Internationally adopted children with PHIV: Application of the Family Adoption Communication model to adoption and HIV disclosure narratives

**Abstract**

A growing population of families in the United States seek to adopt children with perinatally-acquired HIV (PHIV) from other countries. While the number of internationally adopted children with PHIV (IACP) is increasing, the needs and experiences of these families are largely unknown; in particular, the narratives shared with children regarding their adoption and HIV status. Narratives play an important role in the development of personal identity among adoptees. The purpose of this project is to elicit and analyze adoption narratives constructed by parents to explain their child’s adoption; particularly when and how a child will learn of his or her HIV status. Parents of IACP often must construct narratives without full knowledge of the child’s history while also integrating the child’s HIV status into the story. HIV-related stigma can make disclosure of a child’s status particularly challenging. The Family Adoption Communication Model (FAC) provides a framework to analyze family dialogue around adoption and how communication changes as the child matures, yet has not been applied to communication around HIV. Twenty-five parents with IACP will be interviewed at two points in time, applying the FAC model to HIV disclosure within the context of evolving adoption narratives.

**Personal Statement**

Mikahala Roy, a native activist in Hawai’i striving to create a resource center for locals, left us with simple advice: to have the courage to self-discover. Her words continue to echo time zones away, as I reflect on my intellectual journey that has led to my interest in how people construct personal narratives, and the influence of these narratives on their wellbeing.

I first understood the importance of personal narratives last summer, when I partnered with a program that provided a summer camp experience for lower-income children from Baltimore who lacked access to camp. While I understood their childhood experiences were different from mine, these children’s stories revealed the extent of disparities such as having a stable living environment. In the midst of practicing watercolors, they would mention walking home alone through dangerous streets, waiting for hours after dark for their parents or guardians to return. Their stories revealed the absence of mentor figures and lack of stability.

We encouraged self-discovery among the children that extended beyond their life circumstances and focused on their internal experiences. The resulting narratives became the focus of camp activities designed to foster internal stability in the face of uncertainty. Exploring sources of internal stability and identity of these children originated from understanding how they viewed their circumstances, and how they translated their experiences into stories.

During the 2018 winter term course, “Hawai’i: Nation or State,” I met Keahe Warfield, the executive director of Keaukaha One Youth Development, an afterschool program for teens in Hilo, HI. Keahe’s program strives to reconnect teens to their ancestral ties with the ocean, helping them build awareness of their identities which they can draw upon as a source of stability when facing obstacles instead of engaging in high risk behaviors such as drug use. By incorporating the ‘aina (land) and ocean into their daily lives and sharing cultural stories, Hawaiians use narratives as a tool to combat the constant cycle of structural violence that leaves many locals homeless with poor health outcomes and few resources. While this program emphasizes narratives as a source of power useful in understanding the development of a culture, it also highlights existing health disparities within Hawai’i. Social determinants of health that are associated with health disparities include geographic location, race/ethnicity, and socioeconomic status; all of which can be construed as part of one’s identity. The ability of identity to influence an individual’s health and, in turn their community, is one of the core issues in our society that drove me to the public health field. Learning about Keahe’s program reaffirmed my commitment to addressing health disparities through culturally sensitive programs.

Before this course, I had primarily examined health disparities from afar in the classroom. Before this course, I looked to outside sources for personal stability such as relationships with friends and family. Now, I am able to directly see how cultural identity can be a source of strength to address health disparities in specific cultural contexts. Now, I am inspired by the Hawaiians, who seek stability from the self in order to promote social change. Further, I want to explore the role of the relationship between identity and personal stability through the medium of stories told by marginalized communities.

I have also seen personal narratives emerge as protective factors in my coursework. Fall 2017 I took Dr. Cynthia Fair’s Honors Seminar, Pregnancy and Childbirth, and we discussed the powerful impact of birth stories. Renowned midwife, Ina May, suggests that birth stories are a way for mothers to reflect and process their experience, and empower themselves and other women. Birth stories are both an internal source of stability for the mother telling the story and an external source for other women. Writing and sharing birth stories increases mothers’ childbirth self-efficacy, and decreases the risk of post-partum depression.

I hope to foster individuals’ balance and stability within programs built from existing cultural norms that use individual and community narratives to address health disparities. The Lumen Prize would allow me to continue to analyze the complex internal and external factors that influence the stability and identity of others; specifically, adopted children from other countries living with HIV. The narratives told by their parents regarding the adoption process, their biological families, and their illness will shape the development of their own life story. I want to expand my analysis of storytelling into other cultures in an effort to better understand the intersections between identity, health, and stability. I will be able to apply my deeper understanding of the power of narratives in the future as I explore international public health graduate programs.

**Project Description**

**Focus**

In 2010, loosened restrictions on the immigration of HIV-infected individuals allowed children with HIV, most of whom were infected through mother-to-child transmission (perinatally-acquired HIV: PHIV) to be adopted in the U.S.. As a result, an increasing number of U.S. families have pursued the adoption of children with PHIV from other countries (Crary, 2011; Goldman, 2009). Data on the number of internationally adopted children with PHIV (IACP) are not systematically collected, nor is there much information about the families who seek to adopt children with PHIV from other countries. However, Gibson and Fair’s qualitative study (2016) found that many adoptive families work with faith-based adoption agencies and report that their decision to pursue adoption was inspired by divine guidance. Further, some families in the study had adopted multiple children, many with special healthcare needs.

The process by which parents communicate about adoption-related issues with their HIV-infected child is largely unknown. Families raising children with HIV often struggle with balancing normalcy with uncertainty (Mawn, 2012). Seminal research on adoption suggests that the level of openness of family communication around adoption can influence the well-being of adoptees (Kierk, 1964; Stein & Hoopes, 1985). Family communication surrounding adoption narratives and HIV disclosure has the potential to impact the adopted child’s perception of stigma, creation of relationships, and development of personal identity.

*Internationally adopted children with PHIV*

The literature focused on internationally adopted children can serve as a springboard for understanding the challenges facing those children with PHIV. Adopted children frequently experience difficulties with attachment and disruptions in eating and sleeping (Tirella, Tickle-Degnen, Miller, and Bedell, 2012; Shapiro, Shapiro, & Paret, 2010). Institutional care prior to adoption, common in non-Westernized nations, can be particularly damaging to young children who often suffer from more significant behavioral problems than children cared for in a family setting (Mohanty & Newhill, 2006).

The only article published to date on outcomes of internationally adopted children with PHIV (IACP) in the U.S. included a study of 79 youth from clinics (mean age 6.1 years, range 3.7-8.6) in Washington and Colorado, 90% of whom were born in African countries (Wolf et al., 2016). The researchers found that severe immunosuppression was rare, and the most common medical issues were relatively mild dermatologic and gastrointestinal conditions. However, almost half of children had emotional and behavioral issues impacting their sleep, school performance, and relationships. IACP must contend with challenges related to language/cultural differences, previous loss, illness, and medication adherence, as well as the effects of HIV-related stigma. Adoptive parents must make decisions about disclosing the child’s HIV status to others inside and outside the family, including how and when this information will be shared with the child. Religious beliefs of adoptive families may also shape the narrative that is shared (Gibson & Fair, 2016).

*Adoption Narratives*

Fisher (1987) notes that storytelling is part of the human experience. Stories and narratives help individuals understand their lives. Adoption narratives can influence an adopted child’s perception of stability and the creation of relationships. Sharing information in the form of a story with the adopted child can increase their confidence and furthers the development of their identity (Feast & Howe, 2003). Often, the story that parents tell their child becomes the story the child then tells others as they grow into adulthood, emphasizing the lasting impact the narrative leaves on how an adopted individual processes life experiences (Chatham-Carpenter, 2012). The act of continuously remembering experiences and telling stories creates an evolving sense of self crucial in the creation of identity (Eakin, 1999). This process begins with the initial story told by the parent to the child. The creation and telling of this story gives the parent control over how HIV, and other aspects of the adopted child’s history, will be shared and thus influence her or his identity. Previous research suggests that adolescent self-identity is most commonly influenced by peers and parents (Wim & Maja, 1995). Feast and Howe (2003) emphasize that increased openness regarding discussion of adoption results in a closer relationship between the parents and the child. Narratives are the medium of communication in which openness can flourish to build strong relationships within the family.

Disclosure of a child’s HIV status can challenge open family communication due to the stigmatized nature of the illness (Santamaria et al., 2011). Although parents often fear the stigma their children will face when HIV status is disclosed, adolescents who knew their status reported less anxiety than those who were not aware (Santamaria et al., 2011). Other positive outcomes associated with disclosure include increased likelihood of disclosing status to a sexual partner, improved adherence to medication, and a greater atmosphere of trust with caregivers (Weiner, Mellins, Marhefka, & Battles, 2007). Research on critical disclosure moments reveals that youth with PHIV were strongly encouraged to keep their status a secret by both doctors and parents (Dorrell and Katz, 2014). This secrecy results in feelings of isolation and inability to talk about HIV, reinforcing the the stigmatized atmosphere around HIV. Research consistently supports the positive correlation between HIV-related stigma and increased depression, as well as decreased use of health services (Rueda et al., 2016).

*Family Adoption Communication Model*

This project will examine adoption narratives using the Family Adoption Communication (FAC) model that tracks family communication surrounding adoption through three Phases: Original Story, Adopted Child Questioning, and Adopted Child Information Gathering (Grotevant & McRoy, 1998). Movement through the phases is driven by the child’s responses to information parents share about adoption (Wrobel, Kohler, Grotevant, & McRoy, 2003). The model emphasizes the power of the parent in determining the openness of conversation regarding adoption. The parent(s) can develop a story in which they choose to share all known information regarding the adoption, withhold some information, or a combination of both. The FAC model portrays the adoption narrative as an evolving story (Wrobel et al., 2003). Viewing adoption narratives as fluid entities is compatible with the adopted child’s development. As cognition develops and understanding evolves, the child will become more curious and, in response, parents may increase the amount of information shared. The FAC model is largely dependent on child behavior and parent decision-making as to what information is shared (Wrobel et al., 2003).

This model has been used to explore adoptive family dynamics, but it has not been applied to families with internationally adopted children with HIV. The goal of this project is to focus on Phase 1 of the FAC model to determine where HIV appears in the adoption narrative and explore the openness of family communication and dialogue surrounding HIV.

Specific questions include:

* How has the adoption narrative changed over time?
* How do parents incorporate their child’s HIV status into the narrative and how is this story shared with children? With others?
* How do parents integrate difficult information such as abandonment, loss, and family rejection into the adoption narrative?

The FAC model can provide insight into how familial communication regarding adoption and HIV could impact the development of a child’s identity and his or her perception of social stigma. The FAC model would treat HIV as a fluid aspect of the child’s identity developed through narrative and dialogue rather than a static label the child must navigate. Ultimately, understanding how parents share HIV-related information with their adopted child may be useful for adoption personnel, educators, and healthcare providers to support IACP as they mature into adolescence and young adulthood. Preliminary evidence from healthcare providers suggests that adoptive parents of IACP may be hesitant to share sexual and reproductive health information with their children due to religious beliefs that prioritize abstinence before marriage (Alger & Fair, 2018). Insight into the messages shared around HIV disclosure narratives could further promote helpful dialogue with adoptive parents who may need additional support around sexuality as their child transitions into adolescence.

**Scholarly Process**

In order to understand adoption and HIV disclosure narratives, semi-structured phone interviews will be conducted with 25 families who have IACP and had them in their care for at least one year. A purposive sample of parents will be recruited from the Helen DeVos Children’s Hospital, Seattle Children’s Hospital, and the NC Children’s AIDS Network. It is likely that some of the adopted children will be under the age in which HIV disclosure is relevant. The American Academy of Pediatrics encourages disclosure of HIV infection status to school-age children (1999). Most IACP cared for in the recruiting clinics are under 7 years of age. However, parents will likely still have a narrative they have been developing about how they will tell the story when the child is old enough. Therefore, eligibility will not be limited to those parents whose ICAP are aware of their HIV status. Questions will be adapted for families who have and have not yet disclosed to the child.

Interviews will be recorded, transcribed and coded using a content analysis technique (Saldana, 2009). Families will be interviewed again 1 year later to allow a more nuanced understanding of how, if at all, the adoption and HIV disclosure narratives have changed.

Questions will be adapted from Chatham-Carpenter’s (2012) research with parents who adopted children from China including:

Time one questions:

Tell me how you told your child about being adopted.

Probes: What did you tell them about being adopted?

What did/will you tell them about their HIV status?

How does your child respond to the story about their adoption and HIV status (if appropriate)?

Time two questions:

Now that your child is older, how, if at all has your adoption story changed?

Has any previously withheld information been shared?

What, if any, questions has your child asked you about his/her story?

How have you responded?

What did/will you tell them about their HIV status?

Talk about how you have disclosed your child’s HIV status to others since our last conversation.

Probes: What advice will you give your child about disclosing their HIV status to others as they mature?

**Proposed Products**

* Modified visual graphic that incorporates HIV into the FAC model
* Formal presentations/abstracts: SURE, SURF, APHA, presentations to providers and parents at the Helen DeVos Children’s Hospital, Seattle Children’s Hospital, and the NC Children’s AIDS Network
* Peer reviewed manuscripts: Findings on the integration of HIV into adoption narratives among IACP will be submitted for publication in *Adoption Quarterly*. A paper focused on practice implication for psychological and medical providers will be submitted to *AIDS Care*.

**Feasibility Statement**

The major challenge for this research is access to eligible participants. My mentor, Dr. Fair, has extensive experience in the field of children and adolescents living with perinatally-acquired HIV. Through her previous research with medical and psychological providers who care for IACP, she has identified two pediatric infectious disease physicians who have expressed interest in facilitating recruitment of adoptive parents. Dr. Rosey Olivero from the Helen DeVos Children’s Hospital in Michigan and Dr. Claudia Crowell from Seattle Children’s Hospital care for a significant number of IACP. I plan to interview 25 parents who have adopted children with PHIV from other countries during summer 2018 and re-interview them in summer 2019.

Several years ago, Dr. Fair completed an exploratory project with Elon alumna, Eliza Gibson, that focused on parents’ motivations for seeking to adopt an international child with HIV. Findings indicated that adoptive parents were eager to participate in the research and share their experiences.

Further, Dr. Fair has extensive contacts with providers in the North Carolina Children’s AIDS Network (NC CAN). NC CAN is the primary provider of infectious disease care to HIV-exposed and HIV-infected children and teens in North Carolina. NC CAN institutions include Duke University Medical Center, UNC Hospital, Carolina Medical Center, Wake Forest University Baptist Medical Center, and East Carolina University School of Medicine. Each site has a team of medical providers consisting of physicians, nurses, and social workers that care for a total of 350 HIV-infected and exposed children. Many of the NC CAN providers, as well as NC providers who care for adults with HIV infection have participated in previous research projects under her guidance. In May 2017, six NC CAN social workers participated in a focus group on the needs of adoptive parents caring for children with HIV. They noted an increase in the number of IACP receiving care at their clinics over the past five years and believed their adoptive parents would be willing to be interviewed about their adoption experiences. Therefore, I feel confident I will be able to successfully recruit adoptive parents with IACP for my project.

Completing research of this caliber will be a new and exciting experience for me; however, I feel that I am prepared to conduct this research with both past experiences and planned future opportunities. My past coursework has provided me with a foundation of skills including thinking critically about intersections within fields of study and identifying themes in writing. Many of my honors seminars have culminated in research proposals which have both exposed me to new fields of research and taught me to think critically. From my study abroad courses in Italy and Hawai’i, I have learned to understand the role of narratives in constructing identity. Pregnancy and Childbirth, an honors seminar I took with Dr. Fair in Fall 2017, gave me the unique opportunity to explore the role of birth stories in framing mothers’ experiences and attitudes towards childbirth.

I plan to expand my knowledge and awareness of the field during my SURE experience this summer at Elon. During SURE, I will begin to work with the providers who will facilitate research participant recruitment. This will strengthen the relationship with the families who will be invited to participate in my research. I will also gain the valuable experience of developing open-ended questions, applying for IRB approval, and conducting interviews. The International AIDS Conference and National Adoption Conference will help me become more familiar with current research and insights in the field regarding this emerging population.

I plan to gain technical skills by attending RIVA Qualitative Methods Training in Rockville, MD. Through this interactive webinar, I will learn to apply qualitative methodologies and produce concise written insights from research material. I plan to further expand my knowledge of qualitative research through taking ANT 215 Qualitative research methods where I will learn to use Dedoose, qualitative research methods software.

Lastly, my desire to learn about how individuals construct their identities in a cultural context, as well as the role of stories in the construction of these identities, drives me to dedicate the necessary time and commitment to this research. I am incredibly excited about this research on families who choose to adopt children with PHIV from other countries.

**Budget**

*Participant Incentives*:

* 25 Families ($25 Amazon gift card per family per interview) $1,250

Subtotal: $1,250

*Equipment and Services*:

* Tape a Call Phone App ($19.99/yr.) $20
* Used iPhone to ensure privacy of taped conversations $75
* RIVA Qualitative Methods Training; Rockville, MD
  + Webinar Fee $95
* Transcription Service (rev.com)
  + $1/min rate
  + 40 interviews, 60 min each $2,400
* Visit to medical facilities (1 night each)
  + Flight from RDU to Michigan $400
  + Food and Accommodations in Michigan $250
  + Flight from RDU to Seattle $300
  + Food and Accommodations in Seattle $250

Subtotal: $3,790

*Conferences*:

* International AIDS Conference (July 23-27, 2018)
  + Flight from RDU to Amsterdam $1,200
  + Food and Lodging (7 days with travel) $1,180
  + Registration Fee $300
* National Adoption Conference (June 20-22, 2019)
  + Gas for drive from Elon to DC $80
  + Food, Parking, Accommodations $530
  + Registration $525
* National HIV Prevention Conference (March 18-21, 2019)
  + Flight from RDU to Atlanta $300
  + Food and Accommodations $560
  + Registration Fee $175

Subtotal: $4,850

*Tuition*:

* 2018 Fall Study Abroad at the DIS Public Health program; Copenhagen, DK $5,210
* 2019 Public Health Practicum in India (PHS 381) $4,900

Subtotal: $10,110

*Total*: $20,000

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**Timeline**

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|  | **Proposed Experiences** | **Proposed Products** |
| **First Summer Term** | * SURE * Volunteer at the Open Door Clinic in Burlington, NC * Attend International AIDS Conference in Amsterdam | * SURE Presentation * Refining interview questions * Time 1 interviews of families developed, piloted, and completed * Learn about how Open Door clinic resources are allocated to local families and gain communication skills helpful for research interviews * Gain awareness and knowledge in the HIV/AIDS and field of research |
| **First Fall Term** | * Study abroad at DIS in Copenhagen   + Courses: Health Delivery and Prioritization, Health Disease and Prevention, Epidemiology   + Study Tours to Helsinki and Tallinn: Finnish Cancer Registry, Primary Care Facilities * Apply to SURE | * Greater understanding of cultural differences between primary healthcare systems * SURE application |
| **First Winter Term** | * 1 research credit 499 * Israel Birthright   + Developing identity, studying narratives in cultural context | * Submit abstracts for National Adoption Conference 2019 |
| **First Spring Term** | * 2 research credits 498 * Qualitative Methods course at Elon (ANT 215) | * Honors Thesis Proposal * Code and analyze Time 1 interviews * SURF Presentation Time 1 interview analysis |
| **Second Summer Term** | * SURE | * Conduct Time 2 interviews * SURE Presentation * Presentation at National Adoption Conference * Visit Hospital facilities in Seattle and Michigan to present findings with collaborators |
| **Second Fall Term** | * 3 research credits 498 * Writing Honors Thesis | * Analysis of second round of interviews * Submit applications to Graduate degree programs |
| **Second Winter Term** | * India Practicum PHS 381   + Health care delivery systems in rural Jamkhed, India | * Journal of weekly reflections * Analytical report and presentation |
| **Second Spring Term** | * 3 research credits 498 | * Defense of Honors Thesis * Development of modified visual graphic of FAC model * Submission of manuscripts to *Adoption Quarterly* and *AIDS Care* * SURF Presentation of Time 2 interview analysis * Presentation at the National Conference on Undergraduate Research in Montana |