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‘WHAT I GOT TO GO THROUGH’: NORMALIZATION AND HIV-POSITIVE ADOLESCENTS

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Abstract

Therapeutic breakthroughs have transformed HIV into an illness that is routinized within the clinic. It is unclear, however, how these breakthroughs shape the lives of newly infected adolescents who are beginning to receive what will be life-long care and treatment. The reframing of HIV as no longer exceptional influences the lived experience of urban adolescents, whose futures must shift to incorporate expectations that they live a full life with HIV. They must now manage the clinical demands of a chronic and infectious disease, while navigating the transition from adolescence to a ‘normal’ adulthood, which, for some, means completing education, finding jobs, and building careers. Drawing on ethnographic research conducted in Baltimore, Maryland, I examine the tensions adolescents face as their experiences with HIV conflict with policy makers and researchers’ reframing of HIV as a disease like any other.

Keywords

Adolescent; ethnography; HIV/AIDS; normalization

During a meeting of the Baltimore City Commission on HIV/AIDS in fall 2011, commission members discussed how to frame the cover letter for a report describing the HIV/AIDS epidemic in the city. As commission members debated whether the letter captured the nuances of how HIV had impacted the lives of people in Baltimore, the director of an organization dedicated to supporting HIV-positive black women expressed reservations regarding some language in the letter, specifically the sentence, “What was once a certain death sentence is now no different from diabetes”. “These words,” she told the commission, “stunned me to a place where I almost couldn’t move.” She went on to explain her feelings:

Though HIV/AIDS might become chronic in one sense, it’s different from hypertension or diabetes. If we say it’s a treatable chronic illness that implies it can be cured and treated, it makes it sound like you can eat it away, or exercise it away ... I sat with a couple of physicians and I heard that HIV/AIDS is now manageable.

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MEDIA TEASER: The dominant clinical narrative – that HIV is a chronic and manageable illness – does not fully capture urban adolescents’ experiences.

But with other diseases you don't have behaviors and stigma. I'm tired of it, this idea that you can take one pill a day and you can live your full life with this disease.

This commissioners' sentiment summarizes much of what I saw in the course of my research: the rhetoric that HIV/AIDS is a disease 'like any other' does not resonate with the lived experiences of the HIV-positive urban adolescents who I came to know.

In this article I argue that, although clinical care and treatment for HIV has become routinized, there is nothing routine about the lives of HIV-positive adolescents. I show how being HIV-positive affects urban adolescents' vocational intentions such as trying to finish school, locate a job, and develop a career. I demonstrate how an HIV diagnosis can challenge 'normal' psychosocial development and the uncertain socio-economic futures HIV-positive adolescents face. I also depict instances where the friends, family, and colleagues of HIV-positive adolescents subject them to societal disciplining practices with a goal of diminishing differences and promote standardization. In the following, I first describe how the emergence of physical signs of difference during high school can lead adolescents living with HIV to socially withdraw and not graduate from high school. I then explore how adolescents' experiences selecting a job and career path can conflict with clinical expectations that HIV has become routine. Finally, I question how adolescents' attempts to maintain employment can complicate their relationships with employers, colleagues, and clinicians, and how HIV reconfigures adolescents' relationship with their own future.

HIV/AIDS AS AN EXCEPTIONAL DISEASE

As a result of the medical capabilities to treat HIV, clinicians, researchers and policy makers at places like the National Institutes of Health (NIH) and Centers for Disease Prevention and Control (CDC) have created social, policy, legal, and institutional discourses that have placed HIV/AIDS in the same category as other chronic illnesses (Rosenbrock et al. 2000; Russell and Seeley 2010). The goal of these discourses is to integrate HIV-related patient care into a generalized clinical setting, reduce requirements for consent and pre- and post-test counseling to increase the number of individuals identified and subsequently placed on treatment, and to lower rates of stigma (Branson et al. 2006). This push to reframe HIV/AIDS as a chronic illness is in direct contrast to the beginning of the epidemic when activists, HIV-positive individuals, physicians, and public health officials lobbied for policies that would differentiate HIV/AIDS from other infectious diseases (De Cock and Johnson 1998).

The notion of 'HIV/AIDS exceptionalism' emerged in the United States in the late 1980s to express how the approaches to, management of, and funding for HIV differed from those of other diseases (Jansen 2005). Activists and people living with HIV/AIDS employed what Epstein (Epstein 1998) referred to as their 'moral credibility' to describe why this exceptional status was necessary. Reasons for this exceptionalism included high levels of HIV-related stigma, the concentration of HIV among vulnerable racial and sexual minorities, the stigmatized methods of transmission, that it was an infectious disease, and medicine's powerlessness to treat it (Bayer 1999; Bayer and Fairchild 2006; Rosenbrock et al. 2000).

This status of exceptionalism was evidenced by phenomena as diverse as allowing anonymous testing (in contrast to other infectious diseases like syphilis), the creation of HIV-specific policies and services, and the development of a social-activist sector devoted to promoting the rights of HIV-positive individuals (Bayer 1999; Bolan 1999; Epstein 1998; Jansen 2005;).

From the mid-1990s public health professionals, researchers, and activists in the United States began to question whether HIV should maintain its status as an exceptional disease (Bayer and Fairchild 2006; Casarett and Lantos 1998). This shift was accelerated with the advent of highly active antiretroviral therapy (HAART) in 1996. From 1995–1997, HIV-related mortality decreased by two-thirds in the US (Jones et al. 1999; Palella et al. 1998); an individual diagnosed in 2008 is expected to maintain a life span close to that of the general population (Cooper 2008).

Researchers at the CDC updated the HIV screening guidelines in 2006 to include HIV as part of routine testing for individuals 18–64, with those deemed ‘high risk’ to be tested annually. In addition individuals are now able to ‘opt-out’ of receiving a test, as opposed to the previous method of ‘opting-in’ (Branson et al. 2006). The goal of this change was to both increase the number of people getting tested and to solidify HIV-testing as a routine diagnostic procedure.

As a result of these larger rhetorical and practical shifts, HIV researchers and policy makers in the global north have made claims that HIV/AIDS is a routine and unexceptional chronic disease, and no longer characterized as a state of emergency (Kippax and Race 2003). This biomedical norming of HIV/AIDS, and the subsequent discussions and policies, have focused on creating a clinical routinization of testing, diagnosis and treatment; they have little to say about life stages and processes for those who are positive. Because medical knowledge has reasserted control over HIV and provided a treatment if not a cure, researchers argue that HIV should be normalized outside the clinic. There is often a disconnect, however, in the relationship between a clinical discourse around the routinization of HIV/AIDS and the challenges of enforcing processes that would normalize HIV in the social sphere. Though policy makers have argued that HIV’s shift to a chronic illness might reduce the stigma faced by HIV-positive individuals and improve their quality of life (ONAP 2010), this structural reframing often had little influence on the everyday lives of the HIV-positive adolescents I came to know.

This routinization of care, and expectations of a full life with HIV, has a particular impact on adolescents due to their life stage. Adolescent development is premised on a tension between identity and role confusion (Erikson 1968), a shift which researchers state is imperative for individuals as they develop their own identity, struggle with social interactions and moral issues, and establish a philosophy of life (Erickson 1966, 1968). Adolescents requires special medical attention, particularly those with chronic illness who often work to withdraw from their families and place themselves within broader society (Blum 1992; Prescott 1998). An HIV diagnosis must be incorporated into an adolescent’s own developing sense of morality and life philosophy, which can be complicated by fears of rejection and stigma (Erikson 1968; Muuss, Velder, and Porton 1962). A chronic illness diagnosis may be

particularly difficult when it interferes with perceived attractiveness, sexuality, and interpersonal skills (Muscari 1998) and can result in higher rates of depression, anxiety, and feelings of social isolation and stigma (Futerman, Chabon, and Hoffman 2000; Pao et al. 2000; Safren et al. 2004).

THE RESEARCH PROJECT

As a result of recent therapeutic breakthroughs, the current cohort of adolescents is one of the first to be able to imagine living a 'full' life after acquiring HIV. This means that young people with HIV are concurrently confronted with the clinical demands of managing a chronic and infectious disease and the challenges of navigating the transition to adulthood, which, for some, means completing education, finding jobs, and building careers. In this article, I draw from interviews and informal conversations with eleven HIV-positive adolescents in Baltimore, Maryland, aged 17–24, who attended an HIV clinic at a university teaching hospital. I recruited these adolescents through the University Clinic so that clinic staff could serve as a point of introduction and help me locate adolescents with a range of ages, disease histories, family backgrounds, and experiences. Upon meeting each adolescent, I introduced myself as a doctoral student interested in learning about his or her daily life and how HIV fit within that.

I conducted six interviews with each adolescent over the course of one year, from January 2011 through March 2012. An adolescent's first interview occurred in the University Clinic, but we subsequently moved outside the clinic and we met in their homes, places of work, restaurants, parks, and parking lots. Over time I was able to meet their families, friends, neighbors, and significant others. Each interview typically lasted 60 to 90 minutes, and was digitally recorded, and transcribed. The interview guide covered an adolescent's social and medical history, relationships with family and friends, and whether these individuals were involved in adolescents' clinical care. The purpose of these interviews was to allow adolescents to speak candidly about their HIV diagnoses. However, I did not explicitly raise HIV/AIDS-related topics until the fourth interview, thus allowing the adolescents to talk about them in ways most natural to them. Once I brought up the topic of HIV, I asked adolescents to describe the ways clinic staff talked to them about things like their general health, clinic visits, and future goals. I also asked them how clinicians discussed treatment options, particularly how, why, and when they should begin medication.

Below, I draw on the experiences of Monique and Tyrone (pseudonyms). Monique is an African American woman who was 19 at the start of my research and Tyrone is an African American male who was 23 when we first met. Both were born and raised in Baltimore. Although I highlight their stories, their experiences illustrate patterns I saw throughout my interviews and observations. For example, during the year I followed these adolescents only one maintained steady employment; four others cycled in and out of jobs at fast food restaurants, clothing retailers, warehouses, and call centers. Two attended job-training programs and four supported themselves through the receipt of federal disability payments. Some of my analysis of Monique and Tyrone's stories, such as their interactions with peers, makes use of other adolescents' experiences similar to theirs.

McCabe and Barnett (2000) argue that a substantial number of adolescents, particularly those in low-income urban areas, may be unrealistically optimistic about future career options given their educational attainment; they frequently describe wanting to become famous musicians or athletes. The inability to fulfill these future aspirations may place adolescents at risk for disillusionment and alienation as they develop and find their career goals unattainable. Though three of the adolescents I came to know had completed high school, the remainder had not. Nearly all of them talked about getting a diploma through a Graduate Equivalency Degree (GED) program, an exam that certifies the test taker is proficient at the American high school level. However the adolescents often attended no more than three or four sessions before dropping out. The reasons adolescents gave for abandoning their studies were that it was tiresome, dangerous to walk to at night, and that they did not like the other attendees. Though the adolescents described future careers goals (e.g., becoming a social worker or a store manager), they seemed to have little understanding of the type of schooling required or of how to get the information needed to begin to achieve such goals. In addition, the adolescents had limited employment experience. Few had set concrete educational or occupational goals, and those who had such goals tended to limit their thinking to a distant future (e.g., “When my children are older”).

IT MAKE ME FEEL LIKE SOME TYPE OF WAY

Monique was at Job Corps throughout the interview period, with a goal of obtaining a trade and completing her GED. Job Corps is a U.S. Department of Labor program that provides free education and vocational training to at-risk and low-income individuals ages 16–24 to help them build a career and earn a high school diploma (Job Corps 2013). The Job Corps campus was approximately 30 minutes north of Washington DC and located in a rural area just off of the freeway. The students lived on campus Monday through Friday, but were allowed to go home on the weekends. The Job Corps campus had dining facilities, a health clinic, gym, and classrooms and vocational-related teaching facilities. Monique was the shyest of the adolescents I came to know, and had only disclosed her HIV status to her parents and clinic providers. Once, during our meetings, she asked me to close the window even though the blinds were drawn and the nearest people were over 50 meters away. Monique withdrew from school in her sophomore year upon receiving an HIV diagnosis, with the withdrawal precipitated by severe acne outbreaks that occurred around the same time:

Monique: My face was breaking out and all that. I had spots on my face. So I stopped going to school.

Morgan: What about the spots made it hard to go to school?

Monique: I keep getting questioned. What’s that on your face? Why is your face like that? I didn’t want to get questioned. I was tired of getting questions. Everybody kept on asking. I was stressed out. Dealing with this every day. What I got to go through with people looking at me all weird?

Monique’s description of being questioned reflects the values that youth place on being like their peers, a process that becomes complicated by the emergence of physical signs that could mark her as different (Remien et al. 2003). This desire to be accepted by peers, and the

assumption of an imaginary audience, is particularly salient during adolescent development (Sanders 2013). Having people ask about the spots on her face, even without referencing HIV, was cause enough for Monique to remove herself from the situation. Her experience with HIV was complicated by the fact that she had to begin taking antiretroviral medication almost immediately upon diagnosis. These side effects made Monique feel sick, and thus different from her peers:

And I had to go to school regardless. And I looked different and all of that and people came up to me and said, 'What's wrong with you, you sick?' 'You look so skinny', 'Why are you losing all that weight?' I hate that. I don't like it when people say that. It make me feel some like some type of way...

As a result of these questions, Monique believed people were assuming things about her health status – that she was HIV-positive. As both Remien (2003) and Sevelius (2010) have also shown, for some HIV-positive people, the medication rather than the virus can make them feel sick and cause others to question their health. This has led some people to adjust their medication in order to avoid anticipated side effects and drawing attention to themselves and their disease.

The adolescents often described explaining away differences resulting from HIV-related treatment in ways they thought would be acceptable to their peers. Monique told me that her HIV medication turned her eyes slightly yellow, something her doctor described as an expected side effect. This did not help Monique because, "people ask me, 'why are your eyes so yellow?'" She did not want to tell them that it was due to medication for fear they might start rumors about her health. To deflect her discomfort she would explain it by saying, "'Because I smoke weed'. Well then they would say my eyes don't get that [when I smoke]... I say 'well everybody is different so...'"

Throughout the interviews, the adolescents described wanting to be accepted, and were hyperaware of any action or appearance that might place them in a different category than their peers. When people highlighted Monique's differences, she began a process of self-regulation to appear like her peers. This occurred even when individuals did not ask about Monique's HIV status. Adolescents' general inability to accommodate difference resulted in them engaging in processes of normalization. By process of normalization, I mean moments where individuals worked to 'correct' HIV-positive adolescents' experiences so that their life-course stages would appear no different from those of their HIV-negative peers. Examples of this included adolescents' friends, family members, and colleagues commenting on their skin, weight, eyes, number of pills or frequent doctors visits as a way of suggesting an adolescent eliminate such differences. Such regulation occurred because if an adolescent were outwardly sick or suffered significant weight loss, this would challenge the biomedical expectation that HIV was routinized within the clinic and normalized outside of it. These intimate and everyday moments of difference represent instances when HIV-positive adolescents' presentation of self did not conform to the biomedical and social expectations of how an individual with HIV/AIDS should appear at this moment in the epidemic. As a result, the adolescents I worked with had to develop strategies to ensure that they appeared as healthy and self-regulated individuals.

An example of such a moment occurred for Monique when classmates questioned her physical appearance and why it did not conform to a ‘healthy’ standard. Monique felt unable to appear healthy and self-regulated, and so she chose to retreat by dropping out of school: “In high school, that’s why I never went to school. That’s why I’m here [Job Corps]. I was feeling ashamed. I didn’t really want to go to school...I didn’t know what was going on.” Unable to control her weight fluctuation and skin outbreaks, Monique struggled with the physical manifestations that accompanied her HIV diagnosis and treatment. The very medication that transformed HIV into a chronic disease threatened her daily routine and ability to integrate into her peer group.

This process of identity development can lead to struggles to appear similar to peers, whether in physical presentation or through presenting as disease free. HIV-negative adolescents frequently report skin and weight-related insecurities, a fact that was complicated for Monique due to her eyes, skin, and weight change. Monique’s struggle with identity construction and understanding of the body was also affected by her developmental stage, as studies suggest that adolescents are more open to socialization than adults (Lupton and Tulloch 1998; Scheper-Hughes and Lock 1987). Lupton and Tulloch argue that an HIV diagnosis in adolescence occurs at a time when the body is still “unfinished,” and “in a state of becoming, requiring intensive self-surveillance and work” (1998: 23). This forces adolescents to integrate HIV into an understanding of personal identity and the body, while also undergoing aspects of development that are unique to adolescence (Freund 1988; Ingram 2012; Scheper-Hughes and Lock 1987). According to developmental theorists, adolescents are especially likely to internalize norms that govern appropriate social behavior during this socialization period in order to achieve the best possible self (Lupton and Tulloch 1998). Physical appearance and the presentation of self as healthy are central in conveying to others one’s high levels of self-control, body maintenance, and regulation of life (Ingram 2012; Lupton and Tulloch 1998).

Upon dropping out of high school and joining Job Corps, Monique struggled to keep her medication secret from those around her. She initially stored it at the on-site health center, but felt that arrangement restricted her movement: “It’s too much. I used to go to dinner and come here [the clinic] and back to the dorm. Dorm, room, dinner, here. It was too much to keep up. So. yeah. But I try to stay on top of it.” In addition to the extra time that keeping medicine at the clinic required, Monique felt that going to the clinic would invite speculation regarding her health status. To avoid questions about her time at the clinic, Monique began leaving her medication in her dorm room. She hid the medication in her closet, however, so her “nosy” roommate would not find it. Monique spoke openly about feeling monitored—both by the clinic and those who might see her take medication. Although Monique said that she would continue taking medication to maintain her health, she hated how it put her under constant scrutiny in the eyes of her friends, family, and clinicians:

My RA (resident assistant) was like: “What is wrong with you? You look different. You losing a lot of weight.” She was like, Girl, you need to do this exercising. They is nosy, nosy as crap. They want to know every little detail. I’m like oh my god. None of their business. You know they care man, but still.

Monique wanted to change medications as a result of weight fluctuation and the yellowing of her eyes, but was afraid the new medications would cause another round of physical side effects that would expose her to inquiry. Her descriptions suggest she felt subjected to disciplining practices by her fellow Job Corps students, and she strove to present herself as identical to her peers. Monique's fear stemmed from her previous experience changing medication when, "My body was swollen man. Like it really broke down, I can't do nothing ... My body would change and I would've been sick and all of that. And then they would have sent me home on leave." Monique also worried that initiating a new medication regimen might make her sick, which would force her to miss time at Job Corps. Missing this time would extend her tenure there, and so prolong the time it would take her to finish the GED course and get a job in Baltimore.

As the HIV-positive adolescents struggled to integrate health-related expectations from the clinic with expectations from friends and family members, they were also confronted with how HIV might limit their job choices. Adolescents told me how friends and family members felt that certain jobs were too risky for people living with HIV. Pressures from friends and family, then, could cause adolescents to limit career prospects. Officially, the only employment sector an HIV-positive individual cannot enter in the United States is the military. However, there are many assumed barriers that can influence how adolescents imagine their futures. For example, Monique wanted to use her culinary training from Job Corps, but when I asked her where she would like to work, it became clear that she felt limited by her HIV status:

Monique: I had thought about daycare. But because of my HIV they might not put me there but I don't know why. They are going to check me for all that... I guess you can't be around children if you have HIV. It's crazy yeah.

Morgan: Who told you that?

Monique: Someone in class today... she said they are going to check you for all of that, to see if you got stuff and all of that. There is no way. You can't have it ... I ain't ask no questions. I just say "yeah okay, alright".

When I last saw Monique, she had completed her GED and had only a few weeks remaining before she finished Job Corps. She had been unsuccessful at finding a job, an issue faced by many adolescents in Baltimore (US Census Bureau 2012). Monique talked about attending an open house at some local fast food restaurants, jobs she had mentioned as a possibility prior to completing her GED and culinary training.

I WOULD BE LIVING OFF THE GRID

During the time I knew Tyrone, he oscillated between short-term jobs and unemployment. He was the most articulate and well read of the adolescents I met. He frequently showed me quotes from his favorite book, *Paradise Lost*, which he always carried with him and had annotated heavily. Tyrone graduated from high school, though had to take a few summer courses because he said he frequently cut class to read biology textbooks in the library. As a ward of the state, he had received a full scholarship to a local university. However, over the course of three years and despite multiple attempts, he was never enrolled for longer than a

few months at a time. His stated goal was to gain the skills to be financially independent so he would not need to live with his grandmother or his boyfriend. Tyrone felt his HIV status hindered his ability to become fully independent and develop as a 'normal' adolescent. He felt that receiving an HIV diagnosis forced him to re-imagine his future because his health needs, particularly the need to access medication, bound him to society in ways that he did not want. Were he not HIV-positive, Tyrone said, he

(p)robably would have packed up and moved somewhere by now. Just like on the fly... Just say I want to just move into the woods for two or three years, by myself, and not see nobody. I can't do that no more. Like I'm tethered to the government or the world. Like what if, what if I wanted to stay out there indefinitely or go to a jungle somewhere, just explore the world. Some places won't even let me in cause I'm HIV positive. That changed my life. And it's just like, that really eats me up. Since I'm kind of tethered to clinics and medications and things like that, I can't just dip like I want to. That's probably the major thing. I would be living off grid.

The possibility of illness led Tyrone to feel dependent on the state for medical care. This dependence also subjected him to increased levels of surveillance; he could never truly "be living off the grid." This forced reliance on institutions can complicate adolescent development, which is expected to be a period of increased independence and separation from family support. Studies of adolescents with other chronic diseases, such as sickle cell anemia, have described them as feeling at the mercy of their illness (Atkin and Ahmad 2001). Moments of anxiety, frustration and powerlessness undermined normal coping mechanisms, and made it challenging for the adolescents I worked with to fulfill developmental stages in the ways other HIV-negative adolescents might (Atkin and Ahmad 2001).

Even when Tyrone successfully obtained employment, he described strategies to avoid circumstances where friends, family, and colleagues might label him as different, or make assumptions about his health. Approximately eight months into our interviews, Tyrone began a job at a power company. He told me about the anxiety he felt related to colleagues' questions about his fluctuating weight. Although he insisted that the weight loss was due to the changing seasons, he felt it singled him out:

My coworkers saw some pictures on Facebook from last winter. They was like you got skinny since then. I'm like those pictures aren't even from recently. They're from a whole year ago in the wintertime when I was stuck in the house being a fat boy. They like oh, we thought it was from a few months ago. I'm like no, y'all need to check the dates on those pictures. That was when me and [my boyfriend] first got together and I was happy. I picked up a few pounds. I always lose all that weight by the time the summertime comes...

After describing this exchange, Tyrone acknowledged that such interactions and occasions should not cause insecurity or tension, especially since he believed that his coworkers did not mean to be accusatory. Regardless, he felt unable to ignore their comments and believed that his observable weight loss, although unrelated to HIV, risked exposing his medical status. He believed that his HIV status might make coworkers skeptical of his ability to be a good and productive employee. For Tyrone, these comments represented a means of social

disciplining and a way for his colleagues to promote standardization. As a result, Tyrone worked to project an image of health.

Atkin and Ahmad (2011) argue that individuals with chronic illness emphasize the importance of moving on with their lives and resisting any moments that mark out their difference. Adolescents strive to show that they are similar to their peers through focusing on areas of their lives that are apart from their disease, such as work and family. Being able to integrate into peer groups this way, however, requires heightened levels of attention and regulation to manage illness. This self-surveillance, with a goal of appearing as everybody else, occurs not only during the moments of tension to explain away difference, but also in daily life so as to avoid the emergence of these moments (Gagnon, Jacob, and Guta 2013). Gagnon and colleagues (2013:62) claim that this type of normalization uses “continuous regulatory and corrective mechanisms” to achieve its goals, and that it achieves them not by threatening death, but by identifying a healthy norm and then measuring and appraising people in terms of the extent to which they deviate from this norm. Although Tyrone’s colleagues were unaware of his HIV status, he interpreted their comments about a healthy weight through a lens of potential difference. The group-level examination leads to an identification of individual-level non-normative practices, which, ideally, are then corrected (O’Byrne 2012). This moment of normalization became a point of tension since Tyrone interpreted his colleagues’ comments as a suggestion that he was somehow unhealthy.

Gagnon (2008) argues that although the enforcement of social norms is enacted to benefit individuals who are being targeted for change, those subjected to this normalization may internalize it in unanticipated ways. Tyrone described how this moment with colleagues made him realize that, “I need to stop focusing on other people and just focus on me. Focus on my job. Focus on working, saving up some money or my health. Do those things and then worry about somebody else.” Developing a vocational identity is critical to the identity formation process, and Erikson noted that it is “the inability to settle on an occupational identity which most disturbs young people” (1968:132). The inability to establish an occupational identity is associated with negative outcomes and behaviors for adolescents (Blustein, Devenis, and Kidney 1989; Erikson 1968). The challenges HIV-positive adolescents face in finding a job and developing a career are complicated by structural barriers such as low high school graduation rates, labor market discrimination, and racism (Blustein et al. 1989; Erikson 1968). These constrained how the processes through which the adolescents with whom I worked were able to form a vocational identity and connect to future careers (Ladany et al. 1997). Such structural inequalities both influence the rates of infections among urban adolescents and contribute to the fact that their lived experiences do not conform to expectations that they lead long, healthy, lives.

Maintaining a full time job created challenges for adolescents who had to negotiate clinic appointments, medical uncertainty, and medication adherence. Tyrone told me how having a job made it difficult for him to pick up his medication each week. Although he could extend the time period between medication refills, he reminded me that “we know how that turned out last year,” in reference to his last period of non-adherence. As a result, Tyrone continued the weekly medication schedule but relied on his grandmother to retrieve it from the pharmacy. This was complicated because she was initially unaware of Tyrone’s HIV status

and only discovered it through picking up his medication. Although Tyrone's grandmother collected his medications, he still found adherence challenging with his current work schedule, especially due to the side effects:

I don't want to take it like in the morning because then I'm sleepy all day. If I take it in the afternoon, as soon as I get home, I'm going straight to sleep. Any time I take it, I'm like medicated. To where I get this warm feeling to my face like I've been drinking." As a result, Tyrone's doctor told him that, "he wants to stop me from taking medication. 'Cause I'm fucking it up. And I am fucking it up. I am really fucking it up. I don't know how. It's just so easy, just one pill a day.

Like many adolescents with whom I worked, Tyrone balanced HIV and mental health diagnoses. This dual diagnosis made it challenging to attend the necessary number of doctors' appointments while working full time. Some adolescents had multiple clinic visits in a month; others reported they "felt like" they were at the clinic every week. Though Tyrone tried to schedule his appointments back-to-back to avoid being absent from work, he sometimes missed an appointment when the clinic was running behind schedule:

I had an appointment with my psychiatrist. But I missed it. My doctor was running late that day, so I didn't see my primary doctor until it was time for my second appointment. I couldn't wait for my second one. So I went straight back to work. Now I could have waited for my second one, but I did not want to risk anything with my job. I just let them know that I didn't get a chance to see my second doctor 'cause they was running behind again. It's like we understand. So I had to make an appointment with him all over again.

The types of employment that many of these adolescents obtain do not always allow for flexible leave time or the option to switch schedules to keep a medical appointment. Adolescents who are often absent may lose their jobs, be questioned by superiors about frequent absences, or given reduced hours. A few months after Tyrone talked about his job at the local power company, he was fired for testing positive for marijuana during an unannounced drug test. Tyrone reported particular frustration that his marijuana use led to his firing. He told me across multiple interviews that he wanted to stop smoking, but also described marijuana as the only way he knew to help mitigate feelings of depression and anxiety regarding his HIV status.

DISCUSSION

Medical and research communities commonly employ a discourse depicting HIV as a routinized chronic illness, but for adolescents trying to build a meaningful future while living with HIV this discourse seemed misplaced. In this article I argue that this rhetorical shift does not necessarily translate into individuals diagnosed as HIV-positive being able to return to their previous life (Atkin and Ahmad 2001). Living with a chronic illness requires the integration of medicalization into daily life, which makes coping strategies to normalize life increasingly challenging (Ladany et al. 1997). The adolescents I worked with reported uncertainty regarding their socio-economic futures, and their narratives present a challenge to the 'normal' developmental pathway described in the literature. The stories the adolescents shared, and what I observed of their lives, depicted how family, friends, and

colleagues invoked disciplining practices to promote standardization and the presentation of HIV-positive adolescents as healthy individuals.

Adolescents living with other chronic illnesses face many of the same tensions as HIV-positive adolescents, specifically around issues such as medical appointments and medication adherence (Boice 1998; Britto et al. 1998; Muscari 1998). Some researchers have suggested that many experiences HIV-positive adolescents encounter are also similar to those of their HIV-negative peers (Wolman et al. 1994). Adolescents in Baltimore faced low rates of high school graduation and high rates of unemployment compared to the rest of the United States (Baltimore Department of Health 2010a; Baltimore Department of Health 2010b; US Census Bureau 2012). The adolescents I worked with come from a stigmatized and disadvantaged group where expectations of a normal path to adulthood, irrespective of one's HIV status, are difficult to fulfill. Though HIV-positive adolescents may gain access to services as a result of their diagnosis (e.g. case management), none of the adolescents I worked with received housing or disability payments as a result of their HIV-status. In addition, adolescents with chronic illness, particularly HIV, face a unique set of challenges associated with stigma, medication side effects, and the need for consistent clinic visits (Futerman et al. 2000). As my research suggests, a chronic illness diagnosis can disrupt identity development and expectations of a future life course for HIV positive adolescents in ways that make the normalization of their social routine particularly challenging. Especially in this current moment of economic instability, HIV-positive adolescents struggle with social and economic stressors such as finishing their education and obtaining employment.

Adolescents' experience of HIV as a chronic illness cannot be discussed in isolation from the broader context of 'growing-up' and life transitions. An HIV diagnosis does not dominate all aspects of life, however, and these young people had to make sense of life transitions in the same way as their peers (Russell and Seeley 2010; Russell et al. 2007). Receiving an HIV diagnosis during adolescence can disrupt identity and orientation towards future life courses, but it does not fundamentally alter the course of adolescent development (Atkin and Ahmad 2001); developmental stages, such as locating jobs and finding careers, still occur (Muuss et al 1962). Being HIV-positive, however, can threaten to turn these stages of development into moments where adolescents must manage knowledge surrounding their HIV status to avoid moments where they might be labeled as different. This led to increased levels of self-surveillance as the adolescents I worked with tried to appear like their peers. Processes of standardization were sometimes socially imposed, particularly when young people found themselves excluded because of their families' and friends' inflexible attitudes (Atkin and Ahmad 2001). This led some adolescents to employ methods such as avoidance for fear of being unable to manage secrecy surrounding their HIV diagnosis. Having friends and colleagues comment on potential differences caused adolescents to respond to their HIV diagnoses in unanticipated ways that threatened the assumption that HIV has become 'a disease like any other'. This assumption that HIV is now similar to other chronic diseases is also challenged by the side effects brought on by HIV medication, particularly for adolescents who are just beginning a lifetime of HAART. Research among older adults outlines the health consequences of long term medication use, suggesting that therapeutic breakthroughs do not necessarily mean that HIV is no longer 'special', but it has become special in a different way (Carr and Cooper 2000).

Social policies, clinics, friends, and family do more than simply provide care and support to HIV-positive urban adolescents. They also mold and influence them in intentional and unintentional ways. These moments of molding then become instances where individuals enact practices of normalization to reinforce how an HIV-positive adolescent should behave within a given situation. When Monique's fellow student described the limitations she believed were placed on HIV-positive individuals, she was enacting corrective strategies that encouraged the incorporation of specific habits, attitudes and actions (Futterman et al. 2000; Muuss et al. 1962). These corrective strategies work to control potentially deviant individuals and, by extension, society as a whole (Kinsman 1996).

Normalizing technologies are employed so individuals are qualified and judged against predetermined objectives (Gagnon and Holmes 2008), which in Monique's case was a healthy, HIV-negative, individual. As a result of such moments, Monique described herself as feeling monitored by multiple types of individuals (her friends, colleagues, and doctors). The goal of this monitoring was to promote Monique's incorporation of healthy behaviors which were aligned with societal norms (Gagnon and Holmes 2008). These practices, however, may have unintended consequences. Monique remained in a sick role, suggesting that, for her, HIV had not become normalized, even as those around her would assume otherwise, in the basis of her medical presentation and undetectable viral load.

From a clinical standpoint, healthcare providers worked to apply these technologies of normalization to create adolescents who were healthy and employable citizens. These two processes, however, were often opposing. To be a good patient, an adolescent must engage with medication related side effects, miss time at a job or school, and address questions as to why, at a young and supposedly healthy age, he or she continued to attend clinical appointments. To be a good employee, an adolescent must be healthy, productive, and punctual. Tyrone repeatedly described how he had to miss time at work to attend appointments, and at one point missed an appointment for fear of being late for work. HIV-positive adolescents, who must negotiate what are sometimes competing forms of normalization, face challenges in fulfilling both medical expectations that they lead full lives and societal expectations that they find jobs and build careers.

There are a few potential limitations of this project. I followed a group of adolescents in Baltimore, Maryland who had access to a University Clinic, and the wrap-around services that this affords. For example, in addition to medical care they had case managers who could help them obtain housing, mental health services, and jobs, and to identify programs that would help them complete their GED. This could influence how the HIV-positive adolescents I worked with experienced educational attainment and career development. These adolescents also were all recruited from the same clinic, though they lived in different neighborhoods throughout Baltimore, suggesting a variety of experiences.

In this article, I have drawn on the experiences of two HIV-positive adolescents to demonstrate how an HIV diagnosis strongly influences how they build their lives. While HIV-related clinical treatment has become routinized, life outside of the clinic and the formation of careers continues as before, calling into question whether HIV can be considered a chronic disease 'like any other.' Adolescents' futures do not continue along a

standard developmental pathway as policy makers and researchers in previous eras imagined they now would. In fact, upon HIV diagnosis, adolescents experience a radical shift, one that does not conform to expectations in public discourse that they lead a normal life. To move this line of research forward, it is important to continue work with both HIV-positive adolescents and adolescents living with other diseases that have recently come to be seen as chronic. Future studies might also question how an HIV diagnosis other aspects of adolescents' development, such as building interpersonal relationships and family formation.

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Biography

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