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Sara L. Valek Date

Not Made of Glass: A Qualitative Analysis of Resilience Processes Among Adolescent and Young Adults Living with HIV/AIDS in Atlanta, Georgia

By

Sara L. Valek
Degree to be awarded: MPH

Hubert Department of Global Health

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Sophia Hussen, MD, MPH
Committee Chair

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By

Sara L. Valek

Bachelor of Arts, International Studies
Wright State University
2009

Committee Chair: Sophia Hussen, MD, MPH

An abstract of
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Abstract

Not Made of Glass: A Qualitative Analysis of Resilience Processes Among Adolescent and Young Adults Living with HIV/AIDS in Atlanta, Georgia

By Sara L. Valek

Background: Rates of adolescent and young adults (AYA) living with HIV continue to rise in the American Southeast. AYA populations face unique challenges such as disclosure considerations, stigma and discrimination, and housing and financial instability related to the developmental phase of emerging adulthood. **Objectives:** This research project seeks to highlight factors that promote positive health maintenance activities among youth living with HIV, to inform future programs targeted at HIV treatment in AYA populations. **Methods:** AYA patients from the Grady Ponce de Leon Center in Atlanta, GA took part in in-depth interviews with questions related to the transition process from pediatric clinic to adult services and interviews. A total of 14 in-depth interviews were coded analyzed and a grounded theory approach was used to construct theories on participants' coping behavior. **Results:** The adversities facing participants at various stages in their lives were seemingly insurmountable challenges and major disruptions to stability, ranging from domestic violence to blatant discrimination and recurrent financial difficulties. Findings were organized in the following three thematic areas: (1) promotive factors used to cope with adversity, including support networks, autonomy, solidarity with others living with HIV/AIDS, and personal growth and acceptance (2) pervasive stigma and discrimination, including identity, stigma as an obstacle to success, and ability to trust others (3) socioeconomic disparities, including substance abuse, financial struggles, and housing instability. **Discussion:** Our findings are consistent with the literature related to coping mechanisms in the AYA age group, as well as other groups coping with chronic illnesses. We found that AYAs enable an array of promotive factors to cope with challenges in their daily lives, some of which have been nurtured over extended periods of growth in the face of adversity. Health care professionals can assist this population by providing them with the services and tools needed to continue fostering positive coping skills and strengthen existing support networks.

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Review of the Literature

Introduction

Advancements in treatment for HIV/AIDS have turned what was once considered a death sentence into a manageable, chronic illness. However, the rates of HIV continue rise throughout the Southeast region of the United States, particularly among adolescents and young adults (AYA) between the ages of 13-24 years old in Georgia. The South and Southeast regions rank highest for rates of new infections among the 13-19 year old age bracket (1). More than 50,000 people become infected with HIV every year in the United States, and approximately 13% of those newly infected are between the ages of 13-24 years old (2). While the rates of perinatal transmission are significantly lower, those having acquired HIV at birth are surviving into adolescence and now comprise upwards of 30% of the current population of youth living with HIV (3). Youth HIV disproportionately affects ethnic and sexual minority populations, who experience higher rates of poverty and marginalization, including lack of resources such as access to adequate healthcare and education (3). Furthermore, AYAs living with HIV are more likely to suffer poorer mental health outcomes including depression, attention deficit/hyperactivity disorder (ADHD), and post-traumatic stress disorder than their HIV negative peers (4) (5). To cope with these adversities, AYAs living with HIV and other chronic illnesses exhibit a range of strategies with both negative and positive outcomes.

Youth HIV in United States

The AYA age group has the fastest growing rates of HIV in the nation, with those between the ages of 13-24 years old representing 21% of newly diagnosed people in the year 2013 alone (2). By the end of 2012, an estimated 62,400 people from this age group were estimated to be living with the disease, over half of whom were not aware of their HIV status (3). Heterosexual contact remains the number one cause of HIV transmission among women, however the majority of new infections nation-wide are attributable to male-to-male sexual contact among men (1). Indeed, new infection rates among gay and bisexual males increased by 22% between 2008 and 2010 (3). The face of the youth HIV epidemic is increasingly that of racial minorities, with higher rates between both African American and Latino groups. In 2010, African American males accounted for 47% of new youth infections, and white and Latino males followed with 17% of new youth infections each (6). In 2013, injection drug use accounted for 1.4% of new infections among males aged 13-19 years old and 1.6% among those aged 20-24 (1). The rates of infection among females who inject drugs were 6.1% and 9.8% for the 13-19 year old and 20-24 year old age brackets, respectively (1).

Medical breakthroughs and policy shifts over the past decade have contributed greatly to the reduction in number of children born with HIV, however those born before widespread knowledge of how to prevent vertical transmission have now aged into adolescence and as such comprise a significant segment of the overall population of youth HIV in the United States. Among youth aged 13-24 living with HIV in 2012, 12% of males and 37% of females were infected through vertical transmission (2).

Statistics and Disparities of HIV Infection

Throughout the United States, disproportionately high rates of HIV/AIDS are seen in racial minority populations and persons from lower economic classes. AYAs living with HIV and other chronic illnesses are more likely to be experiencing poverty and lacking health insurance compared to any other age group (7). The rate of new HIV infections among African Americans is approximately 44%, despite the fact that African Americans make up approximately 12% of the US population (8). Nearly 70% of newly diagnosed cases among 13-24 year olds are African American, while African Americans comprise only 14% of the population of this age group (1). Conversely, only 11% of newly diagnosed cases were white, though they represent 55% of the 13-24 year old age group (1).

African Americans are overwhelmingly affected by HIV, a health issue exacerbated by the statistical likelihood of African American citizens residing in resource-poor settings, including the lack of accessible and adequate healthcare. African Americans are significantly more likely to not have health insurance compared to Whites, in that almost three-quarters of African Americans work low-wage, blue-collar jobs that do not offer health benefits packages (9). In addition, African Americans experience lower rates of full-time employment, and overall family income compared to Whites is two and a half times more likely to be below the federal poverty level, making it more difficult to obtain private insurance (9). Lack of education about disease prevention, stigma, discrimination, and transactional sex in exchange for food, shelter or other resources, contribute to the large disparity between African Americans and Whites (6). Furthermore, the prevalence of HIV is much higher in African American communities, and it has been shown that African Americans tend to engage in sexual behavior with those of the same race, thus increasing the likelihood of HIV transmission (6). The presence of sexually-transmitted infections (STI) can increase the risk of HIV transmission as well, and African American AYAs are significantly more affected than Whites by one or more of the most common STIs (10). Almost 50% of the teenage girls between the ages of 14 and 19 infected with either human papilloma virus, chlamydia, herpes simplex virus or trichomoniasis in 2006 were African American, compared to only 20% of White teenage girls (10). Among the 15-19 year age group, the rate of African American males with gonorrhea was 1,503.8 per 100,000 compared to 38.4 per 100,000 among White males (10).

The racial disparities surrounding access to healthcare can also be seen in the rates of vertical transmission of HIV. Women who are diagnosed early in pregnancy and given appropriate and routine treatment can significantly reduce the risk of transmission by 2% or less (fewer than 2 out of every 100 births) (11). However, regular and adequate access to such treatment is not an option for many low-income minority women, and as such a large disparity can be seen among rates of infants born diagnosed with perinatally acquired HIV infections. As of 2009, 9.9 African American infants per 100,000 live births were diagnosed with HIV, compared to 0.1 per 100,000 White infants (12).

HIV rates in Georgia

Georgia is located in the American Southeast, a region with exceptionally high rates of HIV infection. The state ranks as the fifth highest in the country in terms of total new incidence of AYA HIV diagnosis, after Florida, California, Texas and New York (13). The epidemic of HIV in Georgia is primarily focused around the Atlanta

Metropolitan Statistical Area, in which the Fulton and DeKalb health districts exceed the statewide rates with respect to incidence of Stage 3 diagnoses, prevalence, and new infections (13). Statewide, the rates of newly infected youth aged 13-19 are 13.9 per 100,000, and a staggering 86.9 per 100,000 for those 20-24 years of age (1). The disease prevalence of those aged 13-19 years is 36.2 per 100,000, whereas prevalence for 20-24 year olds is 301.7 per 100,000 (1).

Healthcare for HIV Youth in Atlanta

Grady Infectious Disease Program Clinic

Seeking healthcare from the standpoint of AYAs living with HIV presents many concerns, the most pressing involving accessibility, availability and affordability. In the city of Atlanta, there are many options for those seeking treatment and assistance in coping with HIV/AIDS, both in terms of physical locations to access services as well as state and local provision of services.

The Grady Infectious Disease Program (IDP) clinic is located within the Grady Ponce de Leon Center in the downtown area of Atlanta and provides comprehensive services to pediatric and adult patients living with HIV in the Atlanta Metropolitan Statistical Area (MSA). The IDP was established through the Grady Health System in partnership with Emory University and serves upwards of 5,000 clients, 800 of which are infants, children or adolescents (14). Out of the clients seen at the clinic, 29% are women, 80% are African American and 64% are at less than 100% of the Federal Poverty Level (14). The Ponce de Leon Center is unique in that is one of few comprehensive clinics in the United States for HIV/AIDS treatment, offering primary care services for children and adults, psychiatric and urgent care, dermatology, oncology and many additional services (15).

Medicaid and Ryan White Program

People living with HIV in the United States are eligible to receive HIV/AIDS related medications at no charge from the AIDS Drug Assistance Program (ADAP), under Ryan White Part B. There are 10 Ryan White Medical Care providers in the Atlanta Metropolitan Statistical Area, five of which are located in the immediate downtown and midtown areas of the city (16). Funds from Part B are designated on a local level, however Congress has earmarked ADAP funds for the specific goal of providing medications to patients (17). The ADAP Program also provides financial assistance for patients to obtain health insurance that would further enhance their abilities to maintain adherence to their treatment medications, as well as health monitoring services. There are restrictions, however, to the ADAP Program on a state-by-state basis, in terms of which medications are offered, and eligibility criteria in terms of CD4 count and percent income below the Federal Poverty Level. Highly Active Antiretroviral therapy (HAART) therapy can cost upwards of $12,000 per year, not including the associated costs of living with chronic illness such as treatment of opportunistic infections, and transport and financial loss to attend regular medical appointments (17). Georgia received $43,107,383 in ADAP funding in 2012, and funding has grown consistently since 1996 (18). In 2012, the 6.6% of total clients of the Ryan White HIV/AIDS Program in Georgia were 13-24 years of age (17). Clients served by ADAP in 2012 totaled 6,216, 4.9% of which were 13-24 years old (18). Georgia also receives funding from the Ryan White Part A Program, which can be utilized to provide access to the continuum of care and treatment, including but not limited to: outpatient and ambulatory medical care, oral health, pharmaceutical assistance, health insurance premium and cost-sharing assistance, home and hospice services, and medical case management (19). Medicaid is the single largest payer of HIV/AIDS services in the US (20).

Mental Health and Wellbeing Implications of Youth HIV

It is difficult to gain a true understanding of how HIV/AIDS illness impacts mental health, as the youth population living with HIV already suffers disproportionately from factors that contribute to mental health morbidity, including poverty, physical and sexual abuse, and posttraumatic stress disorder (4). Small sample sizes and lack of research focused specifically on minority populations limit the generalizability of results for the greater youth population in the United States, which is disproportionately affected along socioeconomic and/or racial and ethnic lines (21). That being said, there is a significant body of research that indicates a prevalence of lifetime mental health issues, including that of major psychiatric disorders, such as depression, substance abuse and conduct disorder among youth living with HIV (22). In a study of 50 AYAs between 16-21 years old living with HIV in an urban clinic in Washington, DC, 85% of those interviewed by a child psychologist showed symptoms of at least one of the DSM-IV Axis I diagnoses, and 44% had major depression (23). Another study of 174 HIV-positive youth aged 13-24 sampled from an inner-city clinic showed higher levels of major depressive disorder (15%), generalized anxiety disorder (17%) and post-traumatic stress disorder (28%) when assessed for exposure to violence and mental health disorders via the Clinical Diagnostic Questionnaire and compared to national samples (24). In a large nation-wide cross-sectional study of HIV-positive AYAs with a mean age of 20.3 years, it was observed that AYAs with behaviorally acquired infection, compared to those perinatally infected, had twice the odds of reporting clinically significant psychological symptoms on the Brief Symptom Inventory, a 53-item measure used to assess mental health issues (21). It is possible that this difference is related to perinatally infected youth have had greater access to physical and mental services over time, reducing the risk of presenting clinically significant psychological symptoms (21).

Difficulties with adherence

Adherence to highly active anti-retroviral therapy (HAART) continues to be a complicated issue for AYAs, as this population faces a range of pressures affecting the likelihood of maintaining treatment. While there is no gold standard for recommendations to assess whether a patient's level of adherence is sufficient, several studies have defined a compliant patient as adhering to 80% or more of one's prescribed doses (25-27). This rate of adherence is difficult to attain for youth populations regardless of what chronic disease they may be facing (28). Additionally, adherence failure increases the risk of medication resistance, an issue with serious health repercussions among young adults that can limit the number of ARVs available to them later in life (29). Inability to maintain viral suppression increases the risk of transmission to others, a public health risk that can be exacerbated the fact that adolescence and young adulthood are periods marked by social and sexual development (29). What's more, the adolescent stage of development is marked by “immature concrete reasoning,” often further complicated by peer influences and denial of diagnosis, decreasing the likelihood of optimal adherence (30). The most commonly recognized factors that contribute to poor adherence among the AYA population include simply forgetting, stigma and fear of disclosure and painful reminder of illness, inconsistent daily routine, low health literacy, and related to burden of the HAART regimen itself (31, 32). Mental health disorders and structural barriers, such as housing instability and lack of insurance, are also barriers to maintaining adherence among AYA populations in the United States, and these affect HIV infected AYA disproportionately compared to other AYAs.

The stigma surrounding HIV/AIDS is pervasive, and it is one of the major contributing factors to why AYAs find total adherence to their treatment medications difficult. A common barrier to treatment adherence mentioned by many AYAs is that medication is a reminder of having a chronic disease (33, 34). In a study of 31 HIV-positive youth aged 13-24 years old, Belzer et al. found that 32% of youth reported “reminds me I am HIV-positive” as the reason for missing medication (34). Perhaps one of the greatest barriers in the AYA population to maintaining adherence is balancing a social life with keeping one’s medication private. One 16-year old woman discusses not be able to participate fully in social activities because pausing to take her medications would invite questions regarding her disease status that she does not want to share with her peers (31).

Despite major advancements to the treatment for those living with HIV over the past three decades, the pill burden as recommended by the US Department of Health and Human Services (HHS) remains cumbersome, particularly for AYA populations. HHS guidelines currently recommend initiating HAART using three medicines from at least two different drug classes to be taken daily (35). Recent innovations in drug therapies have alleviated much of the burden, with the development of combination pills from one or more drug classes (36). Depending on the provider and the patient's disease status, it is possible that one's drug regimen could be a single pill per day, however it is worth noting the common issues associated with adherence in general. With regards to a treatment plan, regardless of disease, it has been observed that as the number of doses per day increases, adherence decreases, a trend seen both among HIV-infected adolescents in a previous study as well as among adults with other chronic illnesses (32, 37, 38). Murphy and colleagues found that only 41% of HIV-infected adolescents reported consistently adhering to their medication regimen (32). 71% of participants reported at least one missed dose in the previous month, and only 28.3% of those surveyed reported total adherence (32). In a study of behaviorally infected AYAs aged 15-24 years old, Belzer et al. found that the most commonly cited reason for missing medication is "too many pills (43%) (34)." The patients at the time of Belzer's research were on a prescribed regimen of 3 pills per day (34).

Maintaining adherence to HAART is a serious responsibility for any age group, however it is apparent that youth populations require significantly more support from friends, family, and healthcare providers to remain healthy. Not only are AYAs highly susceptible to peer influences, but simultaneously have reported needing support from their guardians to navigate health maintenance activities (31). Many AYAs cite depending on their parents for assistance and guidance with their HAART regimen, or not taking their medication due to no present symptoms of feeling unwell (31). A 20-year old participant in a study of AYAs aged 12-24 at Yale's Pediatric AIDS Care Clinic mentioned not "know[ing] what's going on inside of [him]" and questioning the necessity of taking medication given that he had no visible symptoms of sickness (31). In a study of 186 vertically and horizontally infected youth in five major US cities, Murphy et al. discovered that unlike those of adult patients, health literacy has no significant association with medication adherence, despite education level, viral load or self-efficacy (32). Indeed, some parents who chose to not disclose disease status to the child might be faced with the issue of children and teens who rebel against their drug therapies by not taking them or hiding them. Young patients who observe their healthy peers not having to take pills on an ongoing basis may not understand why their own treatments are necessary (23).

Mental health comorbidity, specifically depression, is consistently associated with low rates of adherence. There are few studies related to youth populations and the intersection of mental health disorders with adherence, and much of the body of knowledge related to this topic originates from research focused on adults, as well as studies using data from the Reaching for Excellence in Adolescent Care and Health (REACH) project (39, 40). The REACH Project was a prospective cohort study of 496 adolescents (325 HIV-infected, 171 non-infected participants) recruited on a national level over the period of 1996-1999 in an effort to gain a better understanding of HIV-disease progression in an understudied population, with the goal of improving healthcare management (41). In nationally representative sample of adults living with HIV and enrolled in treatment, that patients without evidence of a psychiatric disorder were more likely to be adherent to their medications than those who had been assessed to have a probable psychiatric disorder (39). Overall, 36% of those with probable psychiatric disorder reported adherence, and the lowest rates of adherence were seen among those suffering from depression, generalized anxiety disorder, and panic disorder (39). Among AYAs living with HIV, it was observed that those who suffer from depression have are 55% more likely to not adhere to their medications compared to those not experiencing depression, (42). In a study of 396 AYAs recruited on the criteria of horizontal infection, there was correlation found between a formal diagnosis of a major mental health disorder and adherence (43). Rudy and colleagues attribute this lack of correlation to using chart abstraction to determine mental health diagnosis, whereas other studies that found a correlation between mental health disorders and adherence used more direct measures of assessment that do not appear at the clinical level. Thus, many patients with depressive symptoms may have been overlooked in Rudy's study (43).

AYAs living with HIV face additional structural barriers to maintaining treatment adherence that include lack of insurance, homelessness, and other disruptions to consistent treatment adherence such as incarceration and dropping out of school. At baseline evaluation, the REACH Project revealed that a 26% of males and 25% of females had no health insurance, and 27% of both males and females reported experiencing homelessness at least once in their lives, and a quarter of both males and females had been placed in a detention facility at least once (41). In an examination of structural barriers, including questions related to transportation to retrieve medication or attend doctor appointments, problems in school or at one's workplace, and problems with medical insurance, Rudy et al. found that every barrier except for having a place to sleep at night, have a significant association with adherence (43). The quantity of these barriers was directly correlated with a lower rate of adherence, and of those experiencing two or more barriers, 40.2% were adherent to their medications, compared to 72% of those who reported experiencing none of the barriers assessed for (43). Disruptions to daily routine are a significant factor to maintaining adherence. In a study of 114 adolescents, 33.3% of participants cite disruptions in daily routine as a major factor contributing to nonadherence to HAART (42). Given the number of barriers associated with AYA populations to maintaining adherence, disruptions to a daily routine could have major ramifications for one's health.

Stigma and discrimination

Stigma is commonly cited as one of the major factors leading to the continued spread of the HIV epidemic in the United States, contributing to lack of institutional response in provision of accessible care, as well as the internalized sense of fear, shame and anxiety dealt with by HIV positive individuals (44). Stigma is enormously pervasive and leads to discrimination in healthcare settings, familial and romantic relationships, and academic and work environments, thus hindering the capacity of HIV positive individuals to thrive emotionally, economically and socially. The multi-faceted nature of stigma creates difficulties in terms of how to determine when stigma occurs, particularly in that many of those committing discrimination due to stigma do not recognize their actions as stigmatizing (45). Link and Phelan conceptualize stigma as a combined effect of four components, that: 1). individuals differentiate and label differences between humans, 2). the dominant culture has labeled those who deviate with negative or undesirable stereotypes, 3). labeled persons are categorized in order to create a separation of “us” versus “them,” and 4). those labeled with negative stereotypes undergo loss of status and discrimination leading to unequal outcomes (46). Based on a review of literature and the aforementioned components of stigma, Mahajan et al. developed a conceptual framework as a means to measuring stigma, beginning with a foundation of social, political and economic power which stigmatizers use to enable each component of stigmatization (47). The framework divides discrimination into three sub-components, including self-imposed discrimination, individual discrimination, and structural/institutional discrimination (47).

Disclosure

Sharing one’s disease status can be a significant stressor in a young person’s life, in that disclosure means having to weigh potential negative outcomes such as violence and stigma with sharing an important aspect of one’s daily life with loved ones. Disclosure is a deeply personal choice, one that can conjure conflicting feelings of empowerment, guilt and shame (48). AYAs participate in various social realms including school, extra-curricular activities, employment, family life, and romantic and sexual relationships, all of which require varying degrees of discretion, depending on the individual. Despite ongoing efforts by public health organizations, the stigma surrounding HIV persists throughout the United States. In a national poll conducted by the Kaiser Family Foundation in 2011, 45% of Americans claim they would be uncomfortable if someone with HIV prepared their food, 36% would be uncomfortable living with an HIV positive roommate, and 29% would not want their child in a classroom with an HIV positive teacher (49). When choosing how and when to disclose their serostatus, AYAs must consider multiple scenarios and determine if the benefits of disclosure are worth the potential for discrimination.

Within the academic environment, students and their parents may be forced to disclose disease status to school administrators and instructors in an effort to ensure successful academic performance amidst health complications, and/or in order to request special accommodations for the student. While the pill burden for adolescents has decreased substantially over the last two decades and AYAs may only have to take one pill per day, certain school districts have policies that prohibit a student from dispensing their own medication during school hours (36). These regulations would require the student to store their medication with school healthcare professionals, increasing the risk that their status will be subject to secondary unwanted disclosure throughout the school. Unfortunately, confidentiality is not a guarantee when disclosing to an academic institution, nor is the freedom from stigma. In a series of case reports from the Children's Hospital AIDS Program in Boston, researchers found that perinatal infection HIV was more heavily stigmatized due to the implications of fatality and death, even when compared to childhood cancer, which is commonly disclosed because the idea of hope involved (50). Fear of stigma upon disclosure is perhaps even more justified given the results of a phone survey conducted in 2001 in which less than half of the adult respondents in the southern United States agreed that HIV positive children, even if showing no symptoms, should be allowed to participate in group activities (51). Furthermore, evidence shows that peers holding inaccurate information about routes of HIV transmission are more likely to have stigmatizing views about the idea of having classmates with HIV (52).

Outside of the classroom, in the realm of one's social circle and family life, efforts to maintain privacy regarding HIV status can be painstaking, and often involve special lifestyle accommodations and maneuvering of routine activities in order to prevent others from knowing their status. In some cases, AYA patients report a gap in healthcare due to not wanting to disclose status to a parent who is the primary beneficiary of a health insurance plan (53). If a young person is able to seek healthcare, doing so in and of itself can present additional privacy concerns in that many times health centers that specialize in HIV are labeled as "infectious disease clinics," or using other names mentioning HIV/AIDS that make it difficult to maintain secrecy within their community (54). Perhaps one of the most frequently cited post-disclosure fears among AYAs is that of rejection from loved ones. In Fair's study of 35 perinatally infected AYAs between the ages of 15-30, almost all participants experienced a negative outcome upon disclosure, the most common being rejection (55). These experiences caused participants to be reluctant to trust others and fear having to disclose their status to future partners and friends (55).

There is a large body of qualitative research involving disclosure in sexual and/or romantic relationships across AYA age groups and into older and middle aged participants, and many of the themes related to how and when to disclose remain universal. For instance, Relf and colleagues observed three categories of thought surrounding disclosure in terms of sexual relationships among behaviorally infected men at an urban HIV clinic in Washington, DC that include "avoiding sex," "just sex" and "going somewhere" (56). Participants described their considerations for when to disclose based on the level of seriousness of the relationship, such as those in the "going somewhere” category, in which length of relationships ranged from 2-7 years (56). However, some participants expressed such anxiety and fear over having to disclose, that they avoided sexual activity altogether, whereas other participants viewed casual encounters as “just sex,” with no emotional attachment nor need to share their serostatus, as long as they were protecting their partners (56). Gorbach and colleagues observed similar findings among a group of 55 HIV positive men who have sex with men (MSM) in both Los Angeles and Seattle, in which likelihood of disclosure depended on the desirability and potential for emotional attachment of a sexual partner (57). Many of the participants expressed that with casual sex partners, “just sex,” and no interest in an ongoing relationship lessened the likelihood of disclosure to their partners (57). Several men also decided not to disclose their serostatus to sexual partners due to having low viral loads, and therefore feeling that their risk of transmission was decreased and not worth sharing with their partner(s) (57).

In addition to the universal themes of disclosure mentioned across all age groups, AYA populations in particular are at a developmental stage in which they are continuing to develop a sense of identity and empowerment. Additional concerns in their relationships include maintaining confidentiality, negotiating condom use, educating one’s partner about the disease, as well as managing intimacy to avoid becoming too attached, thus feeling obligated to disclose (55, 58). In Fair and colleague’s study, participants recounted various experiences elucidating these issues, including one 27-year old participant who mentioned that despite disclosing her status to her male partner, he refused to use condoms (55). Another young woman told of sharing her status publicly at a younger age during school, and as such, experienced significant discrimination and teasing when embarking upon her first relationship (55). Indeed, disclosure complicated further in that after disclosing, one no longer has control and must rely on others to maintain confidentiality. Among AYAs, many expressed having to choose their friends wisely, and contemplate the consequences if a friend might share their status out of spite after an argument or conflict (59). One of the positive aspects of disclosing one's status, however, is the act of disclosure can be a form of support to others living with HIV, and educating those who may still hold ignorant and/or stigmatizing beliefs regarding the illness (59). Several participants in Hogwood and colleague's study discuss their wishes to use disclosure of their status as means to educating their peers and acting as a positive example of someone living with HIV (59).

It is important to note that for perinatally acquired HIV, the onus of disclosure is initially on the caregiver, and there are many things to consider when deciding the right time to let a child know their status, including doing so before an adolescent's sexual debut, giving them a sense of ownership and control over their own health, as well as helping them cope with questions regarding the frequency of medical appointments and doctor visits, compared to one's peers (60, 61). Before a caregiver discloses to a child or adolescent, it is important to consider the reasoning behind the HIV positive individual to want to disclose their own status in the future, such as "alleviating shame" or relieving the burden of "leading a double life (55)." It is generally assumed that sharing distressing information with others has a positive effect on psychological health (62, 63), and that actually suppressing a burdensome secret such as one's serostatus can contribute to a gradual decline in heath over time (64). Furthermore, revealing one's status can also mean revealing information of a parent or sibling, and as such invite further stigma upon the parent regarding the manner of transmission (65). Further more, after years of being told not to disclose one's status, perinatally infected AYAs may associate their positive status with shame (66).

Reported unfair treatment in healthcare settings

Despite decades of campaigns to reduce HIV stigma, discrimination towards PLWHs within the healthcare setting is a present-day issue in which upwards of 25% of patients report facing stigma in the healthcare system (67). While there is a dearth of research related to discrimination against AYA populations specifically, there is substantial evidence involving the intersection of positive serostatus with racial/ethnic minorities and low-income populations with stigma within the healthcare setting. Examples of discrimination by healthcare providers include avoiding a patient, extreme protective measures such as wearing masks, protective suits, and two pairs of examination gloves simultaneously (67), to more severe cases in which physicians refuse to touch patients during examinations (68), or denies patients treatment altogether (69). In a focus group of women living with HIV in the rural Deep South, for instance, one participant mentioned having to travel a significant distance to a large city for hip replacement surgery, and upon discovering her serostatus, the originally scheduled orthopedic specialist had another surgeon perform the surgery (70). In a study examining attitudes of healthcare professionals in Los Angeles County, between 2003-2006, it was reported that 56% of skilled nursing staff, 26% of cosmetic surgeons, and 47% of obstetricians refused to provide any services to PLWH regardless of severity of the disease (71).

The National HIV/AIDS Strategy for the US, released in late 2015, states that in order to continue increasing access to care and treatment and eliminate barriers to healthcare, the HIV workforce and service delivery must ensure that services are culturally competent to address the unique needs of patients related to gender, socioeconomic background, and race and ethnicity (20). It has been observed that stigma against HIV positive individuals is particularly severe in the Southeast region of the United States, in which socially conservative values are especially present even among healthcare providers (45). In Mississippi and Alabama, 35% of health service providers agreed with the statement that "People get infected with HIV because they engage in irresponsible behaviors," and while almost all respondents agreed that PLWH should not feel ashamed of their status, 40.7% agreed that they would feel shame if they were living with HIV (45).

Themes of shame and blame are prevalent throughout healthcare settings, an example of which can be found in a qualitative study of 48 low-income adults residing in Los Angeles, in which Sayles and colleagues observe an innocence-punishment dichotomy (67). Participants note the accusatory tone healthcare providers assume when asking about how HIV was contracted and the entitlement with which such a personal question was asked (67). Providers treated patients as victims if HIV was contracted through blood transfusion, vertical transmission or rape. Conversely, healthcare providers treat patients as though they have a "scarlet letter on [their] chest" if contracted via consensual sexual activity or injection drug use (67). Furthermore, participants expressed concern when being forced to see another healthcare provider outside of their primary "HIV doctor," in situations of emergency or unavailability of their regular physician. Not only do participants report compromising their own care by not disclosing their current medications to a new or temporary provider, but they also report that providers in emergency room settings have claimed that health issues are of minimal risk in an attempt to force the patient to return to their regular provider (67).

HIV/AIDS tends to affect populations that are already marginalized based on race/ethnicity, socioeconomic status, and/or sexual preferences, and as such those with HIV in Southern States may already be coping with one or more forms of societal or structural discrimination (69). One of the most concerning forms of discrimination seen has been the withholding of ART from patients due to their race, as well as the low rates of racial minority receipt of HAART (72, 73). In one large, multisite study of urban healthcare settings across the US, it was found that African-American patients are less likely to be prescribed or receive HAART, even after controlling for utilization of outpatient care (73). Perceived stigma can have a detrimental effect on patients initiating treatment, and whether they continue to be engaged in care. In a study of 223 low-income individuals, comprised of 46% African Americans participants, one-quarter of participants reported experiencing at least one of the four measures of stigma used in the study (74). It was found that perceived stigma by a healthcare provider was associated with low levels of access to care and baseline (adjusted OR=3.29; 95% CI=1.55, 7.01) and at 6-month follow-up (OR=2.85; 95% CI=1.06, 7.65) and a poor relationship with a provider has been associated with lower levels of treatment adherence (74). It is clear that stigma and discrimination have a profound effect on the existing disparities in health among minority populations.

Resilience in Chronic Diseases Section

AYAs populations living with HIV/AIDS face significant challenges to maintaining their health and remaining on the path to a successful and productive adulthood, yet have shown a myriad of ways in which they cope with adversity. To facilitate understanding of the resilience processes utilized by AYAs, researchers Stevenson Fergus and Marc A. Zimmerman have developed the Framework for Understanding Healthy Development in the Face of Risk. Fergus and Zimmerman describe resilience not as a personality trait, but as a process that one enables to "overcome the negative effects of risk exposure, coping successfully with traumatic experiences, and avoiding the negative trajectories associated with risks (75)." The process of resilience itself includes both promotive factors and risks that either encourage a positive outcome or reduce the chances of a negative outcome. Promotive factors include assets, which are positive traits that are internal to the individual and include tools such as competence, self-efficacy and coping skills, as well as resources, which are external to the individual and include support systems, adult mentoring and community organizations. Assessing resources available to AYAs provides a greater understanding of the ecological context with respect to the individual, and emphasizes the dynamism of resilience, as it is dependent upon environmental factors as well as character traits (75).

Much of the literature on the AYAs population related to resilience and coping with health adversity is related to research on AYAs living with cancer and Type 1 diabetes, and is focused on "emerging adulthood," a time in which AYAs are developing their own sense of personal autonomy, values and identity, as well as exploring and building intimate and sexual relationships (76). For quite some time, chronic illnesses were considered to be themselves protective factors, in which opportunities for adolescents to partake in risk-taking behaviors were limited by the illness (77). However, a nation-wide cross sectional survey conducted in Switzerland observed that young people with a chronic condition are no less likely to partake in risky behaviors than their healthy peers, suggesting the need for health care that addresses the potential risks associated with this age group (78).

The risk factors most commonly related to the AYA population living with chronic disease include the major lifestyle changes associated with a newly diagnosed illness, disease stigma, and financial difficulties. Initiating treatment for a chronic disease can be a major life change. Building one's life around medical appointments, procedures, and medication dosing can cause significant disruption to one's social life, creating additional social and emotional distress, as well as the stigma and marginalization that come with having a chronic disease (79). In addition, financially independent AYAs with chronic illnesses face significant challenges related to out-of-pocket expenses associated with the disease such as transportation to the clinic, meals while away from home, as well as the loss of income from having to miss work to attend appointments (80). AYAs also face financial difficulties related to a healthier lifestyle. For instance, in a workshop consisting of AYA cancer patients aged (15-29), one of the biggest challenges mentioned was the high cost of fresh, non-processed, and/or organic foods, and other factors in healthy living such as a gym membership (80). In terms of negative coping such as substance use, data remain inconsistent due to social desirability biases of self-reporting and lack of objective measures such as drug screenings to confirm levels of use (81). However it has been observed that alcohol is the most commonly used substance among AYAs, regardless of the disease (82, 83).

Some of the most widely cited and important promotive factors that enable resilience processes among AYAs living with chronic illnesses include parental support, community involvement, the need to maintain routine normalcy, and a positive health care provider. A patient's healthcare provider is integral to their success in avoiding factors that put them at risk, and it is important for a provider to maintain credibility with AYA patients by ensuring open communication and avoiding a punitive tone when discussing prior risky behavior with a patient (84). It is important to keep the amount of life disruption minimal, to maintain a good quality of life; One of the most important things AYAs with cancer need are opportunities to partake in a normal social life (85, 86). AYA patients experiencing cancer often must rely on parents throughout their treatment, more than their peers would be relying on their parents at this time. It is important to reduce the amount of disruption caused to a patient's social life and to maintain a level of normalcy that allows a patient to interact as normally as possible with their peers (80). It has been observed that interaction with other AYA patients or survivors have been highly beneficial to those still coping with cancer, some patients actually reporting that the support received from survivors were more invaluable that that received by family and friend, thus the incorporation of support groups in AYA cancer treatment are a valuable asset to positive psychosocial growth (87).

Conclusion

AYAs constitute one of the fastest growing rates of new cases of HIV in the American Southeast, and HIV overwhelmingly affects AYAs from ethnic and sexual minorities as well as low socioeconomic backgrounds. While current rates of perinatal transmission in the United States have reduced drastically over the last decade, a significant portion of AYAs living with HIV/AIDS were infected perinatally, and face a somewhat different set of challenges regarding earlier considerations for disclosure and familial tumult. AYAs living with HIV/AIDS face significant obstacles to physical, emotional and mental wellbeing, including stigma and discrimination, financial instability, and vulnerability to anxiety and depressive disorders. Despite these challenges, AYAs living with HIV/AIDS engage in a range of promotive factors to overcome risks, exhibiting resilience processes in the face of adversity.

Research Study

Introduction

Despite medical advancements and considerable progress the efforts to combat stigma and discrimination, rates of HIV/AIDS continue to rise throughout the United States. The Southeast region ranks highest in the United States for rates of new HIV infections among 13-24 year olds with the state of Georgia ranking fifth in the nation for total new incidence of AYA HIV diagnosis (1, 13). Furthermore, nearly 70% of newly diagnosed cases among 13-24 year olds are African American, while African Americans comprise only 14% of the population of this age group (1). AYAs living with HIV are more likely to suffer poorer mental health outcomes including depression, attention deficit/hyperactivity disorder (ADHD), and post-traumatic stress disorder than their HIV negative peers (4, 5), are less likely to be experiencing poverty and more likely to be lacking health insurance (7).

AYAs living with HIV face additional challenges such as disclosure considerations, stigma and discrimination in the academic or workplace setting, maintaining medication adherence in social settings, and housing and financial instability. The period of growth associated with the AYA age group means that cognitive processes such as concrete reasoning are still being developed, while attempting to gain more control from guardians, and still needing to rely on familial support (30). AYAs are particularly vulnerable to peer influence, as well as the stigma-related backlash that could occur if their disease status were discovered. Hence, AYAs navigate a particularly complex set of health maintenance activities in order to maintain discretion, as well as face the reality of their illnesses.

As a growing number of youth infected with HIV are progressing into adulthood, it is becoming increasingly more important to ensure that transition processes from pediatric care settings into adult-care clinics are smooth and efficient. Lack of planning or guidance throughout the transition process can discourage patients in continuing to seek steady treatment due to unfamiliarity and discomfort with the new clinic environment. The Grady Ponce de Leon Center in Atlanta, Georgia cares for patients both vertically and horizontally infected with HIV, each of which face significant barriers to care. Patients with vertical infections face considerable treatment challenges such as antiretroviral resistance as well as balancing medication adherence amidst the emotional tumult that comes with adolescent development. The majority of those having been infected due to behavioral transmission come from ethnic minority backgrounds and are more likely to be of lower socioeconomic status, increasing the likelihood that they will be confronted with social stigma and discrimination based on disease status, race or income (7). Researchers and providers from Grady Ponce de Leon Center conducted the IDP Transition Study in order to gain a greater understanding of how to maintain patient engagement in care during the care transition. Data from the IDP Transition study was used to observe behaviors among adolescent and young adults (AYA) between the ages of 20-30 years old.

AYAs living with HIV present a unique challenge to healthcare providers in that many factors contribute to the success of a young patient's treatment program, and can be affected by medication side effects, stigma and discrimination, peer and familial relations, and concomitant psychiatric disorders. There is a dearth of research regarding HIV diagnosis in AYA minority populations, and the resilience strategies utilized by patients to cope with the stress of illness and other adversities. This research project seeks to highlight factors that promote positive health maintenance activities among youth living with HIV, to inform future programs targeted at HIV treatment in AYA populations.

Methods

Parent Study

Data was obtained from the study "Optimizing Transition from Pediatric to Adult-Oriented Care Among Youth Living with HIV," a mixed method study (herein referred to as the IDP Transition Study) carried out at the Grady Ponce de Leon Center with a grant from the Emory Medical Care Foundation during 2015-16 in Atlanta, Georgia.

The objective of the overall study was to evaluate the existing transition processes for youth living with HIV (YLHIV) as they move between the pediatric-oriented Ponce Family and Youth Center (PFYC) to the adult-oriented main Infectious Disease Program (IDP) clinic, using qualitative feedback from patients, parents/guardians and providers, as well as to assess patients' successful transition from the Ponce PFYC to the main IDP using a retrospective review of patient clinical records. Given the sensitive and personal nature of the topics being discussed, researchers chose to conduct one-on-one, in-depth interviews with patients. Pediatric and adult-oriented healthcare providers were able to share their experiences from the transition process during focus group discussions with a trained facilitator. Two focus group discussions of adult-oriented providers and two sessions of pediatric providers were conducted, however for purposes of this paper, only the transcripts from the patient in-depth interviews were analyzed.

Recruitment and Eligibility

Participants for the IDP Transition Study were recruited from within both the PFYC and IDP clinics using referrals from healthcare providers. The study also recruited participants using provider patient lists containing age and contact information. Providers were asked to recommend patients who were considered communicative and interested in discussing their experiences with HIV and the transition process between the PFYC and IDP clinics. To be considered eligible for the study, patients at the PFYC clinic must have been 22 years of age or older and anticipated to transition to the IDP clinic within the upcoming two years and patients at IDP must have been 26 years of age or older and have transitioned into the IDP clinic at least one year prior to the time of enrollment. Upon referral, patients were screened for eligibility and enrolled via phone by the IDP Transition Study team members. Patients were given $50 to compensate them for time and travel related to participation in the in-depth interviews. Verbal informed consent was obtained before each interview. The Emory University Institutional Review Board approved the research protocol.

In-depth Interviews and Guide

For purposes of this paper, a total of 14 in-depth interviews with patients in both pre- and post-transition phases were analyzed. Interviews were conducted by trained graduate research assistants from the Rollins School of Public Health and Emory School of Medicine and took place over the course of approximately one hour. The interviews were held at the Grady Ponce de Leon Center in a private room located on the PFYC clinic floor, and were digitally recorded. All recordings of in-depth interviews were sent to an external transcription agency and subsequently transcribed verbatim for purposes of textual analysis.

Graduate student researchers and medical practitioners with a background in youth HIV and familiarity with the Grady Hospital System developed the interview guide. Using prior knowledge of the transition process at the Ponce de Leon Center and the transition literature as a whole, researchers developed questions related to known barriers to care and problem areas observed throughout the process. The interviews were semi-structured in nature; pre-written, open-ended questions accompanied by relevant probes were used to encourage the participant to share personal information, and allow for the interviewer to steer the interview in a manner that garnered the most in-depth response. The interview guide (Annex 1) contained questions related to the following broad topics: general life questions; experiences with HIV testing, care and the transition process; living with HIV; and closing questions involving recommendations for improving the transition process.

For purposes of analysis, the authors focused on the following questions from the in-depth interview guide:

1. Are things in your life working out the way you envisioned they would at this age?
2. How do you cope when things are not going as planned?
3. How has your life changed since you found out that you were HIV positive?
4. Who have you told about your HIV status?
5. Could you tell me about a time in which you felt like you were treated differently because of your gender, race, status or sexual orientation?

Data Analysis

All transcripts were uploaded into the MAXQDA qualitative data management software for review and analysis. The first author began the process of analysis with close reading of the transcripts and identifying sections of text pertinent to the following questions based on the key components of Fergus and Zimmerman's concept of resilience as described in the *Framework for Understanding Healthy Development in the Face of Risk* (75):

1. How are AYAs affected by receiving an HIV diagnosis and how does it affect their transition to adulthood?
2. What promotive factors (assets and/or resources) do AYAs living with HIV engage in order to cope with stress of illness and other adversity?

To aid in the identification of salient and meaningful themes, all transcripts were used to draft memos throughout the data on text segments for reference. Several rounds of memo-writing were conducted in order to note connections between underlying issues and highlight experiential nuances among participants. Based on previous research of literature regarding adolescent patients facing chronic and/or terminal illnesses, the first author approached analysis with several deductive codes in mind, namely “support systems,” “stigma and discrimination,” and “disclosure.”

Upon completion of the first round of reading and drafting of memos, the first author proceeded to develop a codebook (Annex 2) with explicit definitions to apply to the data. In order to facilitate analysis based on the Fergus and Zimmerman framework, the codes were grouped together into three categories (“Assets,” “Resources,” “Risks”), and an additional two uncategorized codes (“Regret,” “Disclosure”) to allow for analysis related to broader themes of the path to adulthood. In addition, to capture the multi-dimensional and complicated experience of stigma and discrimination, sub-codes for the “Stigma and Discrimination” code were developed after consulting the “Conceptual Framework for HIV/AIDS Related Stigma” from Mahajan et. al. (47) The sub-codes include “self-imposed discrimination,” “structural discrimination,” “stereotyping, etc.”

To ensure reliability of code application, after the first author coded 2 in-depth interviews, an additional graduate student not affiliated with this paper nor the IDP Transition Study proceeded to apply codes to the same set of data using the aforementioned codebook. The level of inter-coder agreement was observed between the two sets of coded data and the first author discussed the clarity and coherence of the code definitions with the volunteer coder, after which several codes were revised before moving forward with coding of the remaining transcripts.

The first author selected 14 transcripts for richness and depth of data on which to focus the thematic analysis. The interviews were re-read closely to identify overarching themes and patterns that addressed the primary research questions. A grounded theory approach was used to construct a theory about participants' coping behavior that emerged throughout analysis of the appearance of coded segments under each respective theme in MAXQDA (88).

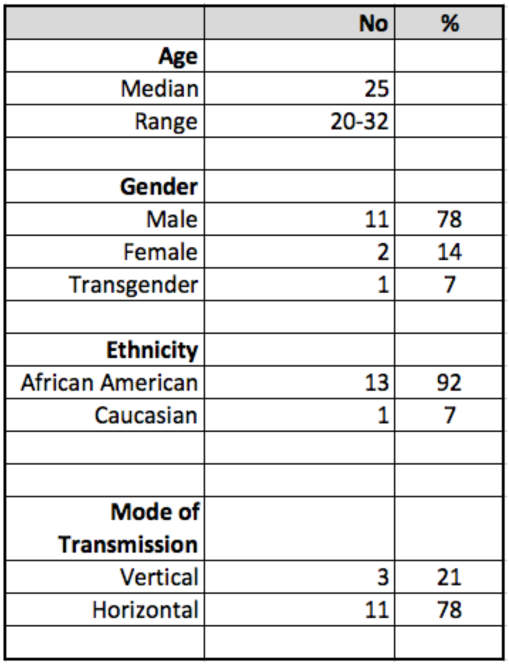
Results

Characteristics of Study Participants

Out of a total of 16 in-depth interviews, 14 were used for this analysis. One interview was eliminated based on the lack of rich data in the participant's responses, and another interview was eliminated due to the participant not being born in the United States. The resulting sample study population was majority male (78%), African American (92%), and contracted HIV through male-to-male sexual transmission (78%), reflecting the epidemiological profile of new diagnoses of HIV in the Atlanta MSA (see Table 1). The median age was 25 years. Some participants reported being born and raised in other states, but all participants claimed the Atlanta MSA as their current place of residence and were all currently enrolled in the Grady Ponce de Leon IDP or PFYC at the time of publication of this paper.

Participants provided elaborate and deeply personal accounts of their lives that allowed the authors to observe how AYAs living with HIV use promotive factors to cope with the stress of illness and other adversity within the context of day-to-day life. All participants spoke very highly about the various support systems they utilized to overcome personal struggles. Several other resilience-related themes also emerged, including autonomy and internal locus of control, solidarity with others also living with HIV/AIDS and personal growth. The adversities facing participants at various stages in their lives were seemingly insurmountable challenges and major disruptions to stability, ranging from domestic violence to blatant discrimination and recurrent financial difficulties. Our findings will therefore be organized in the following three thematic areas: (1) promotive factors used to cope with adversity (2) pervasive stigma and discrimination (3) socioeconomic disparities, including several subcategories.

Table 1. Demographic Characteristics of Participants (n=14)



	No	%
Age		
Median	25	
Range	20-32	
Gender		
Male	11	78
Female	2	14
Transgender	1	7
Ethnicity		
African American	13	92
Caucasian	1	7
Mode of Transmission		
Vertical	3	21
Horizontal	11	78

1. Promotive factors used to cope with adversity

1a. Support Networks

There was an overwhelming sense of connection and appreciation among participants for the various forms of support networks of which they were part of and/or have built intentionally. Support networks for the study participants came in many forms, and in this sample included: immediate and extended family, parental/guardian relationships, friends, romantic partners, and other influential relationships such as teachers and mentors. Participants defined a strong support system as providing unconditional support, despite factors such as disease status or sexual orientation. In addition, support systems were comprised of those who provided unwavering support at all times, and those who did not flee in the midst of trying times. Trust remained a pertinent issue to the study participants, and it was common for them to mention keeping their social circles small, containing only those that they can rely on:

> *And so, those few people that see me in real life, and are there for me all the time – those are the people I consider like my friends, (my close friends). Because they're always there when I need them, and they always think about me when they're doing stuff, so I keep those people really close to me. Um, but they've kept me in the right headspace, I guess you could say, so. Um, they give me a lot of support. (Male, 32 years old)*

Perhaps the most important factor in determining the value of one's support system was the ability for a participant to truly feel as though they could be unabashedly themselves and wholly free from judgment:

> *And hang around my friends and know that we can spark the conversation about anything, and we'll go on going. And it's just – it's good to have friends that I can go around and enjoy myself, and be myself without being judged, or talked about, or worrying about – did I do something wrong or anything of that nature, that's just fun to me. (Male, 21 years old).*

Families have shown unwavering support, despite their own difficult circumstances, such as drug addiction, low socioeconomic status and mental health issues. One participant, after experiencing an emergency situation, was able to call upon his sisters for assistance:

> *Driving me to the doctor visits and stuff, taking me to the hospital and everything, so -- they just there. Like especially for you to wake up and you're eight months pregnant and you need to come get me from my house because I had hemorrhoids so bad and it was just bleeding….They come get me. Get out of your bed and you're eight months pregnant and take me to the hospital and stay there with me, yeah. I don't think none of my other friends would have even got up and they're not even pregnant. (Male, 24 years old)*

1b. Autonomy

Participants have demonstrated a very strong desire to attain a high degree of autonomy and locus of control over their lives that was reflected in their stories of goal-seeking and health maintenance. Not only did participants strive to achieve professional and academic success that afforded them financial stability, but it also was apparent that in taking ownership of their health, they were able to lessen the severity of their HIV status and be seen as a non-infected person.

> *You know, it's…I'm going to die just as easily as you would at this point, so, um, don't treat me like, you know, I'm made of glass. You know, that's part of the reason why I don't really disclose to – is because I don't want to be treated differently. I don't want to have you look at me and all you think of is, like, "Oh, that poor boy, or Wow, I wonder how sick he is right now? Or, well, who is he sleeping with, and do they know?' And, that's not your business, so that's why I don't tell people. (Male, 32 years old).*

Participants did not want to be seen as helpless or incapable, and in many situations, it was as though their disease status served as the main motivator to achieving their goals towards self-sufficiency.

> *And, um, I guess that's just one of the things that keeps me going is, um, just my strength and my, um, my, you know, like um, just surviving or not even surviving like fighting and trying to make a living. I don't know, it's just – it's something that I don't want to give up on or I don't want to make it seem that this has control over me to where I can't get myself together, you know? (Transgender female, 26)*

1c. Solidarity with Other PLWHAs

Another promotive theme that emerged from the data was that of the collective sense of solidarity and calling to provide support and guidance to those who were living with or coping with someone who was living with HIV/AIDS. Provision of support to other PLWHAs fell along a spectrum from wanting to take part in as many research studies and clinical trials as possible in order to be a part of the cure for HIV, to forming support groups, to actually counseling strangers after an HIV diagnosis.

> *I remember this one day, I was talking to this man and he was like, oh, well, I don't have a regular life now. I'm like, "why?" He's like, "Because I just found out I have HIV." I'm like, "That don't mean nothing like that – just take your medicine. You're still human. I'm like, "You're still a regular person. You don't have to stop what you were doing – partying and stuff." He's like, "Well, uh, well, kind of sad." I'm like, "It's okay to be sad. It's okay to wonder this and wonder that, it's okay. You just have to take your medicine every day, and like enjoy life like keep your head up." And like, I gave him my number to see, like, to check on him and see how he's doing. He's still kind of depressed. But later on in the year, like, he was calling me. He was like, "I'm okay now. Thanks for the advice. (Female, 24 years old).*

Having faced discrimination and mental anguish in their past experiences, participants felt better equipped to help their peers, in addition to feeling a certain duty to help others cope with initiating treatment and incorporating it into their daily lives.

> *I guess, some of my friends have it, and I was like the last to find out. So everybody that I've met is way more emotional than me. So I guess it's kind of like, 'hey, come here. I can give you a hug, like, I know what you're going through, I understand'. I mean, I don't feel like you, like suicidal and stuff, you know. But I do understand why you feel like you feel or whatever. And so, I have like this meeting at my house where like a lot of us come and we discuss, like, what's going on or how do you feel about this, or do you need somebody to talk to? Oh, okay. We'll all get together and we'll go for food or you know*

> *something. So I guess in that aspect, I more so can relate more to my friends that do have it. (Male, 24 years old).*

1d. Personal Growth & Acceptance

Upon receiving their HIV diagnosis, or being told by their parents if perinatally infected, most participants provided accounts of their own struggles with depression, suicide attempts, adolescent rebellion, and mental breakdowns. In order to cope with the trauma of living with HIV, participants cited the importance of acceptance of their disease, which was acquired over a period of personal growth and emotional maturation. According to the participants, it was only after one accepts their HIV status that they could begin to start on the path to protecting their health, and better deal with the effects of HIV stigma.

> *Because at the end of the day, we've got to live for who we are and in the process of living who you are, you have to sit and realize, this is going to be something that you're going to deal with for the rest of your life. But in the process of dealing with it for the rest of your life, it will not kill you. It cannot, if you take care of yourself, it will not kill you. If you take care of yourself, you can stand with this for a really, really long time and it not be effective to you at all. Like there are people who are just like, "My life is over." Your life isn't over, it's just starting in a different way. You have to do things a little bit differently. But I'd rather do things a little bit more differently, like take your pill every single day of my life and it keep me going versus, you know, the alternative. (Male, 26 years old)*

2. Pervasive Stigma & Discrimination

Participants shared deeply troubling personal instances of discrimination, as well as the various aspects of their lives that have been affected by stigma. The authors sought to examine the intersection of race, serostatus and sexual orientation with stigma and discrimination. Participants told of experiences of discrimination based on sexual orientation and sexual behavior, disabilities, race/ethnicity, gender, and disease status. The authors analyzed the multifaceted nature of stigma and discrimination by examining instances of stereotyping, structural/institutional, individual, and self-imposed discrimination in the data. It was evident that the threat of stigma, whether experienced first-hand, indirectly through systems, or internalized, is a pervasive one that is carefully considered on a regular basis. The predominant themes that emerged were those of identity, success, and ability to trust others.

2a. Identity

Many of the participants received their HIV diagnoses during their late teens or early twenties, a period for many that was marked by exploration and development of identity. The concurrence of their diagnoses at this developmental time meant that much of their identity was being formulated around HIV, and the stigma that was associated it. The effects of stigma on the participants could be dehumanizing, causing one to feel like less of a person, and less valued in society. One participant described his common experiences with perceived racism while going about his daily life:

> *Going into a predominantly white area or a restaurant and being urban sometimes I feel uncomfortable because I know they're looking like, "Oh my God!*

> *Are they about to rob us! Are they about to do this." Just those experiences mainly. I try to usually be prepared when I go places … not that I can fit in. So that I can feel comfortable. I usually try to dress the part, speak the part, be prepared and that's the most discrimination that I get. (Male, 26 years old)*

Being treated differently in everyday situations could be exhausting and humiliating, and could add to the effects of how a young person viewed himself in society. Another participant describes a situation in which his friend disposes of kitchen utensils after he had eaten off of them, fearing infection:

> *No, like, she did it while she was in the kitchen because I heard the trash can open and her trashcan is loud. So, I know, and I hear something clink. And I'm just like, "Did you throw a plate a way?" And she says, "No, no, I didn't." "Okay." So, I didn't, I didn't call her a liar. I was just like, "It's cool. You don't know anything." Like, there are a whole bunch of people who don't know anything. (Male, 26 years old)*

Participants have also discussed being exposed to significantly stigmatizing views on homosexuality and its association with HIV/AIDS that may have caused them to internalize a sense of fatalism and fear regarding where they may not be welcome in society. One participant's father, upon hearing of his sexual orientation around age 15, told him that he would die in the next few years:

> *Um, when my dad found out, he told me that I wasn't going to make it 20 because I was going to die of AIDS by 18. (Male, 24 years old)*

The same participant went on to express his fears of riding the Atlanta rapid transit system after hearing about so many stories throughout his adolescence about assaults and harassment:

> *It is because there are certain spots where just because you're dressed a certain way, or just because you're a certain race, you get beat up, or because you're a certain gender, or because you like this, or this is your ring tone, you got those shoes, like, it's so many different factors. So the fact that I'm young, I'm black, I'm a male, and I'm gay, it's like… I'm just there.*

Many participants discussed attempting to keep their sexuality a secret from their family, due in part to overt homophobia expressed by certain family members:

> *Hearing him talk was just like hearing how everybody else is wrong and he was right. That fags are evil. Fags are dead to me. Fags are disgusting people and I'm just like this, these people are all going to burn in hell, whatever. (Male, 26 years old).*

While individual stigma and discrimination could be very harmful to one's sense of value, instances of indirect stigma, such as that has been mentioned in passing or in an attempt at humor can also have a negative effect. One participant mentioned having been in conversations and having to hear stigmatizing sentiments on HIV:

> *Uh, well, I feel just being in group conversations and the topic of HIV or AIDS coming up and just seeing the negative reactions and responses to it. Not even knowing that there's someone in their midst with it. Uh, just that alone makes me kind of apprehensive about it, so. I guess, just that alone, like, I've never put*

> *myself in a situation for someone to find out and then have to explain or something. (Male, 28 years old)*

2b. Stigma as an Obstacle to Success

Stigma and discrimination could also have a major effect on one's academic and professional success, as well as one's capacity to take care of themselves to the best of their abilities. Many participants in the study sample already came from significantly disadvantaged backgrounds, so the effects of stigma and discrimination on their attempts at a more stable future are all the more damaging.

Several participants have had experiences in which they have had to remove themselves from school due to HIV rumors or sexual discrimination. One participant recounted a story of having told her elementary school teacher about her status, and having to leave school due to the stigma-related bullying:

> *Like, like, she got HIV and don't sit next to her. So I was wondering why everybody like didn't sit next to me or didn't talk to me anymore, so….The only person I told is our teacher. She [friend] was like, "Well, she's going around telling everybody". I was like, "Oh wow". And I told my grandma and the girl came up there, and she was like fussing with her back and forth. And I had to be dropped out the school because it was so ridiculous. (Female, 24 years old)*

Another participants remembered being kicked out of his college dorm room:

> *Yeah. I was only there for a week. I was – I went – I just moved back to [hometown], because I was – I had just like, I had just tried the college*

> *experience, saying, "Well, okay, I'm going to go to college; it's going to be great". I didn't know I was going to have a homophobic roommate that's going to throw all my stuff out, and say, "Hey, get out of here faggot". So, I just left. (Male, 20 years old)*

Stigma and discrimination caused disruptions in a steady housing and employment, hindering the success of participants in their endeavors to go back to school or build up a savings. One participant described the situation after his grandmother, his guardian and whom he was living with at the time, discovered his HIV status:

> *And, um, my grandmother went out of her way to make me feel like I was – I-I-I, actually, I was a leper, basically. She didn't want anything to do with me. She wanted me to come and get all my stuff. And she just wanted nothing else to do with me after that point, and, um, it was rough. (Male, 32 years old)*

Due to malicious rumors at this place of employment, another participant was terminated from his job:

> *And it was during my time at [chain restaurant] ...and a lie was spread that cost me my job there, about me saying that I was going to cut myself and put my blood in the glaze and blah, blah, blah, which was stupid. When you think about it from a scientific aspect, it's stupid, it doesn't make sense. It's not even possible...At the end of the day. No one wanted to advocate from, on my behalf. My district manager was my original general manager, and he even was – wouldn't even respond to a message from me. (Male, 26 years old)*

2c. Ability to trust others

Many participants discussed the difficulties that are present in terms of their ability to trust in others due to the fear of stigma associated with their status. Due to personal or observed experiences with discrimination, participants found that they tended to keep their social networks small, with only those who they could be sure are trustworthy. Many stories arose of secondary disclosure, in which a formerly trusted person in their lives shared their HIV status out of anger or spite. There are several instances in which this occurred with romantic partners, such as one male participant:

> *And my ex did something and they [sisters] was over there --he did something that made me mad. Like, he was, he was texting somebody and I was looking. I read the text message. You know how you glance over and I was like, what are you saying? Like, it was inappropriate… And we just got into it and he kind of blurted it out on purpose.... Like, he did it just out of spite. " (Male, 24 years old)*

Other participants shared devastating stories of getting infected from partners that they trusted, and later finding out that their partners knew of their positive status. These instances often enforced the importance of using condoms and protecting their future partners.

One female participant was witness to a close friend having been betrayed by her family members via social media, and how that situation caused her to be more reticent about sharing her status with others:

> *I don't ever – like one of my friends that goes to the clinic – she, her family put it on Facebook, like, "You're dying, bitch you're dying – that's why you HIV positive. AIDS is killing you." I'm like, yeah…Like me and my friends we argue,*

> *but they're never going to go that far. NEVER! I'm like, I was crying for her – how hard she is… Like that is wrong. I don't ever want that to happen to me at all, just putting out her business like that. (Female, 24 years old)*

Participants also discussed anxiety associated with dating and when or if to disclose one's status. There is an element of contemplating the legality of romance, in that HIV disclosure may not be necessarily a personal choice, but enforced by state legislation:

> *But if[worst] comes to [worst] and she does get and she does not know. I mean, I think that's like attempted murder or something like that. I mean it's major, major charge. I'm like, "Nope, I don't want to do that." Um, man, I mean, I really wouldn't wish this on anybody. I mean it's probably one of the easiest diseases to deal with. Um, but at the same time for people that's not used to it, it's very difficult. Um, so I'm just wary about who I tell. (Male, 26 years old)*

3. Socioeconomic Disparities

In addition to stigma and discrimination, most participants faced significant challenges related to socioeconomic disparities that contribute to disruptions in stability and prevented participants from realizing their potential to live healthily and free from harm.

3a. Substance use and addiction

Several participants have mentioned partaking in drug use, or coping with the repercussions of addiction among family members. One participant described reconnecting with his mother in Atlanta after many years, and having to rely on her for temporary housing despite her involvement in selling drugs:

> *And I didn't know where she lived or like her situation or anything. And I went over there and I found out she was living in a hotel. That she was running drugs and stuff. I was like, Oh, my goodness. This is like a lot. But I want to get to know my mom, so, I let all that not get to me. But then I got really bad, like, I wasn't strung out on drugs or anything. But I started smoking, smoking weed a lot… I was smoking with my mom, and I did cocaine for a little bit. (Male, 20 years old)*

Another participant discusses how his parents were able to provide a certain degree of emotional support to him regarding his diagnosis, but are currently coping with their own issues surrounding addiction and recovery:

> *My mom gives me a ton of support. She can't financially give me a ton of support, because she's dealing with her own stuff – and same with my dad. They're both going through their post-addiction things. (Male, 32 years old)*

3b. Financial struggles

The majority of participants have dealt with ongoing financial instability, related to several factors including but not limited to: low socioeconomic status of one's parents, unexpected financial setbacks, and lack of support system in geographic proximity. Several participants described difficulty maintaining consistent enrollment in higher education. One participant described being unable to devote enough time to studying due to having to work longer hours for more money. Another participant told of how he wanted to go directly to college after high school, but encountered issues with his mother who did not fully understand the student loan process, and had to wait until he was old enough to file as an independent:

> *I wanted to do something. So after that, I just went to school by myself, I just filed, just single, like, I didn't have a parent because I was just like, if you're not going to at least push me to go into school then no, because she kept on assuming that they was gonna charge her for the loan. (Male, 24 years old)*

Out of the 14 participants in this study, six grew up outside of Atlanta, and several cited moving to the city for economic opportunity not found in their hometowns. This left many participants vulnerable, however, as their support networks were not available for them to rely on as easily. Moving to a new city with no connections and no professional skills can put youth at risk:

> *Because I remember... um, being 14, out in the streets, the only way I knew – I learned to make money from the people out in the streets was that you had to escort/prostitute... Like, I was just selling myself to – I was like having sex with men for like money. Like, I was just doing, like, oral. I wasn't like having like penetration, just oral. And that was like how I survived. (Male, 20 years old)*

Housing instability

Lack of financial stability was closely related to housing instability, and many participants described relying on others for places to stay temporarily, until they were able to support themselves financially once more. Not having a consistent space of one's own could have a negative effect on one's mental health, as well as physical health:

> *Um, I mean, well – well, stability. And like you know, um, a foundation for myself, like I feel like, um, [sigh] like I'm 26 and I have – I'm like I'm still living with, you know, a friend or whatever and I don't have a job, I still haven't completed my education, or, um, I just feel like I have wasted a lot of time, like, just, um, I don't know. (Male, 26 years old)*

A serious consequence of lack of housing and financial stability was the disruption of a daily routine, which some participants have said made it increasingly difficult to adhere to life-saving ARVs:

> *The only issue, um, that I'm having now is just how hard they are on your system. Um, and since I just recently moved in my house; a lot of financial issues, sometimes I'm not able to eat enough. And um, I found out, um, probably about a month, a month and a half ago, if I don't eat enough, like I get majorly sick. Enough that I end up having to miss work the next day. Um, so that's just kinda been my main struggle. (Male, 26 years old).*

Discussion

The findings from our study provide a glimpse into the challenges and successes of AYAs living with HIV/AIDS. The aim of this qualitative study is to observe what promotive factors AYAs living with HIV/AIDS utilize to cope with the stress of illness and mitigate risks. Our findings demonstrate the overwhelming importance of support systems as a promotive factor in helping our participants overcome issues of identity, instability and health maintenance struggles. Disruptions in housing and financial stability are common to nearly all participants and factored into one's ability to achieve success in terms of health, education, or employment. However participants overall stress the importance of accepting oneself as a means to cope with these adversities. Perhaps one of the most striking, albeit not entirely surprising findings is the pervasiveness with which stigma factors into the formulation one's identity, motivation to seek healthcare, and trust others.

Social Support

Our findings show that the most important qualities that a supportive figure must possess are the ability to be trusted, provide a non-judgmental safe space, and provide unconditional support despite challenging circumstances. Social support is commonly associated with positive psychosocial outcomes among individuals living with medical conditions (89), and there is evidence of an association between depressive symptoms and social support in both cross sectional (90, 91) and longitudinal studies (92).

Consistent with the literature, most of our participants express a deeper connection with friends and partners, as opposed to family (29, 93, 94). Several of the participants report being only somewhat satisfied with their level of social support, and express a desire for more emphatic support from their loved ones. This perceived lack of support by participants could be due to the heavy emotional burden placed on friends and families that they do not feel adequately equipped to deal with (29). AYA populations living with HIV/AIDS could benefit from more opportunities within the healthcare or social services settings to engage in community activities and support groups that are facilitated by trained professionals who can provide additional HIV-specific support.

Housing and financial instability

Almost all of our participants report experiencing some degree of housing instability due to financial insecurity, socioeconomic background, and/or health issues. Housing and economic insecurity can also lead to health issues, and several participants report cessation of drug therapy from working erratic hours, and difficulties with side effects due to lack of money to purchase food. As such, homelessness and other housing instability is a very salient issue for the AYA population in that has been shown to be positively associated with physical and mental health status (95), including delayed and poorer access to medical care, poorer adherence to HAART, and higher viral load (96-98). Stable housing is associated with overall better physical health (99), increased engagement in care, and a reduction in risk behavior (97, 100). For many individuals living on the streets and attempting to satisfy the basic survival need of finding shelter, seeking HIV treatment or adhering to treatment is not a primary priority (101). Research suggests that for those experiencing the most severe housing problems, treatment programs that incorporate immediate housing assistance could provide significant health benefits (95).

Stigma and discrimination

Participants reported significant levels of stigma and discrimination at the individual and structural levels. Additionally, the effects of perceived stigma are substantial in that they cause participants to internalize negative thoughts about their own identities and their feelings of self-worth. With the majority of our study participants being gay, African

American, and HIV-positive, they face multiple stigmas that manifested into discriminatory actions at various times in their lives. This is consistent with previous literature that discusses the prevalence of homophobia among religious groups deeply entrenched in African American culture is a major contributor to internalized homophobia, which further stigmatizes HIV (102, 103). This stigma and discrimination has been shown in other work to have significant implications for HIV treatment and prevention. In one qualitative study of 31 African American MSM in New York City, researchers observed that internalized homophobia and HIV stigma increased the perceived lack of self-efficacy to adhere to PrEP due to feelings of low self-worth (104). Internalized stigma in AYAs, whether based on sexual orientation, race or disease status can have major ramifications for public health efforts to curb the HIV epidemic, as it has been shown that feelings of shame and low-self worth were associated with unprotected sex (105, 106).

Acceptance of disease status

Despite the experiences of stigma and discrimination described by the participants, there is an overarching theme of personal growth and acceptance of one's disease status as a means of coping with the stressors of life. This is consistent with additional research regarding acceptance of other diseases such as depression and alcohol addiction, in which emotional acceptance of the disease was seen to encourage a "therapeutic coping process," that resulted in the positive outcome of overall life satisfaction and increased quality of life (107). Participants described resilience behaviors that suggest Social Problem Solving (SPS) skills were used to overcome adversity. SPS is a general coping process in which individuals cope with challenges by reframing and adapting their emotional responses (108). This coping process is further broken down into the “problem orientation” or “rational problem-solving style” components that determine how one views the situation from the outset and how they will then proceed in mitigating the potential risks involved (109).

Limitations

This research project analyzed data taken from the IDP Transition Study, designed to understand pediatric to adult-oriented clinic transition issues, therefore the sample size limited our ability to obtain thematic saturation related to this study’s research questions. Furthermore, the first author was not present during the in-depth interview process; therefore the secondary analysis conducted did not take into account participants’ physical and/or nonverbal nuances, though every effort was taken to understand the cultural and linguistic context with which the participants provided responses.

Summary

AYAs living with HIV/AIDS are a unique population that faces significant challenges, and requires a comprehensive package of healthcare that is well integrated with social services in their geographic sphere. While there is a substantial amount of research related to individuals with perinatally acquired HIV, it would be beneficial to conduct additional research with regards to the emotional and sociocontextual ramifications of behaviorally acquired HIV infection among AYAs. More specifically, there is a dearth of research focused on the intersection of HIV/AIDS and individuals experiencing the developmental phase of “emerging adulthood,” an age group that spans from late teens to late 20s, and that is commonly marked by both sexual and social exploration, as well as a time in which one is setting the economic foundation for one’s future (76).

We found that AYAs enable an array of promotive factors to cope with challenges in their daily lives, some of which have been nurtured over extended periods of growth in the face of adversity. The ability to overcome risks and show resiliency exist, and health care professionals can assist this population by providing them with the services and tools needed to continue fostering positive coping skills.

ANNEX ONE:

In-Depth Interview Guide (Patients):
Thank you for agreeing to interview today. My name is ________ and I am a research assistant from Emory University. The purpose of this interview is to learn about your life with HIV including information about your upcoming or previous transition from the 2nd floor pediatric clinic to the main clinic. I am interested in your personal experiences, opinions and views on the topics we discuss today. Please, feel free to share as much as you want because I am here to learn from you. I have prepared a list of questions, but you can bring up any topic you feel is relevant. This will take approximately 60 minutes of your time. Your participation is completely voluntary. Some questions are sensitive and personal so if you don't feel comfortable answering or want to stop at any time please let me know.

I will take some notes, but in order to capture our discussion I will also record this session. Only my research team will have access to the recording. The contents of the interview will be confidential and will not be used for any other purpose besides this research project. Your responses will be anonymous and there will be no identifying information in the reports. Do I have your permission to record our conversation?

Opening Questions: Life Questions

The following questions are broad questions about your life

1. Tell me about your life right now.
   a. Probe: How do you spend most of your time? Are you in school? Are you working?
   b. Probe: What do you do for fun?

2. Who do you spend your time with?
   a. Probe: Why do you spend most of your time with them?
   b. Probe: How did you meet them?
   c. Probe: How do you think they affect your daily life?

3. Are things in your life working out the way you envisioned they would at this age?
   a. Probe: Why? Why not?
   b. Probe: What things are going well?
   c. Probe: What things are not going well?

4. How do you cope when things are not going as planned?
   a. Probe: Who do you rely on for help? Friends? Family?
   b. Probe: How satisfied are you with this type of support?

Key Questions: Experiences with HIV Testing and Care/Transition Process

These questions are about your life with HIV.

5. How did you find out about your status?
   a. Probe: (If behaviorally infected) Why did you decide to get tested?
   b. Probe: (If perinatally infected) When did you find out about your status (age)?
   c. Probe: What was your reaction when you found out? Who was with you?
6. How did you end up coming to the IDP clinic?

   a. Probe: How long did it take to get from the positive test result to come here and see a provider?
   b. Probe: What barriers were there to initially getting into care here?

7. What were your first experiences with the pediatric clinic?
   a. Probe: What do you think about the care you receive?
   b. Probe: Probe: Do you have any trouble coming to the clinic?
   c. Who do you come to the clinic with? Alone?

8. (Pre-transition patients): Now, you have heard that you are almost 25 and so getting closer to the age where you have to move to the main clinic (downstairs for men, women's clinic for female patients). What have you been told about this transition process?
   a. Probe: How did your doctor bring up this topic?
   b. Probe: What was your reaction? What are your thoughts on transitioning to the adult clinic? Have these thoughts changed since you first heard this news?
   c. Probe: What has your pediatric provider done to prepare you for this transition?
   d. Probe: How do think transitioning will affect your care?
   e. Probe: Are you anxious or nervous about this change? If so, why?

9. Post-transition patients: Now, you used to be seen in the pediatric clinic but now that you are over 25 you are seen in the main (or women's) clinic. How did your pediatric provider first let you know that you were moving to the adult clinic?
   a. Probe: How did you feel about that news? Have your feelings changed?
   b. Probe: Did your pediatric provider do anything in particular to prepare you for this transition?
   c. Probe: Describe your first transition with your adult provider. Was it different, similar? How so?
   d. Probe: How has the transition process been for you?
   e. Probe: How does the adult clinic compare to the pediatric clinic?
   f. Probe: Did you face any challenges in making the transition from peds clinic to the adult clinic?
   g. How did the doctors and staff help during the process?

Key Questions: Living with HIV

10. How has your life changed since you found out that you were HIV positive?
    a. Probe: What things have been more challenging for you?
    b. Probe: How often do you think about your status?
    c. How has your idea of HIV positive people changed since you became positive?

    d. Can you tell me about the strategies you use to overcome challenges in your life?

11. Who have you told about your HIV status?
    a. Probe: How did you tell your family/friends? What were their reactions?
    b. Probe: If you got it through a sexual experience, did you tell your partner? How did you decide to tell him/her? How did that conversation go?
    c. Probe: When you're in a new relationship, how do you go about disclosing your status?

12. Do you think people treat you differently after they learn your status?
    a. Probe: Have you had any experiences with discrimination?

13. Could you tell me about a time in which you felt like you were treated differently because of your gender, race, HIV status or sexual orientation?

Closing Questions: Recommendations

14. How can we improve the transition process in the future?
15. How can we improve clinical care more generally?
16. What are some suggestions you would give to young people to help them deal with living with HIV? To prevent them from getting HIV?
17. Are there things that you wish the clinical team had done differently?

Thank you for responses. Please, let me know if you have any questions.

ANNEX TWO:

Data Analysis Codebook:

- **Disclosure:** Use this code for any reference made to share one's HIV status with another individual, including contemplation and ruminating over how the other party might react, and the ramifications of doing so. This could include apprehension about disclosure, as well as the reasons behind whether or not to disclose, as well as weighing the pros and cons and debating the seriousness of a relationship. Ex. "Um, so I'm very weary of who I tell, when I tell, and if I know if I think that this might be something real, you know, then I might, if not then I usually kinda start stepping back."

- **Regret:** Use this code any time that a participant mentions wishing they had done something differently. This includes regret regarding their disease status, or how they were infected, as well as not following through on opportunities or relationships. Ex. **"**Um, you know I mean it really makes me sad that I didn't, because you know if I would have stayed in school and actually pushed my potential, like, I don't know where I would be."

Assets:

- **Internal Locus of Control:** Use this code any time a participant mentions their own ability or belief in themselves to complete tasks, or having control over a situation. Ex. "So, then something just came to me – it's like, okay, you need to sit down and really see what this thing is, and how you can help yourself beat it. So yeah. I just sit – sometimes I just – sometimes, now, I just sit down and read up on it still, because it's more information that's coming out about it, so."
- **Positive outlook:** This code should be used whenever a participant expresses a positive attitude in the face of adverse or potentially upsetting situations. Ex. " I can win the fight, and I can actually beat this, you know? And, um, I guess that's just one of the things that keeps me going is, um, just my strength and my, um, my, you know, like um, just surviving or not even surviving like fighting and trying to make a living."
- **Goal-seeking behavior:** Use this code each time a participant discusses their plans for the future in terms of career, education, family, etc. This code also includes participant mention of currently engaging in activities that contribute to pursuing their passions or goals, such as saving money to return to school or working to advance their careers. Do not use this code if a participant mentions work/employment without connecting it to a greater goal. Ex. "Um, well, music right now as far as me – um, I'm working with a producer as far as him writing the song, and local production, and unlimited studio time, for a good, good amount of money, like a good price, and it's for me."
- **Health maintenance:** This code should be used any time a participant mentions taking their medication and activities they partake in to remain healthy, such as diet or exercise, or treatment adherence. This code should also be used for any

instances in which a participant discusses their experiences with linkages to care at IDP after their initial diagnosis. Ex. “And that’s where I began to, you know, make sure I was on point with, you know, making my visits and having my follow-ups and you know even starting my meds. And, even though I’ve been a little inconsistent with taking them, you know, on and off, it’s like they still have I believe they made like a dramatic, um, change for the better.”

- **Leisure activities:** Use this code any time a participant mentions engaging in leisure activities that they enjoy, such as shopping, hiking, spending time with friends and loved ones.
- **Religiosity:** Use this code any time a participant references using prayer and God to cope with any adversity or seeking guidance from God. Religiosity refers to one’s personal relationship with a higher being-do not use this code for attending church or engagement in church-related activities. Ex. “But I think I, um, maybe I understand it’s in my best ability on my own, or like you know, just asking, or just praying and asking God for guidance and strength and all sorts of things, anything that I need.”
- **Providing support:** Use this code whenever a participant mentions providing support to others. This could include the participant reaching out to others to check in, providing others with financial, housing and/or emotional resources in the other person’s time of need.

<u>Resources:</u>

- **Support System:** This is a category for any reference the participant makes regarding someone that they go to for emotional support, as well as someone that they trust and feel comfortable with. This can also be used for reference made by the participant to a person who cares about the health of the participant. Do not use the codes below for negative reactions or non-supportive actions from any person(s).
    - <u>Family connection:</u> Use this code any time a participant references feeling supported by family members, discusses having a special bond or closeness with family members. Ex. “I’m blessed to say that I have – I come from a great family and have all those people, those, you know, people around. And my mom is my biggest advocate, my grandmother.”
    - <u>Parental/Guardian monitoring:</u> Use this code any time a participant references being supported by their parent(s)/guardian(s) or seeking them out for emotional support as well as any time a participant mentions a parent/guardian helping them maintain their health through the administration of medication, reminders to take medication or attend appointments, and any time the participant discusses a parent/ guardian monitoring their actions to protect them. Ex. “She [mother] just want to make sure I’m okay and protected, and stuff, because she know it’s a crazy world.”
    - <u>Positive healthcare provider:</u> Use this code when a participant discusses positive interactions with their healthcare provider, or expresses satisfaction with the relationship they have with their provider. Providers can include medical doctors, nurses and physician’s assistants at Grady Ponce de Leon Center (pediatric clinic or IDP).

  - Friends: Use this code any time a participant references supportive relationships with friends or seeking them out for emotional support. Friends can include acquaintances, ex-partners and co-workers.
  - Partners: Use this code any time a participant mentions seeking out their romantic partner for emotional support or references feeling supported by their partner.
  - Other: Use this code for any time a participant mentions someone providing them with emotional support, or someone who has been influential in their positive outlook or goal-seeking behavior, that is not included in any of the categories above. Ex. “And, I can say, for myself from talking to all of my teachers who are all retired, but they still teach at my elementary school. They molded me a lot into the person that I am.”
  - **Self:** Use this code any time a participant references coping with adversity through being alone, not outwardly expressing their emotions/sentiments towards others, and purposefully isolating themselves to deal with a difficult situation.
- **Community involvement:** Use this code any time a participant references engaging in community organizations, church-related activities, or extracurricular activities. Also use this code for participation in social advocacy, peer-education, or support groups and other activities provided to patients as a means of coping with illness.

Risks:

- **Substance use:** Use this code any time a participant makes reference to using drugs other than ARVs or drugs prescribed to them, as well as mentioning being in the same proximity as someone using drugs. Drugs include recreational use of prescription medication and illicit substances such as marijuana, cocaine, opiates, etc. Do not use this code for smoking or chewing tobacco.
- **Unprotected sex:** Use this code any time a participant mentions partaking in sexual activities without the use of condoms. Only use this code for activities that include penile penetration and oral sex.
- **Poor health:** Use this code when a participant mentions being ill or not being healthy. This includes mention of not feeling well due to a detectable viral load, an opportunistic infection, other common ailments such as influenza or a cold. Use this code when a participant discusses issues or history of depression or other mental illness.
- **Fear/anxiety of becoming ill:** Use this code when a participant references a fear or anxiety of becoming sick. Ex. “...sometimes I’m not able to eat enough. And um, I found out, um, probably about a month, a month and a half ago, if I don’t eat enough, like I get “majorly” sick.”
- **Poor opinion of healthcare providers/setting:** This code should be used every time a participant expresses unhappiness or dissatisfaction with their healthcare providers or the clinic setting at Grady Ponce de Leon Center.
- **Disappointment:** Use this code any time a participant mentions that someone they know might be disappointed in them, or explicitly stating so, including

because of their disease status or not living up to certain expectations. Also use this code any time a participant mentions being disappointed in themselves.

- **Disruptions in Stability:** This is a category for any time a participant references a time in which their stability was disrupted due to illness, financial constraints, relationship termination, stigma, etc. Use the codes below for times in which a possession of housing or a job with steady income or school were interrupted.
    - Housing: This code should be used any time a participant mentions having to move from their current residence due to some unforeseen circumstance. Housing can include living with family members, informal spaces supplied to participants by friends or living with romantic and sexual partners, etc.
    - Finances/Job: This code should be used any time a participant mentions not having enough money due to an unforeseen financial burden, as well as unexpectedly becoming unemployed or having to quit a job.
    - School: Use this code any time a participant mentions that they were attending school regularly, but were forced to stop attending due to financial issues, illness, or some unforeseen circumstance.
- **Stigma/Discrimination:** This is a category for codes involving the many forms of stigma and/or discrimination due to disease status, socioeconomic status, gender, sexual orientation or race/ethnicity. The codes below are divided into varying forms of stigma/discrimination and should be used if any point throughout their lives a participant mentions having felt as though they were discriminated against per the respective code.
    - Self-imposed discrimination: Use this code any time a participant discusses avoiding a particular setting or person(s) due to anticipated stigma or discrimination. This could include not going to the clinic for fear of being seen by others and having their disease status revealed.
    - Individual discrimination: This code should be used any time a participant shares an instance of one-on-one discrimination. This could include others not sharing the same food or silverware as the participant for fear of becoming infected with HIV.
    - Structural/Institutional discrimination: This code should be used any time a participant discusses feeling stigmatized or discriminated against in a larger setting such as at the place of employment or at school. An example of structural/institutional discrimination would be a participant is terminated from their employer due to fears that the participant will spread the virus to others.
    - Stereotyping: Use this code each time a participant mentions that someone has assumed that the participant exhibits negative stereotypes associated with their race, socioeconomic background, disease status, etc. This could include someone claiming that a participant became infected from engaging reckless sexual behavior with multiple partners. This code could also be used for when the participant expresses how they perceive(d) others with HIV/AIDS, or racial and sexual minorities.
    - Secondary disclosure: This code should be used when a participant describes a time in which their status was disclosed against their will or

without their permission. An example would include a schoolmate disclosing a participant’s disease status to others at the same school after they discovered it by chance or it was disclosed to them in confidence.

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