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Negotiations of Blame and Care among HIV-positive Mothers and Daughters in South Africa's Eastern Cape

Research delineates two epidemiological categories among HIV-positive adolescents: those who contract the virus sexually and those who inherit it as infants. In this article, we are interested in how tacit inferences about adolescents' mode of infection contribute to their experiences of HIV-related blame, and their ability to achieve care, in their intimate, everyday settings. The analysis arises from ethnographic research with 23 HIV-positive adolescents living in South Africa's Eastern Cape. From these, we draw particularly on the narratives of four HIV-positive teenage girls and their HIV-positive mothers. The article explores the social stakes entailed in ascriptions of adolescents' mode of infection, particularly in terms of how blame was allocated between mothers and daughters. It further considers how these families have sought to negotiate repudiation and thereby sustain intergenerational care. The article furthers limited research on the life projects and dilemmas of this HIV-positive adolescent cohort. [HIV/AIDS, adolescents, blame, South Africa, intergenerational care]

Introduction

Over the past decade, antiretroviral therapy (ART) has become increasingly accessible in sub-Saharan Africa, attended by declining HIV/AIDS morbidity and mortality (Todd et al. 2014). As public ART has expanded and HIV has become an increasingly manageable disease, many have expected the shame and recrimination of HIV/AIDS to dissipate (Ashforth and Nattrass 2005; Castro and Farmer 2005). Yet studies from sub-Saharan Africa suggest that stigma remains a core feature of the

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HIV experience (Campbell et al. 2011; Denis 2014; Gilbert and Walker 2010). Our aim in this article is not to account for this persistent reproach. Rather, we hope to elucidate some of the ways in which it circulates among a growing population of HIV-positive adolescents in South Africa, about whom we still know very little. Almost a quarter of South Africa's new HIV infections occur among adolescents and young women (Shisana et al. 2014). And the increased availability of ART means that a growing cohort of HIV-positive children is surviving into adolescence.

For the purposes of this article, we are interested in blame as a form of symbolic stigma that positions some people as morally culpable for, and morally damaged by, adolescent HIV. Drawing on ethnographic research with 23 HIV-positive adolescents (age 10–19) and their caregivers who live in South Africa's Eastern Cape, we consider some of the ways in which blame for adolescents having contracted HIV is attributed and felt, suggesting that young women and mothers are vulnerable to recrimination.

The analysis we present here gives particular attention to the narratives of four adolescent girls (ages 15–19) within this sample, as well as their HIV-positive mothers. Each of these adolescent girls was diagnosed through antenatal screening. Their HIV diagnoses ignited both real and perceived vulnerability to blame, whether from health providers, fellow support group members, or their own mothers. Indeed, for these adolescent girls, securing medical, psychosocial, and familial care was often intertwined with assuming blame for HIV. The risk of opprobrium arose from the exposure of their "untimely" sexuality, the HIV risk to their unborn babies, and their perceived misconduct as daughters and/or young women.

The dual diagnoses of pregnancy and HIV not only made these adolescent girls vulnerable to recrimination, it also prompted defensive responses from the girls' mothers. Mothers appeared to feel shame in light of possible inference that they had failed to raise and protect their daughters adequately. This was particularly fraught when mothers were themselves HIV-positive, and thus vulnerable to the accusation that they were the source of their daughters' HIV.

In addition to exploring how blame for adolescent HIV is felt and ascribed by mothers and daughters, this article considers the tactics through which generations of women have sought to manage potential blame. This has often meant guarding against particular accounts of adolescents' presumed mode of infection. Through euphemism, omission, and redirection, both mothers and daughters seemed to protect—or at least make possible—the narrative that daughters had contracted HIV sexually rather than perinatally. In doing so, they upheld norms of adult respectability and youth deference, which, in turn, bolstered renditions of intergenerational care and dignity.

Women in the HIV Epidemic—Entanglements of Blame and Care

The burden of South Africa's HIV/AIDS epidemic is conspicuously borne by women. Almost twice the numbers of women live with HIV than men (HSRC 2014). As a consequence of antenatal screening, women are also more likely to test for HIV. In 2012, annual HIV testing was 52.6% among women, and only 37.5% among men (HSRC 2014). An opt-out HIV testing policy for pregnant women has frequently been received as mandatory procedure (Groves et al. 2010).

Partly due to higher HIV testing rates, women have often been the first in their family or partnership to know they had HIV. Frequently, "this 'discovery' has attached to them as blame, since in their discovery they are also perceived as creating the disease" (Barolsky 2003, 38). Women are often positioned as both the source and the vectors of AIDS, attributed to their "contaminating sexual promiscuity" and perceived disavowal of traditional values (Campbell et al. 2006; Denis 2014; Leclerc-Madlala 2001).

While high volumes of HIV diagnoses among women have made them especially vulnerable to blame, this has also meant that women access HIV care in far greater numbers than men. In 2011, 60% of eligible women in South Africa were receiving ART, compared to 41% of their male counterparts (Cornell 2013).

Because it is largely women who are tested for HIV, the risks and responsibilities of disclosing HIV are gendered. While disclosure can augment familial support, it can also be met with condemnation or rejection (Mills and Maughan-Brown 2009, 2). For many HIV-positive women, then, presenting oneself for care, and getting seen by those who can provide it (whether family or health staff), entails being brought under a particular kind of spotlight: one that both protects and indicts, sometimes in the same breath.

Mode of Infection

Because so many HIV diagnoses unfold in antenatal clinics, mothers have taken on a particular symbolic potency in the South African HIV epidemic—as objects of disproportionate public health attention, but also weighty recrimination. Maternal blaming has carried into the categorization of HIV-positive adolescents by mode of infection.

Vertically infected adolescents are described as having contracted HIV through "mother to child transmission." Now a default phrase in HIV care programs, mother to child transmission arguably assigns blame to mothers, in contrast to more neutral alternatives like vertical transmission (Young et al. 2011). Here, mothers of HIV-positive infants have experienced guilt and blame for having failed in their "appropriate" role as carers, responsible for the next generation (Lawless et al. 1996, 1371; Vale and Thabeng 2016).

Motherhood also carries import for South Africa's sexually infected adolescents. Having contracted HIV more recently, these adolescents often do not present at clinics until their 20s—unless they become pregnant, in which case they are immediately initiated onto ART (Li 2008, 64; MacPhail et al. 2009). Amid a scathing public discourse surrounding teenage motherhood, adolescents' early pregnancy, particularly when coupled with HIV, is often viewed as both dangerous and untimely (Macleod 2003), sometimes prompting discrimination from health workers (Okoror et al. 2014; O'Reilly and Washington 2013). The mothers of pregnant teenagers might also be vulnerable to indictment. Mkhwanazi's (2010) research in Nyanga has shown that mothers are often held responsible for teenage pregnancies, believed to have failed in teaching their daughters to conduct themselves properly.

The limited research from South Africa suggested that, numerically, sexually infected adolescents outnumber those infected at birth (Li et al. 2010). Yet perinatally infected adolescents are disproportionately represented in HIV care (Li et al.

2010). This is partly because these adolescents are likely to have been coopted into care at an early age, having fallen sick or entered care alongside sick parents. But it is also a consequence of low rates of enrollment among sexually infected adolescents.

Having been more recently infected, sexually infected adolescents generally remain healthy longer, with very low rates of HIV testing. Unless they are diagnosed while pregnant, these adolescents are also unlikely to be in immediate need of ART. As a consequence, many do not return for regular health monitoring and are thus largely absent in the health system (Snyder et al. 2014, 2). Among those enrolled in HIV care, the small number of adolescents presumed to be sexually infected were, for the most part, initiated as pregnant teenagers.

Until recently, it was assumed that vertically infected babies would not survive more than a few years without ART. But recent reports from sub-Saharan Africa show a substantial minority of vertically infected adolescents presenting at clinics untested and untreated (Ferrand et al. 2009; Shepherd et al. 2015). These "slow progressors" have often survived more than a decade without ART. This has complicated assumptions that those diagnosed as adolescents are certainly sexually infected. The knowledge and understanding of an adolescents' mode of HIV infection are contingent, subject to an array of shifting factors. These categories are nevertheless socially imbued, and, as we will show, are often implicated in intimate appropriations of blame and shame.

Blame and Care within HIV-affected Families

Sub-Saharan literature on adolescent HIV has started to explore intergenerational dynamics of HIV-related blame and shame within families, particularly insofar as these relate to HIV disclosure. Both parents and children have been shown to face dilemmas in disclosing HIV to one another. Given their role in transmitting the virus, biological parents were reluctant to initiate potentially blaming and hurtful conversations about their own and their child's HIV status (Kiwanuka et al. 2014; Kyaddondo et al. 2013; Mandalazi et al. 2014). Young people infected through sexual intercourse had similar challenges telling their parents. Indeed, norms of respectful intergenerational interaction, particularly discretion in matters involving sex, have mitigated HIV disclosure within families (Kajubi et al. 2014; Mburu et al. 2014). For both groups, disclosing HIV was associated with the fear of blame, stigma, and discrimination, as well as shame and guilt related to perceived sexual misconduct. But the literature also suggests that there are practical imperatives for disclosure in terms of gaining access to support, treatment, and material resources (Cluver et al. 2015; Kyaddondo et al. 2013; Toska et al. 2015).

This article furthers existing research on how HIV-positive adolescents and their families have sought to negotiate recrimination within families and preserve intergenerational care, often through tactical decisions about what to say and when (Daniel 2014; Kunapareddy et al. 2014). It makes a unique contribution by addressing how adolescents' presumed "mode of infection," and not simply the disclosure of HIV, factors in negotiations of blame between generations. It suggests that this blame often takes on a particularly gendered dimension, affecting mothers and daughters in particular. As such, the articles adds to another growing literature

(Kyakuwa and Hardon 2012; Rhine 2009, 2014), which explores how women live with a deeply discrediting virus and defuse concerns about their ability to run, and be part of, respectable households.

Methods

This research forms part of a collaborative mixed methods research project, titled *Mzantsi Wakho*, which investigates ART-adherence and sexual and reproductive health among HIV-positive adolescents in South Africa's Eastern Cape. In 2012, the Eastern Cape's HIV prevalence was estimated at 11.6% (HSRC 2014), with 29.1% prevalence among its antenatal attendees (Department of Health 2013). Given the complexity of adolescence and the heterogeneity of young people's transitions to adulthood, age-based definitions of adolescence are largely arbitrary. For the purposes of this research project, we adopted the World Health Organization definition of adolescence (age 10–19), which is broad enough to capture both adolescents who inherited HIV from their parents and those who contracted it later in life.

The findings presented in this article derive from a small constitutive part of the project, which used ethnographic methods to explore appropriations of ART care among 23 HIV-positive adolescents (age 10–19). Data for this smaller study were collected by Beth Vale and her research assistant Mildred Thabeng. Between August and December 2013, they conducted ethnographic fieldwork in rural villages of an area we call Mtembu. Peri-urban fieldwork ran between January and April 2014 in the informal settlements of a small town, dubbed Ridgetown.

Adolescent participants for this smaller ethnography were purposively sampled, with the intention of varying age and gender, while also incorporating harder-to-reach subgroups. The latter included adolescents infected sexually, those unaware of their HIV status, and those who had defaulted on treatment. The majority (18) of participants were recruited through nongovernment ART-support groups. Given low rates of HIV testing and enrollment among sexually infected adolescents, these support groups catered predominantly for younger, perinatally infected adolescents, who had been coopted into care at an early age. Clinic-based recruitment helped fill gaps in the sample, particularly through the referral of four adolescents assumed to be sexually infected.

Throughout fieldwork, Vale and Thabeng visited participants and their families regularly. In most cases, in-depth interviews were conducted with adolescents' guardians. These explored guardians' caregiving experiences by tracing adolescents' life histories, including their HIV diagnoses, ART initiation, and present-day pill-taking. Adolescents themselves were engaged on a much more regular but also much less formal basis, with informal conversations taking place over multiple home visits. To observe their interactions with ART care, Vale and Thabeng also accompanied participants on regular health appointments. This was complemented by informal and occasionally interview conversations with health workers. Research activities were conducted in both English and isiXhosa. Real-time translations allowed for immediate interpretation and follow-up questions. While the researchers conferred regularly about how translations were captured, the translation is ultimately coproduced by the interviewees and the subjective readings of Thabeng as the translator.

Only four of the 23 adolescent participants in this study, all girls, were assumed to have been sexually infected. We call them Lindiwe (age 15), Koketso (age 18), Yoliswa (age 19), and Nokutula (age 18). These participants are the primary focus of this article, although we also refer to other adolescent participants with whom these young women interacted. Lindiwe was recruited through an adolescent HIV support group in her village. Koketso was referred by a rural nurse who had initiated her onto ART a few years prior, to prevent onward transmission to her baby. With her virus still supressed, and in accordance with South Africa's then guidelines for the initiation of ART, Koketso was not yet considered eligible for lifelong treatment. Nokutula and Yoliswa were referred by a Ridgetown clinic and had each started ART while pregnant.

When Vale and Thabeng met them, all four of these adolescent girls were living with their biological mothers, three of whom they also knew to be HIV-positive. All but one lived in households of only women. Male relatives or boyfriends visited occasionally but were otherwise entirely absent. Rampant unemployment and declining marriage rates have contributed to the diminishing role of men in South African domestic life (Ferguson 2013, 231; Walker 1995, 431). Meanwhile, the mass distribution of state social grants, for which women (in their position as child bearers and child carers) are primary recipients, has bolstered female-centered homes (Ainslie 2014; Bank 2001).

The assumption that these four participants contracted HIV sexually was premised on the stories that they and their mothers relayed to us and their having been diagnosed with HIV after a positive pregnancy test. They showed no signs of long-term illness or delayed treatment, which often result in vertically infected adolescents experiencing stunted growth or pubertal delay (Lowenthal et al. 2014).

Over the course of the fieldwork, our assumptions about how these four adolescents contracted HIV would unravel, as we uncovered inconsistencies, omissions, and revisions in their own and their mothers' accounts. Redirections and silences about mode of infection not only characterized the narratives told to our researchers, but also those told to health workers, relatives, and others. The analysis presented here is an attempt to make sense of how mothers and daughters perform, mask, and uphold particular narratives about adolescents' mode of infection as well as their purposes in doing so. For the mothers and daughters who are the primary subject of this article, these acts of telling and concealing might be interpreted as fragile negotiations of blame and care, in which information about mode of infection is tactically framed to preserve standards of intergenerational care.

The research project's extensive ethics protocol was approved by the Universities of Oxford and Cape Town as well as the South African Department of Health. Written, informed consent was sought from both adolescents and guardians, whose anonymity is protected through the use of pseudonyms.

Mothers, Daughters, and Antenatal HIV Screening

On the day she found out Nokutula was pregnant, Nokutula's mother, Gugs, received a phone call from her eldest daughter to tell her that Nokutula had been admitted to the hospital. Gugs's eldest daughter lived in a neighboring town, where Nokutula had been visiting for the weekend. Upon hearing the news, Gugs rushed

to meet her daughters. When she arrived at the hospital, the doctor informed her that Nokutula was pregnant and had been admitted due to a complication with the positioning of the fetus (interview, February 14, 2014).

Nokutula told us how embarrassed she had felt when her doctor unveiled the pregnancy to her mother (field notes, February 14, 2014). Until then, she believed her mother had been totally ignorant of her sex life.

In her interview (interview, February 14, 2014), Gugs confirmed that she had been shocked at the news of Nokutula's pregnancy. She said Nokutula had later conceded that she had known she was pregnant before visiting her sister but had not told anyone. Nokutula had said to Gugs that it was only when she fell ill and was taken to the doctor that her pregnancy was revealed.

A few days later, Nokutula gave us a different account than what she had told her mother: She told us that she had taken a pregnancy test at home. Discovering that she was pregnant, she informed her boyfriend. Together, they had decided that she would get an abortion. This was the real reason she had traveled to see her sister that weekend. Nokutula had hoped that her sister would finance the procedure and that by having it in the neighboring town, she would be able to keep both the pregnancy and the abortion a secret from her mother. Nokutula recounted this visit to the doctor, in which she was told that her pregnancy exceeded the gestational age permitted for abortion, and that she would therefore have to continue the pregnancy (Hodes 2013). The secret of her pregnancy would thus need to be disclosed.

While Gugs assured us that she had always encouraged Nokutula to use contraception, Nokutula denied that she had ever talked with her mother about sex until her pregnancy was exposed. Yoliswa also insisted that, until her pregnancy, no one had ever spoken with her about sex. Ironically, it was only after she became pregnant that people in the street would call out to her, saying that she should have used a condom. When Yoliswa described being pregnant, she said: "It was not nice. [...] I was shy to walk on the street. [...] I was scared of people. [...] I thought they would laugh at me." Similarly, Lindiwe's mother conceded that she had not had this conversation with Lindiwe prior to her pregnancy, believing she was too young. Anthropological research (Mkhwanazi 2010) among Xhosa communities in Nyanga has shown that norms surrounding appropriate and respectful intergenerational conduct have limited sex talk between mothers and daughters. Yet, in this study, it was often mothers who prompted their daughters to take a pregnancy test, noticing that they were gaining weight, missing periods, or experiencing unusual symptoms.

For the four young women who are of primary interest here, an opt-out HIV testing policy for pregnant women resulted in a diagnosis that they would not otherwise have sought. When Nokutula was released from the hospital, she and Gugs returned to Ridgetown, where Gugs accompanied Nokutula to the clinic for some "stomach checks." "While they were busy with those [check-ups], they took some blood tests. The sister [nurse] called in and said, 'Nokutula has something to tell you.' And Nokutula said she was HIV-positive. It was the most painful news ever" (interview, February 14, 2014).

The stories presented here are not indicative of the empowered "voluntariness" so regularly touted in HIV testing campaigns, where audiences are encouraged to

take responsibility for their health by opting to "know their status." Like many others, these young women came to know their HIV status incidentally rather than voluntarily.

Both Nokutula and Lindiwe's mothers were called into consultation rooms to receive the news of their daughters' HIV diagnoses (interview, August 21, 2013). The disclosure of these young women's HIV status to their mothers functions rather as a form of exposure, since they had no control over when or how the information escaped. Health staff played an important role in bringing the sexuality of these young women under maternal authority. By calling in mothers, health providers acted in ways that were both punitive and protective. The act served simultaneously as one of concern and discipline. Very quickly, the misfortune of the adolescent girls becomes a shared responsibility of their mothers—a process mediated by other older, female authorities.

Pregnant bodies provoke a particular reading from health workers when coupled with an HIV diagnosis. Gurevich and colleagues (2007, 15) argue that antenatal HIV screening brings the status of women as "containers of wombs" to bear. Nokutula's nurse said that, "for the sake of the baby," HIV testing was compulsory (field notes, February 14, 2014). After testing, Yoliswa was told that "the [antiretroviral] pills" were "very good" and would "protect her baby" (field notes, February 18, 2014). Hence, in securing HIV testing and treatment, Nokutula and Yoliswa also came under a particular public health gaze from their health workers, in which they were primarily viewed as "vessels," culpable for their babies' protection.

By enrolling in HIV testing (however reluctantly), the four young women under discussion here received much-needed medical care. Yet, when diagnosed pregnant and HIV-positive, all four adolescent girls reported being fearful about revealing the news to their mothers.

Their anxieties recalled a story that Thabeng overheard and then recounted after a few months of fieldwork in Ridgetown (field notes, April 14, 2014). One afternoon, while spending time in Ridgetown township, a young woman told Thabeng about her friend and neighbor, also a young woman, who we will call Nandipha. Despite having been tested HIV-positive and experiencing severe illness, Nandipha had delayed disclosing her HIV status to her family or enrolling in ART. This was until she became pregnant and began treatment to prevent transmission to her baby. After learning of her daughter's HIV diagnosis, Nandipha's mother reportedly felt ashamed, suggesting that she perceived the diagnosis to also be a reflection on her. To protect themselves from gossip, the family continued to keep Nandipha's status a secret. Reflecting on Nandipha's story, Thabeng said: "Families are too exposed. [...] There's so much work that goes into hiding stuff."

I will return to the social functions of this secrecy later. For now, it is worth exploring further how, for many young women, enrolling in HIV care comes to be attached with an acute sense of vulnerability to recrimination.

Blame and the Terms of Care

To explore this nexus of care and blame further, we turn now to Lindiwe's story: After observing that Lindiwe had gained weight, her mother sent her to the local clinic for a pregnancy test, after which she was also tested for HIV. Both tests came

back positive. While the pregnancy turned out to be a false alarm, her HIV-positive diagnosis stuck and she was soon initiated onto ART. When our team met her, however, we were told by her mother that she had not taken ART in over a year.

A few months into fieldwork, Lindiwe explained that although she knew she was HIV-positive, she did not believe it (field notes, October 20, 2013). She cited her misdiagnosed pregnancy as an indication that the nurses made up lies about her. In Lindiwe's mind, the clinic staff had not simply made a diagnostic error, but were responsible for a deliberate fabrication. Her misdiagnosed pregnancy, rather than being a faulty scientific reading, was, in her view, a personal indictment—a form of malicious gossip. This "HIV thing," she thought, was also a lie.

Lindiwe was indeed a source of much pernicious gossip in her village and she was well aware of this. A number of older women, including Lindiwe's teacher, had told us stories of her disobedience and sexual misconduct. For these elders, Lindiwe may have served as emblematic of a wider erosion of tradition and respect. Indeed, local etiologies of AIDS in South Africa have often attributed the misfortunes of AIDS to the widespread flouting of social norms, particularly by women and youth (Posel et al. 2007; Stadler 2003). "People think I don't respect other people," Lindiwe told us once (field notes, October 22, 2013). "Everyone is always blaming me."

As with the misdiagnosed pregnancy, Lindiwe treated her HIV-positive diagnosis as a hateful rumor, which she said the nurses had spread throughout the village. To reinitiate ART would therefore entail a form of admission—something that Lindiwe seemed to consider unacceptable.

Stigma and Transmission

Lindiwe's story also reveals how inferences about adolescents' mode of infection can shape the potency and distribution of HIV-related blame. Lindiwe was the only adolescent in her village support group who was presumed, by counselors, to have contracted HIV sexually. She was a contentious figure among adolescents in her support group. One of them, Thembakazi, said Lindiwe had "at least 10 boyfriends" (field notes, September 16, 2013). Siya, a young man in the group, told us that when they were both younger, and Lindiwe had not yet been diagnosed with HIV, he had had a crush on her. But after discovering that she was not a virgin, and therefore "not a real girl anymore," his feeling dissipated.

I was struck by how vehemently some perinatally infected youth seemed to stigmatize young women's sexuality. Doing this seemed particularly important for a young man like Siya, whose frail, scarred, and stunted body unsettled his performance of masculinity and had been a source of teasing. Unlike Lindiwe, Siya could not escape external readings of his body as a site of physical decay: He spoke of others in the village referring to him as a leper. To deflect recrimination, Siya sought to delineate his own bodily "degeneration" from the "moral degradation" of adolescents like Lindiwe.

A conversation we had with Khaya (age 18), also a vertically infected young man in the support group, is another useful example. Khaya remarked that many in his community were having sex "too young," and that consequently, teenage girls were getting pregnant. He worried about how public perception might draw links between HIV and forms of "deviant" behavior. "People think HIV is for those who

drink and have sexual activity," he said. He was concerned with showing others that he, and people like him, were different: that HIV "doesn't choose" (field notes, January 31, 2014).

Mothers, Daughters, and the Tactical Distribution of Blame

Inferences about adolescents' mode of infection had real social consequences for how they felt and managed HIV-related blame. But they also had implications for their families, and their mothers in particular. As a virus transmitted through blood and sex, HIV is ultimately relational. It implicates others. For the four adolescent girls to whom we give primary attention here, managing information about HIV was shared between mothers and daughters, who were both involved in its related secrets and disclosures.

For some mothers who were also living with HIV, the ambiguity of their daughters' mode of transmission seemed to prompt a worry that they would be held culpable for her diagnosis. When we asked Lindiwe's mother, Tina, how she felt on hearing her daughter's HIV diagnosis, she said: "I felt so bad because I always took her for [HIV] tests. Because I knew that she was born [HIV] negative. So I was quite disappointed in her" (interview, August 21, 2013). Tina thus deemed it important to clarify to us that she was not implicated in Lindiwe's result—that she was not responsible for transmitting HIV to her daughter.

I had no way of knowing whether or not Lindiwe had contracted HIV sexually. Tina told me, in her interview (August 21, 2013), that she herself had been diagnosed with HIV in 2003, five years after Lindiwe was born. This sat uncomfortably with her account of testing Lindiwe at birth.

In Yoliswa's HIV narrative, too, there seemed to be subtle strategies for redirecting assumptions about her mode of infection. When Yoliswa first shared the story of her HIV diagnosis, it was during a conversation alongside her mother, aunt, and cousin, only a few days after the birth of her baby girl. Every member of her household was on ART, including Yoliswa's newborn baby who was receiving Nevirapine to prevent vertical transmission. Yoliswa explained that she had first tested for HIV soon after discovering her pregnancy. Although she disclosed the pregnancy to her mother immediately, she said she delayed HIV disclosure for months, afraid of her mother's reaction (field notes, February 8, 2014). Later, Yoliswa told us that although she had been receiving the contraceptive injection prior to her pregnancy, she had missed a few appointments (interview, February 18, 2013). She further conceded that she had not used condoms prior to her HIV diagnosis. In her narration, then, Yoliswa seemed to suggest that she had contracted HIV sexually.

A month or so later (field notes, March 24, 2014), we accompanied Yoliswa and her baby to a clinic appointment. During the consultation, Yoliswa's nurse reviewed her medical folder. Scanning its pages, she announced that Yoliswa had defaulted on HIV treatment in 2011. This surprised us, since, as far as we knew, Yoliswa had only started HIV treatment in the past year, soon after she became pregnant. Reading the folder aloud, the nurse narrated that Yoliswa had presented at the clinic three years prior with scabies, shingles, and a persistent cough. She was subsequently tested for HIV and initiated onto ART. It was only recently that

Yoliswa had restarted treatment. Yoliswa was reportedly reinitiated onto ART at the hospital's antenatal site, where she had tested for HIV, despite already knowing her status.

Yoliswa had therefore re-presented herself at the antenatal site as an untested and untreated pregnant teenager. She appeared to have done this deliberately as a way to write over her past nonadherence, for which she would likely be admonished.

Yoliswa's recorded medical history had since unraveled her secret. After discovering that Yoliswa had been restarted on treatment after defaulting, the nurse's response to her changed to mistrust. By reading the folder aloud, the nurse began enacting a public reprimanding. The knowledge that Yoliswa had previously defaulted became doubly potent in light of her pregnancy. Yoliswa was given a long and stern talk about the importance of taking the pills on time. The nurse recounted stories of other "deviant" mothers whose defaulting had resulted in them transmitting HIV to their babies.

Up until this point, we had assumed that Yoliswa was sexually infected. Knowing that she had suffered AIDS-related illnesses years before her pregnancy muddied our assumptions.

During our next visit with Yoliswa, we asked again about the first time she tested for HIV. It was significant that on this occasion, neither her mother nor any other member of her family was present. While the nurse reported that Yoliswa's AIDS symptoms had mandated her first HIV test, in this revised account, Yoliswa said that she had tested as a responsible precaution. Yoliswa's decision not to directly challenge the nurse is located within a wider practice in which submission and deference to health authorities is considered a requisite for accessing care (Vale et al. forthcoming). Indeed, in a system where obedience is prized, adopting an attitude of silent compliance would do more work in salvaging Yoliswa's respectability than contesting the nurse's account.

As she expanded on her story, Yoliswa went on to explain that her mother had been HIV-positive while pregnant with her. Yoliswa had therefore suspected that she herself might have HIV. Having interviewed Yoliswa's mother about her own pregnancy, it was evident that this had been deliberately concealed from us. Since Yoliswa had been born years before HIV treatment became publicly available in Ridgetown, it was now apparent that she had most likely contracted HIV as an infant.

Given this new information, we were surprised that she had not been tested for HIV much earlier. There had evidently been a deliberate delay in finding out for certain whether Yoliswa had contracted HIV from her mother. This delay was made possible by the slow onset of Yoliswa's illness. After discovering her HIV status, Yoliswa had said she delayed disclosing her HIV status to her family, afraid of their reaction. Perhaps she was worried about how the implicit accusation that her mother had transmitted the virus to her would impede household conviviality. By disclosing her HIV status after her pregnancy and thus after she was known to be sexually active, the mode of infection was rendered ambiguous, possibly tempering the potential dangers for how an attribution of vertical infection might affect the mother–daughter relationship. In retrospect, Yoliswa must have been

working concertedly, during our initial meeting with her family, to position herself as sexually infected.

The uncovering of Yoliswa's perinatal infection recalled a conversation with Nokutula a few weeks earlier. While sitting together in a clinic queue, she told us that she and her mother used to collect their medication on the same monthly date. "My mom is also taking pills," she said, "for the same thing that I am taking" (field notes, March 7, 2014). Until then, we had not known that Nokutula's mother, Gugs, was HIV-positive. One of the reasons Gugs might have withheld her HIV status from us, despite an extended interview, may have been that this revelation would make it plausible that Nokutula had contracted HIV at birth.

The way Nokutula disclosed her mother's status might also be revealing. That her mother was taking the same pills as her could have been Nokutula's only clue to her mother's HIV status. Perhaps she and her mother had never spoken of their shared diagnosis directly, although we suspected there was at least tacit knowledge of this, given that they used to share the same pill collection date (field notes, March 7, 2014). "She takes the same pills I am taking" may also have been a euphemistic way for Nokutula to refer to her mother's HIV status, while still protecting her mother's reputation through discreet speech.

Nokutula's story gave rise to questions of timing—that is, when particular pieces of information are revealed. None of us knew for sure when Nokutula had contracted HIV. But because she was diagnosed after becoming sexually active, her mother was able to point to her boyfriend as the source of HIV. Indeed, after learning about Nokutula's HIV status, Nokutula's mother told her that her boyfriend would be the person she "got this [HIV] from." "She is not the child who dates everybody," we were told.

During her interview, Nokutula's mother, Gugs, warned us that her other daughter was not aware of Nokutula's HIV status. She explained that, although her two daughters got along, when they fought, Nokutula's sister was known to "bring out secrets." As an example, Gugs said she might say: "You're younger than me and now you're pregnant!" By virtue of her lack of discretion, Nokutula's sister was therefore deemed a threat to the sociality of the household.

After finding out Gug's HIV status, we wondered about the ways this knowledge was protected in the home. Would the revelation of Nokutula's HIV status also lead to her mother's HIV status being disclosed to her older sister? Whatever the extent of knowledge among the women in the household, much remained unspoken, or carefully guarded. Mothers and daughters seemed to appropriate a form of tacit knowledge in which information might be mutually known, but by virtue of not being spoken, was also tamed.

Preserving intergenerational mutuality may have been especially important for Nokutula and Yoliswa, whose children were being cared for by their mothers. By assuming blame for HIV, Yoliswa and Nokutula may have been guarding their mothers' status as household caregivers and moral authorities.

One might also consider the story of a grandmother in our study, who was taking ART alongside her orphaned grandchildren. To account for her HIV, she explained that before she had known how HIV transmission worked, she had done her grandchildren's laundry despite having cuts on her hands (field notes, September

13, 2013). This is how she said she contracted HIV. It was a very unlikely story, which would have been refuted in the many HIV education workshops she attended. Nevertheless, the narrative preserved her moral integrity and, relatedly, her credibility as a caregiver.

Blame and Care

Why have young women like Yoliswa and Nokutula worked so hard to protect their mothers' standing, particularly when it meant putting themselves at increased risk of opprobrium? Nduna and Jewkes's (2011) research with youth in the Eastern Cape suggests that many young people choose silence as a means to contain potentially hurtful or volatile situations in the home. In their study, discretion also served to demonstrate deference to elders, show gratitude for care, and protect mothers (in particular) from upset. Wood and Lambert's (2008) research in the Eastern Cape illustrated that knowledge about AIDS was kept tacit as a way of circumventing disrespect. Through omission or diversion in their HIV narrative, the adolescent girls under discussion here seemed to shoulder blame on their mothers' behalf. How might we understand this as a manifestation of particular ideals about the mother–daughter relationship?

Lindiwe's schoolteacher once commented that Lindiwe "gave her mother a hard time" by disappearing to "visit her boyfriends" (field notes, September 16, 2013). While Lindiwe's disappearances would certainly worry her mother, there seemed to be more to the teacher's statement: that Lindiwe's actions were inadvertently directed at her mother. "Many people think I love a man and don't love my mother," Lindiwe once lamented to me. "But I love someone that respects older people" (field notes, October 20, 2013), said Lindiwe, seemingly in an effort to affirm ideals of youth deference and respect.

The shame of Lindiwe's "out of control" sexuality, and the shared HIV status of mother and daughter, was felt both by Lindiwe and her mother. More so, shame seemed to stem from how this reflected on their mother–daughter roles: their ability to appropriately care for one another. Tina had delayed disclosing her HIV status to Lindiwe for seven years. When she first told Lindiwe, she had asked whether Lindiwe could "still love her" (interview, August 20, 2013). After her disclosure, Tina said her relationship with her daughter changed and they were not getting along. Lindiwe would regularly be away from home. When Lindiwe's mother found out Lindiwe was pregnant and HIV-positive, she was reportedly "very rude," threatening to no longer buy things for her. But she had also comforted Lindiwe, saying she could "live a long life" (field notes, September 4, 2013).

These simultaneous articulations of blame and care are significant. By coaxing their daughters into motherhood, and enforcing appropriate conduct, mothers reasserted idealized maternal roles, which may have been unsettled by their daughters' pregnancy and HIV diagnosis. Hence, by exonerating themselves from blame, subtly shifting blame to their daughters, mothers might also (paradoxically) be augmenting their ability to care for them. Meanwhile, by seeking their mothers' support and assuming a position of obedience, daughters might seek to salvage care and respectability amid recrimination. Throughout fieldwork, both Lindiwe and her mother were concerned with regularly insisting to us that they were trying to

improve their relationship: Lindiwe through obedience, and her mother through being strict.

Caring for young women, then, seemed to be wrapped up with bringing their sexuality to order and encouraging appropriate respect for elders. Lindiwe's mother, for example, described her sexual misconduct as symptomatic of Lindiwe's generation (field notes, August 20, 2013). Uncomfortably, boundaries between care and stigma might blur and merge. AIDS stigma has been characterized as a form of "psychological policing," in which "those who are seen to breach power relations of gender and generation are disciplined and punished" (Campbell et al. 2006). Hence, the apparently opposing orientations of stigma and care become interlaced with a similar social project—one of maintaining ascriptions of gender and generation.

We have already noted a growing literature that highlights the importance of euphemism, omission, and discreet speech as strategies for preserving respectability (Nduna and Jukes 2011; Rhine 2009, 2014; Wood and Lambert 2008). For the families under discussion here, adolescents' early pregnancy coupled with a discrediting virus posed an immense threat to the dignities of mothers and daughters alike. We suggest that, in these instances, the silences and euphemisms that both mothers and daughters adopted about adolescents' mode of infection have served to protect mothers from being held responsible for transmission. In doing so, these speech acts have reinforced maternal authority and child deference, creating the opportune environment to rebuild intergenerational care and respectability.

Conclusion

This article contributes to a small but growing qualitative literature about the experiences of HIV-positive adolescents in sub-Saharan Africa. This literature has explored secrecy and diversion as practices of care, through which adolescents and their families manage life with a discrediting illness. In this article, we suggest that inferences about adolescents' mode of infection, and not simply their HIV status, might ignite threatening possibilities for shame and blame within families, particularly for mothers and daughters. Tactically adopting particular narratives about adolescents' mode of infection worked to reassert respectable generational roles, and thereby cement relationships of care. Familial care was enmeshed with the preservation of adult virtue and the censure of young women's sexuality. These findings further our understanding of the social stakes entailed in adolescents' HIV diagnosis as well as the precarious contexts in which their social–moral needs are met.

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1. Slogans of the 2014 First Things First HIV-testing campaign in South Africa.

References

- Ainslie, A. 2014. Harnessing The Ancestors: Mutuality, Uncertainty and Ritual Practice in the Eastern Cape Province, South Africa. *Africa* 84: 530–52.
- Ashforth, A., and N. Nattrass. 2005. Ambiguities of "Culture" and the Antiretroviral Rollout in South Africa. *Social Dynamics* 31: 285–303.
- Bank, L. 2001. Living Together, Moving Apart: Home-made Agendas, Identity Politics and Urban–Rural Linkages in the Eastern Cape, South Africa. *Journal of Contemporary African Studies* 19: 129–47.
- Barolsky, V. 2003. (Over)extended. Pretoria. University of Pretoria: Centre for the Study of AIDS.
- Campbell, C., Y. Nair, and S. Maimane. 2006. AIDS Stigma, Sexual Moralities and the Policing of Women and Youth in South Africa. *Feminist Review* 83: 132–38.
- Campbell, C., M. Skovdal, and C. Madanhire. 2011. "We, the AIDS People...": How Does Antiretroviral Therapy Enable Zimbabweans Living with AIDS to Cope with Stigma? *American Journal of Public Health* 101: 1–15.
- Castro, A., and P. Farmer. 2005. Understanding and Addressing AIDS-related Stigma: From Anthropological Theory to Clinical Practice in Haiti. *American Journal of Public Health* 95: 53–59.
- Cluver, L., R. Hodes, E. Toska, K. Kidia, M. Orkin, L. Scherr, and F. Meinck. 2015. "HIV Is Like a Tsotsi. ARVs Are Your Guns": HIV-disclosure and Adherence to Antiretrovral Treatment among Adolescents in South Africa. *AIDS* 29: S57–S65.
- Cornell, M. 2013. Gender Inequality: Bad for Men's Health. Southern African Journal of HIV Medicine 14: 12–14.
- Daniel, M. 2014. Keeping the Secret: How HIV-positive Children in Iringa, Tanzania, Respond to the Perceived Need for Silence and Secrecy. *Journal of Child & Adolescent Mental Health* 27: 11–23.
- Denis, P. 2014. New Patterns of Disclosure: How HIV-positive Support Group Members from KwaZulu-Natal Speak of Their Status in Oral Narratives. *Medical History* 58: 278–97.
- Department of Health. 2013. National Antenatal Sentinal: HIV and Herpes Symplex Type-2 Prevention Study 2012. Pretoria. http://www.hst.org.za/publications/2013-national-antenatal-sentinel-hiv-prevalence-survey-south-africa (accessed June 10, 2015).
- Ferguson, J. 2013. Declarations of Dependence: Labour, Personhood and Welfare in Southern Africa. *Journal of the Royal Anthropological Institute* 19: 223–42.
- Ferrand, R. A., E. L. Corbett, R. Wood, J. Hargrove, C. E. Ndhlovu, F. M. Cowan, E. Gouws, and B. G. Williams. 2009. AIDS among Older Children and Adolescents in Southern Africa: Projecting the Time Course and Magnitude of the Epidemic. AIDS 23: 2039–46.
- Gilbert, L., and L. Walker. 2010. "My Biggest Fear Was that People Would Reject Me Once They Knew My Status": Stigma as Experienced by Patients in an HIV/AIDS

- Clinic in Johannesburg, South Africa. *Health and Social Care in the Community* 18: 139–46.
- Groves, A., S. Maman, S. Msomi, N. Makhanya, and D. Moodley. 2010. The Complexity of Consent: Women's Experiences Testing for HIV at an Antenatal Clinic in Durban, South Africa. *AIDS Care* 22: 538–44.
- Gurevich, M., C. M. Mathieson, J. Bower, and B. Dhayanandhan. 2007. Disciplining Bodies, Desires and Subjectivities: Sexuality and HIV-positive Women. *Feminism & Psychology* 17: 9–38.
- Hodes, R. 2013. The Medical History of Abortion in South Africa, c. 1970–2000. *Journal of Southern African Studies* 39: 527–42.
- Human Sciences Research Council. 2014. South African National HIV Prevalence, Incidence and Behaviour Survey 2012. Cape Town. http://www.hsrc.ac.za/uploads/pageContent/4565/SABSSMIVLEOfinal.pdf (accessed June 8, 2015).
- Kajubi, P., S. Bagger, A. Katahoire, D. Kyaddondo, and S. Whyte. 2014. Spaces for Talking: Communication Patterns of Children on Antiretroviral Therapy in Uganda. Children and Youth Services Review 45: 38–46.
- Kiwanuka, J., E. Mulogo, and J. Haberer. 2014. Caregiver Perceptions and Motivation for Disclosing or Concealing the Diagnosis of HIV Infection to Children Receiving HIV Care in Mbarara, Uganda: A Qualitative Study. *PloS One* 9: .e93276.
- Kunapareddy, C. J., W. Nyandiko, T. Inui, S. Ayaya, D. G. Marrero, and R. Vreeman. 2014. A Qualitative Assessment of Barriers to Antiretroviral Therapy Adherence among Adolescents in Western Kenya. *Journal of HIV/AIDS & Social Services* 13: 383–401.
- Kyaddondo, D., R. Wanyenze, J. Kinsman, and A. Hardon. 2013. Disclosure of HIV Status between Parents and Children in Uganda in the Context of Greater Access to Treatment. *Journal of Social Aspects of HIV/AIDS* 10: 37–45.
- Kyakuwa, M., and A. Hardon. 2012. Concealment Tactics among HIV-positive Nurses in Uganda. *Culture, Health and Sexuality* 14: 123–33.
- Lawless, S., S. Kippax, and J. Crawford. 1996. Dirty, Diseased and Undeserving: The Positioning of HIV Positive Women. *Social Science and Medicine* 43: 1371–77.
- Leclerc-Madlala, S. 2001. Demonizing Women in the Era of AIDS: On the Relationship between Cultural Constructions of Both HIV/AIDS and Femininity. *Society in Transition* 32: 38–46.
- Li, R. 2008. Growing up on HAART: The Experiences and Needs of HIV Positive Adolescents in Care and Treatment in the Western Cape Province of South Africa. M.Phil. Thesis, University of Cape Town.
- Li, R. J., H. B. Jaspan, V. O'Brien, H. Rabie, M. F. Cotton, and N. Nattrass. 2010. Positive Futures: A Qualitative Study on the Needs of Adolescents on Antiretroviral Therapy in South Africa. AIDS Care 22: 751–58.
- Lowenthal, E. D., S. Bakeera-Kitaka, T. Marukutira, J. Chapman, K. Goldrath, and R. A. Ferrand. 2014. Perinatally Acquired HIV Infection in Adolescents from Sub-Saharan Africa: A Review of Emerging Challenges. *The Lancet* 14: 627–39.
- Macleod, C. 2003. Teenage Pregnancy and the Construction of Adolescence: Scientific Literature in South Africa. *Childhood* 10: 419–37.
- MacPhail, C., A. Pettifor, W. Moyo, and H. Rees. 2009. Factors Associated with HIV Testing among Sexually Active South African Youth Aged 15–24 Years. *AIDS Care* 21: 456–67.
- Mandalazi, P., C. Bandawe, and E. Umar. 2014. HIV Disclosure: Parental Dilemma in Informing HIV Infected Children about Their HIV Status in Malawi. *Malawi Medical Journal* 26: 101–4.

- Mburu, G., I. Hodgson, S. Kalibala, C. Haamujompa, F. Cataldo, E. D. Lowenthal, and D. Ross. 2014. Adolescent HIV Disclosure in Zambia: Barriers, Facilitators and Outcomes. *Journal of the International AIDS Society* 17. http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3956312&tool=pmcentrez&rendertype=abstract (accessed June 22, 2015).
- Mills, E, and B. Maughan-Brown. 2009. Ties that Bind: HIV Disclosure as a Consequence and Catalyst of Stigma and Support in Households. In CSSR Working Paper, Vol. 266. University of Cape Town: Centre for Social Science Research.
- Mkhwanazi, N. 2010. Understanding Teenage Pregnancy in a Post-apartheid South African Township. *Culture, Health and Sexuality* 12: 347–58.
- Nduna, M., and R. Jewkes. 2011. Silence: A Strategy to Deal with Psychological Distress by Young People in the Eastern Cape, South Africa. *Vulnerable Children and Youth Studies* 6: 360–72.
- O'Reilly, M., and L. Washington. 2013. Young Women from Informal Settlements Report on Their Experiences of Accessing Sexual and Reproductive and Other Health Services from Clinics. *Agenda* 26: 126–38.
- Okoror, T., R. BeLue, and N. Zungu. 2014. HIV Positive Women's Perception of Stigma in Health Care Settings in Western Cape, South Africa. *Health Care for Women International* 35: 27–49.
- Posel, D., K. Kahn, and L. Walker. 2007. Living with Death in a Time of AIDS: A Rural South African Case Study. Scandinavian Journal of Public Health 69: 138–46.
- Rhine, K. 2009. Support Groups, Marriage and the Management of Ambiguity among HIV-positive Women in Northern Nigeria. *Anthropology Quarterly* 82: 369–400.
- Rhine, K. 2014. HIV, Embodied Secrets, and Intimate Labour in Northern Nigeria. *Ethnos* 79: 699–718.
- Shisana, O., T. Rehle, L. C. Simbayi, K. Zuma, S. Jooste, N. Zungu, D. Labadarios, and D. Onoya. 2014. South African National HIV Prevalence, Incidence and Behaviour Survey, 2012. Cape Town: HSRC Press.
- Shepherd, B. L., R. Ferrand, S. Munyati, S. Folkard, K. Boyd, T. Bandason, S. Jallow, S. L. Rowland-Jones, and L.-M. Yindom. 2015. HLA Correlates of Long-term Survival in Vertically Infected HIV-1-positive Adolescents in Harare, Zimbabwe. AIDS Research and Human Retroviruses 31: 504–7.
- Snyder, K., M. Wallace, Z. Duby, L. D. H. Aquino, S. Stafford, S. Hosek, D. Futterman, and L.-G. Bekker. 2014. Preliminary Results from Hlanganani (Coming Together): A Structured Support Group for HIV-infected Adolescents Piloted in Cape Town, South Africa. Children and Youth Services Review 45: 114–21.
- Stadler, J. J. 2003. Rumor, Gossip and Blame: Implications for HIV/AIDS Prevention in the South African Lowveld. AIDS Education and Prevention 15: 357–68.
- Todd, J., M. Mahy, and P. Byass. 2014. Editorial: Measuring HIV-related Mortality in the First Decade of Antiretroviral Therapy in Sub-Saharan Africa. *Global Health Action* 7: 2.
- Toska, E., L. Cluver, R. Hodes, and K. K. Kidia. 2015. Sex and Secrecy: How HIV-status Disclosure Affects Safe Sex among HIV-positive Adolescents. AIDS Care 27: 47–58.
- Vale, B., and M. Thabeng. 2016. Redeeming Lost Mothers: Antiretroviral Treatment and The Making of Home among Adolescents in South Africa's Eastern Cape. Medical Anthropology. DOI 10.1080/01459740.2016.1145218

- Vale, B., M. Thabeng, R. Hodes, and L. Cluver. Forthcoming. Bureacracies of Blood and Belonging: What Documents Tell Us about the Relationship btween HIV-positive Youth and the South African State. *Development and Change*.
- Walker, C. 1995. Conceptualising Motherhood in Twentieth Century South Africa. *Journal of Southern African Studies* 21: 417–37.
- Wood, K., and H. Lambert. 2008. Coded Talk, Scripted Omissions: The Micropolitics of AIDS Talk in South Afssrica. *Medical Anthropology Quarterly* 22: 213–33.
- Young, S., M. Mbuya, C. Chantry, E. Geubbels, K. Israel-Ballard, D. Cohan, S. Vosti, and M. Latham. 2011. Current Knowledge and Future Research on Infant Feeding in the Context of HIV: Basic, Clinical, Behavioural, and Programmatic Perspectives. Advanced Nutrition 2: 225–43.