2018

	2016	2016	2017	2017	2018 (Jan-June)	2018 (Jan-June)
	Peds N=18	AM N=16	Peds N=20	AM N=13	Peds N=6	AM N=5
Viral load <200 copies/mL	50% (9)	81% (13)	60% (12)	54% (7)	17 % (1)	80% (4)
CD4 cell count >500	33 % (6)	44% (7)	55% (11)	69% (9)	67 % (4)	40 % (2)

Co-Morbidities Transitioned Clients 2016 – June 2018

	2016 N=34			2017 N=33			2018 (Jan.- June) N= 11		
	Perinatal	Behav.	Other	Perinatal	Behav.	Other	Perinatal	Behav.	Other
Severe	11	-	1	6	1	-	2	-	-
Moderate/mild	1	6	-	3	5	-	1	-	-
None	2	13	-	4	14	-	2	6	-
Total	14	19	1	13	20	0	5	6	0

Co-Morbidities

Severe co-morbidities:

HIV nephropathy, HIV encephalopathy, HIV cardiomyopathy, HEP C, and severe mental health diagnoses (including schizophrenia and mental retardation)

Moderate co-morbidities:

obesity, metabolic syndrome; LTBI or gynecomastia were considered to be mild co-morbidities

Less severe mental health disorders (anxiety, depression) are not included.

Summary

- From January 2016 - June 2018, the majority of clients transferred to adult settings in the community, and not to the nearby public hospital (Jackson Memorial)
- Underutilization of JMH Transition Clinic: only 15% of all clients transitioned to the transition clinic 2016 - 2017
- Linkage to adult care – (clients keeping their first appointment with the adult provider) - was successful: most pediatric clients kept their first appointment with their adult provider (89% of clients in 2016, and 85% in 2017)
- Pediatric clients got disengaged from adult care in the first post-transition year (~ 33% in 2016 and 45% in 2017)

Outcomes

Transition Protocol:

- What are the transition and adult services provided?
- Who are the transition contact persons
- Transfer of medical records (in person/electronically, and which medical information is needed)
- Transfer of case management services if needed
- New patient visit appointment: appointment made by transition staff before the patient transitions (within 3 months after the last visit with the pediatric/adolescent provider)
- New patient visit: transition staff accompany patient for 1st visit if desired
- Patient (loosely) followed by pediatrics for first year post-transition

Outcomes

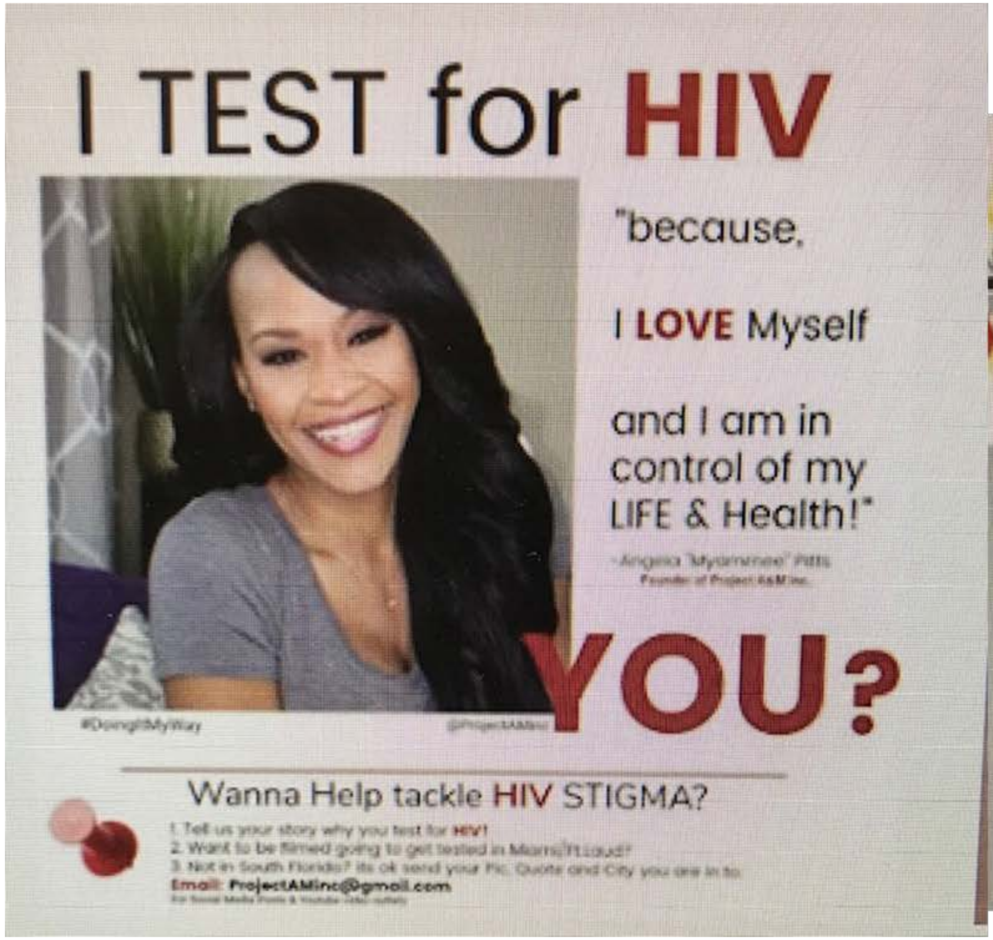
- Development of mobile app OhMD!

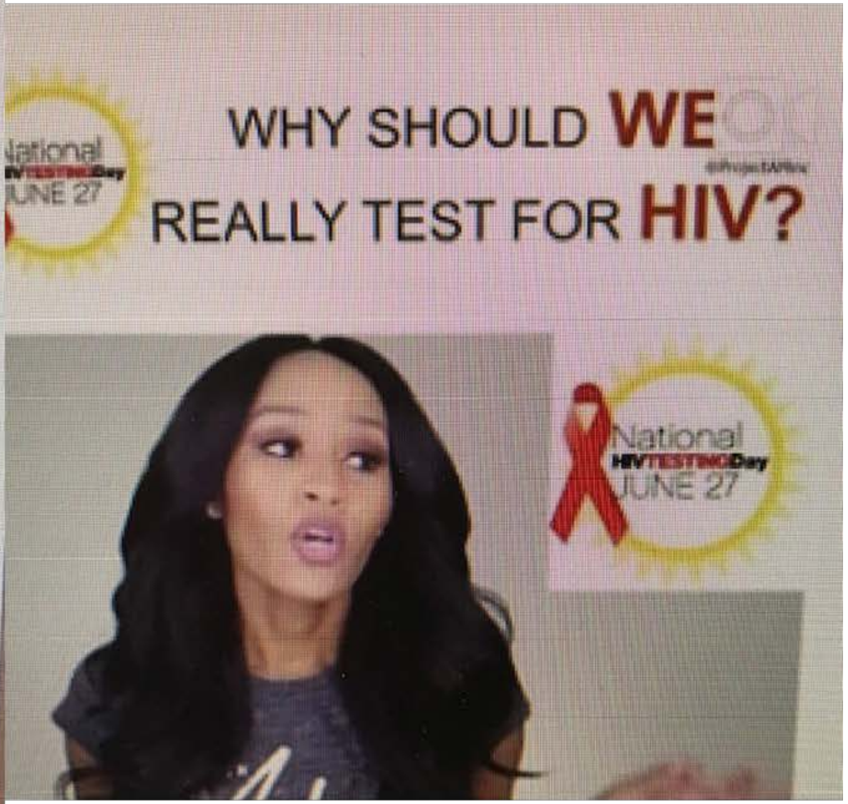
  secure 2-way communication (not a chat room)
- Focus group participants requested support groups/peer support
- Development of short informational / educational videos (Angela “Myamee” Pitts)
- Update existing website for Adolescent Counseling & Testing Site (ACTS)

What is the best way to stay in contact post-transition?

No: will not pick up if number is unknown; participants change phone #, forget # of clinic: have thousands e-mails in mail box

Yes: easier accessible when it suits participants; confidential.


I TEST for HIV
"because,
I LOVE Myself
and I am in control of my LIFE & Health!"
YOU?
Wanna Help tackle HIV STIGMA?
1. Tell us your story why you test for HIV!
2. Want to be filmed going to get tested in Miami/Ft.Laud?
3. Not in South Florida? its ok send your Pic, Quote and City you are in to:
Email: ProjectAMinc@gmail.com


National HIV TESTING Day JUNE 27
WHY SHOULD WE
REALLY TEST FOR HIV?
National HIV TESTING Day JUNE 27

Promote to Prevent: ACTS – Adolescent Medicine

https://promote2prevent.org/

Take Away Message….

- Duplicate models that work
- Ask your patients – *observe* (the power of focus groups)
- Evaluate your activities
- HRSA can be your best friend…..ask for supplemental funding