



THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM

UNDERSTANDING THE ROLE OF PERINATAL HIV DISCLOSURE IN ADHERENCE TO ANTIRETROVIRAL THERAPY

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Background

Perinatally infected HIV patients can survive into adulthood thanks to advanced ART treatment. This increasing number of patients presents unique challenges to medical providers. HIV disclosure to children is reported to increase treatment outcomes and decrease negative psychological impacts.

There is a need for clear and comprehensive guidance for disclosure protocols for this patient population. The AAP and the WHO encourage that children be told of their HIV status when they are school aged.

Additionally, The AAP states patients should be aware of their sero-status by adolescence. Our clinic recognizes the unique challenges and complexity of disclosure this population presents and seeks to identify best practices in perinatal HIV disclosure processes.

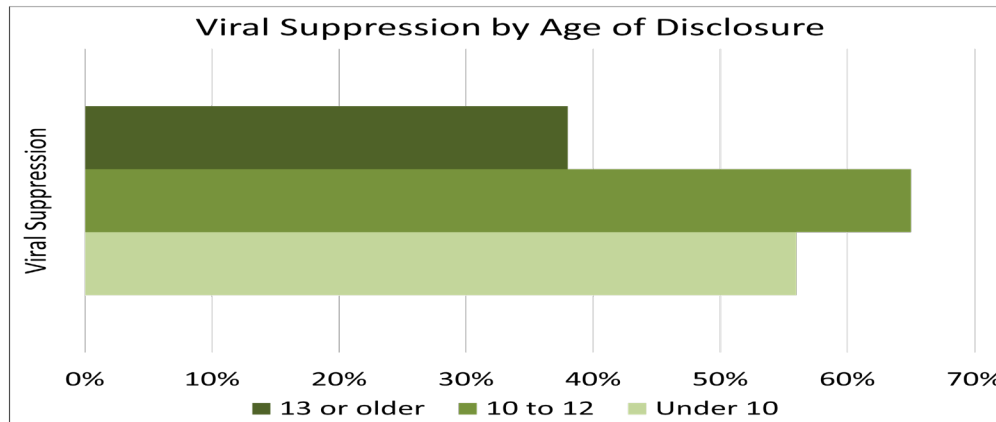
Methods

- **Setting: Ryan White Part B and D recipient**
 - the only medical clinic serving HIV positive pediatric patients within a 250-mile radius of Birmingham, AL
- **Sample: N=61**
 - disclosed, perinatally infected patients seen for medical care within the past ten years.
 - lower cutoff of 14 years of age was chosen to reflect the age of medical consent in Alabama
 - 80% non-white, 49% male, 51% female
 - vital status – 5 of the 61 were no longer living before the age of 25
- **Analysis: retrospective frequency analysis**
 - medical records dating from 2008 -2018
 - age of disclosure and viral suppression (HIV DNA PCR <200 copies in 80% of the annual viral loads over of 5 years)
 - living arrangement and longitudinal viral suppression

Results

(calculated after removing missing data)

Age of Disclosure and Longitudinal Viral Suppression	Age at Disclosure – <10 years % suppressed – 55%	Age at Disclosure – 10 -12 years % suppressed – 65%	Age at Disclosure – > 13 years % suppressed – 38%
Living Arrangement and Longitudinal Viral Suppression	Living arrangement- domestically adopted % suppressed - 46%	Living arrangement- internationally adopted % suppressed – 90%	Living arrangement- raised by biological family % suppressed – 42%



A bar graph chart depicting viral load suppression rates by age of disclosure. This graph shows viral load suppression is higher when a child is disclosed to between the ages of 10 and 12 years old. Viral load suppression is lowest when a child is disclosed to at 13 years old or later.

Discussion

- **Age at Disclosure**
- Decreased viral suppression is seen when disclosure happens after age 13
- Children disclosed to between the ages of 10 years old and 12 years old have the best viral outcomes
- **Living Arrangements**
- Strongly influence longitudinal viral suppression
- 90% of internationally adopted patients were longitudinally suppressed between the ages of 14 years old and 18 years old
- **Ethical Implications of Disclosure in Adolescence**
- Legally capable of consenting and/or assenting for their own medical treatment, however they were unaware of their HIV diagnosis

Future Research and Notes

- Internationally adoptees were on average, disclosed to 3 years before other patient populations. More research is needed to determine specific factors contributing to the more adherent viral loads of internationally adopted patients.
- The number of perinatally infected infants born in the United States continues to decrease however, there continues to be a consistent number of internationally adopted HIV positive children entering the United States. This could lead to future research focused on the unique needs of HIV positive internationally adopted patients.
- Budhwani H*, Mills L, Marefka LEB, Eady S, Nghiem V, Simpson TY. Preliminary study on HIV status disclosure to perinatal infected children: retrospective analysis of administrative records from a pediatric HIV clinic in the southern United States. BMC Research Notes. 13,253doi: 10.1186/s13102-020-05097-z.
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