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Integration versus Disintegration: A Grounded Theory Study of Adolescent and Young Adult Development in the Context of Perinatally-acquired HIV Infection

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Perinatal HIV infection, also referred to as vertical or mother-to-child transmission (MCT), is the transmission of HIV infection from a pregnant woman to her child. Perinatal transmission can occur during the antenatal period, labor and delivery, or as a result of breastfeeding (Centers for Disease Control and Prevention [CDC], 2007). The first cases of perinatal HIV infection were described in 1982 (Centers for Disease Control, 1982). In 1985, the Centers for Disease Control began to recommend testing for HIV infection among pregnant women as a means of identifying those infants at risk for perinatal HIV infection (Centers for Disease Control, 1985).

A peak in cases of perinatal HIV infection was noted in 1991. During that year, 1,650 infants were diagnosed with HIV infection in the United States. From 2002 to 2006, between 144 and 236 HIV-infected infants were diagnosed each year (Mofenson et al., 2006). Currently about 100 to 200 infants are diagnosed with HIV infection annually in the United States (CDC, 2007).

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The reduction of perinatal HIV transmission rates from 25% to 30% to less than 2% is related to a number of medical interventions. HIV screening of pregnant women, use of antiretroviral medications for maternal treatment and prophylaxis of the infant, avoidance of breastfeeding, and the use of elective cesarean sections when indicated have contributed to the decrease in perinatal HIV infection rates in the United States (Mofenson et al., 2006).

The most recent data from the Centers for Disease Control and Prevention (2010) reported that 57 children under the age of 13 years were diagnosed with HIV infection in 2010. The racial/ethnic composition of perinatal HIV infection mirrors that of adult HIV infection, with the majority of new cases noted among racial/ethnic minorities. Of the 57 cases diagnosed in 2010, 69% of the children were African American.

Just as advances in antiretroviral therapy (ART) have decreased mortality and morbidity in adults, ART has increased the life expectancy of HIV-infected infants and children. A recent study of 364 HIV-infected children born between 1986 and 2004 reported that 6-year survival rates for children born during the 1980s, 1990s, and the 2000s were 57%, 76%, and 91% respectively. Children who received ART during the first 6 months of life had a 6-year survival rate of 94% (Kapogiannis et al., 2011).

Advances in ART has increased the life expectancy of perinatally-infected infants; therefore, survival into adolescence and adulthood is now more likely than before (Kapogiannis et al., 2011). The adolescent period is a time of transition from childhood to adulthood that includes the developmental tasks of future planning, career planning, and the development of intimate relationships. The presence of a chronic illness during this period can interfere with the achievement of these developmental tasks (Lubkin & Larsen, 2006). The impact of other chronic illnesses such as diabetes, cancer, and cystic fibrosis have been described in previous studies (Cohen, 1999; Gannoni & Shute, 2010; Martin et al., 2012), but adolescents and young adults with other chronic illnesses do not experience illness-related stigma like that experienced by adolescents and young adults with HIV infection (Swendeman, Rotheram-Borus, Comulada, Weiss & Ramos, 2006). In this aspect, HIV infection is unique and it cannot be assumed that the extant research about other adolescent and young adult chronic illnesses will be the same for adolescents and young adults perinatal with HIV infection.

Review of the Literature

A review of the literature over the past 15 years revealed a number of studies that have focused on perinatal HIV infection. As life expectancy increased and perinatally-infected infants survived into childhood and adolescence, these children and adolescents experienced a number of HIV-related health issues. These health issues include physical, psychological, and cognitive aspects of perinatal HIV infection.

In terms of the physical effects of HIV infection, a study conducted by Bomba and colleagues (2010) with Italian children with HIV infection ($n = 27$) reported reduced physical health and quality of life when compared to age and sex-matched uninfected controls. Jacobson and colleagues (2011) noted that children with perinatal HIV infection had lower mean height, weight, and body mass index (BMI) when compared to HIV-

exposed, but uninfected controls. HIV-infected children also had a lower percentage of body fat, but an increase in truncal fat, which is associated with cardiovascular disease risk. HIV-infected children may also experience pubertal delay. A prospective cohort study of 983 children between the ages of 6 and 18 years reported that both males and females with severe immune suppression were less likely to enter adrenarche, and were less likely to begin puberty when compared with non-immune suppressed controls (Buchacz et al., 2003). A study by de Martino and colleagues (2001) conducted in Italy with 212 perinatally-infected children noted pubertal delays in both sexes, but reported that the age of pubertal onset was not related to clinical or immune status, medications, or weight and height for age at the onset of immune suppression.

A few other physical health issues were identified that affect perinatally-infected children and adolescents. Compared to uninfected children, perinatally-infected children were more likely to have body fat distribution abnormalities and increased cardiovascular disease risk (Jacobson et al., 2011). These specific physical changes are related to both ART as well as the generalized inflammation that results from HIV infection (Grinspoon & Carr, 2005).

The psychological effects of perinatal HIV infection can be divided into psychiatric/mental health conditions and psychosocial aspects of HIV infection. In terms of the psychiatric/mental health condition, Scharko (2006) conducted a meta-analysis of eight published research papers on the prevalence of psychiatric disorders among HIV-children and adolescents. The prevalence rates of attention deficit/hyperactivity disorder were 28.6%; anxiety disorders were 24.3%; and depression was 25%. The sample sizes of the studies were small, and only two of the eight studies reviewed in the meta-analysis were control studies. Malee and colleagues (2011) compared mental health problems of 295 HIV-infected children with 121 HIV-exposed, but uninfected children and noted that mental health problems were higher in HIV-exposed (38%) than HIV-infected children (25%). The high rates of mental health problems of the two groups were related to parent/caregiver characteristics (such as a diagnosis of a psychiatric disorder, poor limit-setting, and health-related limitations of the parents/caregivers), as well as child characteristics (younger age and lower IQ), noting the importance of mental health screening for both infected and exposed children and their families (Malee et al., 2011).

Children with perinatal HIV infection also experience a number of psychosocial issues. Bomba and colleagues (2010) noted that a sample of 27 children with perinatal HIV infection in Italy experienced psychosocial conditions such as impaired social ability, school problems, and delinquent behavior. Mawn (2011) conducted a qualitative study of seven children with perinatal HIV infection aged 9 to 13 years, and noted four major themes. These themes included a positive self-perception, various levels of HIV knowledge, lack of awareness and concern of the disclosure process, and knowledge of the need to conceal their HIV status from others (Mawn, 2011). Other psychosocial conditions explored in a qualitative study of 10 families over a 7-year period reported that families experience periods of normalcy versus uncertainty, struggle with issues related to disclosure, medication management, and changing HIV treatments (Mawn, 2012).

Some researchers have documented the cognitive functioning of children with HIV infection. A comparison of vocabulary and reading ability of 206 HIV-infected and 134 HIV-exposed children aged 9 to 16 years of age noted that HIV-infected participants scored lower on vocabulary and reading than HIV-exposed children. Immune status (CD4+ counts), disease classification, and viral load (HIV RNA levels) were not associated with vocabulary and reading scores. HIV-infected children receiving antiretroviral therapy (ART) had lower reading scores than those not taking medications (Brackis-Cott, Kang, Dolezal, Abrams & Mellins, 2009). Concurrent language impairment was associated with a viral load greater than 400 copies/ml, an AIDS-defining disease classification, and initiation of ART before 6-months of age (Rice, et al., 2012). Smith and colleagues (2006) examined cognitive development of 117 HIV-infected children compared with 422 HIV-exposed children, and noted that an HIV infection versus AIDS-defining disease classification was associated with impairment of cognitive development across all domains. Children with HIV infection, but not an AIDS-defining disease classification performed as well as HIV-exposed children in all domains of cognitive development.

Despite studies that have documented physical, psychological, and cognitive effects that children with perinatal HIV infection experience, little attention has been given to the processes that describe how perinatal HIV infection impacts adolescent and young adult growth and development. Based on this identified gap in the research literature, this study was designed to qualitatively describe the process by which perinatal HIV infection impacts adolescent and young adult growth and development.

Method

Design

Grounded Theory (GT) was the qualitative research design used. GT was developed by Glaser and Strauss (1967) based on their belief that theories should be grounded in data. GT is concerned with actions, interactions, and social processes shared by participants that can be depicted as categories of information that comprise a theory.

Sample

Participants were recruited from a University-based Pediatric Infectious Diseases & Immunology outpatient clinic in the southeastern United States using theoretical sampling. Theoretical sampling equates to selecting participants who can best describe the phenomenon under investigation to assist in development of the theory (Strauss & Corbin, 1990).

To participate in the study, participants were required to meet inclusion criteria. Participants were required to be: a) diagnosed with perinatal HIV infection; b) age 18 to 24 years of age; and c) able to read and understand English. Participants not meeting inclusion criteria were excluded from participation.

The sample size was determined by saturation of the data. Saturation was subjectively determined by the first author at the completion of the twentieth interview. Saturation was achieved when no new information or categories were found in the interviews (Glaser &

Strauss, 1967). Five additional interviews were conducted in order to substantiate the previous interviews.

The sample consisted of 25 adolescents and young adults 18 to 24 years of age with perinatal HIV infection. A more complete description of the sample is included in Table 1.

Procedure

This study was approved by the University's Institutional Review Board (IRB). The first author recruited participants from an outpatient clinic as previously described. The remaining authors assisted the first author in recruiting participants by referring participants who met inclusion criteria. The first author conducted all 25 interviews in a private conference room located at the clinic site.

The interviews were conducted with the use of a structured interview guide. This interview guide ensured that each participant was asked the same questions. Additional questions were added, deleted, or modified based on previous interviews, which is consistent with GT methodology (Strauss & Corbin, 1990). Questions that were included in the interviews are included in Table 2.

After ensuring that participants met inclusion criteria, the first author obtained written informed consent. A second written informed consent was also obtained simultaneously that granted permission to audio-record the interviews, as required by the University's IRB. After completing the interview, the participant was reimbursed with \$50 in cash for time spent in participation.

The audio-recorded interviews were transcribed verbatim. Interviews lasted an average of one hour. At the conclusion of each interview, the first author wrote field notes in order to maintain an audit trail as described by Strauss and Corbin (1990). The field notes allowed the first author to reflect on the interview and to decrease pre-conceived perceptions in an attempt to gain a less biased interpretation of the data.

Data Analysis

Data were analyzed using the procedures outlined in GT according to Strauss and Corbin (1990), which involves three stages of coding: open coding, axial coding, and selective coding using the constant comparative method. During open coding, the first author read through each of the 25 interview transcripts to develop a list of major categories. As each interview transcript was read, categories were compared to each previous category in an attempt to develop an exhaustive list of possible categories. A central phenomenon is identified during open coding that is the central component of the theory.

During axial coding, the relationships between the categories were developed. At this stage the researcher connected each category to other categories as well as to the central phenomenon. Axial coding is used to develop a figure that represents the theoretical model of the study.

The final stage of coding, selective coding occurred when the researcher developed statements that inter-relate the categories. This is accomplished by identification of the influences, contexts, conditions, and consequences of the study's findings. Selective coding can be presented as a narrative summary of the theory or a set of hypotheses or proposals for further investigation (Strauss & Corbin, 1990).

Data Validation Strategies

Three methods of data validation were used to document the accuracy of the findings. These include clarifying researcher bias, peer review/debriefing, and providing rich, thick descriptions that allow readers to judge the transferability of the study's findings (Creswell, 2007). Clarifying researcher bias is a necessary component of data validation because all members of the research team with one exception (the last author) have clinical experience in providing care to adolescents and young adults with perinatal HIV infection. This clinical experience may have influenced the data collection and data analysis. In order to decrease the risk of researcher bias, the author verified the categories identified by the first researcher by comparing the categories to the original data. Comments made by these authors were incorporated into the study's findings.

Peer review/debriefing was also used. All members of the research team with experience in providing clinical care to this population were asked to confirm the study's findings. The first author met with each additional author to review the findings and the interview transcripts as needed in order to confirm the study's findings and to ensure that the data were congruent with clinical experiences. Comments made by this author were incorporated into the study's findings.

In order to make the study's findings transferable to other settings that provide care to adolescents/young adults with perinatal HIV infection, rich, thick descriptions of the results are provided. Rich, thick descriptions of the participants and the findings allow readers to determine if the results can be transferred to other settings based on participant characteristics and study findings (Creswell, 2007).

Results

The purpose of this study was to develop a theory grounded in the data that explains how perinatal HIV infection impacts adolescent and young adult growth and development. Participants provided rich descriptions of how their lives were impacted by perinatal HIV infection. The descriptions provided by the participants resulted in a theory named *Integration versus Disintegration* that details how these participants' growth and development have been impacted by HIV infection. The theory is presented in Figure 1.

Disclosure of HIV Infection

The origin or antecedent of *Integration versus Disintegration* began when participants first became aware of their HIV status. All 25 participants reported remembering their disclosure by their parents, caregivers, or healthcare providers. Two participants reported that they did not remember how old they were when they were disclosed. Age at disclosure ranged from 7 to 16 years ($M = 10.69$, modes = 7 and 11 years). During disclosure participants were told to

keep their diagnosis a secret and not to discuss it with any person, including family members. The need to conceal the diagnosis from family and friends created confusion and distress because the participants expressed a need to talk to someone about their diagnosis, but instead respected the wishes of the family. This is described by participants:

Because when I was young my mother told me to never talk about it... well then I was stuck in a rut where I wasn't supposed to talk about it. It was really hard because I would be like, (I wanted) to talk with my friends and maybe they would (help me). It was one of those things that I just held inside of me. And it was one of those things that I just wanted to talk about. I wanted to say it out loud. (Hispanic female, age 24)

You learn not to run your mouth, yeah. You just be quiet. People don't know how to talk about it. They are uncomfortable with it... That's how I am. I keep everything inside. I don't tell nobody. Because you hold a lot of stuff and let it build up, but me I don't tell nobody. (African American male, age 18).

Disruption of the Familial Self

Despite the fact that participants were instructed not to talk about HIV infection within or outside the family unit, all participants agreed that HIV infection had a profound impact on the family. One of the most significant was the *Loss of the maternal figure*. Over half of the participants reported that their mothers had died of HIV infection. Some of the participants have little or any recollection of their mothers, and were raised by other family members. The maternal loss had a lasting impact on their lives, as reported by the participants:

But the thing is, I miss my Mama a lot... She was my best friend (repeats). It's been her I been thinking about. It's only her I miss... She was there for me. She would be there for me. Everywhere I go she'd be there for me. But there's nobody here. That's why it hurts so bad. (African-born male, 21 years).

Even if there was a cure, I'm going to be so honest, my life will not change because my mom, she's dead and gone... Damn!... I'm still going to have that effect in my life that my Momma died from it... I would like to have known her. I would like to say, "Come on, Ma. Come to the movies. Come on, Ma. Let me take you shopping." Hell, I would like to do something (like that). And it be (*sic*) so hard that I can't go (African American male, 21 years).

Family Communication and Dynamics

All participants reported that HIV influenced family communication and dynamics. HIV's impact on the family was not only confined to concealing the diagnosis, but it also contributed to dysfunction in the family, including blaming parents for HIV infection or becoming angry with parental denial of HIV infection, as reported by one participant:

I'm angry at my dad because he infected my mom and that's how I got it. I mean, what kind of father are you? When he drinks, he drags everything out. He doesn't know that I can't stand him for what he did. He gets real angry with me sometimes. I mean, how can you be angry with someone that you gave it (HIV) to them? My

mom denies that she has it, so that's kind of hard because I know that I didn't get this from having sex. It didn't come from a blood transfusion or anything, so it can only come from her. My sister has it, so I know it came from her, but she still denies it. (African American female, 19 years).

Many participants noted that other family members who are not infected with HIV often treat family members with HIV infection differently. This differential treatment ranges from avoidance to violence directed at those family members who are infected with HIV, as reported by one participant:

Coming up in my household there wasn't really no family thing. Yeah, we would have a little get together sometimes, but I would want to work on my own family and I would want to give my kids what I didn't have coming up, so I think that is the one thing that HIV is holding me up on...because we got some family members that when you talk to them, they'll sh*t on you and there's no kind of hurt like family hurt. I don't care—you can get hurt from your friends, your boyfriend, your girlfriend but there's something different about that family hurt...because seeing this and then, people talking about my family members (with HIV), "Oh don't be around her. She got AIDS. Don't be around him...because he has AIDS. You don't want to shake their hands because they got AIDS." And all kinds of bullsh*t man... was trying to be that impact that pulled my family back together. That's the only thing I was trying to do...because there comes a time in my life when I be (*sic*) like, I'm tired with my family fighting and fussing with each other. Why can't we just go to a barbeque and have fun? Ok, yeah we can get drunk and talk sh*t, but dang! We ain't got to fight each other. We (are) family. We (are) supposed to keep that gel, supposed to keep that bond with each other, man. (African American male, 18 years).

Disruption of the Coping Self

Awareness of HIV infection combined with altered family dynamics and family communication resulted in a disruption in coping, according to the participants. This altered coping is manifested in a number of ways such as *Searching for Meaning*, *Concealing the Diagnosis*, *Struggling with Adherence*, and *Avoidance Coping*.

In an attempt to understand and make sense of their diagnosis, many participants reported that they began *Searching for Meaning*. This is described by one participant who was continuing to look for meaning in her situation:

I know that everything happens for a reason, but I really don't understand why I out of all people have it...I think that everyone born on this planet is here for a purpose. They're not just here to be here or whatever. They're here for a purpose and especially if they're young I doubt that they've actually found out what that purpose is yet. And I think that you should live to see what you have to offer this world and your community (African American female, 18 years).

All participants reported the need to keep their HIV status from others. This need reinforced messages from the family regarding the need to conceal the diagnosis. Twenty participants

endorsed *Concealing the Diagnosis* as a method of self-protection. Choosing to conceal their diagnosis versus disclosing the diagnosis and facing possible rejection from others was the method that nearly all of the participants chose:

...So people with HIV they mostly stay quiet. We're very quiet and we're always thinking we should stay that way. (Haitian female, 19 years).

I don't want to have to hide myself for what I have because I don't mind being myself, but that one secret I have got to hide every time... I would lie every time and I hate lying, but I have to do it. If I got rejected or whatever, I wouldn't mind, but the stress of others knowing –I don't want that. (Hispanic male, 20 years).

Treatment of HIV infection requires that clients adhere to medication regimens. All participants reported that adherence required a great deal of commitment and effort. Because of a lack of support from family and the need to conceal the diagnosis from others, participants reported that it was difficult to be adherent, despite knowledge that adherence to ART was the only way to control HIV infection. This resulted in *Struggling with Adherence*, whereby participants knew that adherence was necessary, yet they made a conscious effort not to adhere to their medication regimen:

I mean, I have to be the one to want to do it (be adherent with medications). Nothing can make me want to do it. I have to be the one to say, "Listen, you're going to take your medicine even if it makes you sick for two weeks." I have to be the one to say that. Nobody or no money can make me do it until I really want to do it. (Jamaican female, 19 years).

In an effort to cope with HIV infection, nearly all of the participants reported that they engaged in *Avoidance Coping*. Participants either became engrossed in school or work to help them forget their diagnosis, or just avoided the topic as much as possible:

Now with school and everything I rarely think about it besides when I get the appointments and everything, but I just try not to think about it honestly. It is always there in the back of your mind, but I just try not really dwelling on it too much. .. but just talking about feelings. It is kind of touchy. (African American female, age 21).

The only time you think about it is when you are about to take your medicine or when the doctors call you or when you see a paper about it. (African American male, 18 years).

Disruption of Physical Self

Nearly all participants reported physical changes that were associated with HIV infection manifested as body habitus changes associated with side effects of ART, resulting in *Body Image Changes*. These changes included weight loss and HIV-associated skin changes, for example. The participants who expressed distress regarding these physical changes were concerned about not only the impact of these changes on body image, but that these changes might disclose their HIV status to others. The following comments regarding the physical self were made by participants:

My weight goes up and down. My arms and legs are skinny and then people say, “Oh, you are losing weight.” My stomach is too big and everywhere I go people say, “Oh, are you pregnant?” I even have to wear a girdle! (African American female, age 18).

These body habitus changes associated with disruption of the physical self were stressful for participants because participants wanted to appear “normal” and did not want to be identified as having HIV infection because of physical changes. This was summarized by one participant:

Some people look at me (and) they don’t know that I have HIV because, you know, I don’t look like I’m sick at all...That’s one thing I am really happy about. I don’t want to walk down the street and people say, “Why are you sick? Why do you look like that?” I don’t want people to see me like that because it would make me feel really bad, you know? (African American male, age 21).

Disruption of the Psychological Self

All participants reported that living with HIV infection resulted in a number of psychological/mental health issues. Because of the impact of HIV infection, the participants reported that *Mental Health Issues*, *Substance Abuse*, *Reading/Learning Disorders*, and *Transition Issues* were components of this category.

Mental Health Issues—Nearly all participants reported that HIV resulted in mental health issues. The most common mental health issues that were identified by participants were depression and low self-esteem. Living with HIV infection and dealing with issues surrounding the management of HIV infection caused the participants a great deal of psychological distress. This psychological distress was manifested by depression and low self-esteem, as summarized by participants:

My situation makes me feel depressed. Like I can’t clearly explain my case, it’s just something I have to deal with. I am concerned about my son, ...but you know, my life doesn’t revolve around HIV. You have to survive, especially if you have kids...I can’t be depressed and be sitting there, you know? My child is going to be depressed too, and I can’t take that (African American male, 24 years).

My self-esteem is low, ... and it makes me sad because I think about HIV and how it has affected my life...I cry almost every week...It makes me feel sad because I just want to be like other people...I feel left out (African American female, 18 years)

Substance Abuse—In an attempt to cope with HIV infection and mental health issues, some participants reported that they engaged in substance abuse. Participants reported that the substances used were limited to marijuana and alcohol. The use of substances was summarized by two of the participants:

Sometimes I am into staying out too late and doing other things. I like going out and partying. ...I still drink, but that’s at parties (African American male, 18 years)

I use marijuana a lot. Marijuana to me, there's nothing wrong with it. It's just, you smoke, get stoned, you like other things. The other drugs to me they make you do crazy stuff. Marijuana makes you be (*sic*) chilling, your mind feels—you don't have to worry about doing anything wrong. It's not going to make you do anything wrong. You just chill in and stuff. (African American female, 21 years)

Reading/Learning Disorders—Some of the participants reported that their diagnosis of HIV infection often influenced school performance. These participants noted that success in school was impeded by reading/learning difficulties. These reading/learning difficulties often were related to difficulty with attention. Difficulty with attention combined with reading/learning difficulties resulted in school performance issues:

School was average for me. I had some problems. But everyone has problems...No one noticed I couldn't read until 2nd grade... like I would be in reading class and have like tutors and go to special classes in school. (Hispanic female, 24 years)

I always got to be closer to the teacher. I have to sit in the front row. If I sit in the back, I'm not going to learn. When I sit in the back I just wander around and don't pay attention (Haitian male, 23 years)

Transition Issues—About half of the participants voiced concerned about the transition to adult care. Because of the age range of the participants, all were in some phase of the transition process. These participants have been receiving care at this clinic most of their lives, and the transition to adult care provided some concerns as reported by one participant:

I'm used to people caring and I'm not sure if they are going to care as much at the adult clinic. Since you are an adult, you are supposed to take care of yourself. (African American male, 19 years)

Another participant provided more information on her concerns regarding the transition to adult care:

I don't want to leave. I mean, I know everyone here because of the family and they know me and we've always come here. I will be so sad...(In the adult clinic) they're not as friendly and upbeat as you are with kids. ...and I am never going to act like an adult. Not there. There are new people there and they will have to deal. I was kind of nervous about it (transitioning to adult care), but not too much anymore because it's going to be something new. Things change. I got to keep going because I'm getting older. So once you get older, these things change. Over here (in the pediatric clinic) they help you too much. It's kind of bad because when the kids get older and go to the other clinic (adult clinic), they aren't prepared to do a lot of things on their own... They ain't going to play with you there. (African American female, 19 years)

I feel bad about that when I will go to a clinic with so many more people there than here. But, I am happy because look at us. We are doing well and living longer. We don't have to be in the hospital anymore. Yes, I will be leaving here and will feel mixed about it. (Jamaican female, 19 years)

...We need more places like this. I mean everyone's open. Everyone's very friendly. I mean, you can joke about stuff. When it comes to talk(ing) about HIV, you are serious about it, but they make it a bit more humorous. They make it not so hard to talk about....It is a serious thing, but it is so much funnier over here than it is in any other place... Just the atmosphere is awesome....I can talk to my friends about my HIV, but it won't be like when I'm talking here 'cause everyone here knows a lot more than my friends. (Hispanic female, 24 years)

Disruption of the Social Self

All 25 participants reported that HIV infection had an impact on their social lives. The impact on their social lives included peer relationships as well as their relationships with their communities. *Disruption of the Social Self* includes the subcategories of *Peer Disclosure*, *Community Stigma* and *Stigma from the Church*.

Peer Disclosure—All participants reported that social relationships were disrupted because disclosure to peers was a challenge. Participants reported that peer disclosure was hampered by the fear of rejection, or that their HIV status would be disclosed to others without their permission. In order to prevent this, participants chose not to disclose their diagnosis to peers. Because participants felt that they could not disclose to their peers, social support from peers was not available. One participant described the challenge of peer disclosure:

I haven't told anyone because I am afraid. I am really afraid of their reaction because I have been living with this so long. I don't want somebody to treat me differently because I am living with this. I want them to treat me the same. (African American male, 18 years)

Community Stigma—All participants reported that community stigma influenced their social relationships. Participants reported that they often heard negative remarks about people with HIV. In addition, some participants reported that they had observed differential treatment of others with HIV infection that was probably related to fear of HIV infection and a lack of knowledge of HIV transmission factors. Fear and a lack of knowledge often resulted in stigma from the community, as summarized by one participant:

I wish people would be more educated. I mean, everybody knows about it (HIV), and that it's out there, but a lot of people don't really want to understand it. If they don't have it, they don't want to understand it. People would rather not know and they would rather not ask questions (African American female, 20 years)

Stigma from the Church—The last factor that influenced the social lives of participants was stigma that stemmed from the church. Some of the participants reported that they were involved in their church, but many felt uncomfortable because of stigma that they experienced from the church. Some participants stopped attending religious services because of this stigma:

When I went to church they were like, 'Oh yeah, this is the guy who has it (HIV).' I would be looking at them and they would say, "Hey, how are you doing?" Don't

feel sorry for me. I don't go to church anymore because they talk too much. I'm not into that, you know? You're in the church of God. You're supposed to be worrying about church and God. You don't need to worry about everybody else's business.
(Haitian male, 23 years)

Disruption of the Sexual Self

All participants reported that a diagnosis of perinatal HIV infection resulted in sexuality issues. These issues included the subcategories of *Reproductive Issues*, *Disclosure Issues*, and *Sexual Relationship Issues*.

Reproductive Health Issues—All female participants and some of the male participants voiced reproductive health concerns that were related to HIV infection. These participants were concerned that they would vertically transmit HIV to their child; therefore, participants noted the need to plan for pregnancy. The need to plan for pregnancy was unique to those with HIV infection, according to the participants:

That fact that I have HIV means that if I decide to get pregnant, I won't get pregnant sexually. It would have to be with a sperm donor or whatever they call it. So it won't be exactly sexually. It would have to be done another way, besides sexual intercourse. (African American female, 18 years)

Disclosure Issues—All participants also reported difficulty with disclosing their HIV status to their sexual partners. Just like with disclosure to peers, participants feared that disclosure would result in rejection or disclosure to others without their permission. To avoid this, many participants reported that they would engage in sexual behaviors without disclosure. In addition, in order not to raise suspicion among sexual partners, some participants reported that they would engage in high risk sexual behaviors with sexual partners. This was described by one participant:

I was 14 the first time I had sex. The first time I didn't use a condom.. but I said, "Damn! Because I know the law says you should tell the girl, even if you don't want to tell the girl. You should always tell the girl." She could have it and then I could go to jail for life. Damn! I'm praying to God that she doesn't have it!
(African American male, 18 years)

Another participant added: I felt that if I was using protection I didn't have to tell. I didn't worry about infecting anyone because of protection. I used to think that I'll go out and do it with everybody, but I was like, "Oh my God! I can't believe that I said that." (African American female, 24 years)

Sexual Relationship Issues—All participants reported that perinatal HIV infection had an influence on their sexual relationships. The participants believed that many people their age who were not infected with HIV were more free to engage in sexual relationships. This was not the case for those with HIV infection because of the need to prevent transmission of HIV to others. In order to prevent transmission, participants knew that they should disclose their diagnosis and practice safer sex behaviors. Because many participants did not want to disclose their diagnosis and believed they could not practice safer sex behaviors without

disclosing their HIV status, this had an impact on their sexual relationships, as reported by these participants:

You can't rush everything. You can't do the same things as your home boy does. He goes out and does who ever. You can't really do that. You got it (HIV) and you could give it to somebody else and then that person gets it and it's going to cause problems...and if that person is nasty, you will get locked up or something...
(African American male, 19 years)

Well, you are the only person that is going to know about this. One time I almost had sex with somebody without protection, but I stopped it because because I don't want to put (that person) at risk... I'm not going to lie. I did want to go there (have sex) but at the same time I was thinking about the other person because I don't want to be like my father and just put it out there... Some people don't care and they'll just do it (have unprotected sex) anyways. (They) will give it to anybody like my father did. (African American female, 18 years)

Integration versus Disintegration

Participants provided numerous ways that HIV infection impacted adolescent/young adult growth and development. According to the participants, HIV infection provided barriers (such as familial, physical, psychological, social, and sexual issues) to achieving the developmental milestones that typically occur in these stages. Despite these barriers, a number of the participants reported that they were able to surmount these barriers and assimilate HIV infection into their lives. This dichotomous view led to the over-arching category of the theory that describes the process by which HIV infection impacts adolescent/young adult growth and development. This over-arching category of this process is termed *Integration versus Disintegration*.

Participants verbalized a number of factors that assisted in the integration of HIV infection into their lives. Those who reported successful integration and were able to manage their illness noted that the basis of integration was support received from others. This social support from others in turn allowed these participants to offer support to others living with HIV infection, as summarized by one participant:

My friend has HIV. She never really wanted to talk to anybody or anything. And I feel like I helped her break out of her little cage, like when me and her hang out, we talked about other stuff too. But we talked about it (HIV). Like, "How are you doing this? How are you doing that? Do you need any medications?" We actually share sometimes...we just talked about it. We let each other know how everything is going in our life and (how things are) affecting us. I help her out. She helps me out. She comes and sleeps over my house most of the time... (Hispanic female, 24 years)

Drawing on the support from others as well as offering support, participants were able to talk to others about their diagnosis and the challenges experienced. Participants reported that talking about their illness was cathartic and allowed them to further access support from those to whom they were able to disclose. These were discussed by one participant:

I mean, sometimes people sit down and talk about it and have real conversations, but it doesn't happen, like every day or every month... But it should be talked about more often than it is....People with HIV can only talk about it with their doctors. Talking has actually helped me a lot because I get information from other people. I have information myself that I can tell people. Talking is what I do.
(African male, 21 years)

Some participants reported that they accessed spirituality to assist them in integration and management of HIV infection. These participants attended and were actively involved in religious services or groups. Spirituality was used to assist with coping and integration:

I ain't going out of control with it. It is not all about HIV. You just pray to God and believe by faith that you can be healed... It'll keep holding you down. It's like a mountain that don't want to move. That's why you got to pray over and make the mountain leave... It's only by God, the power of God. That's how I deal with it.
(African American female, 18 years)

A few participants reported that disclosure and safer sex practices helped with integration. Disclosure of the diagnosis to others and practicing safer sex with partners to whom they had disclosed added to a sense of accomplishment and integration. This was described by a participant who became pregnant without disclosing her diagnosis:

I have a baby with a guy. He came here to the doctor's office with me and he did the test and he's negative...It was so scary for me (to tell him that I had HIV), but the outcome was so different than I thought it would be. I was so happy that I did tell him (that I had HIV)...Person to person, I could do anything if I could deal with this. (African American female, 21 years)

Other participants reported that integration was assisted by identifying the "positives of being positive." This was the realization that all aspects of living with HIV infection did not have a negative impact. In fact, participants were able to identify some ways that HIV infection had a positive impact on their growth and development:

You know, it challenges you, and you start to think about life and appreciate it a little more. You have a view on life a bit differently... You just got to cherish each day like it's your last day on earth... HIV has affected me in a positive way because it made me stronger. Because I'm undetectable first of all and I'm fine as long as I do what I have to do. I'm fine just like everybody else out there...but I wish I can stay longer than my mom did. (African American female, 18 years)

Just as participants were able to detail the integration of HIV into their lives, participants were also able to provide examples of how HIV negatively impacts adolescent and young adult growth and development and results in *Disintegration*. According to the participants, the stem of disintegration is maintaining secrecy and silence about HIV infection. Maintaining secrecy and silence did not allow participants to deal with or cope with HIV infection, as described by a participant:

I just, I ain't one (to talk about HIV). That is one thing about me... I don't tell people my business. What's my business is my business. I will go to the grave

about my business. I'm not really a talker like that and you want to feel special to get me here, boy. Because I don't really open up...I just got to have it on my own. ...It's hard man, to build trust. It is. (African American male, 21 years)

Participants noted that disintegration was influenced by issues surrounding adolescent/young adult sexuality. Because participants reported difficulty disclosing their HIV status to sexual partners, participants in disintegration managed this issue in two ways. First, some participants reported that they avoided sexual relationships completely in order not to have to disclose their HIV status:

I've never had sex. I've dated guys, but I never got too attached. I'm always distant. My last boyfriend said, "Something's wrong with you. You don't express what's going on with you." I never got deep in the relationship. I never introduced him to my family. If I got too attached, someone is going to hurt me and then they are going to leave me anyway. (Bahamian female, age 23).

The second method was failure to disclose. Some participants reported that they did not disclose their HIV status to others, but engaged in unsafe sexual behaviors:

I had sex with a girl...I met her at a party...It was just one time. I didn't use a rubber and I did not tell her...As I got older though I knew that I had to tell the person, but I didn't. I didn't feel guilty about it because I didn't see her anyways. I don't go back to the past. I move forward. (Haitian male, 23 years)

Another factor that was a component of disintegration was failure to find meaning. These participants reported that they struggled to find meaning in their lives, but were unable, as described by one participant:

And sometimes I feel like, I ask myself why. Of all people, why am I the one being punished? Like why is God punishing me? I'm smart, you know I'm not the perfect person. I try my best in school...I don't hurt other people. I've never been arrested or anything. I don't really do a lot of stuff that a lot of other teenagers or kids are doing today. I haven't had sex. I'm still a virgin. So, it's like, sometimes I ask myself why am I the one being punished because a lot of teenagers who are sexually active they just don't care...I still can't believe that I have it because I haven't done anything. (African American female, 18 years)

Non-adherence was also included in disintegration. Some participants reported non-adherence to medications and appointments that were related to the need to conceal their HIV status from others. Participants also reported that they were tired of being adherent with medications because they had been receiving ART for a number of years. This choice to be non-adherent is described by one participant:

Yeah, I told everybody that I'm still taking the medicine, but really I wasn't. So I just came back (to the clinic) and told them, "I got to stop wasting you alls time filling these prescriptions because I'm not taking (them). So I guess they went and talked for a little bit and said, "Listen man, we're just going to take off it off" (stop the medications), and that's what they did. They took me off and ever since I've been off medication... (African American male, 21 years)

Other sources of risk comprised the final component of disintegration. Participants reported that a failure to cope with their HIV status resulted in deteriorating mental health and substance abuse, which resulted in participation in other high risk behaviors. Evidence for other sources of risk were provided by participants:

Most of the people (with HIV) I hear that they put themselves in these situations. Because you know what it is, nice prostituting and shooting up. You know what's what and you are asking for it really... Because they are not doing what's right. (African American female, 21 years)

Yeah, I feel like I'm blessed now. I feel like I'm blessed, man. But I'm still here. Like the little altercation that happened in my little neighborhood at the dice game. We was (*sic*) gambling and all, and somebody came with an AK47 and shot at the whole dice game. And I ran. Two other people got shot and two of them died. And I got away. I don't know man... They always killing, man. Kill, kill, kill. (African American male, 21 years)

I never ever really had no real job, all I knew was to hustle... getting fast money... Fast money be like selling drugs and all that... I am addicted to that fast a** money... So I felt like, ain't no man in the house, so you know what? I'm 13. I got to be the man in the house seeing as there ain't no man here and I'm tired of Grandma feeding me... so I had to step up to the plate and be like, you know what? ... I'm not saying I was out there heavy trafficking and doing all that crazy sh*t. I was just out there doing a little bit, earning a little money, a couple of hundreds a night. So I was used to fast money. I was used to it at an early age, (sometimes) there's no other ways. (African American male, 18 years).

Discussion

This study presents the process by which perinatal HIV infection impacts adolescent/young adult developmental tasks. To our knowledge, this study is the first grounded theory (GT) study that describes this process. The theory, named *Integration vs. Disintegration*, describes the process by which perinatal HIV impacts growth and development, and how adolescents/young adults with perinatal HIV infection either learn to integrate or fail to intergrate the management of the aspects of HIV infection into their lives.

This study's findings provide some important clinical implications for nurses and other healthcare professionals who provide care to this population. The participants in this study reported that disclosure of their HIV status had a profound effect on them because it was a source of extreme stress. This finding contradicts a previous research study that noted that disclosure resulted in less anxiety and did not impact psychological functioning (Santamaria et al., 2011). A plausible explanation for this study's findings on stress associated with disclosure may be related to the altered family dynamics and difficulties with family communication that were reported by the participants. Clinicians need to be aware that disclosure of HIV infection to children and adolescents may be a stressful experience, and may have a lasting impact on growth and development.

Participants in this study reported that HIV infection impacted family coping. A previous study of coping among families with HIV infection reported that because of HIV-associated stigma, families with HIV infection relied less on external social support and more on intra-familial support (Martin et al., 2012). If this support from the family of origin is not available, as was reported by many of the study's participants, adolescents and young adults with HIV are left without available social support. This is concerning because social support is essential in mitigating many psychosocial aspects of HIV infection (De Santis & Barroso, 2011). People with HIV infection without social support are likely to experience poorer physical and mental health and lower quality of life (Remor, 2003).

Both antiretroviral therapy (ART) and HIV progression have been linked to body image issues among adults that is manifested as psychological and social distress, anxiety, and fear of disease progress (Reynolds et al., 2006). The findings in this study regarding body image issues among adolescents/young adults are unique and provide new information that requires further exploration. Although this is a unique finding that has not been previously documented in the literature, it is not surprising that adolescents/young adults would report issues with body image, since a major concern among adolescence and young adults (Erikson, 1968). Clinicians need to assess the physical and psychological impact that body habitus changes related to HIV disease or ART has on the adolescents/young adults with HIV infection.

Mental health issues are a significant concern among people living with HIV infection, including adolescents and young adults. People with HIV infection experience increased stress that results in an increased rate of psychiatric morbidity, especially in terms of depression that is either related to the physical effects of HIV, the effects of ART, or the stress of living with HIV infection (Wood et al., 2009). The participants in this study also reported issues with substance abuse, that is supported by a previous study that noted the relationship of mental health and substance abuse among people with HIV infection (Williams et al., 2010). Clinicians providing care to this population should routinely screen for mental health and substance abuse as a part of routine HIV care.

Both pediatric and adult providers need to be aware that transition to adult care creates stress for the adolescent/young adult with HIV infection because of unfamiliar providers, increased responsibility, and a concern about the unfamiliar environment (Fair et al., 2012). This study's findings are supported by Betz and colleagues' work (2013) that focused on adolescent and emerging adults' perspectives on transition to adult care. Clients transitioning to adult care need to be included in the transition process, and require providers who are sensitive to their needs and listen to their concerns about transition (Betz, Lobo, Nehring & Bui, 2013). These clients can be assisted with transition by following evidence-based transition protocols that have been developed specifically for this population (Maturo et al., 2011).

Adolescents and young adults have a number of issues in relation to sexuality such as unprotected sex with multiple partners and difficulty with disclosure. Unprotected sex was also related to a decrease in condom use because of decreased intimacy and the fact that condoms were a reminder of HIV infection (Fernet et al., 2011). In addition, high risk sex

among this population has been linked to depression, anxiety, and substance use (Murphy et al., 2001). This study's findings point to the importance of screening for high risk sexual behaviors in addition to screening for mental health and substance abuse disorders as a part of routine HIV care.

Clinicians need to be aware that adherence is an issue with this population. Previous researchers have noted that non-adherence is related also to mental health and substance abuse issues (Hosek et al., 2005). The participants in this study did not link non-adherence to mental health or substance abuse, but reported that non-adherence was related to the need to conceal their diagnosis from others, and fatigue associated with adherence. Perhaps the explanation provided by this study's participants for non-adherence is in fact a manifestation of mental health that was not explicitly stated by the participants. Reasons for non-adherence as described by these participants require further exploration.

HIV-related stigma has a profound impact on coping as reported by the participants, and previous research (Rao et al., 2007). An interesting finding in this study was that some participants reported stigma from places of worship. This is a concern because stigma affects adherence (Rao et al., 2007). A previous study with this population noted that spirituality promotes adherence (Park & Nachmar, 2010). Among some adults with HIV infection, religion and spirituality are a source as social support (De Santis & Barroso, 2011). If participants are experiencing stigma from places of worship, this could not only affect psychosocial functioning, but may impact adherence as well.

When females with HIV infection experience stigma, many silence themselves as a protective coping strategy (De Marco et al., 2002). Self-silencing was also used by some of this study's participants. A possible explanation for this may be that the participants learned these behaviors from their mothers or other caregivers with HIV, and view self-silencing as a means of protection from various sources of stigma. Clinicians need to be aware of these self-silencing behaviors so that clients can be encouraged to verbalize their experiences in order to begin the process of coping with the psychosocial aspects of HIV infection.

The findings of this study are congruent with previous research on childhood chronic illness. Childhood chronic illness often results in a disruption of normalcy because of an intrusion of the illness into activities of daily living, uncertainty, and disruption of the developmental tasks of peer relationships, communication, and disclosure. Coping with a chronic illness requires social support, the ability to problem solve, spirituality, and maintaining normalcy (Stewart, 2003). Chronic illness also impacts lifestyle, education, self-esteem, social relationships, physical functioning, stress processing, and future planning (Gannoni & Shute, 2010).

As mentioned previously, the need to maintain normalcy during childhood chronic illness is essential (Sartain, Clarke & Heyman, 2000; Stewart, 2003). Participants in this study did not discuss the need to maintain normalcy probably because of the secrecy surrounding their HIV status. Perhaps by concealing and not discussing their diagnosis, this may be a method that participants used to maintain normalcy. Further research is needed to explore how adolescents/young adults with HIV infection attempt to normalize their illness.

Consistent with chronic illness theory of childhood, the participants in this study reported the impact of HIV infection on adolescent/young adulthood developmental tasks via disruption in peer relationships, the perceived need to conceal the diagnosis from others, and the management of physical and psychological aspects of HIV infection. It was interesting to note that none of the participants in this study discussed the uncertainty of HIV infection. Previous research with adults noted the unpredictable nature of HIV infection that resulted in uncertainty (Brashers et al., 2004). More research is needed to explore uncertainty in the context of HIV with this population.

This study provides some new information on this population that has not been previously documented in the literature. First, some participants reported that they searched for meaning of their diagnosis. This is logical given that children with HIV infection have always been described as the ‘innocent victims of AIDS’ because these adolescents and young adults did not engage in any high risk behaviors that placed them at risk for HIV infection (Schellenborg, Keil & Bem, 1995). This search for meaning has been described in other chronic illnesses of childhood (Gannoni & Shute, 2010), so it is expected that this study’s participants would also be interested in searching for meaning. Although this search for meaning in the context of an HIV diagnosis has been described in the adult literature (Guillory, Sowell, Moneyham & Seals, 1997), it has not been described in the pediatric literature.

Second, the findings concerning maternal loss are unique. Given that a number of the study’s participants experienced loss of their mother, this loss may be a source of unresolved grief. Maternal loss among the study’s participants occurred because few treatment options for HIV infection existed when these participants were born. Because of maternal loss, a number of these participants were raised by grandparents, other family members, or even the foster care system. The resultant familial disruption obviously had an impact on the participants, and requires further exploration.

Finally, the findings in terms of additional sources of risk are important to note, especially in terms of commercial sex work and distribution of illicit substances. Commercial sex work among people with HIV infection has been described in the international pediatric literature (Cluver, Orkin, Gardner & Meinck, 2011), but has not been described among adolescents and young adults with HIV infection in the United States. Further research on additional sources of risk including commercial sex work and distribution of illicit substances among adolescents and young adults with HIV infection is warranted.

The results of this study provide a few areas that can be a foundation for intervention development. An intervention needs to be developed to help adolescent/young adults disclose their HIV status to both peers and sexual partners. With sexual partners, an intervention to assist with negotiating safer sex behaviors is also needed. The issue of disclosure and negotiating safer sex in the context of perinatal HIV infection may be addressed by teaching these adolescents and young adults communication skills that could help with disclosing their diagnosis and negotiating safer sex while promoting a sense of self-worth and self-esteem. However, before these interventions can be developed, more

research is needed with adolescents/young adults with HIV infection to gather their perspectives on how it would be best to develop and deliver this intervention.

Conclusion

Adolescents/young adults with perinatally-acquired HIV infection participating in this grounded theory study provided a comprehensive description of the impact of HIV infection on developmental tasks. All participants agreed that perinatal HIV infection has a major impact on their lives from the moment of awareness of their diagnosis to the present. Although some participants seemed to be challenged with management of multiple aspects of their illness, other participants learned to manage their disease and meet the developmental tasks of their age group. This study was unique because it described the process of how perinatal HIV infection impacted adolescent/young adult growth and development, and demonstrated how some participants were able to meet their developmental tasks in spite of living with a chronic, stigmatized illness.

This study provided some important information for nurses and other healthcare clinicians providing care to this population. For child and adolescent nurses and clinicians, the study highlights the physical, psychological, and social needs of adolescents and young adults with HIV infection. For nurses and clinicians who provide care for adults and who are now providing care to this population, the study provides information that will be useful in providing holistic care to this unique population. As these clients continue to age, more research is needed to see how these clients are similar to, yet different from other adolescents and young adults who acquired HIV infection via other sexual transmission or intravenous drug use.

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Figure 1.
Integration vs. Disintegration

Table 1Sample Characteristics ($N = 25$)

Demographic Variable	Number
Sex	
Female	12
Male	13
Age	
18	6
19	6
20	2
21	6
22	0
23	2
24	3
Race	
Black	23
White	2
Ethnicity	
African American	17
Hispanic	3
Haitian	2
Bahamian	1
Jamaican	1
African	1
Educational Level	
Did not complete high school	6
In high school	4
Diploma/GED	8
In college	5
In trade school	2
Currently receiving ART	
Yes	19
No	6
Most recent CD4+ count	
Unknown	17
<200 cells/mm ³	6
>200 cells/mm ³	2
Most recent HIV RNA level	
Unknown	12
Detectable	7
Undetectable	5

Table 2**Interview Questions^a**

Research studies on people who contracted HIV from their mothers, called perinatal transmission, have shown having HIV affects their lives in many ways.

- 1 Tell me about times during your life when HIV has affected your life (Describing the phenomenon).
 - 2 Exactly how does how does HIV affect your life? (Process of the phenomenon)
 - 3 What was the meaning of these experiences or what did these experiences mean to you? (Describing the phenomenon).
 - 4 Where and when does HIV affect your life? (Context of the phenomenon)
 - 5 What allows HIV to affect your life? What prevents or stops HIV from affecting your life? (Influences)
 - 6 What happens or could happen to young people like you with HIV infection? (Consequences)
-

^aInterview questions are based on Grounded Theory methodology as described by Creswell (2007) and Glaser and Strauss (1967).