

What we want you to know: Advice to clinicians from adoptive families living with HIV

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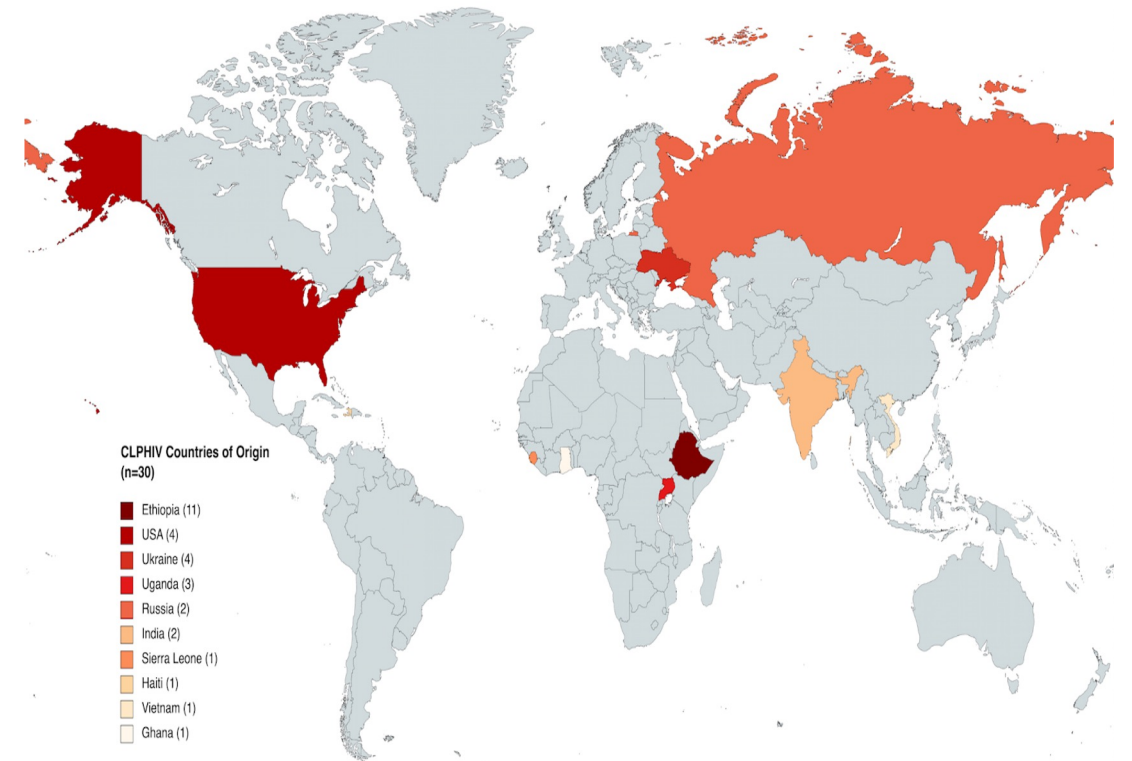
Background

- Three parents (and co-authors) who have domestically and internationally adopted youth living with HIV share ways that clinicians can support adoptive families and their child(ren).
- Findings from a study on the journey of 23 adoptive parents included.

Pictures included are used with permission.

Overview of research

- Participants:
 - Parents of domestically (n=4) and internationally adopted youth (n=19) living HIV
- Methods:
 - 60-minute audio recorded interviews exploring parents' perspectives on the health care and the future.
- Interviews were recorded, transcribed verbatim:
 - Coded using the “Sort and Sift, Think and Shift” approach (Maietta et al., 2021).
- Results: Primary themes
 - Parent child attachment
 - Engagement in care through diversity
 - Transition to adult care



Parent child attachment



Research

- Families highlighted the importance of supporting the developing parent-child relationship during all encounters.
 - One parent described the challenges posed by an attachment disorder, *“That’s been our biggest heartache... **attachment is a huge issue.** HIV has just been a disease.”*
 - Parents suggested that providers offer the opportunity for parents to privately share concerns regarding topics such as *“**trauma, attachment, and trust.**”*

Engagement in care through diversity



Research

- Multiple parents underscored the importance of diversity within health care providers as well as access to mental health services.
 - *"It's important for our children to **see themselves represented** with their health care team."*
 - *"We know that they are probably going to need to access mental health services for most of, if not all of their lives, and when you throw on top of that HIV stigma, the research is there that those living with HIV have higher incidence of depression and anxiety because of it as well. So, we need to make sure our kids are set up for success..."*

Transition to adult care



Research

- Most parents expressed apprehension or fear about their child transitioning from pediatric to adult infectious disease care.
 - *“You know, in adult care, it's different there. You don't have a doctor, a social worker, a nurse, a case manager... you don't have a medical care model. They don't text and call you and send you birthday cards. They don't have fall festivals and Christmas parties and stuff like that...I mean, you're just another patient. They have an automated thing call you once a year. If you show up, you show up. If you don't, you don't. Whatever.”*

Conclusions

- Providers should recognize the **important role the parent-child relationship plays** in the overall wellbeing of the child particularly as they mature into adolescence.
- Intentionally **recruiting a diverse health care team** may increase the comfort of adopted youth as well all youth living with HIV from minority populations.
- Families are concerned about the transition to adult care. **Early and consistent preparation** for this inevitable event is warranted.
- **Thank you** to all co-authors as well as the parents who participated in the interviews.