

Women who acquired HIV perinatally or early in childhood

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National Woman and Girls' HIV/AIDS Awareness Day Event

March 10th, 2021

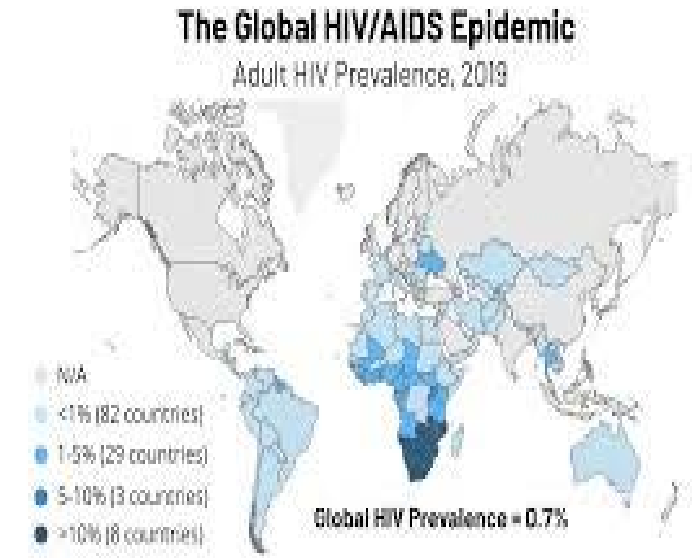


Disclosures

- Gilead scientific advisory board, site investigator under clinical research contract managed through JHU
- Merck scientific advisory board, consultant, site investigator under clinical research contract managed through JHU

Objectives

- Epidemiology of population of women with perinatal or early childhood acquired HIV
- Highlight unique aspects of women with early infection (developmental, neurocognitive, biologic, psychosocial and societal factors)
- Discuss clinical, research, and societal needs to optimize outcomes



The First Pediatric Cases



The First Pediatric Cases

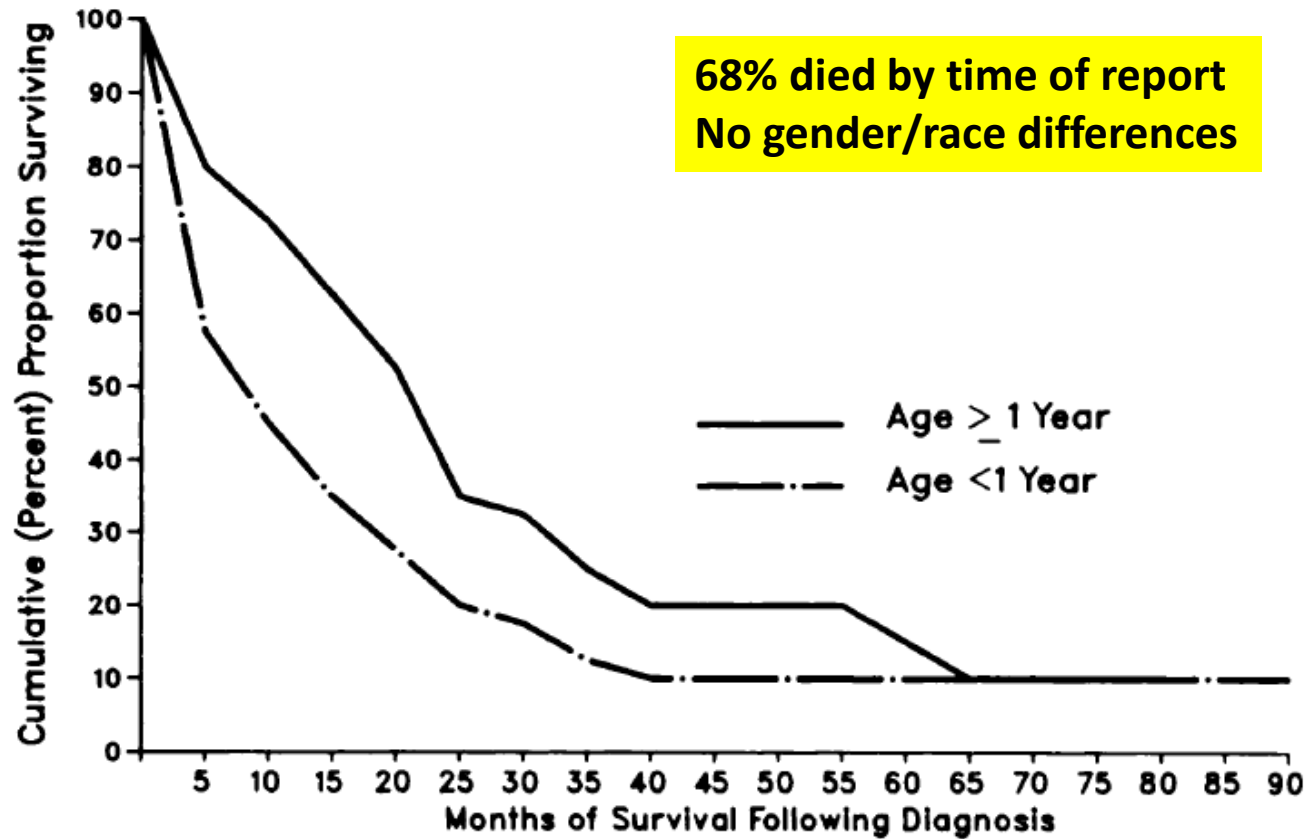


Fig 6. Survival time after diagnosis of AIDS in children less than 13 years of age in whom AIDS was diagnosed as of Dec 31, 1981, and reported to the Centers for Disease Control.

Natural history

- Symptoms develop over months to years
- 25% rapidly progress to AIDS (1st year of life)
- 75% experience slow progression
- 25% mortality by age five
- Annual rate of disease progression (6-8%)

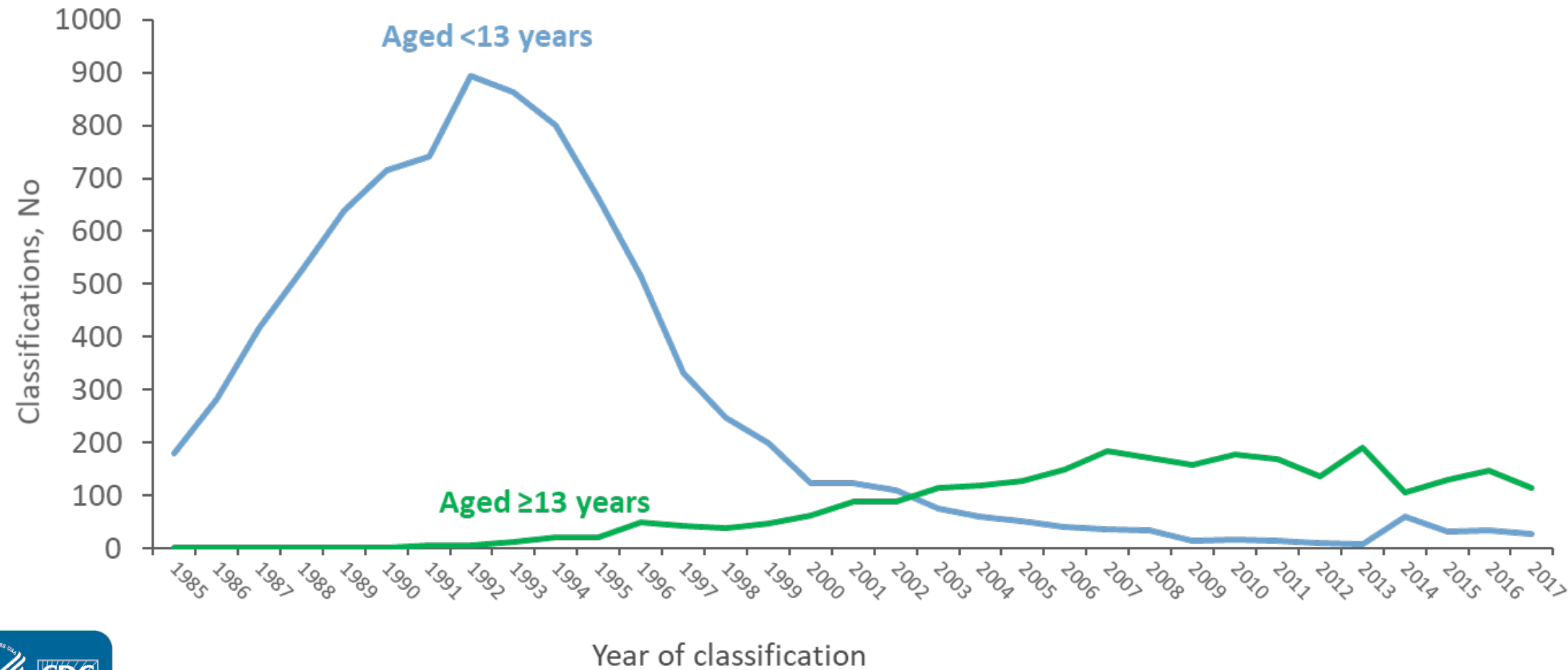
“although they make up only 1% of AIDS patients, they have unique clinical, social, and public health problems that require special attention.” Rogers

Advances → Improved Outcomes



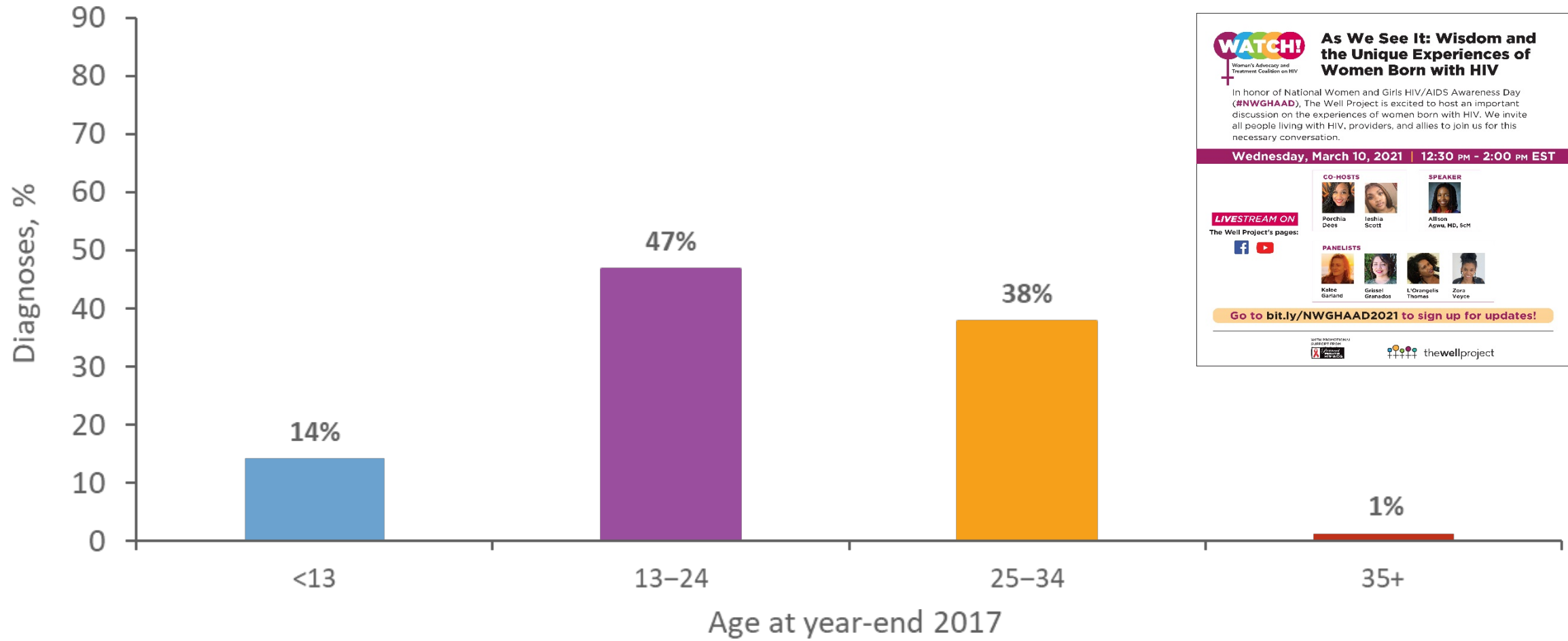
- Diagnostic tools
 - Safe blood supply
 - Earlier diagnostics
- OI prophylaxis and treatment
 - immunizations
- Prevention of maternal to child transmission
- Identification, management, and prevention of co-morbidities
- Antiretroviral therapy

Stage 3 (AIDS) Classifications among Persons with Perinatally Acquired HIV Infection, 1985–2017—United States and 6 Dependent Areas



Age Distribution of Persons Living with Diagnosed Perinatally Acquired HIV Infection, Year-end 2017—United States and 6 Dependent Areas

N = 11,924



WATCH!
Woman's Advocacy and Treatment Coalition on HIV

As We See It: Wisdom and the Unique Experiences of Women Born with HIV

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Wednesday, March 10, 2021 | 12:30 PM - 2:00 PM EST

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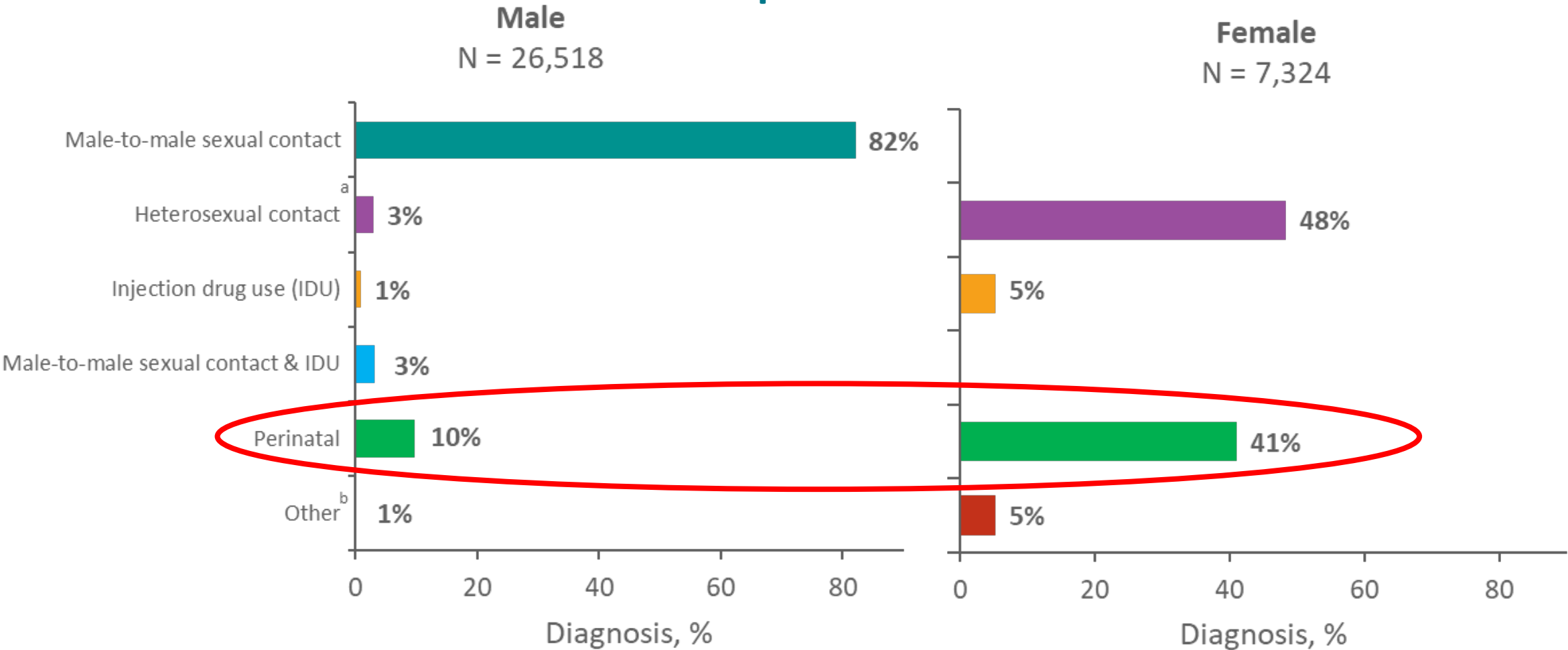
SPEAKER
Allison Agwa, MD, SCM

PANELISTS
Kalee Garland
Grisel Granados
L'Orangelis Thomas
Zora Veyce

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WITH PRESENTATION SUPPORT FROM
HIV Medicine Foundation
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Adolescents and Young Adults Aged 13–24 Years Living with Diagnosed HIV Infection by Sex and Transmission Category, Year-end 2017—United States and 6 Dependent Areas



Note. Data have been statistically adjusted to account for missing transmission category cases.

^a Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.

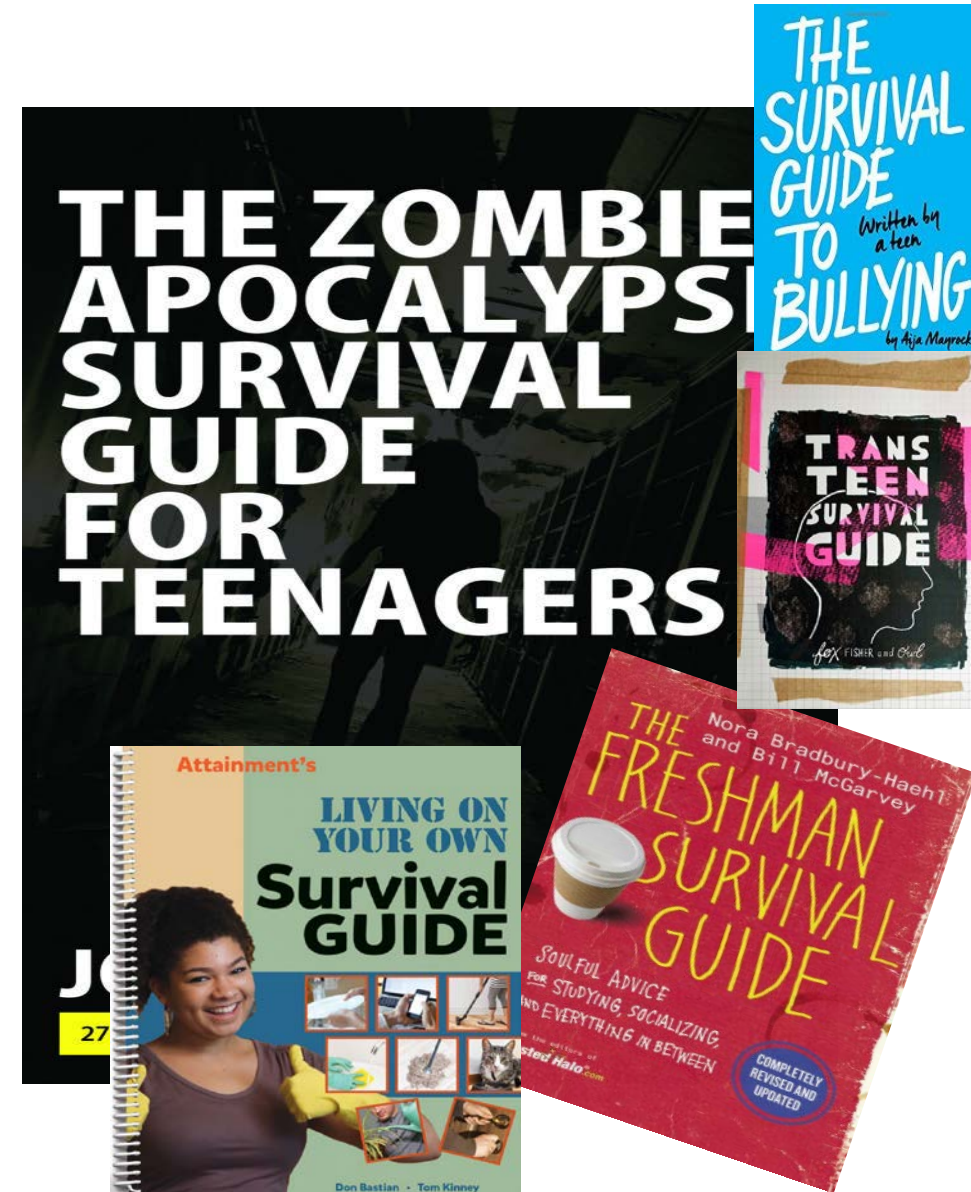
^b Includes hemophilia, blood transfusion, and risk factor not reported or not identified.

Yusuf and Agwu. Adolescents and young adults with early acquired HIV infection in the United States: unique challenges in treatment and secondary prevention. Expert Review of Anti-Infective Therapy. Sep 2020

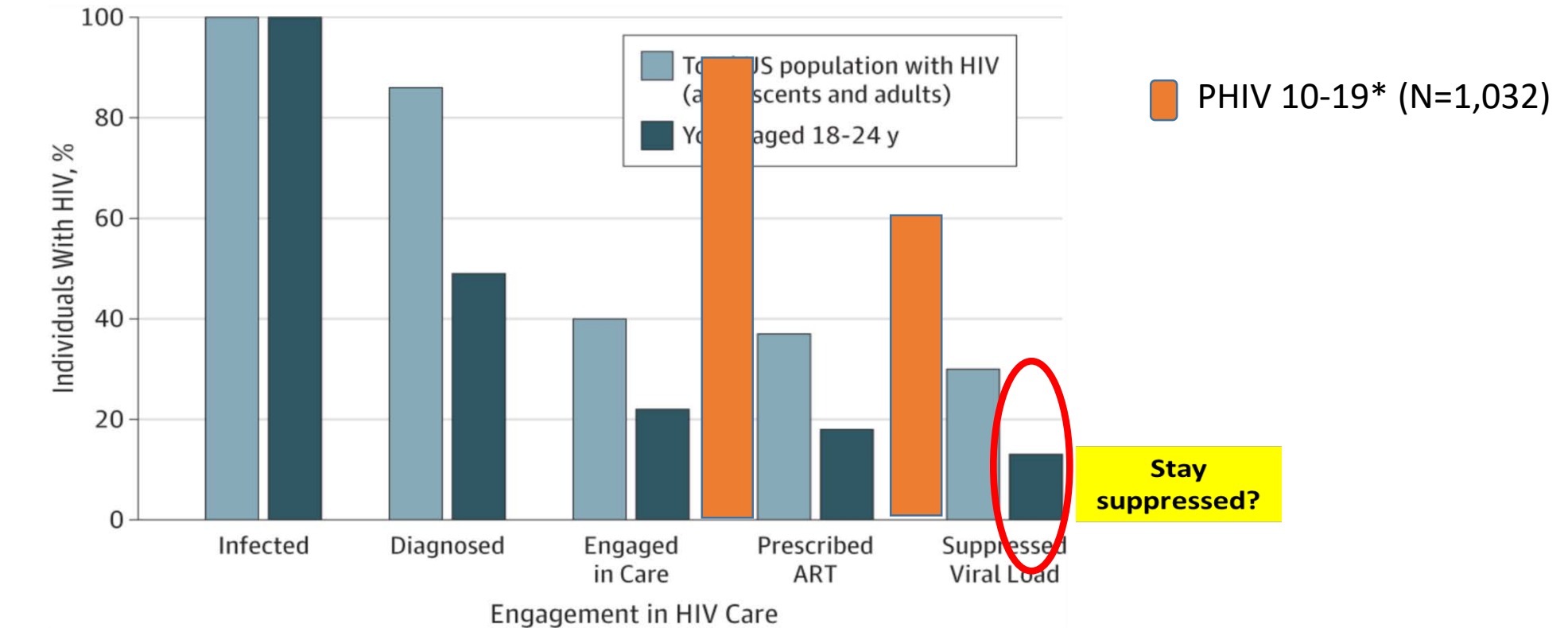


“Survival guide” for women who acquired HIV early

- Find out your diagnosis
- Deal with it
- Take pills every single day forever
- See your provider every 1-6 months
- Blood draws
- Make sure your insurance is active
- Do all of the other life stuff too.....



Continuum of care for youth with HIV infection



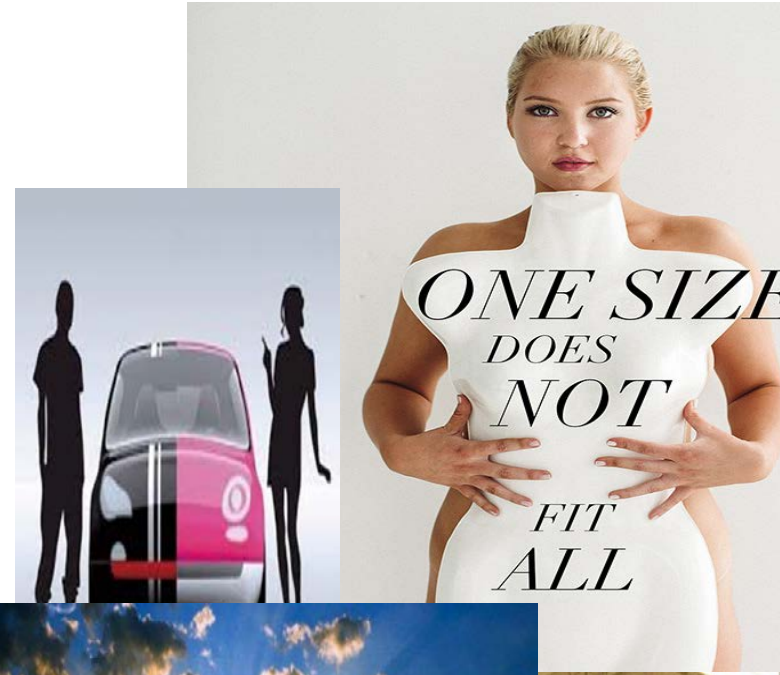
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Wood S, et al. JAMA Pediatr. 2015.

*CIPHER PLoS One 2018

“What are we missing?”

- Life
- Adherence is hard & multifactorial
- Side effects
- Long term toxicity
- One size does not fit all
- Forever is a long time
- Things change
- Fatigue
- Disclosure
- Stigma
- Mental health
- “I don’t want to be here?”
- “This is not my fault!”



Choice
=
Power



Medical challenges

Disease

- Feel normal
- Advanced disease/immunosuppression
- Co-morbidities
- Mental health (anxiety, depression, PTSD), substance use
- Neurocognitive delay and dysfunction
- Delayed puberty and short stature

Treatment

- Treatment experienced
- More complicated ART
- One pill too many!
- Treatment fatigue
- Drug-resistance

Psychosocial challenges

- Stigma (HIV, sexuality, other)
- Disclosure (HIV, sexuality, other)
- Limited support systems
- Poor adjustment to illness/status, self efficacy, outcome expectancy
- Denial/guilt
- Limited health literacy
- Logistic barriers: insurance, children, transportation, housing
- Poverty
- Unemployment/ underemployment
- Attempting to be “normal”



Life Course Perspective for Women with Early Acquired HIV

	2 nd Decade 10-19 years	3 rd Decade 20-29 years	4 th Decade 30-39 years	5 th Decade 40-49 years	≥6 th Decade ≥50 years
					
Environmental/Psychosocial Factors					
Life events	School Trade School/College Employment Parent/guardian loss	Trade School/College Employment Partnerships Children Parent/guardian loss	Employment Partnerships Children Parent/guardian loss	Employment Partnerships Parent/guardian loss	Employment/Retirement Partnerships
Self-management	Parental/caregiver involvement wanes	Self-management			Self-management May need assistance
Disclosure	Disclosure (to self) Disclosure to others	Disclosure of status to partners, children, friends, others			
Stigma	Internal and external stigma				
Treatment and Treatment-related Factors					
Antiretroviral treatment	Simple regimens Increased responsibility of ART	Simple regimen Increased complex regimens due to development of resistance Full responsibility of ART	Simple regimen Increased complex regimens due to development of resistance Full responsibility of ART		
Adherence	May wane with decreased parental/caregiver involvement, stigma and nondisclosure to peers	Adherence variable Increased risk of resistance			





Together, we can change the course of the epidemic...one woman at a time.

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Women with Early Acquired HIV

Submitted on Oct 6, 2020

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How will women with early HIV infection be impacted?

Mental Health

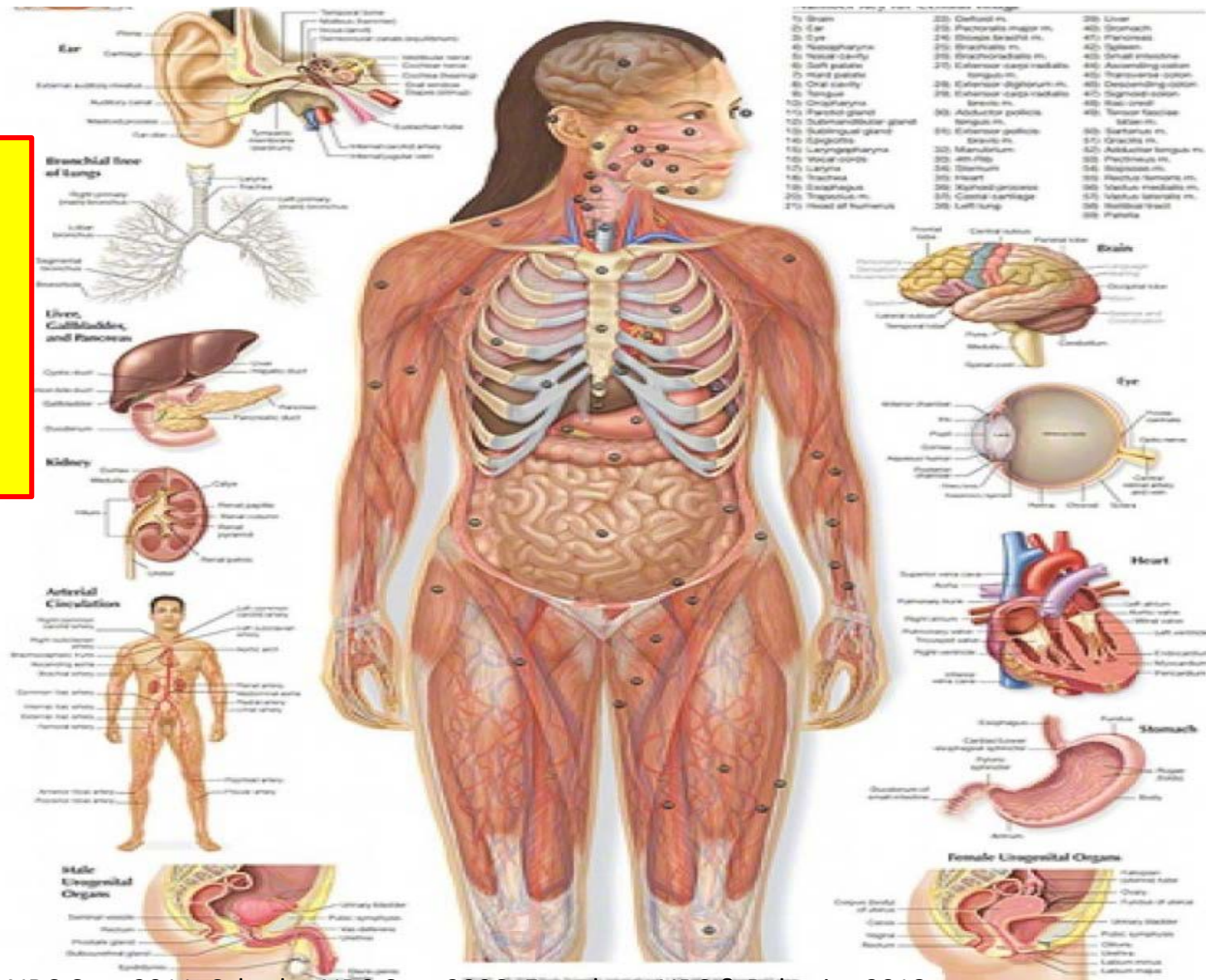
- 25% -60% of PHIV in PHACS had mental health problems (depression, anxiety, ADHD)
- High rates of internalized stigma; associated with depression

Neurocognitive

- Deficits in working memory, executive function, and processing speed.
- Likely defects in visual memory and spatial ability

Fertility and Pregnancy

- No difference in fertility desire or fertility compared to general population
- Antepartum depression rates higher among PHIV (22%) vs. NPHIV 11% vs. HIV- (1%)
- lower CD4 at start of pregnancy; more likely to electively terminate; no differences in pregnancy outcomes



How will we know about emerging morbidity?

- Case reports
- Longitudinal cohort studies?
- Current cohorts*
 - PHACS (AMP Up)
 - CIPHER
 - leDEA
 - NA-ACCORD
 - UK cohorts
 - WIHS
- Modeling studies
 - CEPAC

*not all inclusive; each has limitations



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Lost in the mix.....

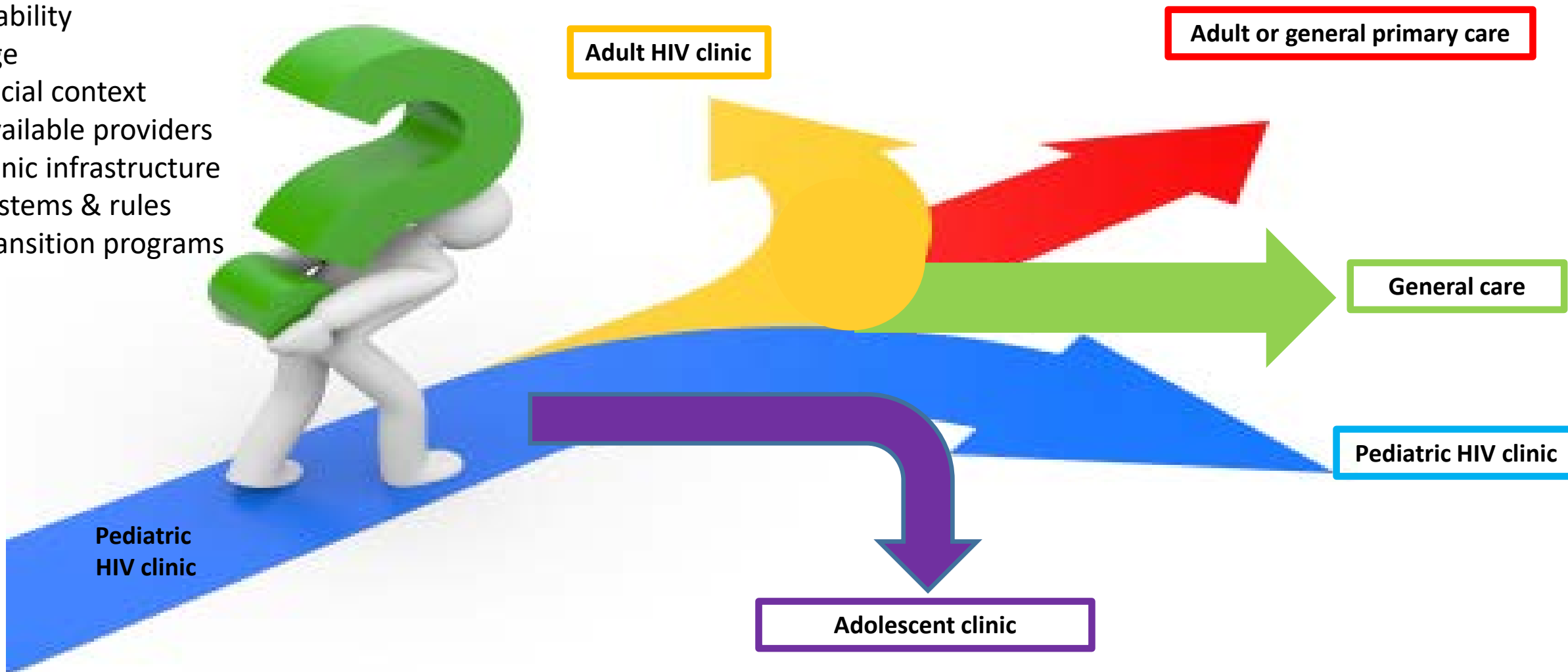
	NADC		MI		ESLD		ESRD	
	No diagnosis (n=60 095)	Diagnosis (n=1405)	No diagnosis (n=29 168)	Diagnosis (n=347)	No diagnosis (n=34 657)	Diagnosis (n=387)	No diagnosis (n=35 365)	Diagnosis (n=255)
Demographics								
Age								
<40 years	29 429 (49%)	317 (23%)	13 749 (47%)	63 (18%)	16 641 (48%)	124 (32%)	16 344 (46%)	94 (37%)
40–49 years	20 584 (34%)	550 (39%)	10 217 (35%)	144 (41%)	12 474 (36%)	160 (41%)	13 042 (37%)	101 (40%)
50–59 years	8 239 (14%)	390 (28%)	4 220 (14%)	106 (31%)	4 528 (13%)	80 (21%)	4 835 (14%)	41 (16%)
≥60	1 843 (3%)	148 (11%)	982 (3%)	34 (10%)	1 014 (3%)	23 (6%)	1 144 (3%)	19 (7%)
Male	46 330 (77%)	1 093 (78%)	23 475 (80%)	298 (86%)	27 354 (79%)	334 (86%)	27 974 (79%)	178 (70%)
Race and ethnicity								
White	25 075 (42%)	692 (49%)	13 429 (46%)	193 (56%)	14 560 (42%)	207 (53%)	15 022 (42%)	30 (12%)
Black	21 658 (36%)	534 (38%)	10 831 (37%)	123 (35%)	11 693 (34%)	108 (28%)	11 452 (32%)	205 (80%)
Hispanic	7 683 (13%)	111 (8%)	3 106 (11%)	20 (6%)	4 379 (13%)	43 (11%)	4 756 (13%)	12 (5%)
Other	3 033 (5%)	44 (3%)	1 308 (4%)	10 (3%)	1 269 (4%)	7 (2%)	1 333 (4%)	1 (0%)
Unknown or missing	2 646 (4%)	24 (2%)	494 (2%)	1 (0%)	2 756 (8%)	22 (6%)	2 802 (8%)	7 (3%)
HIV transmission risk								
MSM	31 370 (52%)	742 (53%)	16 103 (55%)	193 (56%)	17 514 (51%)	180 (47%)	17 114 (48%)	67 (26%)
IDU	6 885 (11%)	204 (15%)	2 971 (10%)	44 (13%)	4 231 (12%)	97 (25%)	3 912 (11%)	52 (20%)
Heterosexual contact	15 397 (26%)	343 (24%)	7 559 (26%)	84 (24%)	9 224 (27%)	73 (19%)	9 065 (26%)	108 (42%)
Other, unknown, or missing	6 443 (11%)	116 (8%)	2 535 (9%)	26 (7%)	3 688 (11%)	37 (10%)	5 274 (15%)	28 (11%)



Transition to Adult Care

Variability

- Age
- Social context
- Available providers
- Clinic infrastructure
- Systems & rules
- Transition programs



Factors impacting site selection: region, availability/accessibility, insurance, patient/provider comfort, parental clinic attendance

What are we adult providers seeing?

- Variable transition (ages, rates of “success”)
- Variability in readiness for transition
 - Struggling with multiple components (e.g., appointments, insurance, life)
- Youth poorly engaged in care before have significant risk of falling out of care following transition.
 - YHIV doing well on peds side tend to continue to do well on the adult side
 - Parental involvement helpful, particularly when co-morbidities exist
- Amazing resiliency
- Depression, hopelessness developing (“I have survived..... so now what?”)
- Limited capacity to maintain prior level of support and engagement
- Continued connection with peds side essential
- Interventions that increase awareness of the unique needs of youth essential to building capacity among adult providers and programs.
- Flexibility important
- Where will they go next? (Peds provider caring for 30+ y/o pts)

Where should we be moving?

➤ Multimodal strategies & approaches for treatment, remission

➤ Biologics

- Fewer pills
- Smaller pill size
- Fewer drug-drug interactions
- Fewer side effects
- Fewer dietary requirements
- More formulations
- Better taste
- Higher barrier to resistance
- More options for treatment-experienced individuals

➤ ART next gen (e.g., long-acting, different delivery modes)

➤ Different strategies

- (e.g., monoclonal ab, activated T cells, vaccines)

➤ Cure strategies (e.g., latency reversing agents)

Case Reports > Lancet HIV. 2016 Jan;3(1):e49-54. doi: 10.1016/S2352-3018(15)00232-5.

Epub 2015 Dec 9.

HIV-1 virological remission lasting more than 12 years after interruption of early antiretroviral therapy in a perinatally infected teenager enrolled in the French ANRS EPF-CO10 paediatric cohort: a case report

Pierre Frange ¹, Albert Faye ², Véronique Avettand-Fenoël ³, Erianna Bellaton ⁴, Diane Descamps ⁵, Mathieu Angin ⁶, Annie David ⁶, Sophie Caillat-Zucman ⁷, Gilles Peytavin ⁸, Catherine Dollfus ⁹, Jerome Le Chenadec ¹⁰, Josiane Warszawski ¹¹, Christine Rouzioux ³, Asier Sáez-Cirión ¹², ANRS EPF-CO10 Pediatric Cohort and the ANRS EP47 VISCONTI study group

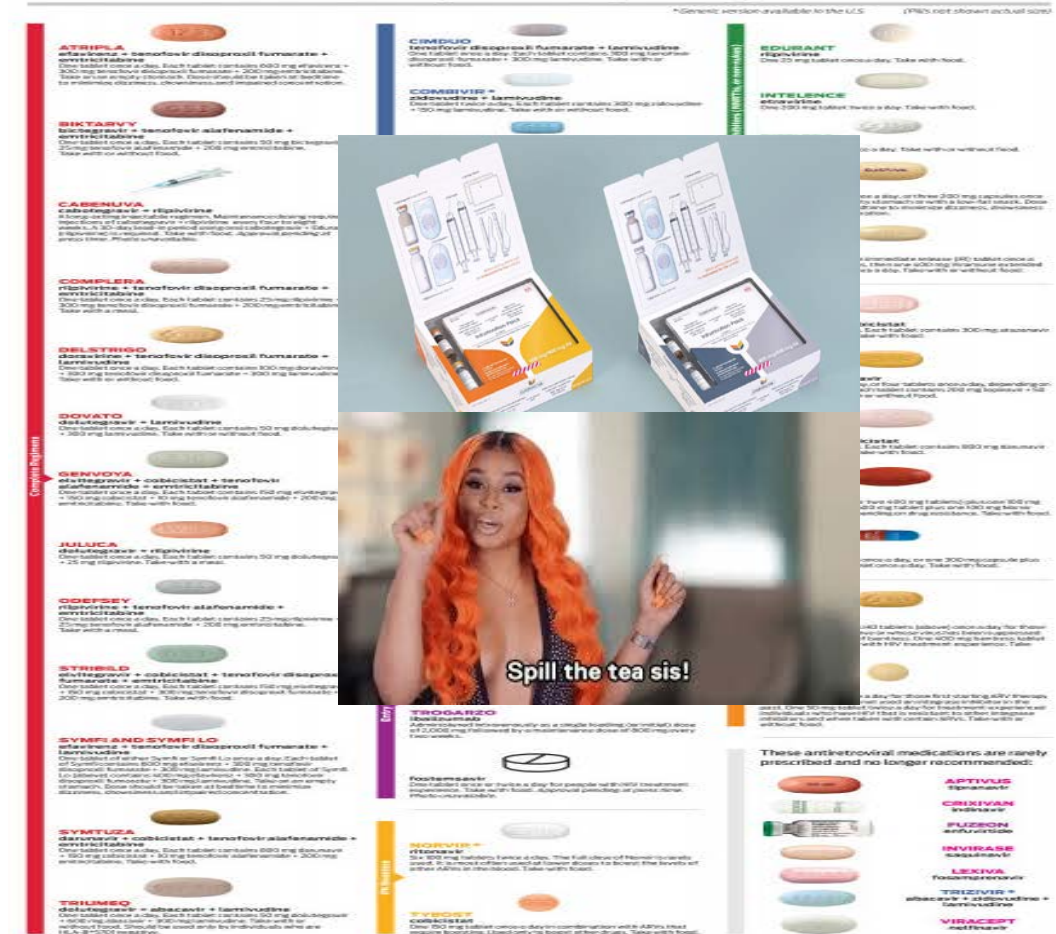
Affiliations + expand

PMID: 26762993 DOI: 10.1016/S2352-3018(15)00232-5

Free article

POZ 2020 HIV DRUG CHART

This quick-reference chart compares antiretroviral (ARV) options for the treatment of HIV, including adult dosing and dietary restrictions. Visit poz.com/drugchart for more info.



What else do we need to be doing?

- Predicting and addressing complications
 - Longitudinal cohorts, biomarkers, surrogates
 - Examine sex differences
 - Optimize mental health, reducing stigma
 - Predict, identify and prevent comorbidities
- Behavioral and community interventions
- Implementation science
- Optimizing care models
 - Alternative “venues” for care delivery;
 - virtual spaces; real-world
- Personalized medicine?
- Consider women with early acquired HIV
 - **Include women early and often**

Don't Just Survive....Optimize!



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“My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor, and some style.”

Maya Angelou

Conclusion

- Women with early acquired HIV are surviving into adulthood
- Many thriving, but significant challenges exist
- Awareness of potential impact of early acquired HIV is key
- Need to specifically consider these women in research, clinical care, advocacy and best practices

Acknowledgements

The Youth!!



ACE

John G Bartlett Subspecialty Team

IPC/PAHAP

WICY team

JHU HIV Clinical Research team (IMPAACT, ATN, Cure, Tech2Check

-Students, residents, fellows, post-docs

Center of Adolescent and Young Adult Health

Pediatric & Adult Infectious Diseases Divisions

Family & support network

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