**Title:** Helping HIV-positive Adolescents Become Healthy Adults: Balancing Individual and Population-level Health Needs in an Era of Biomedical HIV Prevention

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**Abstract:** This paper explores how adolescent healthcare providers balance individual and population-level health needs as the scale-up of biomedical HIV prevention measures brought HIV/AIDS clinical treatment guidelines into alignment with national public health prevention goals. From 2010-2012, I conducted fifty semi-structured interviews with providers in adolescent medicine clinics in eleven U.S. cities and eighteen months of observations in weekly clinical case reviews and grand rounds at an adolescent HIV clinic. My research suggests that providers may not apply clinical treatment guidelines and instead focus on helping adolescents become adherent adults. Clinicians also remained accountable to patients who did not adhere to medication and thus progressed to AIDS, or even death. It is critical to understand how shifts in discourse around the biomedicalization of HIV and—more concretely—in population-level policy around the provisioning of treatment and care for HIV-positive individuals, have affected clinical practice and the lived experiences of HIV-positive adolescents.

## Introduction

This paper explores the dilemmas providers face in daily clinical practice as a result of the clinical treatment guidelines for HIV/AIDS being brought into alignment with national public health prevention goals. Such dilemmas were particularly acute when providers did not follow guideline recommendations or public health goals and instead focused on how to help an adolescent develop into an adherent adult patient, or even remained accountable to patients who did not adhere to medication and thus progressed to AIDS, or even death. Policy makers and researchers at the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH) brought these clinical treatment guidelines and population-level goals into alignment as a result of recent developments showing that highly active antiretroviral therapy (HAART) can confer health benefits to individuals with higher CD4 counts (1-3) and reduces the rate of secondary HIV transmission (4). "Treatment as prevention" (TasP) research demonstrates that earlier medication initiation greatly reduces HIV transmission within heterosexual couples when only one individual is HIV-positive (4). Research demonstrating the ways treatment can contribute to HIV prevention led policy makers and politicians to make claims about the possibility of achieving an AIDS-free generation (5, 6).

Researchers and policy makers incorporated TasP-related research findings into the U.S. National HIV/AIDS Strategy's public health prevention goals: that HIV-positive individuals should remain healthy, and not progress to AIDS or transmit HIV to others (7). To achieve these population-level health goals, government officials and researchers expect HIV-positive individuals to follow a series of steps outlined in the U.S. National HIV/AIDS Strategy (7, 8). These steps follow the "HIV treatment and care continuum" and include being diagnosed as HIV positive, attending clinic appointments, beginning HIV medication, remaining adherent to the prescribed treatment regimen, and achieving an undetectable viral load (7, 8). The government officials and scientists who crafted these public health prevention goals, and the steps necessary to achieve these goals, subscribe to the notion that HIV incidence in the United States will decrease if HIV-positive individuals follow this supposedly linear progression. However, for this progression, and the public health goal of reducing HIV transmission, to be successful, individuals identified as HIV-positive must first initiate, and subsequently adhere to, medication.

To help achieve the goals outlined in the U.S. National HIV/AIDS Strategy, NIH researchers updated the *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* in March of 2012 (9). NIH researchers' most significant change to the guidelines was raising the medication initiation threshold for treatment naïve patients from a CD4 cell count of 350 to 500 (9). Updating this threshold solidified the alignment of national level public health prevention goals and clinical guidelines for the treatment of individuals.

The alignment did not occur in the ways policy makers and researchers at the CDC and NIH imagined in the adolescent clinics where I conducted research. The advent of HAART in 1996 made it possible for today's HIV-positive adolescents to live a 'full' life after acquiring HIV (10, 11). The current cohort of HIV-positive adolescents in the United States is one of the first that can expect a life span similar to the general population (11). These therapeutic breakthroughs have reframed the types of challenges adolescent medicine practitioners face in the clinic. HIV-positive adolescents were initially expected to die of AIDS, and the role of clinic staff was to manage the dying process. With HAART, physicians must now help adolescents manage the clinical demands of a chronic, infectious disease while also navigating the transition from adolescence to adulthood. For adolescents, this can mean finding work, forming families, building careers, and addressing emerging sexuality and individuation.

Policies following from TasP complicated how the providers I observed talked about clinical care decisions. Clinicians remained responsible for adolescent's immediate medical needs, but also worked to help them become healthy adults who would adhere to medication and advocate for their own treatment and care. Moreover, clinic staff had to think beyond how an adolescent's medication adherence might affect his or her current and future health; care decisions now had to address how an adolescent's medication adherence might affect the public's health. This led to tensions within the clinic, particularly when adolescents did not take their medications or follow the steps researchers outlined in the U.S. National HIV/AIDS Strategy. When this happened, providers often felt that continuing to prescribe medication to a non-adherent adolescent would fail to confer medical benefits and place the adolescent at risk for developing resistance to certain classes of medication. Developing drug resistance would lead to fewer medication options in the future, and a time when providers believed adolescents were more likely to adhere to medication. Decisions to stop prescribing medication, however, conflicted with public health goals and clinical treatment guidelines that all patients should begin medication to improve their health and reduce HIV transmission.

The paper describes two types of scenarios that illustrate the work providers faced when clinical guidelines for the treatment of individual patients and national public health goals did not align in the adolescent medicine clinic. The first scenario examines how providers talked and acted when they did not trust an adolescent to adhere to medication. In such moments, providers shifted their attention from prescribing medication to instead helping an adolescent develop the traits necessary to become an adherent adult. This section also illustrates how clinicians prioritized an adolescent's long-term health outcomes by making decisions to withhold medication in spite of clinical guidelines stipulating the use of HAART. The second scenario describes how providers dealt with adolescent death. When adolescents became sicker, and the possibility of a future diminished, clinicians transitioned from working to help them become adult patients who took their medication and, instead, supported their choices leading up to and including moments of death and dying. Providers then constructed this death and dying through a discourse that sought to both absolve them of responsibility for the adolescent's death and reiterate a belief in medicine.

## The Research Project

Data presented in the paper draw from dissertation fieldwork that took place from 2010 to 2012 at a variety of clinic locations throughout the United States. A majority of the research was based on observations and informal discussions conducted at the University Clinic (UC) with providers who treated adolescents with HIV and AIDS. The University clinic is housed in a general adolescent medicine clinic at the Johns Hopkins Hospital in Baltimore, Maryland. Data presented in this paper come from 18 months of participation in UC clinical case reviews, as well as informal conversations and interactions with clinicians that occurred in their offices before or after clinical case reviews. Clinical case reviews happened once a week, lasted two hours, and covered clinic announcements, administrative issues, research studies, upcoming events, and patients who had presented for appointments in the previous week.

During my research, the University Clinic treated approximately 200 patients ranging in age from 12 to 24. Case review discussions addressed adolescents born with HIV and those who acquired HIV through sex. Discussion topics included, among other things, medication (re)initiation and adherence, reproductive health, housing, adolescent development, and advance directives, death and dying. Most adolescents in the University Clinic were in their early twenties and nearing a time when clinic providers expected them to transition to adult care. This imminent transition raised concerns among clinicians as to whether the adolescents were mature enough to take medication and attend clinic visits once outside the support of the adolescent clinic. These concerns were particularly strong for adolescents born with HIV as many had developed resistance to multiple antiretroviral medications over a lifetime of treatment. These patients also tended to have very low CD4 cell counts, a medical vulnerability that precipitated a number of the moments described in this paper.

In addition to participating in University Clinic case reviews, from September 2010 to June 2011, I conducted in-depth interviews with 50 healthcare and social service providers with patient populations similar to the University Clinic. These providers included doctors, nurses, nurse practitioners, social workers, psychologists, and case managers. These in-person interviews occurred in adolescent medicine clinics in eleven different cities in the United States including Los Angeles, CA; Philadelphia, PA; New York, NY; San Juan, Puerto Rico; New Orleans, LA; Tampa Bay, Miami, and Fort Lauderdale, FL; Washington DC; Memphis, TN; and Chicago, IL. Study participation was limited to one interview. Each interview lasted approximately one hour and was digitally recorded and transcribed verbatim. Interviews covered topics such as practitioners' professional history in the field of HIV and adolescent medicine, the integration of the medical and social management of adolescents in the era of HAART, adolescent development and disease management, adolescent medication adherence and death, and how providers imagined the current and future life course for an HIV-positive urban adolescent.

## "How do we turn this into a teaching moment?": Helping adolescents become healthy adults

This section of the paper is based on the experiences of Marcus[1], a 22-year-old African American adolescent infected with HIV at birth. Marcus had cycled off and on of multiple HAART regimens over the course of his life, and when I first heard of him he was not taking medication.  Although the section highlights the story of one adolescent, his experiences illustrate

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[1] The names of all individuals who participated in the research project are pseudonyms

patterns I saw throughout my interviews and observations. Some of the general statements in this section of the paper, for instance how providers talk about trust in the context of their relationships with adolescents, make use of other adolescent experiences similar to those of Marcus.

Like Marcus, nearly two-thirds of the adolescents in the University Clinic had been living with HIV since birth. Most adolescents infected at birth were in their early-to-mid twenties and many had CD4 cell counts below 200, the threshold at which the World Health Organization (WHO) labels an individual as 'AIDS-defined'. These adolescents were born before the advent of HAART in 1996 and had taken multiple medication regimens throughout the course of their lives. Though a lack of treatment options at the time of their births meant that these adolescents were expected to die as children, the introduction of HAART led physicians and researchers to claim that adolescents could now maintain a lifespan similar to that of the general population (10). In order to maximize the benefits conferred by HAART, adolescents have to maintain a lifetime of almost perfect adherence to their prescribed medication regimens (12, 13).

Adolescents in the clinic without drug resistance had multiple medication options and physicians described them as taking at most 3-4 pills once a day. There were fewer medication options for adolescents like Marcus, however, who had a history of non-adherence and, consequently, drug resistance. In order to maximize the chance such an adolescent would maintain viral suppression, providers talked about piecing together multiple types of medication. This meant that adolescents with drug resistance might need to take as many as 8 to 10 pills at multiple times throughout the day. Clinic staff also felt that requiring adolescents to take high numbers of pills might limit their chances of remaining adherent, a worry that is supported by research showing that adherence decreases as the number of required pills increases (14).

Providers stressed Marcus' need to adhere to medication, both for his own health and because providers believed that Marcus was at risk for transmitting HIV because he was having what they assumed to be unprotected sexual relationships. Having unprotected sex, especially for someone with Marcus' CD4 cell count and viral load, directly conflicted with national public health HIV prevention goals. Marcus' high viral load was also problematic because he told clinic staff that he was having sex with multiple women. Though Marcus reported talking about general health issues with one of his girlfriends he had not disclosed his HIV status.

Providers spoke to me about the importance of being able to trust adolescent patients in order to make informed medical decisions regarding adherence. Providers needed to know whether fluctuations in an adolescent's CD4 cell count or viral load were due to non-adherence or medication failure. In the majority of the interactions I observed, however, clinic staff did not trust adolescents to make decisions that would benefit their long-term medical outcomes. This type of patient-provider relationship, and lack of trust, differed from how adolescent clinic staff described the dynamics of adult care. Clinic staff talked about how adult care patients would make decisions around treatment and adherence that would benefit their own health outcomes. This suggests that adolescent clinic staff imagined adult patients as advocating for their own care and having medical outcomes goals that aligned with those of their physicians. Thus, in adult care the mutuality of the patient-provider relationship would be restored from a lack of trust to one where patients' and providers' goals were aligned.

### *"When he's demonstrated adult behavior"*

Clinicians' lack of trust that an adolescent would take his or her medication challenged their ability to remain focused on developing the healthiest version of an adolescent's current self. This lack of trust opened up space for a temporal shift in providers' attention as they looked toward an adolescent's future and an imagined time when the adolescent would mature and begin to adhere to medication. Two of the clinicians' main goals—helping HIV-positive adolescents become adherent to medication in the current moment and helping adolescents develop into healthy and independent adults—were, however, often at odds.

By the time I heard about Marcus, clinic staff felt they had exhausted all opportunities to facilitate his adherence. As soon as Marcus' name was raised in clinical case review, Amber, a nurse practitioner, quickly added, "His t-cells are around 124 and he's at risk of having nothing left in terms of medication if he blows through this...just take your fucking medicine, geez." Not only had Marcus' continual non-adherence violated providers' expectations of how a patient should ideally act, his laboratory results demonstrated that he had lied to practitioners about his intended adherence. During one case review where clinic staff discussed Marcus's situation his primary doctor, Dr. Bixel, told the clinical team, "He's just manipulative and he needs to be treated as an adult."

In making a call to treat Marcus as an adult, Dr. Bixel was also asking that Marcus act as an adult. By saying, "he needs to be treated as an adult", she was suggesting that Marcus should be expected to (re)-fill his prescriptions, take his medication, present for clinical care, and follow the clinic's registration procedures. Being an adult also meant that Marcus should become someone who would come to clinic when he had health problems other than HIV and take steps in his life that would allow him to function independently (e.g. obtain stable housing and employment).

Clinic practitioners chose to act in ways they believed would provide Marcus the best long-term health outcomes, irrespective of expectations policy makers, government officials and physicians held regarding how patients should take medication at this moment in the epidemic. Clinicians' decision not to provide Marcus with medication was in direct conflict with the updated NIH treatment guidelines that an adolescent with his disease status be placed on medication to protect his health and the needs of the broader public. Once it was clear that Marcus would not be adherent, clinicians shifted their attention to determining how to help him develop into a healthy and adherent adult patient. At the next case review I observed, Dr. Bixel told the clinical care team:

> *I'm working harder than he is for this…I don't think he wants to do this, we might just have to let him fail. My thought is if you think he won't follow through, then give him the prescription and let him do it [see if he fills it].*

In saying, "we might just have to let him fail," Dr. Bixel was suggesting that doctors prescribe medication for Marcus even though they believed he would not take it. Clinic staff hoped that such an experience might help Marcus accept that he was not ready to take medication in the current moment. After a long discussion, the clinical team decided to have Marcus initiate directly observed therapy (DOT) in the clinic. This meant that Marcus was required to attend clinic Monday through Friday to take his HIV medications. Using DOT would give him the chance to 'fail' if he did not present for medication, but providers would at least know that he was not taking it. DOT also served as a tool that could bring Marcus into the clinic. Providers felt that increasing Marcus' engagement in the clinic would give them opportunities to teach him the skills necessary for becoming a successful adult patient. These skills included how to present on time, interact with clinic personnel and, hopefully, understand the value of medication. Clinicians hoped that the explicit requirements they laid out for Marcus to fulfill through presenting for DOT would also facilitate his psychosocial development. As Amber explained, "We can use this as an opportunity to teach him to be more adult like. He has no sense of consequences…so what can we do to make this a teaching moment?"

The following week Marcus appeared at the clinic on Monday morning, and again on Tuesday, albeit an hour late. After those two days, however, he failed to reappear. During the subsequent clinical case review clinic staff stressed the importance of using Marcus's failure with

DOT as a teaching moment. As a result of Marcus's unsuccessful attempt with DOT and his problematic behavior in the clinic (e.g. yelling at staff and not registering before entering the clinic), clinic staff felt the next step had to provide an even more explicit structure for fostering adult behavior. Dr. Bixel described her frustrations with Marcus during a subsequent case review meeting:

> *This is a game for him. We have to treat him more like an adult and force him to take the responsibilities that this implies. We can't baby him. When he's demonstrated adult behavior we'll let him take the medication.*

Following a common technique in adolescent medicine, clinicians created a behavioral contract that outlined the (adult) behaviors Marcus would need to demonstrate in order to receive medication (15). Through the creation of this contract Marcus and the clinic staff would agree to certain measures that, if Marcus followed, would allow him to restart his medication. Clinic staff believed that using the contract as a behavioral tool would help Marcus achieve three goals: 1) To become a patient who is respectful to staff and follows clinical protocol; 2) To take medication to improve his current health; and 3) To take medication in a sustainable, long-term way that would empower him to manage his chronic illness, and help him develop into a healthy and adherent adult.

Approximately one month after the social worker and nurse met with Marcus and he agreed to the behavioral contract, the clinic director, Dr. Kelly, began a discussion about whether to keep enforcing it. Marcus had failed to present in the clinic for DOT during that month, and had continued to complain that providers were withholding care. Providers hoped that the contract's stipulation about presenting for clinic appointments and completing housing applications would provide a clear pathway for Marcus to work toward adherence. However, after a few months, Marcus' medication adherence and relationship with the clinic remained unchanged. At the end of the discussion, Dr. Kelly conceded:

> *Letting go of control is such a hard thing even if you know they're heading for destruction but at a certain point you have to say it's their life and they're old enough to be making decisions and it's not what I would choose for them nor is it the right one, but you have to let it go.*

Clinicians described using the contract as a way to demonstrate that they had provided the best care possible given the circumstances. Even as Marcus refused to take medication, clinic staff struggled to find ways to help make him more adherent. Amber summarized this conversation by asking the University Clinic team, "Can we just say to him, 'let us know when you're ready?' We're trying to fix something that can't be fixed."

### *"Getting to the point where the light bulb turns on"*

Clinic staff routinely talked about how an adolescent's developmental stage could challenge his or her ability to adhere to medication. Physicians told me how adolescents' non-adherence and missed clinical appointments were often due to their not yet having reached the 'formal operational' stage of development described by Piaget that would allow for abstract and future thinking (16). Physicians told me how understanding HIV-related notions of disease latency and asymptomatic infection can be complicated for adolescents because brain development necessary for future-oriented thinking does not occur until an individual's early twenties. Many adolescents in the clinic had AIDS diagnoses and CD4 cell counts in the 100s. Despite having quite fragile immune systems, clinicians noted how these youth might not actually *feel* sick (17). Clinic staff claimed that adolescents who did not yet understand the possibility of having HIV and still feeling healthy would be less adherent to HAART than adults, a belief supported by adherence-focused research (18).

Clinicians wanted to make sure that adolescents like Marcus remained alive long enough to reach a stage of maturity where they would take medication. It was important for clinic staff that adolescents reached this stage before transitioning to adult care. Nearly all the providers I spoke with told me stories of adolescents who had not learned to be adherent before transitioning to adult care. Those adolescents rarely kept their adult clinic appointments or filled their prescriptions, and would reappear only years later at the emergency room or adolescent clinic with severe opportunistic infections. Practitioners retold these stories as if to reassure themselves of the importance of helping adolescents become the type of adherent adults who could survive in adult care. One physician in Los Angeles described the importance of keeping adolescents healthy enough until they were ready to take medication. He felt that the best way to facilitate long-term adherence was:

> *Letting them grow up. It's like if we can keep them safe and healthy and moving in the right direction, by the time they transfer out they may have a much better shot at being successful… they can't get their act together and take their medications regularly until they are 23, 24.*

During case reviews and throughout the interviews, providers would circle back to the idea of an imagined moment that adolescents must reach in order to transition toward acting as an adult. Acting as an adult in these contexts meant that the patient would be able to manage their medication and appointments and follow-up with providers without constant reminders. Clinic staff referred to this as the "ah-ha" moment, or the "light bulb finally coming on." Clinicians described this as a pivotal moment, but were not always clear when it would happen, or whether this was a singular moment or a series of moments along a (not necessarily linear) progression. One nurse practitioner told me how she would talk to other staff members to determine whether an adolescent was approaching such a moment, "I'm like, hey, the light bulb turned on with this girl, light bulb's on, no she's not there yet, still flickering, it went back out. But that's the pattern that we've seen." Clinicians were also unsure at what point such a moment would occur in the developmental trajectory. The same nurse practitioner told me, "The light bulb starts to flicker around 21, 22 and then it's on and it's like night and day."

For clinicians, the possibility of adolescents reaching such a moment came to represent an imagined future time when their work to help adolescents develop into a healthy adults would finally be rewarded. This moment also represented a time when adolescents would take the medication that policy makers claimed could transform HIV into a chronic, non-life threatening illness. Clinic staff described these imagined future moments as a way of reiterating how adolescent medicine differed from adult medicine: they were caring for patients before that "ah-ha" moment. Because the clinic staff I observed were treating adolescent patients before this "ah-ha" moment, they felt that colleagues could not hold them responsible for negative patient outcomes in the same ways as they could providers in adult care.

During clinical case reviews providers spoke about some adolescents for whom the imagined moment of becoming an autonomous adult who was adherent to medication never occurred, or came at a time when repeated non-adherence had made their bodies resistant to medications and no longer able to stave off HIV. For Marcus, it remained unclear if or when such an 'ah-ha' moment would occur. Six months after the decision to create a behavioral contract, Marcus' name was again raised because the clinic had not seen or heard from him in over four months. The outreach worker had visited the places where Marcus usually spent time but was unable to locate him.

## "You have to let it go": Death and dying in the adolescent clinic

The advent of HAART has provided the medical capabilities that policy makers claim allow individuals to die *with* HIV but not *of* it (10). At this stage of the epidemic physicians considered an AIDS-related death to be both medically unexpected and unnecessary. Adolescent deaths were rare events, and events that required explanation. In this section of the paper I explore the work providers do in the clinic when an adolescent doesn't survive. I use the stories of two adolescents to examine how clinic staff talked and acted in moments of death and dying:

Kamaya was a 23-year-old African American from Baltimore and 19-year-old Dominic attended a clinic in Philadelphia. As an adolescent neared death, I observed how clinicians worked to explain the death to themselves and each other. One way clinic staff did this was by reframing the types of outcomes for which colleagues outside the clinic could hold them responsible. Clinicians talked about their obligation to follow an adolescent's wishes throughout the dying process rather than following the clinical guidelines and helping him or her develop into a successful adult patient. Clinicians' ability to support an adolescent's process of death and dying could only occur, however, once they had absolved themselves of any blame surrounding the adolescent's impending death.

When I walked into clinical case review on a December morning there was none of the chatter that normally signals the start of a meeting. Once the University Clinic team was seated, Dr. Kelly raised her hand to gather people's attention and share that, "as most of you know, Kamaya died last night in hospice." She paused, and then requested a moment of quiet to remember Kamaya. After about 20 seconds Dr. Kelly broke the silence with a 'thank you' and proceeded with the meeting.

University Clinic staff had worked with Kamaya throughout her adolescence to facilitate adherence. Attempts to facilitate her adherence included using incentives, DOT, and Active Day, a medical service for the elderly and chronically ill adults to help improve their quality of life and medication adherence. Kamaya would take her medication or agree to DOT for a time, but soon disappear from the clinic. Providers' desire for Kamaya to take medication increased as she became sicker. Some clinical staff suggested Kamaya be forced to adhere, whether through at-home DOT or even in-patient treatment. Clinic staff also suggested placing her in a nursing home where she could remain under constant observation, but Kamaya refused, saying that her father had died in a nursing home and she didn't want that for herself. Clinicians made continued attempts to facilitate adherence at the end of Kamaya's life because, even though she had "the number of t-cells you could name", therapeutic options remained. The existence of therapeutic options complicated Kamaya's death and how clinic staff dealt with it.

The University Clinic team discussed treatment options each week during anti-retroviral therapy (ART) review, a portion of the UC clinical case review run by Dr. Bixel and Dr. Stahl, an infectious disease pharmacist. During one ART review, Dr. Stahl ran her finger down the side of a document she had created with Kamaya's medical history. Dr. Stahl described how, in addition to multiple pill options, Kamaya could still take T-20 [a twice daily injection]. Dr. Kelly turned to Dr. Stahl, offered a half smile and placed her hand on Dr. Stahl's forearm, "I think Kamaya would rather die than take T-20." After a brief pause Dr. Stahl tried to start a number of different sentences, "Wait…what…no…I…what" and her shoulders began to sag. Dr. Stahl paused, and then asked Dr. Kelly, "Why won't she take T-20 if it's an option?" Dr. Kelly reiterated simply that Kamaya would not take that type of medication. She recalled that there was only one adolescent in the history of the clinic who had taken T-20 successfully. He had remained adherent for a little over a year, until he ran out of places to inject himself.

A few weeks before her death, Kamaya's name was again raised in clinical case review. She had been admitted to the hospital with Mycobacterium Avium Complex (MAC), cough, and dehydration. Kamaya's social worker described a conversation where she told Kamaya, "You're driving the train, and need to tell us what you want and we'll do it. Let us know if you want (us) to stop prescribing medication and we can stop it." In making this statement, Kamaya's social worker is trying to come to terms with Kamaya's death, and accept her choice to let it occur She also made this declaration to clarify that Kamaya alone could determine her final medical outcome, and that the clinic staff will, "have to let it go".

### *“Society killed him”*

I first heard about Dominic from a psychologist, Dr. Ashley, at an adolescent clinic in Philadelphia. Dominic had come into the clinic a few years after acquiring HIV through sex. According to Dr. Ashley Dominic was, “into gangs and drug running and pretty tough stuff. His response to the diagnosis was ‘I only fuck women, I ain’t no fucking faggot.’” Dominic refused to accept that he had contracted HIV or even consider medication. He never disclosed his HIV status to anyone outside of the clinic. Though the HIV treatment guidelines clearly state that an adolescent with Dominic’s disease status should initiate medication, Dr. Ashley told me:

> *He refused to take medication or to acknowledge the disease and said that it was not something he could live with so he was going to die from it. He was about 19. So he came to us in December and he died the 4th of July weekend. He was in the hospital for the last 4 weeks.*

One night while Dominic was in the hospital the nurses heard him crying and shouting, “I’m a faggot and God is punishing me for being gay.” Dr. Ashley told me how the clinic staff was heartbroken over Dominic’s disease progression as well as his inability to share his diagnosis or sexuality. The clinical staff knew, however, that Dominic wanted to keep his disease status hidden from his family and everybody else. As a result, the physicians chose to intubate him, both because the intubation was medically necessary and so that Dominic would be unable to speak and inadvertently disclose his HIV status.

Dominic progressed to AIDS, and ultimately death, even though he had never taken medication and had no known drug resistance. Throughout this process clinical guidelines—and expectations from doctors outside the clinic that an adolescent like Dominic should be on medication—became irrelevant. Dr. Ashley’s description that she would help an adolescent move through life as he or she wanted, “even if it is not what I would do,” demonstrated how she chose to respect Dominic’s decision not to live with HIV. She upheld this decision even when it meant she had to shift her role as a practitioner from facilitating life to supporting an adolescent's death. Dr. Ashley told me that respecting an adolescent's decisions gave her a sense of pride, regardless of the outcome:

> *If they don't want to take medication, for example, instead of telling them that they have to, my response is, 'that's ok, let's talk about it, what do you feel about that.' It's hard. We've had patients die on us, but that happens sometimes and for me it's more about how we deal with that and how we let them die.*

Dominic went into cardiac arrest after a few weeks on the adolescent ward and was moved to the intensive care unit (ICU). Dr. Ashley described how, once Dominic was in the ICU, she, the adolescent fellow, and a social worker kept a constant bedside vigil. Whenever a new physician entered the ICU one of the three adolescent medicine practitioners approached the physician and described the situation. They would ask the ICU physician not to mention HIV and, instead, say that Dominic had some undisclosed systemic illness. This was important because Dominic's mother, to whom he had not disclosed, was also by his bedside. Dr. Ashley told me, "You know, he wanted to have people think he died of something unknown, or stomach cancer, so we would tell this to the hospital staff and they thought we were crazy." This description, that other hospital staff "thought we were crazy" suggests heterogeneity in clinical responses.

When Dominic died, the adolescent medicine fellow worked with the ICU doctors to ensure that the death certificate listed the primary cause of death as a heart attack. HIV was never recorded. In this instance, respecting Dominic's wishes required concealing his HIV status. Dr. Ashley described the importance of this secrecy as it meant that Dominic's friends and family could remember his death—and life—in a specific way. The story of Dominic's death demonstrates how Dr. Ashley chose to respect his decision not to live with HIV irrespective of what the authors of clinical guidelines and public health goals, or physicians outside the clinic, might claim was medically possible.

### *"She is making her choices"*

When a set of actions resulted in treatment failure or death, clinic staff acted and spoke in ways that mitigated the possibility of blame. The ways clinic staff mitigated blame took different forms. For example, clinicians placed responsibility for the death on the patient, their families, or social situations. Even when clinicians felt they had made the correct decisions given the circumstances, they often spoke to adolescents, adult clinicians, and each other, in ways that divested their responsibility, particularly as adolescents' CD4 cell counts dwindled and they neared death.

Clinical case review discussions about an adolescent's declining CD4 cell counts and lack of medication adherence always came to the same conclusion, that the clinical care team could not be responsible for a patient's behaviors. Even while claiming that the decision to take medication ultimately fell to the adolescent, providers still struggled with whether they had done enough. Clinic staff maintained an underlying faith in science, and the possibilities science offered that would allow adolescents nearing death to become healthy. Unlike the pre-HAART era, progression to AIDS is no longer determined by a physician's ability to treat opportunistic infections. An adolescent's non-adherence or disease progression is no longer a scientific failure but instead a failure of the self (21). Dr. Kelly represented this sentiment during a case review by delineating the "drugs that work" from the people who do not. Dr. Kelly's explanation served to emphasize that adolescent deaths resulted from *human* failure rather than *medical* failure. In the biomedical model, the medical possibilities that allow HIV to be a chronic disease exist, and will be successful for adolescents who choose to engage with them. Even with available medication, clinicians described struggles to facilitate adolescent adherence, and the challenge of having to accept that they had done all they could. When we were leaving a clinical case review a few weeks before Kamaya's death was announced, Amber walked with me into the hallway and stated:

> *It's so hard because we can do all the biomedical stuff in a lab, and make the medication, and you put it in a test-tube and it works. But, then, when real life comes in and the test tube talks back to you and tells you to fuck off, it's a lot harder. There's nothing we can do anymore, you fight for so long but I just have to learn that, she is making her choices. It's like she's wanting to die.*

During my time in the clinic, the UC team was continually frustrated by Kamaya's medical and social situation. Physicians, case managers, nurse practitioners and social workers all pleaded with her to take medication, come to appointments, follow up with housing, find a job, and act in ways that would stabilize her life. Practitioners described feeling that, in Kamaya's case, the goals policy makers and researchers outlined in the National HIV/AIDS strategy had become a collectively impossible task. Even so, Dr. Kelly worked to mitigate the UC team's own responsibility for this unnecessary outcome. As she told the team:

> *Don't beat her or yourself up over this. We have a commitment and responsibility to help people be successful…and we do all we can but stuff comes down to the patient and it's hard because for so long our energy is one of pushing and pushing and pushing and then we shift to pulling off. We switch our energy from a parent who does all we do but sometimes we can't achieve our goal.*

The allocation of blame also occurred throughout the course of Dominic's disease trajectory. This process began in the clinical case review when clinic staff debated how to address Dominic's refusal to take medication. The staff that wanted Dominic to take medication became the voice of what was medically possible. Clinicians' assertions about what science could offer also allowed them to avoid becoming seen as responsible for his death.

The need to allocate blame for Dominic's death was apparent in the psychologist's final comments to me that, "AIDS didn't kill him, society killed him, the social killed him, and that's so frustrating and hard." Her choice of words, "AIDS didn't kill, society killed him" suggests that throughout this process of death and dying there was an understanding that science could have saved Dominic. Blaming society also meant that the existing medical tools, and by extension the clinic staff, were not culpable for this death. In deciding not to take medication or engage with the clinic, Dominic chose another outcome, one that providers decided to label as an undiagnosed systemic illness. Even though clinicians respected Dominic's wishes to die, they placed the blame for his death on society and the stigma it had against Dominic as a gay, HIV-positive man.

## Conclusion

The paper highlights the stories of three adolescents whose stores provide insight into how population level health polices intersect with individuals' clinical needs. These adolescent narratives illustrate the work providers did when public health prevention goals and clinical guidelines for individual patient care did not align in the adolescent medicine clinic, nor adequately address adolescents' inability or unwillingness to take medication.

The individual nature, and potential ambiguity, of clinical work caused practitioners to make what they saw as ethical decisions based on the needs of each specific patient, not clinical guidelines or the public's health. Instead of mechanistically applying clinical guidelines, providers remained accountable to the patient from the moment he or she received an HIV diagnosis. Marcus' experience demonstrates the work practitioners did in the clinic when they did not trust adolescents to take medication or present for appointments. Physicians stopped prescribing medication for Marcus because they believed that helping him mature, and ensuring that he did not become resistant to additional medications, would create the most positive medical outcome. Clinic staff also worked to help Marcus mature because they believed that there was little else they could do in that moment. Clinicians worked throughout this process to demonstrate to themselves and to colleagues that Marcus's lack of adherence was his choice; it did not reflect their ability to treat a patient with his medical status. In the case of Kamaya, I observed how clinicians' shifted their focus from helping an adolescent become an adherent adult to supporting an adolescent through the dying process. Clinic staff remained accountable to Kamaya's medical needs and treatment desires even when her non-adherence resulted in her death.

Physicians and policy makers claim that HIV is a chronic and manageable illness and expect that people living with HIV should want to live a full and healthy life. Adolescents like Dominic challenged these assumptions and forced clinic staff to rethink how these dominant clinical narratives might be applied in the clinic. Clinicians then also had to come to terms with these deaths. These deaths led clinicians to create a discourse that placed responsibility for the death on multiple registers (e.g. the adolescent, society), but it never came to rest with the clinic staff or medicine itself. By creating this discourse, clinic providers worked to reiterate their belief in medical possibilities; they did not question the clinical guidelines or the undergirding of an AIDS-free generation. Instead, when adolescent death occurred providers spoke about it as a human failure, not a medical failure. This suggests that clinicians still believe it is possible to arrive at a moment where no one progresses to AIDS or transmits the virus, it would simply require adolescents to take their medication.

At this moment in the HIV epidemic, the authors of the U.S. National HIV/AIDS Strategy claim that providers' clinical decisions should incorporate the health needs of individual patients and population-level health. The creators of the national strategy cannot appreciate the dilemmas providers faced when trying to incorporate individual and public needs into the clinic, however, because they imagine these needs to be one and the same. Critics of TasP have argued that assumptions about this alignment place clinicians in situations where they are, in effect, having to choose between prioritizing a patient's long-term health or the public's health (19, 26). The clinic staff I spoke with incorporated the expectations policy makers and physicians held that adolescents should be on medication and live a full life with HIV. Clinic staff did not, however, allow these expectations to override decisions to withhold medication or let an adolescent die of AIDS. Even under a regimen of TasP, population-level goals and guidelines for the treatment of individuals did not always align in the clinic. When they did not, providers in the adolescent medicine clinic faced dilemmas between respecting a patient's medical needs and treatment desires, and helping them become healthy and adherent adults. In these complicated and complex moments, clinicians chose to prioritize a patient's needs over the public's health.

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