Young Black men who have sex with men (YBMSM) aged 13 to 24 years are acquiring HIV infection at increasing rates, more than any other demographic group in the United States. Between 2006 and 2009, HIV incidence among YBMSM increased by 48%. These disparities are particularly prominent in the southern United States, which represents an increasing proportion of HIV incidence and prevalence.

Effective interventions to improve treatment and prevention of HIV among YBMSM in the South are urgently needed. Significant public health benefit has been demonstrated from the use of antiretroviral medications (ARVs) to treat both people living with HIV (treatment as prevention) and uninfected high-risk individuals (preexposure prophylaxis). Given the rising HIV rates among YBMSM and the recent shift in focus toward ARV-based prevention approaches, we can anticipate that ARVs will be prescribed to YBMSM with increasing frequency in the near future. However, the efficacy of ARV-based interventions depends on optimal medication adherence, leading to concerns about the feasibility of implementing these strategies with youths. Adolescence and emerging adulthood are high-risk periods for medication nonadherence because of cognitive and developmental immaturity as well as structural barriers (e.g., housing and financial instability) that often manifest during the transition to independent adulthood. In addition to these youth-related obstacles, Black men who have sex with men of all ages frequently experience significant cultural and logistical barriers to obtaining appropriate medical care, including discrimination and mistrust at the community, institutional, and patient–provider relationship levels.

Developmentally and culturally appropriate support interventions must therefore be developed for YBMSM to maximize ARV adherence and the consequent individual and public health benefits. However, there is limited research focusing on sociocontextual factors in the lives of HIV-positive YBMSM to guide development of such programming. Extrapolation of prevention and treatment strategies designed for perinatally infected youths, older adults, or nonminority individuals is likely inadequate to address the unique circumstances of infected YBMSM as they learn to cope with a newly diagnosed chronic illness, manage intersecting stigmatized minority identities, and survive the normal developmental turbulence of adolescence and emerging adulthood. Formative research is needed to fill these gaps in the literature and maximize the likelihood of successfully implementing ARV-based prevention strategies in this growing population. We conducted a qualitative study to explore developmental and health-related experiences of HIV-positive YBMSM and to answer the following questions: (1) How do YBMSM experience the transition to adulthood while living with HIV? and (2) What are the important sociocontextual influences on ARV adherence for YBMSM?

**THEORETICAL BACKGROUND**

Adolescence and emerging adulthood represent crucial stages for developing self-sufficiency, autonomy, and identity. However, significant individual and cultural heterogeneity is found in the timing, goals, and experience of this transition, which are influenced by factors such as socioeconomic status, culture, and ethnicity. Furthermore, the experience of living with chronic illness has a meaningful impact on this developmental transition. The degree and nature of this impact varies depending on the type and severity of disease, as well as other modifying factors such as family context and peer
relationships. A significant body of work has documented the negative impact of various chronic illnesses on attainment of developmental goals in young adulthood; however, the specific effects of behaviorally acquired HIV on psychosocial development remain largely unexplored.

Most behavioral models and theory-based interventions targeting ARV adherence have focused primarily on individual-level factors such as regimen tolerability, cognitive capacity, and self-efficacy. In contrast, Castro has proposed a holistic biosocial framework of ARV adherence that explicitly includes socioeconomic factors, health care system features, social capital, cultural constructions of illness, personal characteristics, psychological factors, clinical factors, and ARV regimen factors. To date, this framework has primarily been applied in resource-limited settings outside of the United States. Given the complex developmental and psychosocial contexts in which YBMSM are situated, we sought to explore ARV adherence within this comprehensive framework to include both proximal and distal influences on adherence.

METHODS

This study was conducted in Atlanta, Georgia, between February and May 2012. Because our questions focused on health care experiences, we recruited a convenience sample from HIV clinical care settings. Potential participants were either approached directly by team members during a clinic visit or were referred by clinic providers and subsequently contacted via phone for screening. Eligibility criteria were, by self-report, (1) Black race, (2) aged 13 to 24 years, (3) HIV-positive serostatus, (4) history of ever having oral or anal sex with a man, and (5) having a regular HIV care provider. We excluded youths with perinatally acquired HIV. We obtained verbal informed consent or assent at the time of the interview and parental consent for the 1 participant younger than 18 years.

In-Depth Interviews

We conducted life history interviews with each participant; these interviews entailed fairly complete narratives of participants’ lives with a focus on subjective experience. Life history interviews are particularly useful for understanding past and present contextual influences on health behaviors, consistent with our biosocial framework. We interviewed participants in a private meeting room in a clinic building. One author (S. A. H.) conducted and digitally audio recorded the interviews, which averaged 1.5 hours in length. The semi-structured interview guide included open-ended questions in 8 conceptual domains:

1. general life questions (regarding current work or school and living situations),
2. early life and formative experiences,
3. identity and intersectionality,
4. sex and relationships,
5. HIV,
6. stigma,
7. health care experiences, and
8. future orientation.

Examples of interview questions with particular relevance for this article included “Tell me a little bit about what your childhood was like,” “Tell me about your life right now,” and “What has taking HIV medications been like for you?” Study team members met periodically, discussed emergent themes, and incorporated them iteratively into subsequent interview questions. After the interview, participants completed a demographic survey and received a $25 gift card as compensation for time and travel.

Thematic Analysis

Two authors (S. A. H. and D. G.) transcribed the interviews verbatim and imported the transcripts into MAXQDA 10 (VERBI Software, Berlin, Germany), a qualitative software package. Our phenomenological approach to the thematic analysis centered around in-depth, case-based analysis of each participant’s developmental and medical history. First, we highlighted segments of text broadly corresponding to transition to adulthood and ARV adherence. We used these text segments to create pictorial diagrams delineating relationships between important constructs for each participant (see Figure 1 for an example). These diagrams are visual devices whose function is analogous to qualitative memos, in that they portray possible relationships between concepts. Five information-rich transcripts were selected and diagrammed by the 2 primary analysts in parallel. We compared diagrams and discussed differences until the approach was standardized, after which the remaining transcripts were divided and similarly diagrammed. Next, we wrote focused analytic memos summarizing each transcript with specific attention to developmental trajectories and adherence. The diagrams and memos provided complementary information; diagrams depicted larger concepts and relationships that were illustrated and explained in the memos. After all 20 transcripts were diagrammed and summarized, we compared cases and analyzed emergent patterns in the data. Pseudonyms were assigned to each participant during analysis; these (as well as the participant’s age) are included when individual participants are referenced.

RESULTS

The 20 participants ranged in age from 17 to 24 years (median age = 22 years) and were
diagnosed with HIV an average of 3 years before the interview. Most (90%) had been initiated on ARV therapy. Participants’ narratives highlighted the following themes: (1) developmental goals during the transition to adulthood, (2) the effect of HIV on the developmental trajectory, (3) resilience, and (4) ARV adherence in the context of the participants’ changing life stage.

Developmental Goals During the Transition to Adulthood

Participants described many developmental goals, or milestones, that they hoped to achieve. Some of these goals fell into classic primary developmental domains of adolescence and emerging adulthood, such as the desire to establish autonomy and solidify an adult identity, and others were specifically related to the experience of living with HIV.

Primary developmental domains: autonomy.

Most of the participants’ self-defined milestones connoted a desire to establish independence from their families. Commonly described markers of such independence included financial self-sufficiency, possession of a car, and renting one’s own place to live. Postsecondary education and career goals were also discussed in many cases. Omar, age 23 years, for example, described the process of separating from his family and outlined his goals in a stepwise fashion:

I don’t think my parents are going to cut me off, especially now that they know that I’m [HIV] positive. . . . I remember trying to tell them once that I wanted to move out. “Move out! To go where?” They never gave my brother that conversation, so, if I can maybe just start on my own and then I’ll worry about doing other things but I need to—I just got a car, the car’s the first step, then I need to find an apartment, then the degree.

Primary developmental domains: identity.

Although our patients were both racial and sexual minorities, gay identity was much more salient in the transcripts than racial identity. Racial identity was described either as unimportant or as an established historical fact.

By contrast, sexual minority identity was dynamic and central to participants’ stories. Self-acceptance and coming out to family were often described retrospectively as defining moments in adolescence. For others, increased comfort with a gay identity was an important upcoming goal. Omar stated, “I don’t wanna lie anymore. My goal for this year is to be out to everybody.”

HIV-related developmental domains: HIV-positive identity. In addition to identity processes related to race and sexual orientation, participants also described nontraditional identity development processes related to coping with HIV and incorporating their diagnosis into their evolving self-concept. This HIV-positive identity was important to most, but not all, participants. Steven, age 22 years, stated,

Though you can’t see it, I wake up an HIV-infected person and I go to bed an infected person at the end of the day. You know my medical history says it, and it’s me, it’s a part of me, it’s not completely me but it’s a part of me, and it has started to shape the person that I am now.

Meanwhile, others such as Andre, age 22 years, were adamant that their identity had not changed:

HIV is a virus, it doesn’t mean that’s me, it doesn’t mean that it cannot be beaten, does not mean that it cannot be dealt with. Whether or not I’m positive should not dictate my life, should not control it.

HIV-related developmental domains: health maintenance.

Several participants defined clinical laboratory measurements (such as improved CD4 cell counts or undetectable HIV viral load measurements) as important goals, such as Andre: “I came here with 44 T cells and I got them to 168, I figured out today, I’m proud of myself.”

Self-sufficiency in navigating the health care system was another milestone that participants discussed. In this context, they described efforts to take control of their health care and gain independence from parents and guardians in terms of going to doctor’s appointments and remembering medications. Omar, for example, illustrated this tension:

At first [my parents] wanted to come with me here to all my appointments and stuff, and I had to put a stop to that, like after the second appointment. And they were upset with me.

Resilience

In our analysis of participants’ early lives, we noted a difference between relatively low-adversity participants, for whom HIV was the first major obstacle faced, and high-adversity participants, who encountered more challenges in their lives leading up to HIV diagnosis. We compared cases to determine whether early life adversity and successful transition to adulthood appeared to be related in our sample. Despite early childhood disadvantage, many high-adversity participants achieved their desired developmental outcomes. Such cases highlighted participants’ resilience, or learned adaptation to adversity.

Every participant described an initial emotional reaction to learning his diagnosis; however, for about half of the sample, underlying HIV infection did not derail them from their original developmental trajectory. For the other half, a significant developmental setback was experienced after diagnosis. The box on page e4 presents representative case histories illustrating these 2 types of trajectories: Steven, whose transition to adulthood was relatively unaffected by his HIV diagnosis, and Vince, for whom HIV diagnosis was a much more disruptive event. Several key differences emerged between these 2 men and the groups that they represent. One major difference was the level of physical illness at the time of HIV diagnosis; within the less-affected group, most, like Steven, were essentially asymptomatic. Within the more affected group, however, the majority of participants were symptomatic at diagnosis, with many requiring hospitalization.

For these youths, illness and temporary disability often led to loss of employment, increased parental protectiveness (as illustrated by Vince), or both, diminishing participants’ self-sufficiency. The second major difference between the 2 story types was age and developmental stage at diagnosis. Vince was diagnosed at age 15 years, at which time he was in high school and living transiently between friends’ homes. Steven, however, was diagnosed at age 20 years after achieving independence; for participants such as him, greater maturity and life stability at the time of diagnosis provided financial and emotional resources to help them adjust to living with HIV.
Effect of HIV on the Developmental Trajectory: Case Studies of Young Black Men Who Have Sex With Men, Life History Interviews; Atlanta, GA, 2012

Case 1: Steven, age 22 years
Theme: Uninterrupted transition to adulthood

Steven was born and raised primarily in Atlanta, with a large and very close extended family headed by his maternal grandmother. He described a “peachy keen” childhood without any trauma or major upheaval. After graduating from high school, he started college but left school to work and save money. By the time he was 19, he had a full-time job at a doughnut shop, paid rent on his own apartment, and had purchased his own car. He described these milestones with pride and distinguishes himself from his siblings, who were still living at home with their mother. He was diagnosed with HIV at age 20 by his primary care doctor. He was asymptomatic but presented to his doctor because of a recent high-risk sexual encounter. His mother accompanied him to receive his test results, and although she was upset, she was immediately supportive. He was quickly linked to care and started on therapy, to which he describes near-perfect adherence. Although his mother and other family members reminded him to take medications, he quickly clarified that he has always gone to his appointments and navigated the clinic system alone, without their assistance. At the time of the interview, he was working full time at a fast-food restaurant and expecting to be promoted to manager soon. He was also living with his boyfriend, with whom he described a stable and equal partnership. Achieving such independence is the single thing that he was most proud of.

Case 2: Vince, age 22 years
Theme: Transition to adulthood interrupted by HIV

Vince was born and raised in the projects of Atlanta. He grew up with his mother and 5 siblings and had a same-age uncle and a grandfather in the house as well. Vince voluntarily left his crowded family home to live with friends at age 15; he was diagnosed with HIV soon thereafter. However, he did not disclose his diagnosis or seek care for a full year, until he became extremely ill with pneumonia, was hospitalized, and was essentially forced to disclose to his mother at that time. Six years after his diagnosis, he described his life situation as follows: “Right now I’m just rebuilding who I am, and I’m going through a transitional stage right now in my life where I’m trying to become a better adult, because I’m trying to become more independent because I tend to [lean] on my mom, especially since I was diagnosed. She basically walked with me and did everything with me ‘cause I felt like I was weak.”

Vince described himself as an excellent high school student, but his developmental and educational and career trajectories were derailed by his HIV diagnosis. Given his academic achievements, he always thought he would be a regular teen going to a 4-year college but was instead a part-time barber and dancer-in-training with an associate’s degree in fashion merchandising. At the time of the interview, he was living with an uncle while trying to save money to move out on his own. Although he was in good health and saving some money, he repeatedly contrasted his actual life to the life that he had expected for himself, and he expressed a great deal of anxiety about the fact that he did not yet have a clear vision for his future.

Note. All names are pseudonyms.
DISCUSSION

This study is among the first to contextualize the medical experiences of HIV care and ARV adherence within a biosocial framework that accounts for the larger developmental contexts of YBMSM. Our analysis showed that the processes of navigating the transition to adulthood, coping with an HIV diagnosis, and adhering to ARVs were inextricably linked in our participants’ lives. We found that HIV affected progress toward self-sufficiency differentially depending on experiences of symptomatic illness. Despite such setbacks, many participants described resilient trajectories that helped them to reach developmental goals. Finally, our participants discussed ARV adherence as a function of their developmental success. Each of these findings has potential implications for future research and intervention.

Our participants were clearly focused on the age-appropriate developmental task of transitioning to adulthood. Their goals fell into well-described domains of autonomy and identity, but they defined these constructs in ways that incorporated their sexual identities, HIV-positive identity, and newfound priorities of health maintenance and ARV adherence. Our findings regarding the detrimental impact of symptomatic illness on developmental trajectories strengthen the public health imperative for early diagnosis and linkage to care because the trajectories of participants who were diagnosed before becoming symptomatic were comparatively undisturbed. To further test this connection, future research assessing linkage to care in YBMSM should consider measuring outcomes such as employment, education, and financial status along with traditional clinical indicators.

The salience of resilience in the narratives strengthens recent calls for resilience-based approaches to HIV-related interventions among MSM. In agreement with the theory in this area, we found that resilience was a dynamic developmental process in which new strengths and practiced coping strategies were applied to changing life circumstances. In addition to individual strengths, strong support networks were also critical contributors to resilience, and further characterization of the support networks of YBMSM is warranted to better understand the relationships between these networks and developmental and clinical outcomes. Because many HIV-positive YBMSM do engage successfully in HIV care, improved understanding of resilience among YBMSM in care holds promise for informing the development of support interventions for their less engaged peers.

The relationship between transition to adulthood and ARV adherence was another key finding. Our nonadherent participants were all depressed and often were not meeting their developmental goals. Existing adherence-promoting interventions in adolescents focus primarily on modifying individual-level cognitive processes, often with limited effectiveness. Our findings suggest that interventions seeking to improve adherence among YBMSM would benefit from including mental health services and vocational and educational support. Successful implementation of ARV-based prevention methodologies such as treatment as prevention will depend on holistic, developmentally appropriate programming to support adherence among YBMSM; such programs would have the potential for significant impact at the individual and community levels.
Examples of Antiretroviral Adherence in Case Studies of Young Black Men Who Have Sex With Men, Life History Interviews; Atlanta, GA, 2012

Case 5: Paul, age 19 years
Theme: Poor adherence with difficulty transitioning to adulthood
Paul grew up in Atlanta with his mother and sister. Paul ran away from home at the age of 13 and describes living in Boston and New York, supported by different older men, until he was hospitalized with pneumonia, diagnosed with HIV/AIDS, and returned to Atlanta at age 16 to live with his mother and get into medical care. His mother was with him in the hospital and has been a source of support ever since. Four years later, at the time of the interview, he was still struggling to completely come to terms with his HIV-positive identity. He declared that “HIV changes your character,” but unlike some others, he did not describe this as a consistently positive change, stating that HIV often makes people angry at the world. He had disclosed his status to his family, his best friend, and some but not all of his sexual partners. He was not employed, and his future goals remained vague and seemingly impractical. For example, he discussed plans to launch his own high-end makeup line, claiming that his skills as a freelance makeup artist gave him entry into very exclusive and high-class social circles. He was living alone in subsidized housing designated for HIV-positive people but remained dependent on financial assistance from his mother to pay his rent. In terms of adherence and engagement in health care, Paul admitted that he had been poorly adherent to medications, both in the past and at the time of the interview. He attributed many of his past adherence problems to stress, depression, and difficulty accepting his HIV status and integrating it into his identity: “I looked at it as though I didn’t have [HIV] but I knew I did... . I allowed stress to really [get to me], I guess I was living in a world that wasn’t real.” He stated that he was getting better about showing up to appointments, but that his medication adherence remained suboptimal. Other adherence obstacles included a transient lifestyle with frequent travel between cities, as well as previous situations in which he was consumed with unhealthy romantic relationships and no longer focused on taking care of himself.

Case 6: Jonathan, age 23 years
Theme: Excellent adherence with developmental success
Jonathan was born and raised in the Atlanta area. Both of his biological parents were addicted to crack cocaine, and he grew up primarily in foster homes and group homes. When he was in high school, he was adopted by a family acquaintance who passed away 5 years later. He was diagnosed with HIV at the age of 17, during his senior year of high school. Before that, he got tested for HIV every 6 months since becoming sexually active. Although he was initially upset at receiving his diagnosis, he stated that if he had the opportunity to go back and change contracting HIV, he would not do so; he believed that having HIV gave him maturity, humility, and compassion for others. He regularly disclosed his status freely on online dating sites, to family members, and in the workplace and had been involved in both formal and informal speaking engagements related to HIV education. At the time of our interview, he was employed full time as a baggage handler at a major airline, had a car, and was living alone. He had been financially independent since graduating from high school, and he expressed great pride in the fact that he did not depend on anybody for monetary assistance. At the time of interview, he reported having had an undetectable viral load for more than 5 years (essentially since he was first initiated on therapy). He told us that he had never missed his HIV medications because he saw them as a part of his overall life plan; when asked how he maintains his adherence, he answered, “I have a mission to accomplish before I get out of here.” Additionally, he described himself as a well-liked patient in the clinic because he was achieving his health care and developmental goals: “I’m taking care of myself and doing things that I’m supposed to be doing. So I love my visits.”

Limitations
Although our data were rich, several limitations bear mention. We interviewed each of our participants once and are therefore viewing their development from a single point in time. Repeated interviews may have yielded additional information about the trajectories of our participants’ lives. Our clinic-based convenience sampling strategy was appropriate given our focus on health care–related experiences; however, the majority of our participants reported being adherent to ARVs, and more theoretic sampling to find cases of nonadherent patients could have further supported our claims. One author (S. A. H.) conducted the interviews, performed some transcriptions, and conducted a large part of the analysis. This could lead to researcher bias; however, we collaborated at every stage, with multiple study team members confirming key thematic findings. Social desirability bias was an additional concern; however, the interviewer was not previously acquainted with any of the participants and took care to advise the participants that their responses would never be communicated to their health care providers.

Conclusions
Despite the burgeoning epidemic of HIV among YBMSM, this study is among the first to explore the impacts of HIV within the developmental contexts of these young men’s lives. We uncovered several key findings with implications for HIV treatment and prevention in YBMSM. Our findings suggest that early diagnosis and linkage to care are likely to minimize the negative impact of HIV on developmental outcomes. Interventions aiming to improve ARV adherence in HIV-positive YBMSM should support successful transitions to adulthood more broadly. Future research should develop and test such interventions to realize the promise of ARV-based HIV treatment and prevention for YBMSM.

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Contributors
S. A. Hussen led conceptualization of the study, coordinated data collection, participated in qualitative analysis,
and led the writing of the article. K. Anses and D. Gilliard contributed to qualitative analysis, interpretations of study findings, and editing of the article. R. Chakraborty, C. del Rio, and D. J. Malebranche contributed to conceptualization of the study, interpretation of study findings, and editing of the article.

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