Transition to Adult Care is BAD for the Health of HIV-Positive Youth

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Disclosures

- No conflicts of interest to disclose
- I am a pediatrician
Transition:

- Transition: shifts from pediatric-focused to adult care settings
- Transition: process of taking responsibility for one's own disease management
- Transition: child → adolescent → adult
Transition to Adult Care is BAD for the Health of Youth Living with HIV
Bad for Retention

- **High-Income Countries**
  - Netherlands: N=59, 86% had an increase in appointments missed. 14% LTFU overall. (Weijsenfeld, 2016)
  - Spain: N=209, 14% LTFU, most patients lost after first year in adult care (Sainz, 2017)
  - Small studies from Italy and Canada (N=24, N=25): 25% LTFU at ~4 years following transition. In Italy, 100% retained 12m post-transition, and 76% 52 months later. (Izzo, 2017; Kakkar, 2016)
  - US: N=72. 97% linked to adult care, 89% retained in first year, falling to 56% in the second year. (Hussen, 2017)
  - US: N=50. 84% linked to adult care. 69% of perinatally infected ALWH retained at 12 months. (Ryscavage, 2016)
Bad for Retention

- **Low- and Middle-Income Countries**
  - Fewer studies reporting on LTFU outcomes after transition
  - Dominican Republic: 10% LTFU after transition; transition to a different site for adult care was associated with higher risk of death/LTFU (p=0.042) (Abreu-Perez, 2016)
  - South Africa: Post-transfer to primary care clinics, retention declined from 90% at 1 year to 84% at 3 years (Davies, 2017)
  - Uganda: 25% LTFU despite use of a transitional clinic with youth-friendly services (Castelnuovo, 2018)
Does not Improve Immunologic Outcomes (CD4)

- Significant decreases in mean CD4 in several studies:
  - UK, N=271: CD4 declining pre-transition, but continued to decline in some groups post-transition. (Judd, 2017)
  - Canada, N=45: CD4>500 64% → 29% post-transition (Kakkar, 2016)
  - South Africa, N=460. Proportion with CD4>500 lower among those transferring at 15–19 vs 10–14 yrs (Davies, 2017)
  - US, cohort of 14 ALWH who all died post-transition: Mean CD4 from 120 → 27 post-transition (Fish, 2014)
  - Italy: CD4 higher at end of follow-up than at transition, but follow-up denominator only those retained in care. (Izzo, 2017)
No Benefit for Viral Suppression

- Most studies show either no improvement in viral suppression or less viral suppression after transition
  - South Africa: N=460, VS decreased slightly at 3 years. (Davies, 2017)
  - Dominican Republic: N=81, At transition, median VL 1759 copies/ml. >50% not suppressed. (Abreu-Perez, 2017)
  - Brazil: N=41, >50% of patients were not virally suppressed at transition. Adherence continued to be bad post-transition. (Carvalho Freitas, 2016)
More Deaths

- Dominican Republic: Transition to a different site for adult care associated with death/LTFU (p=0.042) (Abreu-Perez, 2017)
- Canada: N=25. 76% retained post-transition. 8.9% died post-transition. 60% had less than excellent adherence. (Kakkar, 2016)
- Spain: N= 209, median age at transition 18 years. 2% died. (Sainz, 2017)
- UK: N= 271, median age at transition 17 years, 3% died. (Judd, 2017)
Adolescents Don’t Like It!

- Canada: ALWH felt 18 years was too young for transition. (Kakkar, 2016)
- South Africa: ALWH identified mental health challenges, provider relationship disruption, stigma, perceived “judgment” from adult patients in clinic waiting areas. (Snyder, 2014)
- Kenya: In setting where 67% ALWH transitioned to adult care by 19 years, most felt unprepared and experienced considerable anxiety. (Grewal, 2017)
- Uganda: Common transition challenges included fear of abandonment, loss of peer support, negative perceptions about adult care such as longer wait times, unfavorable appointment days. (Massavon, 2016)
- Kenya: “They will look at you with eyes that will make you want to run away.” (Beima-Sofie, #HIVPED Poster #85)
Mental Health and Substance Use Challenges

- ALWH experience higher rates of substance use, mental health problems, difficulties in adjustment, reduced emotional support (Committee on Pediatric AIDS, American Academy of Pediatrics, *AIDS*, 2013)

- Lack of provider training in mental health and disclosure support for adolescents considered a major barrier to transition in evaluation across sub-Saharan Africa (Pettit, 2013)

- Mental health and substance use challenges may intensify during transition → decreased adherence or retention (Dowshen, 2011)

- Adult care settings may lack coordinated services for mental health, especially for adolescents. (Dowshen, 2011)
More Losses and Trauma

- Feelings of loss with separation from known healthcare team. May be more intense for ALWH who have lost parents/caregivers. (Wiener, 2011)
- Losing relationships with pediatric care team a major challenge, recommend minimizing (Fair, 2012; Kakkar, 2016)
- Considered traumatizing when have to discuss history themselves, repeat histories more frequently.
Pushes adolescents into structural and systems issues

- US studies, 14 clinics: ALWH face structural barriers to care, including insurance eligibility, transportation challenges and HIV stigma (Dowshen, 2011, Tanner, 2017; Philbin, 2017)
- Insurance gaps:
  - In the US, young adults two times more likely to be uninsured than children or adults (Callahan, 2007)
  - Gaps in insurance coverage or functional loss of coverage because of lack of HIV disclosure to policy holder (Dowshen, 2011)
- HIV criminalization laws
Inconsistencies in Treatment

- Lack of communication between providers regarding clinical history (Wiener, 2011)
- US, 14 clinics: Transitioned ALWH describe poor inter-clinic communication about care (Tanner, 2017; Philbin, 2017)
- UK: ≤50% ALWH could name their ART drugs or most recent CD4 and viral load, despite reporting more self-management after transition (Judd, 2017)
- Adult providers may not be trained in adolescent disclosure strategies (Wiener, 2011)
No quantitative data, but youth report anticipated or perceived stigma increasing when accessing adult HIV care services

- South Africa (Snyder, 2014)
- Uganda (Massavon, 2016)
- United States (Wiener, 2011)

Likely heightened for perinatally-infected youth
Adolescent Brains are Not Ready

- Prefrontal cortex: coordinates higher-order cognitive processing and executive functioning (Johnson, Blum, & Giedd, 2009)
- Critical process for maturation = Myelination
- Myelination not complete in the prefrontal cortex until early 20s or later. (Johnson, Blum, & Giedd, 2009)
- Without neuromaturation, have not fully developed impulse control or executive functioning (planning, attention, decision-making)
- Middle adolescence especially vulnerable time: Gap between arousal of socioemotional system in early adolescence and full maturation of cognitive control system in 20s (Steinberg, 2008)
- Transitioning to adult care during this time may lead to higher stress levels, increased emotional arousal and thus increased risk-taking behavior. (Spear, 2013)
SUMMARY

Why is Transition to Adult Care Bad?

- Bad for retention
- Bad for immunologic outcomes
- No help for viral suppression and maybe worse
- Lots of deaths
- Youth don’t like it!
- Bad for mental health
- Adds to loss and trauma
- Structural and systems issues more problematic
- Inconsistencies in treatment
- More stigma
- Their brains are not ready
Despite differences in care systems and time providing ART, impact similar
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SUMMARY
A Few More Reasons NOT to Transition
What about Adolescent-Friendly Services?

- Being “Adolescent-Friendly” may not be enough!

- Have seen some positive results, but findings mixed in both high and low/middle-income countries:
  - **USA, Baltimore:** ALWH in a youth-friendly adult care clinic had no difference in number of 90-day or 6-month gaps in care compared to standard adult care. (Griffith, 2016)
  - **Kenya:** No improvement in LTFU before and after implementation of AYFS for ALWH (Teasdale, 2016)
  - **Kenya:** No difference in LTFU between youth attending AYFS clinics and family-oriented clinics (Ojwang, 2016)
  - **Uganda:** 25% LTFU despite use of transitional clinic with youth-friendly services (Castelnuovo, 2018)
Everyone recommends patient-centered care! (National Academy of Medicine, WHO, …)

**Patient-Centered Care:** “care planned, delivered, managed and continuously improved in active partnership with patients, in order to allow for integration of patients’ specific goals, preferences and values.” (National Academy of Medicine: Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care; Frampton S.B., 2017)

Transition to adult care misses out on the 3 main principles: interpersonal relationships maintained, clinical care maximized, structural system enhanced
It’s just adolescence...

- Is it just adolescence that’s risky, not transition?
- Southern Africa IeDEA (Davies, 2017):
  - Risk of LTFU increases: young adolescents (10–14 years) → older adolescence (15–19 years) → young adulthood (20–24 years)
- Even if that is the case, why risk something that could make it worse???
What about all the parts of the world where there is not *really* transition?

Southern Africa: The Double-Sided Cascade

- Priscilla Tsondai, 2019 IeDEA Southern Africa
- 5,516 ALWH in six Southern African countries: Lesotho, Malawi, Mozambique, South Africa, Zambia and Zimbabwe
- Investigated gaps in care and viral suppression before and after various age “transition” thresholds
- Gaps in care increased with transition at 18 years (N=3864): 17% with gaps → 26% with gaps, difference 9.3 (CI: 7.8-10.9)
- More gaps in care across all transition age thresholds compared to pre-transition
- Did not have significant differences in viral suppression
We miss out!
Special Thanks!

Adolescent transition among young people with perinatal HIV in high and low income settings

Ali Judd¹ and Mary-Ann Davies²

Thanks for ALL the research!

Bibliography

bit.ly/transitionbiblio

SO many studies...