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What we want you to know: Advice to clinicians from adoptive parents raising a child with HIV

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Disclosures



- The presenters have no relevant financial or non-financial interests to disclose.

Learning Outcomes



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

- Describe the challenges, joys, and decisions faced by parents raising children living with HIV, including recounting personal examples from panelists.
- Discuss the different approaches families take when making decisions on disclosure and healthcare.
- Apply the information and advice from the session to improve their ability to help other families navigate difficult choices in parenting children living with HIV.



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Meet the panelists!

Michelle Turner

Holly Ridge, NC



Personal Background

- ❖ 6 children ages 6-13
- ❖ Husband is a Naval Officer
- ❖ Foster parents for over 4 years
- ❖ Son came to us at 2 years old as a foster placement and we adopted him at 6

Professional Background

- ❖ Head of Talent and Strategic Partnerships for Hazel Health
- ❖ MS in Health Science, BS in Psychology
- ❖ Focused career on using technology to bridge gaps in healthcare for vulnerable populations



Jess Wiederholt

Denver, CO



Personal Background

- ❖ 7 children ages: 19, 16, 16, 14, 13, 13, & 11
- ❖ Home Educator for 12 years
- ❖ Baseball, Basketball, Volleyball Mom
- ❖ Plays a mean game of hide-n- seek with kids
They can NEVER find me!

Professional Background

- ❖ Founder & Executive Director - Crazy Love Africa
- ❖ Former Child Life Specialist
- ❖ BS - Child Life, MA- Child & Family Therapy
- ❖ Focused advocate for marginalized populations



Morénike Giwa Onaiwu

Houston, TX



Personal Background

- ❖ 5 children ages 9-19 (3 adopted, 2 bio)
 - Plus 6th “bonus” foster daughter (20’s)
- ❖ Kids’ countries: Sierra Leone, Liberia, Togo
 - Ethnicities: Temne/Mende/Krio; Grebo; Ewe
- ❖ Hubby & I born in US to immigrant parents
- ❖ Quarantined with 2 Class of COVID HS seniors

Professional Background

- ❖ BA: International Relations; MA: Special Education
- ❖ “Professional student” (currently completing PhD)
- ❖ Social justice advocate: race/disability/gender/etc.
- ❖ Educator (higher ed & K-12), public speaker, writer



Me & the Fab Five. Recent pics on top; older pics below.



Brief overview of research



- The number of U.S. parents pursuing the international adoption of children with living with HIV has grown from a few to several hundred over the past several years.¹
- Little is known about the needs of this emerging population.
- Limited research suggests few medical challenges. However, emotional and behavioral issues were more common.²
- Current study explores the journey of 25 adoptive parents.^{3,4}

Participants

- 25 parents (24 mothers) of 28 adopted children living with HIV (27 internationally adopted)
- Recruited from two pediatric infectious diseases clinics and closed Facebook groups
- All participants self-identified as white

Table 1. Parent Demographic Characteristics (n=25)

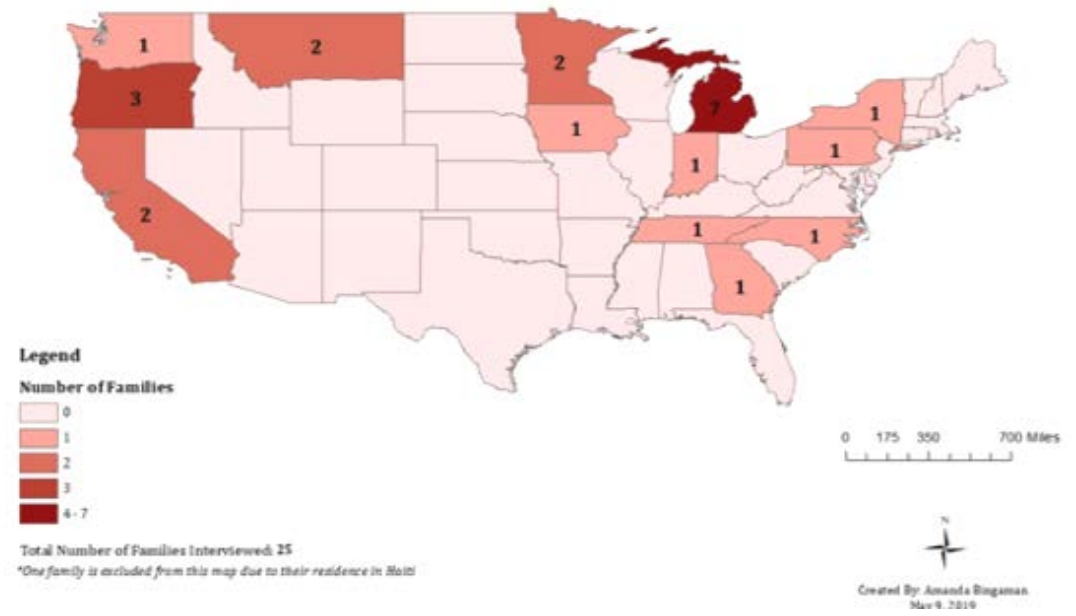
Married	24
Religious affiliation	
Christian	22
None/Atheist	3
Biological children- yes	17 (range 0-5)
Adopted children/family (total)	Mean = 2.3 (range 1-7)

Parent Characteristics

Interview

- Parents completed two semi-structured audio-recorded phone interviews approximately one year apart
- Questions explored:
 - Adoption motivations
 - Medical and psychosocial strengths and needs
 - Joys and challenges associated with adoption
 - Advice to prospective parents

Figure 1. Parent State of Residence



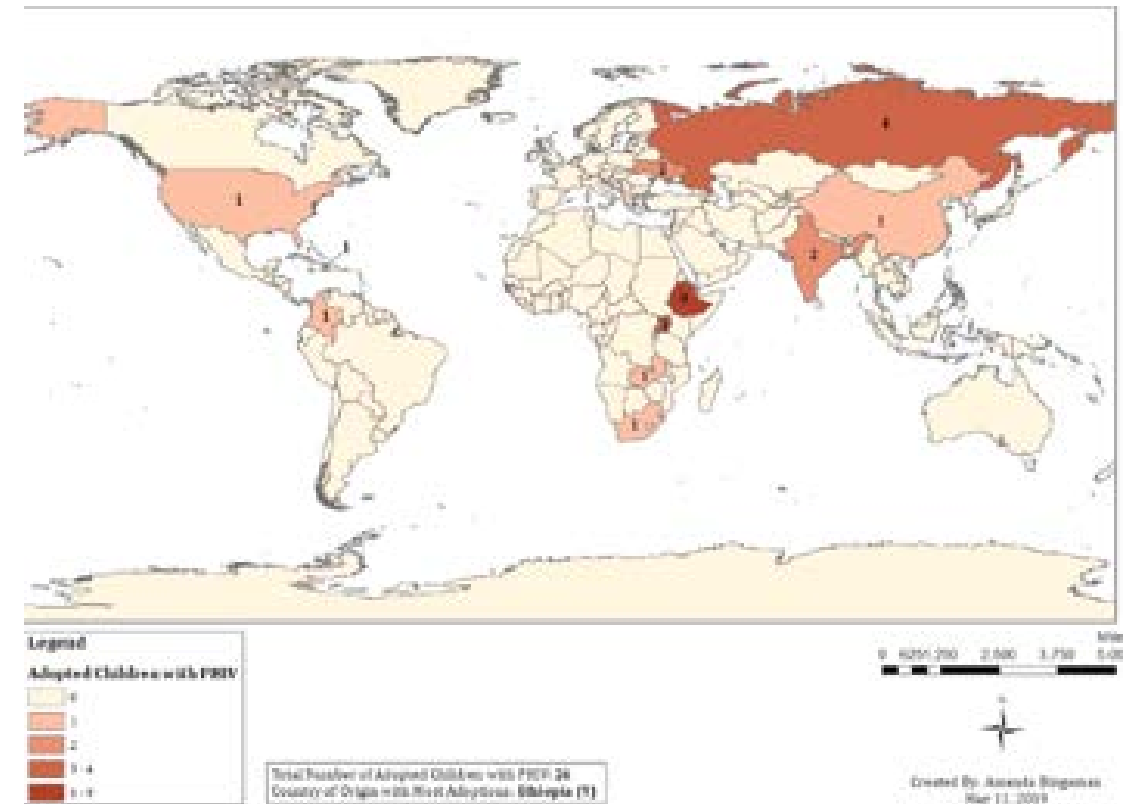
Adoptee Characteristics

Table 2. IACP Demographics, n=28

Age at adoption	Mean = 5.6 (range 1-15)
Age at first interview	Mean = 9.2 (range 2-19)

- 15 females
- 27 currently on ART and 25 virally suppressed

Figure 2. Adoptee Country of Origin



- Medical management of HIV is a “non-issue.”
 - More challenges related to trauma and loss
- HIV-related stigma can be challenging to manage.
 - Most families did not widely disclose their child’s status
 - Many sought to update HIV education in local schools
 - Desire to protect and prepare their child for negative views of HIV
- Support matters but can be hard to find.

Conclusions



- Medically, HIV is relatively easy to manage. However, parents may need support accessing other services related to loss and trauma.
- Levels of HIV education in the community and schools can influence the disclosure experience. Providers can play a role by supporting education outside of the medical setting.
- Consider innovative ways of connecting families to reduce isolation and improve support.



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Panelist Questions



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**How have you been supported by
your providers?**



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**How have you advocated for your
child?**



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Talk about your experiences accessing mental health and auxiliary services. How can providers reduce barriers to those services?



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Describe your experiences with medication management and ways that health care providers can support developing self-management skills in your children.



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**How can providers support the
continuously evolving parent-child
relationship?**



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Talk about ways that providers can facilitate healthy development as your child begins to mature into adolescence and young adulthood.



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What are ways that providers can improve their relationship with their pediatric families during regular visits?



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Final thoughts....



What are your questions?

Time to respond to questions submitted in the chat.

References



- 1 Gibson, E. & Fair, C. (2016). “I would do HIV adoption a hundred times over again”: An exploratory study on families with internationally adopted children with HIV. *Adoption Quarterly*. 19, 26-43. DOI: 10.1080/10926755.2015.1026013
- 2 Wolf, E., Beste, S., Barr, E., Wallace, J., MacFarland, E., Absug, M., Darrows, J., & Melvin, A. (2016). Health outcomes of international HIV-infected adoptees in the US. *Pediatric Infectious Disease Journal*, 33(4), 422-427.
- 3 Bingaman, A., Olivero, R., Crowell, C., Alger, S., & Fair, C. (2020, July). A qualitative longitudinal study of adoption and disclosure narratives among internationally adopted children with HIV in the US. *International AIDS Conference*, San Francisco, CA.
- 4 Alger, S., Olivero, R., Crowell, C., Bingaman, A., & Fair, C. (2020, July). “There’s not even a potential rule book for any of this stuff”: Exploring challenges and advice of US parents who internationally adopt children with HIV. *International AIDS Conference*, San Francisco, CA.

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