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Kathleen E. Fanone
Who's My Family? A
Qualitative Analysis of
Young Adults Living with
Perinatal HIV Infection

ABSTRACT

The purpose of this qualitative study was to explore how young adults with perinatal HIV infection understand and experience the concept of family and to elicit their perceptions of how “family” has helped or hindered their ability to cope with their illness. The sample was composed of young adults currently receiving primary care from the Johns Hopkins Intensive Primary Care Clinic (IPC) located in Baltimore, Maryland. The IPC clinic provides comprehensive medical care and psychosocial support for over 200 children and youth with HIV infection from birth to 24 years. The majority of the patients come from low socio-economic ethnic minority communities in Baltimore City. All patients in the clinic were English speaking. The sample included 12 perinatally HIV-infected adolescents, ranging in age from 18 to 24. Three fourths of the participants were female. All participants self identified as African American. All participants consented to partake in one interviews composed of a series of open-ended questions. All interviews were conducted in the outpatient medical clinic setting.

WHO'S MY FAMILY? A QUALITATIVE ANALYSIS OF YOUNG ADULTS LIVING
WITH PERINATAL HIV INFECTION

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2010

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This thesis is dedicated to the young adults of East Baltimore affected by HIV. Your powerful stories have changed my life and I am grateful that you were willing to share your unique narratives with me. May this research project be the first among many that will honor your experiences.

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CHAPTER I

INTRODUCTION

The term “family” is commonly defined as a group of persons who share the same lineage, or as a social group, usually composed of two parents and their children. The concept of “family of origin” refers to the family into which a person is born, whereas the idea of “chosen family” generally refers to friends who care about each other enough to consider them family. Chosen family can also be used to refer to adoptive relationships. Divided or non-existent biological families may compel young adults to develop or choose a group or groups of friends who can provide love and support. When children are orphaned at a young age, who becomes their family?

The purpose of this study is to determine how young adults with perinatal HIV infection understand and experience the concept of family and to elicit their perceptions of how “family” has helped or hindered their ability to cope with their illness. HIV transmission from mother to child during pregnancy, labor and delivery, or by breast-feeding is referred to as perinatal transmission. Perinatal HIV transmission is the most common route of HIV infection in children and is now the source of almost all AIDS cases in the United States. According to the Centers for Disease Control and Prevention (CDC), since the beginning of the AIDS epidemic in the early 1980s, an estimated 8,460 children were infected perinatally. Of those, approximately 4,800 children have died. Most of the children with AIDS are members of minority races or ethnicities.

In the United States, as well as in other geographic locations with access to resources, the introduction of widespread HIV counseling, testing, and treatment with

antiretroviral therapy during pregnancy resulted in a dramatic drop in the rate of perinatal transmission. In addition, advances in antiretroviral treatment and knowledge of disease progression, have dramatically reduced the morbidity and mortality of HIV infection in the United States (Weiner et al. 2007). As a result, children born in the 1990s with perinatally-acquired HIV have now survived to young adulthood. Family support is important in nurturing their developmental and practical transition from adolescence to independent adulthood. Unfortunately, it is estimated that the AIDS pandemic in the United States has orphaned as many as 80,000 children and adolescents (Caldwell, Fleming, & Oxtoby 1992).

Due to the loss of a biological parent or parents during early childhood or adolescence, this unique cohort has experienced a variety of family constellations. Some children were raised by members of their extended family. Other children have been placed in the foster care system or adopted by another family. Still others were extruded from families and have survived through “chosen families.” Little is systematically known about the construct of family as experienced by youth with lifelong HIV infection. This research is important because it addresses a new emerging population that must navigate the transition from childhood to adulthood in multiple domains: educational, vocational, personal, and healthcare related.

The Johns Hopkins Intensive Primary Care Clinic, founded in 1985, provides comprehensive HIV medical care and psychosocial support for children and youth from birth to 24 years in the Baltimore, Maryland area. Currently the Intensive Primary Care (IPC) team cares for over 200 HIV-infected patients, three quarters of whom are survivors of HIV acquired at birth from their mothers. The median age of this subgroup is

now 18 years, with 71 already past their 18th birthday. This sub-group is diverse in physical health status, emotional health, adherence to care and treatment, and social support networks. The majority of these patients were orphaned, having lost at least one parent to HIV/AIDS.

A striking but anecdotal clinical observation is that youth with fragmented or “dysfunctional” family systems are now dying of AIDS in contrast to their more stable peers. It is critically important for clinicians to step back from subjective assumptions and seek to learn more systematically from the affected youth about their experiences and perceptions of family structure and support, with the goal of improving the effectiveness of HIV care provided. In an attempt to better understand the collective experience, this research study will gather and analyze the unique narratives of these individuals who have learned to navigate the world with a chronic illness.

CHAPTER II

LITERATURE REVIEW

At the onset of the epidemic in the early 1980s, AIDS was viewed as a “death sentence” with only 5 to 10% of individuals living for approximately three years after diagnosis. Social stigma and the risk of transmission resulted in heightened fear among the general public. This in turn was a catalyst for researchers to investigate possible prevention and treatment regimens, and progression of the illness.

Because of advances in treatment and care of HIV, we are currently witnessing a trend of youth with perinatally acquired HIV survive long enough to transition from pediatric to adult care. Between 1996 and 1997, AIDS diagnosis of children 13 years of age and younger declined approximately 40 %. These advances have important ramifications for children and adolescents living with HIV. Infants born with HIV or children infected early in life were not expected to live through their first decade as few medications were available or accessible, and the technology was not available to monitor the effects of treatment or disease progression (Ledlie 2001). As a result, they may not have been raised in a manner that prepared them for adulthood and ultimately independent living. This phenomenon has not been adequately addressed in the literature published on this group of individuals.

Researchers have investigated a broad spectrum of topics related to children and adolescents with HIV including: social stigma, disclosure of positive HIV status to child, treatment compliance, medication adherence, grief and loss surrounding the death of a parent with HIV, coping mechanisms, and the psychosocial issues that directly impact

this cohort. Other researchers have explored why HIV/AIDS has primarily impacted marginalized communities living in urban settings. However, little research has been done that explores how the family unit has been impacted by this illness. Because one or both of the child's biological parents may have succumbed to AIDS, family configurations vary greatly. Little is known about how youth with perinatally acquired HIV define family, and whether their family helps or hinders their ability to cope with their illness.

Medical providers are currently witnessing the first wave of adolescents with perinatally acquired HIV disease transition into adulthood. Providers are confronted with new challenges, such as treatment regimens, medication adherence, disclosure, and permanency planning. New challenges have risen such as relationships, sexual intimacy, college and career planning. Caregivers, who were once told that their child with HIV would probably not live past kindergarten, were not prepared for raising an adolescent with a chronic, sexually transmitted disease. (Ledlie, 2001). Medication regimens, including highly active anti-retroviral therapy (HAART) are time consuming and often cause a number of side effects. On average, an individual prescribed HAART will take seven doses daily, which is potentially a severe burden for the patients and their caregivers.

Many children born with HIV were reared by an elderly caregiver, usually a grandmother or great-grandmother. It is imperative to consider how the primary caregivers' lives are impacted by raising a child with a highly stigmatized chronic illness. Regardless of the family constellation, caring for a child with HIV requires a

considerable amount of emotional energy and time devoted to maintaining medication adherence.

In the late 1970s and 1980s, as rates of divorce and remarriage skyrocketed, researchers took an interest in the shift of a more “traditional” grandparent role from “indulging, spoiling, enjoying” grandchildren to taking on an “unplanned parenthood” role. Currently, grandparents across racial and ethnic divisions are called on to resume the parenting role as more biological parents succumbed to medical illnesses (Winston, 2003). Recognizing that grandmothers care for the majority of African American children orphaned by AIDS, Carole Winston (2003) conducted a qualitative analysis to determine how African American grandmothers grieve the loss of their adult children, while simultaneously parenting their orphaned grandchildren. A snowball sampling method was used to obtain a sample of 10 African American grandmothers between 52 and 70 years of age in the New York Metropolitan area.

Winston asserted that a predominant reason that grandmothers parented their grandchildren stemmed from the belief that “families come first and should stay together at all costs” (95). These grandmothers felt a responsibility to care for their grandchildren, and adjusted their lives accordingly. The data revealed that a spiritual relationship with God served as a significant source of strength for the participants that “enhanced their ability to care for their grandchildren while mourning the loss of a child.” This study is not generalizable to the entire population because of the small sample size; however, the detailed narratives offer insight into their lives and the complexity of raising a child with a chronic illness after experiencing the loss of their own child.

Primary caregivers as well as family members of children born with HIV have to consider when to disclose the child's positive status in a developmentally appropriate way. A number of studies have addressed the issue of disclosure of diagnosis to children born with perinatally acquired HIV illness. Because non-adherence to the anti-retroviral treatment HAART may lead to a form of viral mutation and proliferation, it is imperative that the child adheres to the treatment regimens. When the child grows older, it becomes their responsibility to adhere to the medication. Therefore, without disclosing the illness, the importance of compliance is difficult to communicate. Because sexual exploration is occurring at an earlier age, prolonged delay in disclosure may result in the adolescent engaging in sexual behaviors without being counseled regarding transmission and the practice of safe sex (Lee & Johann-Liang, 1999).

Multiple factors may prevent the parent or caregiver of an HIV positive child to disclose their status including: social stigma, the life-threatening nature of HIV infection, guilt over perinatal transmission, or loss of another family member or friend to AIDS. Disclosure may elicit a number of questions such as, "How did I get it? Who gave it to me? Why me? Am I going to die?" Responses may be difficult to articulate in a developmentally appropriate manner, and may cause hurt or shame from the parent or guardian (Lee & Johann-Liang, 1999). However, resisting disclosure may ultimately cause emotional damage and impact identity development.

Instone (2000) conducted a qualitative study to investigate how school-aged children with HIV infection adjusted to their illness and information from parents or guardians. Participants in this study included thirteen children six to twelve years of age with perinatally acquired HIV infection as well as their parents or guardians. Due to the

small sample size, the study is not generalizable to the entire population of school-aged children with perinatally acquired HIV; however, the sample was reflective of the regional population. The data yielded that the parents withheld the children's positive HIV status for approximately two to eight years after diagnosis. Regardless of when the child learned of their diagnosis, their responses to the questions "suggested severe emotional distress, disturbed self-image, and social isolation." Parents or guardians were ultimately unaware of their children's concerns (Instone, 2000). Although other psychosocial factors impact the participants overall adjustment, it is evident that a lack of attunement to the children's concerns ultimately impacts their ability to understand and cope with their illness.

As children with perinatally acquired HIV transition into adolescence, caregivers must be prepared to address this life stage in the context of a chronic, sexually transmitted illness. Adolescence is characterized by biological, psychological, and social changes. In a quest to define their identity, adolescents generally rely more on their relationships with peers rather than their family unit to obtain feedback in their quest to define the self and establish autonomy. However, disclosure of their positive status to peers is a complex process. Many adolescents fear that disclosing their status to a friend or partner will ultimately lead to rejection. Anxiety related to disclosure of their positive status may effect many of their friendships and intimate partner relationships in the future. Caregivers and clinicians must be attuned to these additional factors that result in an increased level of anxiety or distress.

This stage of social development poses additional obstacles for an adolescent with a chronic illness as they may be more reliant upon family members or caregivers for

transportation to medical appointments or to the pharmacy to pick up medication. With respect to their medication regimen and treatment plan, adolescents may decide that they want a “break” and ultimately discontinue anti-retroviral treatment. The most common reasons that adolescents report for stopping their medication regimens include: side effects (diarrhea, nausea, vomiting, fatigue, weakness, fever, and chills), inconvenience of taking medication multiple times a day, HIV stigma and disclosure, lack of family support, and a reminder that they are HIV infected when they take them (Belzer et al., 1998). As children they may have taken their medication because grandma said to. Now they may consider not to take their medication just because grandma said to (Ledlie, 2001). Notably individuals with HIV that discontinue use of anti-retroviral treatment (or take it inconsistently) ultimately run the risk of developing immunity to the treatment therapy. Subsequently, effective treatment options will decrease. Because of this risk, clinicians working with this population recognize the significance of having a support system in place.

Davey et. al (2009) conducted a research study to determine if it is beneficial for clinicians to use a family support tool to identify perceived levels of family support for individual clients before and after disclosure of the HIV diagnosis to their families. In addition, they considered what the long-term benefits may be from using this clinical tool to inform clinical and medical treatment for youth coping with HIV. The sample included 50 newly diagnosed HIV positive ethnic, minority youth. According to the clinician rated five point family support tool ranging from one (very supportive) to 5 (very unsupportive), participants had a mean score of 3.5 for family support pre-diagnosis, and 4.1 at post-diagnosis. Using a standardized clinical tool to assess family support of newly

diagnosed patients provides a common language for providers to discuss cases. In addition, the assessment tool provided a tangible way to quantify data and to measure progress (Davey et. al, 2009).

Lam, Naar-King, and Wright (2007) conducted a study to describe mental health symptoms in HIV positive youth and to evaluate social support, disclosure, and health status as predictors of symptoms including but not limited to: mood disturbance, anxiety, social problems, suicidal ideation/attempts, and feelings of hopelessness. The sample included 66 HIV positive youth between the ages of 16 and 25. Participants were recruited from an adolescent HIV clinic within a children's hospital located in a major metropolitan area.

Results of this study identified lower social support, higher viral load, HIV-status disclosure to acquaintances, and being gay/lesbian/bisexual (GLB) were all significantly correlated to more mental health symptoms. The percentage of participants with behaviorally acquired HIV, perinatally acquired HIV, or transmission through sexual assault was not distinguished. The way in which HIV was acquired, may largely impact the presence of mental health symptoms in the individual (Lam, Naar-King, & Naar-Wright, 2007).

Murphy et al. (2000) designed a study to investigate the effects of life events, social support, and coping on anxiety and depression with HIV positive adolescents. Adolescents who were infected through sexual behavior or injective drug use behaviors and were currently receiving primary care were eligible for the study. Participants included 230 adolescents from 16 different cities nationwide. The researchers hypothesized that an increase in stressful life events would be correlated to higher levels

of anxiety and depression, but this association would be regulated with satisfaction with social support and by practicing adaptive coping. The results of this study indicated that although life event distress was directly associated with psychological distress, neither social support nor adaptive coping seemed to moderate this association (Murphy et al., 2000).

This study did not account for adolescents with perinatal HIV infection. In addition, it excluded a large proportion adolescents with HIV living in rural areas, as well as those adolescents that are not connected to services. In addition, this study did not consider how differences in race, ethnicity, or socio-economic status may impact social support. Nor did it consider that there may be varying configurations of social support. Stages of development indicate that adolescents' social support networks are primarily composed of their peers. This aspect was not assessed in the study.

Similarly Battles and Weiner (2002) designed a descriptive, longitudinal study to examine the psychosocial factors associated with long-term survival of pediatric HIV. Children enrolled in clinical trials in the Pediatric HIV Working Group of the HIV/AIDS malignancy branch of the National Cancer Institute, along with one of their primary caregivers. Children were administered three separate scales and participated in a semi-structured interview, and their caregivers completed two separate measures. Study measures were administered every 12 months over a period of three years. The results of this study indicated that the transition from adolescence to young adulthood is “not an easy one” as living with “a potentially life-threatening and stigmatizing disease leads to psychological distress as the adolescent enters adulthood.” However social support and disclosure can alleviate some of these affects. Findings specifically demonstrate that there

is a direct correlation between perceived social support and parent-reported problem behavior (Battles & Weiner, 2002).

The sample used in this study is not ethnically or racially representative of pediatric HIV patients living in the United States. In addition, the patient cohort in this study over-presents resourceful families that were able to participate in clinical trials. These families may not face additional life stressors including poverty, violence, and substance use.

At the beginning of the epidemic, HIV infected children were often socially ostracized and attempts were made to prevent them from attending their schools. Because “HIV may adversely affect a child’s neurodevelopment, they are more likely to require special services than uninfected children.” Frequent medical appointments or hospitalizations will result in multiple school absences. Erin Mialky, James Vagnoni, and Richard Rutstein (2001) designed a study to explore the medical, educational, and psychosocial issues that develop among school-aged children living with perinatally acquired HIV. The sample included 54 children and their caregivers who were interviewed about the student’s educational setting, utilization of special services, school performance, number of school absences, medications, absences, activities, and disclosure status.

The data collected in this study yielded that children generally adapted well to taking their medication in a school setting. In addition, the results indicated that HIV-infected children have an increased need for special educational services. However, the study team asserted that it is impossible to determine whether the need for additional services can be attributed to HIV infection, drug therapy, or other environmental factors.

In addition, the results of the study are not representative of the entire population of school-aged children with perinatally acquired HIV (Mialky, Vagnoni, & Rutstein, 2001).

Current literature adequately addresses the ways in which family support is directly correlated to physical health and emotional wellbeing of children and young adults living with HIV infection. However, researchers have not considered the makeup of the family unit itself. This study will consider the definition of family through the unique lens of adolescents with perinatal HIV infection.

CHAPTER III

METHODOLOGY

This qualitative study was designed to determine how youth living with perinatally-acquired HIV define family, and whether or not their family members help or hinder their ability to cope with a lifelong illness. Conducting in-depth interviews allowed this researcher to obtain more information about each participant's unique experience. Conducting a face-to-face interview is more personal, and provides the participant with an opportunity to share their narrative. This chapter identifies the methods employed in this study and describes the sample selection, data collection, and data analysis procedures.

Sample

Study participants were limited to patients ages 18 to 24 with perinatally-acquired HIV infection currently being followed in the Intensive Primary Care Clinic (IPC) at Johns Hopkins Hospital for comprehensive HIV primary care. Patients with significant cognitive developmental delay or serious mental illness, which would preclude safe or meaningful participation in the study interview, were excluded.

The participants for this qualitative study were recruited via a convenience sampling method. The research team created a list of eligible participants by using the clinic roster to identify all IPC patients with perinatally-acquired HIV infection who are 18 years or older. This list was reviewed with the primary care team at the weekly IPC clinical team meeting to remove any patients with serious cognitive developmental delay or serious mental illness. The first 12 eligible participants who came to clinic for a

routine visit, were approached about participating in the study by a member of the IPC team. This researcher then met with interested patients in a private clinic room to discuss the study and obtain written informed consent.

Data Collection

Data collection was gathered via semi-structured interviews conducted in the outpatient medical clinic. Each participant participated in one interview. The interviews were composed of a series of open-ended questions as outlined in the interview guide (see Appendix C). Prior to beginning data collection, procedures to protect the rights and privacy of participants were outlined and submitted to the Institutional Review Board (IRB) at Johns Hopkins Medical Institution for approval (see Appendix A). Each participant was given a copy of the informed consent form, which described their participation in the research study as well as their rights as human subjects (see Appendix B). The researcher carefully reviewed each section of the consent form with the participant and allowed time for questions and clarification. The researcher and participant each kept a copy of the signed document. The researcher will keep the signed consent forms in a secure environment separate from the data for three years after the conclusion of the study as mandated by Federal regulations.

Each interview was digitally recorded to ensure accuracy of responses. The interviews were transcribed by a professional transcription service. Any names or other identifiable information from participants gathered during the interviews were subsequently removed during the transcription process for privacy purposes. The recordings will subsequently be destroyed in concordance with HIPAA guidelines.

After obtaining the signed consent form, the researcher asked each participant five questions in sequential order. The interview questions were intended to elicit the ideas, opinions, and experiences of the participant. At times, the researcher clarified questions or offered probing questions to obtain additional information regarding the topic. Each interview was digitally recorded. The entire interview process, including obtaining consent and debriefing, ranged in length from 30 to 45 minutes. Participants were compensated with \$25.00 in cash for their time and travel expenses. All interviews took place from March through April 29, 2010.

Data Analysis

Data collected during the taped interviews were transcribed and then analyzed for thematic content. The researcher then coded the data. First, the transcripts were sorted by questions, and then into smaller categories based on similar words and phrases offered by the study participants.

As a Caucasian female researcher in her mid-twenties, I considered how my identity and personal experiences impacted the interview process. I recognized that each participant answered the interview questions from their unique lens. In addition, I was cognizant of rapport with each participant. I was cautious of how my personal biases or preconceptions could potentially influence responses or interpretations of responses. It was also imperative that they did not feel coerced into participating in the study given that the researcher was also a staff member and in a position of authority. It was also necessary that the participants understand that the care they receive at the IPC clinic was not going to be impacted by their decision to participate in the study.

All interviews were conducted during regular clinic hours when the primary care team was present on site. The IPC social worker or another member of the primary care team was available in the event that a participant voices distress during or after the interview process. IPC patients with known mental health conditions that might put them at risk for heightened distress were excluded from participation. The questions and content of the interviews are part of the standard psychosocial history collected during routine clinical visits. Some participants may have felt sad or angry while discussing their families or their HIV status; however, there was no greater risk of causing emotional distress in the context of the research interview.

This study offered participants an opportunity to share their personal stories. Knowing that the research team is interested in improving care by learning more about living with a lifelong illness may increase rapport with the patient. Requesting to hear their unique stories and recognizing their level of resiliency, validates that they have confronted enormous obstacles throughout their lifetimes.

CHAPTER IV

FINDINGS

The purpose of this study was to explore how youth living with perinatally acquired HIV describe the composition of their families, and whether their families (as defined by the participant) have helped or hindered their ability to cope with their illness. The sample was drawn from adolescents and young adults currently receiving primary care from the Johns Hopkins Intensive Primary Care Clinic (IPC) located in Baltimore, Maryland. The IPC clinic provides comprehensive medical care and psychosocial support for over 200 children and youth from birth to 24 years. The majority of the patients come from low socio-economic ethnic minority communities. All patients in the clinic were English speaking. The sample included 12 perinatally HIV-infected adolescents, ranging in age from 18 to 24. Three fourths of the participants were female. All participants self identified as African American.

Participant Responses:

The first question posed in the interviews was aimed to elicit the images, phrases, or descriptions that each participant associated with the word family.

1. What does the word family mean to you?

Five out of 12 participants stated that they associate family with the word “love.” One third of the participants described families as a group of people that offers “support and protection.” One fourth of the participants expressed that families are a “source of comfort.”

One participant envisioned her family as a group of individuals that: “tell you, ‘everything is going to be alright,’ or ‘you have nothing to worry about because I am here for you.’ They just hold you if you are about to cry or they will take you in their arms and talk to you.”

The following questions were intended to ascertain whether the participants had families, who they considered to be a part of them, and how they became members of their family. For purposes of consistent, accurate reporting, family constellations were classified as the following: biological, chosen, adoptive, and family by marriage.

2. Do you have a family? Who makes up your family? How did they become members of your family?

Eleven out of the twelve participants reported that they lost one or more of their biological parents to AIDS. Three of the participants were placed in foster homes during infancy and were later adopted. Three-fourths of the participants indicated that extended family members raised them. Two participants indicated that they were raised by extended family members, and then later transitioned into group home settings. One third of the participants defined some of their family members as “chosen.”

Biological Family

This excerpt was extracted from the narrative of a participant who was raised by her extended family following the death of her mother:

“My mother died when I was three. And my father I think died when I was two—one or two. And they both had the virus. My uncle died in ’06, and he had the virus. And other members of my family, they had the virus too ... My grandmother has had me ever since I was two days old ... My family is mainly my grandmother.”

Experience in Foster Care

The following quote was from a participant who spoke vividly about her experience in one foster care home prior to being adopted at age ten:

“I can remember bits and pieces from the house I was placed in before. Her name was _____. And she had me and this other boy, _____, my foster brother. But she sent me back and kept him. She would keep us in this room, and there was no bed, just a mattress on the floor. And we could only eat oodles of noodles. We couldn’t go in her refrigerator, she would beat us if we even went into the kitchen.”

Adopted Family

The following passage was drawn from the narrative of a participant who was adopted in infancy:

“I never met my dad ... well I met him at his funeral. I guess that doesn’t really make sense, but that is how I met him ... I would go to visit my [biological] mom with my foster mother when I was younger, and we would spend time together—so I was close to her. And then she died of AIDS. I knew my real parents, but this is my real family because I’ve been there since I was two months old ... My [adopted] mom, she treats me like I’m one of her own children, not different from her real kids.”

Chosen Family

The following passage was taken from the account of a participant who defines her family as chosen.

“So my biological mother, she’s deceased. She couldn’t take care of me. She was schizophrenic. I was placed into department of social services care. I went into a foster home. I had five other [foster] siblings there. [My foster mom] adopted all five. She didn’t adopt me ... I moved out and basically ever since I’ve been in group homes and foster homes. I wouldn’t say I have my own personal family. I don’t know what the word “family” is ... When it comes to my son, that’s my family ... My son’s godmother, I consider her my sister and I’ve only known her for a year ... A lot of my friends I consider family [members].”

In response to how individuals become members of her chosen family, one participant stated: "By helping me deal with my hardships ... or they just happened to

have been close to me because I was able to tell them about my virus, and about my family, and what I go through. That's how they will become a part of my family."

The third question was intended to clarify whether the participants' perceptions of their families have changed over the course of their lifetime.

3. How has your family changed over time?

None of the participants alluded to major changes in their families. All of the responses indicated that changes included normal fluctuations in size due to births, deaths, or family discord. Despite experiencing multiple losses and shifts in family structure due to HIV/AIDS, none of the participants discussed whether their perceptions of families or their roles had changed over the course of their lifetime. In addition, none of the participants relayed that they lost or became estranged from their family members because of their positive HIV status. One participant commented on her family dynamic:

"We all grew up. We all got older. I mean, there are times when there's points in everybody's life when they feel like they don't want to be bothered or they get agitated fast. Everybody goes through that. But their personalities haven't changed. They're always still the loving, caring people that I know."

The fourth set of questions posed during the interview was intended to elicit whether families (as defined by the study participants) helped or hindered their ability to cope with their illness.

4. How have family members helped or hurt the process of managing your illness? How has your family supported you? In what ways have they made it difficult for you?

All of the study participants reported that their family members support them by reminding them to take their medication. Referring to a chosen family member, one

participant relayed, “She always reminds me to take my medicine. She calls me. She gives me reminders. She sends me alarm clocks and calendars and everything else to remind me.” One third of the participants indicated that their family members also offer support by providing transportation to and from doctor’s appointments and the pharmacy. One third of the participants asserted that their families support them by checking in on them to see if they are doing ok. One participant mentioned that her family provides emotional support regarding her positive HIV status. The following passage illustrates one participant’s experience with her adopted family:

“They don’t remind me that I have it. They treat me like I’m a regular person. They don’t second-guess anything, like when I’m eating my food and I don’t want anymore. They’re like, ‘Can I have it?’ They’ll still eat it and all that stuff and they don’t let the stereotypes about HIV get to them. They stay eating my stuff and they stay drinking my stuff ... They just help me stay grounded. They help me realize I’m still a regular person. I can do everything everybody else is doing.”

Notably, only two participants expressed anger towards their biological mothers for giving them HIV. Only one participant reported that her family makes it difficult for her to cope with her illness. The other 11 participants relayed that their families have not directly or intentionally hindered their ability to cope with HIV; however, they recounted issues and specific incidents that impacted them. The following quotations are a compilation of some of the factors that contributed to their struggle:

“My mother, she’s a real supportive person. And sometimes I get emotional and depressed about my condition, and she tries to help me and tries to talk to me about it. But it don’t really work because she is not in my position.”

“She would literally make me take my medicine. She would put it in my mouth and make me swallow it or she was going to beat me. So either I was going to take it or I was going to get beaten and still have to take it. So I’d just take it and go in the bathroom and throw it up. I thought, ‘I don’t want to take this crap, I’m not sick.’”

One participant who was adopted by a family, shared her experience of feeling like an “outsider:”

“I didn’t know that they weren’t my biological family until middle school ... If you look at my family, they’re more darker than me, so, I’m the lightest one in the family if you took a family photo. And so I wondered, why am I the lightest one in the family?”

One young woman relayed that her family members did not know that about her positive HIV status until she was twenty years old. She recounted that her mother made the decision not to tell anyone until she was on her death bed:

“When she was in the hospital she told them [family] ... When went to the hospital, my grandma told us she was gone. She died after she told them about me ... After that I went into the room to calm my sister done because she was crying ... Then my brother came in, and we all put make-up on her and combed her hair.”

It is notable that all participants identified being reminded to take their medication as the primary manner in which their family members provide support. Because adhering to the anti-retroviral treatment regimen directly impacts viral load and CD4 count, the family members' efforts to remind them to take their medication implies concern for their physical health and wellbeing. Rather than identify emotional support, for example, as the primary source of support, the participants listed functional, practical needs such as: daily reminders to take their medication or transportation to and from their doctor's appointments.

Given that all participants have been aware of their positive status for at least 10 years, their responses may imply that they are more adjusted to having a chronic illness. This common response may also be explained by considering the appropriate stage of development. During adolescence, individuals tend to rely more heavily on their peers for

emotional support rather than their family members. Managing a chronic illness in addition to navigating identity formation may imply the need for additional support.

Another theme that emerged was that three fourths of the participants recounted when they learned of their illness. Although this researcher did not directly ask about the topic of disclosure, many of the participants vividly described when they were informed that they were HIV positive. One participant recalled that he learned that he had HIV when he was 10 years old: “Before I went to bed one night, I peed on the toilet seat by accident. My aunt told me what I got and how I got it—she told me I couldn’t be doing that anymore. I was shocked.” One young woman reported that she learned of her HIV status when she was six years old: “I started getting fevers. I didn’t know what was wrong with me. I started getting very, very sick. So my aunt took me to the doctors and they told me I had HIV.” Another participant recalled, “My [foster] mom told me and she explained what was going on and I felt as though there was a connection because everybody was so concerned, everybody asked me if I was ok.”

The participants were told about their HIV status in different ways and at different stages of their development. Another participant described how she confronted her mother after discovering that she had HIV when she was 12 years old:

“Mom, you didn’t have enough sense to not share a needle with somebody that you knew had it. She knew the guy had HIV or AIDS and she was sharing a needle with him while she was pregnant with me. You should know better not to use drugs while you’re pregnant. She said she caught it from him and didn’t find out until she was eight months pregnant. They keep telling me I can’t blame her. Yes, I can. I can blame her because she knew about it ... My little sister don’t got it. Why it got to be me?”

The data collected indicated that the context of disclosure and availability of support impacted the way in which the participant understood their illness. One

participant relayed that her [foster] mother explained her illness on three separate occasions: at age 7, age 12, and again at age 15. She asserted that at age 15, "she really broke it down to me. She pulled a whole thing up on the internet and had books, and when she talked about it she had stacks of paper about this high ... And I told her, 'no, that's not going to happen, I'm going to die. I'm going to die.'" The participant later acknowledged that although her mother read "a bunch of medical stuff, she really didn't understand it [HIV] herself as much as she wanted to ... but she always wants me to do the right thing and take my medicine."

Conclusion

The findings of this study indicate that all participants recognize a specific group of individuals as members of their family; however, the way in which these individuals became family members varies greatly. Not surprisingly, 11 out of the 12 participants mentioned that they had lost one or both parents to the AIDS virus. As a result, they survive by a composition of extended family, foster, adoptive, and chosen family members. Clinicians must consider these unique family constellations when devising treatment plans and assisting these individuals with managing a lifelong illness.

Study Strengths and Limitations

The results of this qualitative study are not representative of the entire population of young adults living with perinatal HIV infection. Factors that impact generalizability include: small sample size and use of a convenience sampling procedure. Other limitations include a lack of diversity among the following descriptive categories: race, ethnicity, socioeconomic status, gender, and geographic location.

In addition, the reader must consider the cultural bias of the researcher, a Caucasian female in her mid-twenties. Personal biases and preconceptions could have influenced responses or interpretations of responses. However, these narratives provide insight into the experiences of young adults living with perinatally acquired HIV—a population that few researchers have explored. The following chapter will compare and contrast these findings to previous research.

CHAPTER V

DISCUSSION

The purpose of this qualitative study was to explore how young adults with perinatal HIV infection understand and experience the concept of family and to elicit their perceptions of how “family” has helped or hindered their ability to cope with their illness. Researchers published an extensive amount of literature pertaining to individuals with HIV/AIDS. However, there are few studies that examine the lives and experiences of young adults with perinatal HIV infection. The lack of literature is largely due to the fact that children born with HIV during the first two decades of the pandemic were not expected to live beyond childhood. Because of advances in anti-retroviral treatment, an increase in prevention efforts, and knowledge of disease progression, the morbidity rates of HIV infection have dramatically decreased in the United States. Therefore, medical providers are currently witnessing the first wave of adolescents with perinatally acquired HIV disease transition into adulthood.

Family Constellations

The data collected offered tremendous insight regarding how the participants define family. Eleven out of the 12 participants lost one or both biological parents to HIV/AIDS. These results are consistent with the statistics completed by the CDC, which reported that an estimated 80,000 children and adolescents were orphaned since the beginning of the AIDS pandemic. Due to the loss of their primary caregiver(s) during infancy or early childhood, participants conveyed that they were raised by extended

family members, placed in foster care or group home settings, or were adopted. Surprisingly, only four of the participants referred to some of their family members as chosen. Perhaps this can be attributed to society's perception of a family, consisting of two parents and children. The need to have a "normal" family or one that fits into society's construction of a family, may explain why the participants often did not differentiate between biological, foster, and adoptive parents in their narratives.

Medication Adherence

All participants stated that their family members provide support by reminding them to take their medication. However, not all participants clarified whether they were consistently adhering to the medication regimen. Nor did they indicate whether they were more likely to take their medication if they were reminded. Previous research suggests that youth with perinatal HIV infection may stop adhering to their treatment regimen during adolescence for a number of different reasons (Ledlie, 2001). Therefore, stating that they receive consistent reminders to take medication implies that the participants consider the reminders as concern for their physical health and well-being.

Disclosure

Although this researcher did not directly ask study participants about when they first learned of their illness, many included this important event in their narratives. The participants were told about their HIV status in different ways and at different stages of their development. This information confirms previous research relating to the importance of disclosing in a developmentally appropriate manner. The inclusion of the disclosure process without being prompted, confirms that it was a significant life event.

Areas of further research

This large cohort of young adults with perinatal HIV infection is the first, and perhaps the last, due to prevention of HIV transmission from mother to child with advancements in treatment regimens. Therefore, there are multiple topics not adequately addressed in the current literature. Researchers may consider interviewing the foster and adoptive parents, as well as extended family members, that raised these children from infancy. Compiling feedback and gaining insight regarding their experiences may be useful in designing future programs offering support to families with a child with a chronic illness. It would also be beneficial to further explore the ways in which clinicians can facilitate a successful transition for individuals born with HIV from pediatric to adult care. In addition, research that investigates how young adults of different ethnic, cultural, and religious backgrounds cope with chronic or terminal illness would be helpful. Considering individual differences is essential to establishing rapport with patients and to develop appropriate treatment plans to meet their needs.

Implications for the field of Social Work

When working with children or young adults with HIV infection, clinicians should be mindful of how patients cope with their illness and whom they look to for support. Clinicians working with this population may provide the following services: counseling for patients and their family members, support with the adjustment to a highly stigmatized, lifelong illness, risk reduction, assistance with medication adherence and disclosure of positive status to peers, and mobilization of resources. Now, more than ever, clinicians need to take an active role in helping these young adults prepare for the future and independent living.

Conclusion

This research study provided insight into the distinctive life experiences of young adults living with perinatal HIV infection. As they navigate the transition into adulthood with a chronic illness, clinicians have the responsibility to provide support and resources to them and their families. Because this is a new phenomenon, further exploration of the obstacles that this population may be confronted with is necessary.

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APPENDIX A: IRB APPROVAL

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	<p>Office of Human Subjects Research Institutional Review Boards</p> <p>1620 McElderry Street, Reed Hall, Suite B-130 Baltimore, Maryland 21205-1911 410-955-3008 410-955-4367 Fax e-mail: jhmirb@jhmi.edu</p>
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Date: February 25, 2010

NEW APPLICATION APPROVAL

Review Type: Expedited
PI Name: NANCY HUTTON
Study #: NA_00034532
Study Name: "Who's my family?" A qualitative study of young adults living with perinatal HIV infection
Committee Chair: LAURA ROCCO
Committee: JHM-IRB X

Date of approval: February 22, 2010
Date of expiration: February 21, 2011

The JHM IRB approved the above-referenced New Application.

Date of Approval and Expiration Date: The approval and expiration date for this research are listed above. If the approval lapses, the research must stop and you must submit a request to the IRB to determine whether it is in the best interests of individual participants to continue with treatment interventions.

Changes in Research: All proposed changes to the research must be submitted using an eIRB Change in Research application. The changes must be approved by the JHM IRB prior to implementation, with the following exception: changes made to eliminate apparent immediate hazards to participants may be made immediately, and promptly reported to the JHM IRB.

Continuing Review: Continuing Review Applications should be submitted at least 6 weeks prior to the study expiration date. Failure to allow sufficient time for review may result in a lapse of approval. If the Continuing Review Application is not submitted prior to the expiration date, your study will be terminated and a New Application must be submitted to reinstate the research.

Unanticipated Problems: You must inform the IRB of any unanticipated problems involving risks to participants or others.

Study documents:

Written Consent:
FINAL_Hutton NA_00034532 CF_012210 NoLogo.doc

Study Team Members:
Kathleen Fanone

APPENDIX B: INFORMED CONSENT FORM

Approved February 22, 2010

Date: January 22, 2010 Principal Investigator: Dr. Nancy Hutton Application No.: NA_00034532
Patient I.D. Plate

RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM

Protocol Title: "Who's my family?" A qualitative study of young adults living with perinatal HIV infection

Application No.: NA_00034532 Principal Investigator: Dr. Nancy Hutton

1. What you should know about this study:

- You are being asked to join a research study.
- This consent form explains the research study and your part in the study.
- Please read it carefully and take as much time as you need.
- Please ask questions at any time about anything you do not understand.
- You are a volunteer. If you join the study, you can change your mind later. You can decide not to take part or you can quit at any time. There will be no penalty or loss of benefits if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to be in the study.
- Ask your study doctor or the study team to explain any words or information in this informed consent that you do not understand.

2. Why is this research being done?

This research is being done to understand who makes up your family, and whether they help or do not help you with your illness.

Patients of the Intensive Primary Care Clinic who were born with HIV and are now 18 years of age and older may join this study.

How many people will be in this study?

About 12 to 15 people will be in this study.

3. What will happen if you join this study?

If you agree to be in this study, we will ask you to do the following things:

- Participate in one interview.
- The interview will last about 30 to 45 minutes.
- Your answers to the questions will be recorded on the computer, so that I will not

have to take so many notes while we are talking. The recording will then be transcribed and destroyed.

How long will you be in the study?

You will be in this study for one interview.

4. What are the risks or discomforts of the study?

- If you feel uncomfortable or upset when I am asking you questions during the interview, please ask me to stop and I will get a social worker to help.
- You may get tired or bored when we are asking you questions or you are completing questionnaires.
- You do not have to answer any question you do not want to answer.

5. Are there benefits to being in the study?

There is no direct benefit to you for being in this study. If you take part in this study, you may help others in the future.

6. What are your options if you do not want to be in the study?

You do not have to join this study. If you do not join, your care at Johns Hopkins will not be affected.

7. Will it cost you anything to be in this study?

No

8. Will you be paid if you join this study?

You will be given \$25.00 cash at the end of the interview for your time and local travel to and from the clinic.

9. Can you leave the study early?

- You can agree to be in the study now and change your mind later.
- If you wish to stop, please tell us right away.
- Leaving this study early will not stop you from getting regular medical care.

10. How will your privacy be protected?

Johns Hopkins has rules to protect information about you. Federal and state laws also protect your privacy. This part of the consent form tells you what information about you may be collected in this study and who might see or use it.

Generally, only people on the research team will know that you are in the research study and will see your information. However, there are a few exceptions that are listed later in this section of the consent form.

The people working on the study will collect information about you. This includes things learned from the procedures described in this consent form. They may

collect other information including your name, address, date of birth, and other details.

The research team will need to see your information. Sometimes other people at Johns Hopkins may see or give out your information. These include people who review the research studies, their staff, lawyers, or other Johns Hopkins staff. People outside of Johns Hopkins may need to see your information for this study. Examples include government groups (such as the Food and Drug Administration), safety monitors, other hospitals in the study and companies that sponsor the study.

We cannot do this study without your permission to use and give out your information. You do not have to give us this permission. If you do not, then you may not join this study. We will use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside Hopkins who receive your information may not be covered by this promise. We try to make sure that everyone who needs to see your information keeps it confidential – but we cannot guarantee this.

The use and disclosure of your information has no time limit. You can cancel your permission to use and disclose your information at any time by calling the Johns Hopkins Privacy Officer at 410-735-6509 or by sending a letter to:

Johns Hopkins Privacy Officer
5801 Smith Avenue McAuley Hall, Suite 310
Baltimore, MD 21209
Fax: 410 735-6521

Please be sure to include the name of the principal investigator, the study number and your contact information. If you do cancel your permission to use and disclose your information, your part in this study will end and no further information about you will be collected. Your cancellation would not affect information already collected in this study.

11. Will the study require any of your other health care providers to share your health information with the researchers of this study?

As a part of this study, the researchers may ask to see your health care records from your other health care providers. We will ask these other health care providers to give us information about your health status including your T-cell count and viral load.

12. What other things should you know about this research study?

a. What is the Institutional Review Board (IRB) and how does it protect you?

The Johns Hopkins Medicine IRB is made up of:

- Doctors
- Nurses
- Ethicists
- Non-scientists
- and people from the local community.

The IRB reviews human research studies. It protects the rights and welfare of the people taking part in those studies. You may contact the IRB if you have questions about your rights as a participant or if you think you have not been treated fairly. The IRB office number is 410-955-3008. You may also call this number for other questions, concerns or complaints about the research.

b. What do you do if you have questions about the study?

Call the principal investigator, Dr. Nancy Hutton at 410-614-5961. If you cannot reach the principal investigator or wish to talk to someone else, call the IRB office at 410-955-3008.

c. What happens to Data, Tissue, Blood and Specimens that are collected in the study?

Scientists at Johns Hopkins work to find the causes and cures of disease. The data collected from you during this study are important to both this study and to future research.

If you join this study:

- You will not own the data given by you to the investigators for this research.
- Both Johns Hopkins and any sponsor of this research may study your data collected from you.
- If data are in a form that identifies you, Johns Hopkins may use them for future research only with your consent or IRB approval.
- You will not own any product or idea created by the researchers working on this study.
- You will not receive any financial benefit from the creation, use or sale of such a product or idea.

d. What are the Organizations that are part of Johns Hopkins?

Johns Hopkins includes the following:

- The Johns Hopkins University
- The Johns Hopkins Hospital
- Johns Hopkins Bayview Medical Center
- Howard County General Hospital
- Johns Hopkins Community Physician

13. What does your signature on this consent form mean?

Your signature on this form means that:

- You will not give up any legal rights by signing this consent form.
- You understand the information given to you in this form.
- You accept the provisions in the form you agree to join the study

**WE WILL GIVE YOU A COPY OF THIS SIGNED AND DATED
CONSENT FORM**

Signature of Participant Date

Signature of Person Obtaining Consent Date

**NOTE: A COPY OF THE SIGNED, DATED CONSENT FORM MUST BE KEPT BY THE
PRINCIPAL INVESTIGATOR; A COPY MUST BE GIVEN TO THE PARTICIPANT; AND,
IF APPROPRIATE A COPY OF THE CONSENT FORM MUST BE PLACED IN THE
PARTICIPANT'S MEDICAL RECORD.**

Combined Informed Consent/Authorization January 2010 Version 11
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APPENDIX C: INTERVIEW GUIDE

Interview Guide:

1. What does the word “family” mean to you?
2. Do you have a family? Who makes up your family? How did they become members of your family?
3. Have the members of your family changed over the course of your lifetime?
4. How have family members helped or hurt the process of managing your illness? How has your family supported you? In what ways have they made it difficult for you?
5. If I have questions later about this interview, how may I contact you?