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“Not Taking it Will Just be Like a Sin”: Young People Living with HIV and the Stigmatization of Less-Than-Perfect Adherence to Antiretroviral Therapy

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ABSTRACT

Global health priorities are being set to address questions on adherence to HIV antiretroviral therapy in adolescence. Few studies have explored young people’s perspectives on the complex host of social and relational challenges they face in dealing with their treatment in secret and their condition in silence. In redressing this, we present findings from a longitudinal qualitative study with young people living with HIV in the UK, Ireland, US, and Uganda, embedded within the BREATHER international clinical trial. Drawing from Goffman’s notion of stigma, we analyze relational dynamics in HIV clinics, as rare spaces where HIV is “known,” and how young people’s relationships may be threatened by non-adherence to treatment. Young people’s reflections on and strategies for maintaining their reputation as patients raise questions about particular forms of medicalization of HIV and the moralization of treatment adherence that affect them, and how these may restrict opportunities for care across the epidemic.

KEYWORDS

Adolescence; HIV; treatment adherence; qualitative; stigma

Well over seven million young people (three million children (0–15); two million adolescents (10–19); and four million young people (15–24)) are living with HIV worldwide, most of whom have acquired HIV through vertical transmission (WHO 2014). The survival of HIV-positive children into adolescence and adulthood is a fairly novel phenomenon, and with global HIV treatment coverage with antiretroviral therapy (ART) currently reaching about 23 percent of children and adolescents who need it, adequate access and adherence to treatment are central to sustaining these developments (UNAIDS 2015). Yet, young people who have access to care face a host of complex challenges (Bernays et al. 2014). Existing literature covers the scale of adherence problems in this population (Kim et al. 2014; Hudelson and Cluver 2015), interventions to address these (Mavedzenge et al. 2014), and caregivers’ views about managing young people’s knowledge about their HIV status and their adherence to medication (Vreeman et al. 2013). Much less is known about young people’s own perspectives about growing up with HIV and on ART.

Psychological and neurocognitive theories suggest that young people have a developmental tendency to experiment and to take risks (Jessor 1991; Arnett 2000). These theories have been taken up in global public health literature grappling with the health-related behaviors of young people growing up with chronic illnesses such as HIV (Valencia and Cromer 2000; Koenig et al. 2010). This can have the effect of casting aspects of young people as inherently problematic, an approach which is compounded by an increasing focus on the management of HIV as a chronic condition like “any other” (Moyer and Hardon 2014) and on individual responsibility in the context of HIV treatment and transmission more generally (Paparini and Rhodes 2016). There is thus a risk that a notion of *irresponsibility* as an inevitable feature of youth is

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reproduced in research and policy, as well as in the attitudes of caregivers and clinicians (Kawuma et al. 2014).

Against the background of children and young people's active and often resilient agency in the context of HIV (Skovdal and Daniel 2012), there remain many social and material constraints shaping their health behaviors (Bernays et al. 2014). The contextual and relational nature of the "choices" young people living with HIV can make with regard to their treatment, however, remains in need of both delineation and emphasizing. This is particularly the case when peer support, otherwise highly valued for its benefits (Mupambireyi et al. 2014), is limited.

As with adults, there is an inherent paradox between the individual responsibilities demanded of young people for management of a condition such as HIV and the reality of the limits to agency in the context of health practices (Paparini and Rhodes 2016). Such limits shape adherence to ART, as it simultaneously takes on an increasingly central role in HIV prevention and care efforts (Nguyen et al. 2011). Recognizing the interplay of social and relational factors that characterize youth in the epidemic more broadly is thus key to understanding what adherence and non-adherence may look like, day-to-day, for young people living with HIV and on ART.

In this article, we present findings from a longitudinal qualitative study with young people (age 10–22) living with HIV in Uganda, US, UK, and Ireland embedded within an international HIV clinical trial (BREATHIER (Penta 16) Trial Group 2016), and we analyze young people's narratives of treatment adherence negotiations and revelations in clinical encounters. Drawing from Goffman's notions of stigma (1963), we argue that a need to avoid "spoiling" relationships with clinicians in pediatric HIV care, coupled with standardized clinical framings of ART adherence, binds young people in dilemmas about what can and cannot be discussed with regard to their condition and therapy, in ways that both mirror and differ from those of adults.

Background

Adherence in HIV: Adults and young people

Structural, social, community, and individual level barriers influence adherence across adult populations and settings (Underwood et al. 2014). Social aspects of adherence in adults, relevant to our understanding of children and young people's adherence, include relational dimensions of HIV status disclosure and HIV (Katz et al. 2013). Unique characteristics, however, set many young people apart from others living with HIV, because of their medical history and their social status as "youth," limiting the relevance of most research on HIV and ART adherence.

Firstly, children growing up with HIV and on ART have often been taking treatment for some years and face a lifetime of ART. Their therapeutic and clinical history can be complicated as they are likely to have experienced illness in early childhood (Bernays et al. 2014). Secondly, young people's agency takes shape within the boundaries of what is socially, culturally, and morally consented by adults: young people's responses are both curtailed by relational circumstances inside and outside the household and strategic in the performance of these relations across different spaces and settings (Mattes 2014; Vale and Thabeng 2016). Although adults are similarly subjected to social pressures, including because of the widespread stigmatization of HIV, what children and young people can say or do about HIV and ART is further restricted by those around them, because of an age-specific lack of decision-making capacity in many key areas of life, for example, their living arrangements, and legal and economic dependency.

Silences about children's status as people living with HIV are a common feature of growing up with HIV across settings (Kajubi et al. 2016). Such silences persist even after young people have been "disclosed" to, although many young people grow up unaware of their HIV status (Vreeman et al. 2013). Silence often covers the circumstances of their infection and their biological parents. Young people's HIV status may be kept hidden from other close family members, including those with whom they live. Silence might also be encouraged, with young people told not to "think about HIV," discouraged from asking questions, and advised against disclosing to friends, schoolmates, or anyone

else. And silence may be a characteristic of their time in clinical care, where they are rarely spoken to directly or invited to ask questions (Newman et al. 2016).

Such a spectrum of silence has different roots, which include protecting young people and families from social ostracism, distress, and the potential for unnecessary worry (Kajubi et al. 2016). Yet it also has ramifications, for it situates the clinic as a challenging yet unusual space where young people's HIV is, and can be, known. The predominance of medicalized framings of living with HIV feature in adult HIV experience (Squire 2010), but the centrality of clinical relationships from early childhood, may make it harder for young people than adults to imagine a different version of life with HIV, not least when they cannot remember a life unaffected by illness. For those who cannot access peer support, there may be further limits to their capacity to fully explore the implications of their condition and what HIV means for their social and not only their "pharmaceutical" lives (Biehl 2007).

The stigmatization of young people's non-adherence

Conscious of the multi-leveled conceptual dimensions of the notion of stigmatization, and the complexity of defining this process (Link and Phelan 2001; Parker and Aggleton 2003), here we focus on the relational aspects in Goffman's analysis of stigma (1963). Goffman presents stigma as an attribute applied to those who do not meet the definition of "normal" in a given social context. Stigma arises from the lack of congruence between the expectations of what is normal and the particular characteristics of individuals. Importantly however, Goffman points out that stigma is better described by the "language of relationships" (1963) rather than attributes and that the nature of stigma is thus interactive. Stigmatization is therefore the manner through which difference is noted and devalued, via which people's identity is "spoiled."

A growing number of studies have explored the processes and impact of direct and indirect HIV-related stigmatization in the lives of young people living with and affected by HIV. This work concentrates on the effects of direct stigmatization in the social environment (experienced by young people when others come to know their HIV status in those environments where they socialize) (Abadía-Barrero and Castro 2006; Mattes 2014); on indirect stigmatization leading, for example, to lack of disclosure to young people of their status, or lack of HIV testing and care access (Daniel 2015; Kajubi et al. 2016); and on the impact of stigmatization on young people's onward disclosure of HIV status (e.g., to sexual partners) (Busza et al. 2013). Much of this research suggests that young people tend to not disclose their status to anyone outside the household or clinic. As a site where HIV status is already known, where it is not secret, the latter is thus of particular interest to explore whether stigmatizing processes might manifest in ways other than in reaction to, or anticipation of, revelations or disclosure of HIV status itself.

We thus purposefully apply Goffman's notion of stigma as relational to the experiences of young people living with HIV as part of their clinical encounter. These clinical encounters involve unique "performances of deservedness" (Bernays et al. 2010) and patients might commonly "edit" what they discuss with their clinicians to match what they understand is expected (Paparini and Rhodes 2016). Clinical encounters, as critically defining moments in identity formation, may be particularly significant in youth (Newman et al. 2016).

In this article, we propose that young people's "less-than-perfect" adherence to ART is one of the ways children and young people experience stigmatization in the very rare places where their HIV status is known, because missing doses represents a deviation from the biomedical rationality of compliance to ART. We foreground the broader medicalized and moralized framing of HIV and of ART adherence first and then focus on contextualizing how young people interpret, rationalize, and strategize their relationship with antiretroviral medication and with their clinicians.

Methods and settings

This was a longitudinal qualitative study embedded in, but independent of, the BREATHER clinical trial (BREATHER (Penta 16) Trial Group 2016). The primary objective of the BREATHER

randomized, non-inferiority clinical trial was to determine whether or not efavirenz-based ART in short cycles of five days on and two days off (short-cycle therapy; SCT) was as efficacious in maintaining virological suppression as continuous efavirenz-based ART (continuous therapy; CT) in young people living with HIV aged 8–24 years. In total, 199 young people were enrolled between 2011 and 2013 from 11 countries, with 70% of all trial participants recruited from a single center in Uganda. Our study aimed to explore young people's experiences of being in the trial, the SCT intervention, and ART adherence more broadly (Bernays et al. 2017).

All young people recruited into the BREATHER trial sites in the UK, Ireland, Uganda, and the US aged 10–24 years were eligible to participate in the qualitative study, subject to the appropriate consents and self-awareness of HIV seropositive status for at least 6 months. We intended to adopt a purposive sampling strategy (with primary emphasis on sole, shared, or carer responsibility for medication, and secondary dimensions of age, gender, ethnicity, membership of HIV youth support groups, current living arrangements, and school attendance). Yet given the low levels of recruitment into the clinical trial in the UK and Ireland, we involved anybody who was eligible and willing to participate. We adopted the same strategy in the US, given the timing of the fieldwork. In Uganda, we adopted a similar recruitment strategy and then purposively selected the last 10 young people in our sample. Overall, 102 interviews were conducted with 43 young people: 26 in Uganda from one clinic (Kampala), seven in the UK and Ireland from three clinics (London, Nottingham and Dublin), and 10 in the US from one clinic (Memphis, TN). All clinics were urban centers, widely regarded as national “centers of excellence.” They had a good staff-to-patient ratio and are well funded and in the UK and Ireland always offer free treatment at the point of care. The clinics in the US and UK were mixed pediatric services, often providing care for children living with HIV alongside other conditions. The Uganda clinic was a pediatric service within a specialist HIV hospital.

Almost half of eligible trial participants agreed to take part in the qualitative study and the majority remained engaged with the longitudinal design and subsequent interviews. The majority of refusals occurred in the UK and Ireland, where very few participants had previously taken part in qualitative research and were uncomfortable with the idea of the qualitative interviews. Others mentioned not wanting to take on any additional clinic attendance and time commitments.

We interviewed young people at repeated times during the trial, for approximately 1–2 hours per interview. Baseline interviews covered life with HIV on ART as described by young people and included, but did not focus specifically on, young people's perceptions of the trial or of SCT. The second interview reconstructed the life and treatment trajectory of participants since the start of the trial, focusing on adherence and their reflections on intervention and trial acceptability. The third interview, conducted so far only in Uganda, was conducted as participants moved into the follow-up stage of the clinical trial and explored changes in their relationships with their treatment and their attitudes toward continuing in the intervention or control arm.

The qualitative study received all necessary ethical approvals in each site. Interviews were audio-recorded, subject to consent, and assent (for 10–17 year olds) from all eligible participants and their caregivers. We treated informed consent as a process, reminding participants at each stage what the qualitative study was about, answering any related questions, providing information and reiterating that participants could withdraw at any time.

Extensive field notes were also collected by all researchers for each meeting, describing the encounter between researcher and participants, interview environment, and conversations prior and after the interview. Observations were also carried out at trial-related events, including study meetings and dissemination of trial findings in the clinic. Collected data were transcribed verbatim and, when appropriate, translated into English by researchers, with personal identifying details removed. We adopted a grounded analytic approach to thematic analysis, using systematic case comparison and negative case analysis throughout. We orientated analyses by themes emerging within/across individual accounts, exploring the acceptability of the trial; the potential value of SCT; and barriers to adherence as it converges with changing priorities during adolescence. In line with our iterative approach, we analyzed data as we collected it to inform the direction of subsequent interviews, further coding and case selection.

We maintained an audit trail of the analytical process, including analytical memos, field notes and how case comparisons and attention to emerging “negative” cases has informed ongoing analyses.

We conducted analysis by site and across the study sites to identify if gender, age, and country were significant, and so the value of disaggregation, but we found little difference. Instead, we found surprising similarities in young people’s narratives. They spoke in different ways, with participants at the older end of the scale being more confident in articulating their stories, yet neither age nor gender significantly altered the content but only the delivery of their narratives. For example, in the younger age groups, the explanations about why they had missed doses of ART fit the same pattern as the older ones, although not expressed with the same directness or with reference to clinical outcomes such viral load counts, which the younger children may not have been aware of. We also observed consistency across accounts when analyzing the different (low and high-income) settings. We reflect on these notable similarities throughout this article.

Themes

“A conversation from nowhere”: Silences and medicalization

For most study participants, the clinic and household were the only places where their HIV status was known to others. Secrecy not only limited the scope for discussions about HIV with peers, but also the content of any “HIV-talk.” Paradoxically, the profoundly social and collective dimensions of the silences that surrounded their HIV status granted young people little space to talk about how HIV affects them socially. Most had little opportunity to articulate the social implications of growing up with HIV often from when they first were told that they were living with the virus. This was the case for participants in all research sites, even if the threads that made up such silences followed different personal, household, and community HIV biographies.

Both in the home and clinic, HIV was discussed predominantly or exclusively in relation to its irreversible, life-long management via treatment. Young people were told to take their antiretroviral drugs. The social circumstances that might surround treatment taking, such as very common concerns about being seen by others when doing so, and the challenge of sticking to a daily and potentially restrictive therapeutic routine for life, were rarely discussed. The newly discovered condition was thus simultaneously and implicitly made into a medical and silent issue, and with no further mention of other effects, it could have on young people’s present and future:

My mum made me have a day off school ... I was 12 or 13 ... and she gave me this leaflet and she said I’d got it. And that’s basically how she told me.

Q. What did the leaflet say?

It said AIDS/HIV.

Q. And had you ever heard of it?

Yeah ... Because the school tells you all about it in science, they tell you all about the sexual intercourse and stuff.

Q. So when you read the leaflet what did you think it meant for you?

I don’t know because I didn’t know what it meant at the time ...

Q. And did you chat about it with your mum?

No. You just felt like OK there’s a leaflet here, this is what...And I read through the leaflet (Jade, UK&I, 15 years old, Continuous Therapy arm).

As they became used to living with a silenced and medicalized condition, young people interpreted that, outside of ART and adherence, there was little interest in addressing how HIV could impact their lives, thus little accommodation for discussing this:

When I am with mother I talk about the drugs ...

Q. What do you talk about?

When mother has forgotten I ask her what the time is and if I should take the drugs? And she tells me the time. And sometimes when mother is not around I ask father.

Do you also usually talk about drugs with your father?

Yes.

Q. What about talking about HIV?

We don't talk about it.

What about with your mother, do you usually talk about HIV?

No. (Asher, 11, Uganda, Short Cycle Therapy arm)

Silencing of HIV outside of the medical frame fostered the idea that HIV issues and ART issues were separate parts of their lives. The social reasons for non-adherence, for example, how maintaining their therapy and status secret might compete with other activities, wishes, and longings, were not legitimate challenges of which to speak of:

I have had a lot of thoughts of not wanting to be positive anymore, sometimes I even cry at night. But it never even crossed my mind that I wasn't going to take my medicine for this day or the next day or even a couple of days, because I knew what that medication was doing for me. (Ronny, 22, US, Short Cycle Therapy arm)

Young people learned to hold back questions, beyond what may be customary restrictions on intergenerational talk in different settings (Meinert 2009). This became apparent in instances, across the research sites, when young people brought questions to the researchers and, when encouraged to pose such questions to carers or clinicians, reported not having done so in the subsequent interview.

These questions related to fundamental aspects of their past, current, and imagined future lives: Will they be able to engage in relationships now or in the future? Will they be able to have children without passing the virus on? How did they, or their parents, come to live with HIV? Should they discuss their status with their friends when their parents had forbidden this? Clearly not all participants were in the same predicament, yet despite age, gender, and the degrees of support available to them in the clinic, such questions arose in interviews in all settings. "HIV talk" was a possibility during the interview but did not translate as an option outside of that space.

While in interviews, young people spoke of substantial struggles to work out how to deal with HIV, the lack of questioning from young people in the clinic fed into an impression that they had no concerns on their mind. An appearance of lack of interest on the part of young people was in many ways produced by their limited HIV "discursive environment," a function of the few kinds of conversations about HIV they had been taught, or allowed, to have. Many of our participants stated that they did not wish to talk about HIV if avoidable, while also describing the complex emotions that they mostly coped with on their own. In the absence of an initiation of talk in the clinic or the home, unable to start "a conversation from nowhere" (Kitty, 18, Uganda, CT), and wishing to spare themselves (and perhaps others too) the "awkwardness" of "HIV talk," they would rather remain quiet:

No I haven't spoken to my psychiatrist since [finding out HIV status] ... I just left it at that, because she talked to me and then she said, any questions about that? No, just left it at that.

Q. Did you talk about it with your mum?

No.

Q. So you've never spoken about it with your mum?

No.

Q. Would you like to?

No.

Q. Why not?

Because I don't like having awkward moments with my mum, it's kind of awkward and that's why I don't really speak about it. (Lenny, 12, UK&I, Short Cycle Therapy arm)

A lack of any HIV talk that was not ART talk also meant that clinical metaphors often framed participants' narratives of HIV, firmly setting the boundaries of young people's external descriptions and internal understanding:

I didn't mind [when uncle told him his status] because I didn't understand and I saw it as any other usual illness.

Q. Do you now understand what it means to have HIV?

Yes.

Q. What does it mean for one to have HIV?

That they will die if they don't take their drugs. (Asher, 11, Uganda, Short Cycle Therapy arm).

The impact of this framing of “HIV-as-ART” was not only normalizing but also normative, in that it reduced their overall experience to a question of pills and blood counts, while other social aspects of their illness remained unfathomable. This could be compounded by the effort to keep their HIV status secret:

I’m cool, it’s not a big thing. Because the way I see it, it’s one tablet a day, one paracetamol ... It’s just one pill a day, but it’s hard to say, because it does buzz around your head a lot. It goes to the back of your head, but something as small as like a sex joke will bring it straight back up and it’s buzzing around. (Mario, 17, UK&I, Short Cycle Therapy arm)

Moralized “ART talk” in the clinic

Despite a context of silence, the medicalized normalization of HIV-as-ART did not proceed in a vacuum, but instead was accompanied by an intensely moralized tale pivoting on a responsibility to adhere to ART. Underpinning this responsibility was the relationships between young people and their clinicians and caregivers. Although we are conscious of the interconnections within such networks of adults, some also enmeshed in care provider–patient relationships, here we wish to focus here on young people’s feelings toward healthcare workers to provide more depth about the clinic context.

Beyond a sense of duty toward the clinical trial they were participating in, which required specific adherence behaviors, participants more broadly discussed a responsibility to maximize the treatment opportunities afforded to them by the clinic (see Bernays et al. 2016). By and large, their accounts were marked by statements of gratitude for the medical care they received, which pervaded interviews across all sites regardless of variations in the availability and culture of healthcare provision in such diverse income settings:

I love [doctor’s name], I feel like he is my dad and aunt [counsellor’s name] is my mum, I feel she’s my mum. (Kitty, 18, Uganda, Continuous Therapy arm)

Even within these intimate personal relationships with healthcare workers, the social nature of relational dynamics surrounding adherence outside the clinic tended to remain un-articulated once in the clinic:

I went a whole month without taking it, because at that time ... I guess I can say I was going through some things so it was really hard.

Q. Could you tell me what was going on that made you not want to take it for a month?

I was having some issues at home... some problems, and I guess, no, I was frustrated, stress, all of the above. (Omar, 21, US, Short Cycle Therapy arm)

Though multiple factors impinged on adherence, the emphasis was instead continuously placed on adherence as an individual moral endeavor, a personal duty, and “choice.” Yet for our participants, their own non-adherence was a betrayal of relationships that were central to how they had come to understand themselves through their time in clinical care. The clinic had become a place of discipline, exerted through a spectrum of moralized talk that ranged from harsh scolding and threats (e.g., to be “chased out” from the trial or the clinic) to subtle yet judgmental commentary, both forms of stigmatization of non-adherence. With limited ways to respond, participants such as Kitty, who saw her clinicians as “parents,” even rationalized that scolding was the best way to show her care:

I needed someone to get harsh on me. Like doctor [name] would say ‘take your drugs’. Doctor [name] cares a lot. I thought she was abusing me. Yet I was old enough so they also need to be told this is your life. You need to blame them [the patients] and ask them ‘why don’t you take your drugs?’

Participants in all study settings were well aware of the risk of “spoiling” their identity through admissions of non-adherence. Some experienced scolding and reproach, witnessed it, and expected it. Healthcare workers regularly warned against non-adherence, described others who had “failed” to be “responsible” with their therapy, or admonished them when found to not adhere to ART. And so,

they kept their missed doses quiet, creating a cycle of adherence problems that could not be addressed.

Harsh responses were particularly common for young people in Uganda. Yet in all settings, even when discipline was not strict, many young people felt deeply ashamed if they missed ARV doses and worried about disappointing their health care teams. The lack of acknowledgement of young people's social challenges to adherence was an often unintentional but powerful form of disciplining.

In all cases and settings, young people's narratives were shaped by understandings of treatment-taking as "right" and not taking treatment as "wrong," not only in the medical sense in terms of their health, but also in the moral sense whereby non-adherence was tantamount to a "sin":

I just take it [ART] because I know I have to, and not taking it will just be like a sin. I've just been given the treatment to cure myself and then not taking it must be wrong. (Rob, 15, UK&I, Short Cycle Therapy)

If they had not been taking their treatment, even within young people's quiet internal thoughts ("in my head it feels like a taboo..." (John, 17, UK&I, SCT)), moral sanctioning resulted in dilemmas about who and what to tell. By far, they preferred not to tell anyone, to avoid feeling even more ashamed of their own failure, an experience made "singular" by a general lack of peer support and a lack of acknowledgement of the widespread challenges of living with HIV and ART:

Yeah, it [talking about missed doses] is a bit tough. I suppose 'specially to tell family and maybe the consultants themselves as well which you think they care about you so much and if you tell them that you've missed your dose they might think that you're giving up on yourself and I don't care anymore. (Brad, 17, UK&I, Continuous Therapy arm)

Feelings of failure were not necessarily the result of direct reproach, but were interpreted from the silence about potential adherence challenges, and the fears young people projected onto such silence:

I'd hate for them to think that I'm irresponsible even though I know they're not going to react like, oh, you [expletive], they're not going to say all of that, but it's just I get anxious and think that they're thinking, 'oh, he's so irresponsible'. That's just me. If you ask me, 'have you been taking your medication?' you know you're not going to say anything. You know you're not judging me. But me I'm going to think that you're thinking, 'oh, he's so irresponsible, I hate this guy' (Mike, 20, US, Continuous Therapy arm)

Our data suggest that participants understood well how to take treatment and were aware of the potentially serious repercussions to treatment interruptions. But such knowledge was not always sufficient to equip them with tools to manage the different challenges to adherence they encountered. Stigmatization does not need to be explicit to exert pressure. In the context of missed doses and treatment problems, some young people approached the clinical encounter with anxiety rather than as an occasion for care and support.

The truth economy

Participants only elected to tell us about treatment problems and missed doses in interviews once reassured that this was a "safe" setting to do so. Yet when they did discuss these issues, it was at great length and in a lot of detail. Their behavior fell into three broad categories: First, there were very few cases of young people reporting that they had never missed any doses; second, a small number discussed having stopped treatment for a month or more (though significant adherence problems were always described as having occurred in the past); and third, the majority of participants reported occasionally missing one or a few sequential doses and/or taking pills earlier or later than the prescribed time.

However, as they saw any admission that they had not kept to "exemplary adherence" standards as falling short of expectation, they negotiated a form of "truth economy," a practice of managing partial secrets and revelations about their own treatment taking in order to maintain relationships in the clinic and avoid "spoiled" patient identities. The core strategy was to "keep it quiet" in the clinic:

Q. And when you come here [clinic] ... What do they ask you?

'Oh how are you? How's your medicine doing?' And I go, 'yeah it's good'. That's the questions they ask.

Q. And when things weren't going well, did you still give the same answers?

Yeah because it's kind of awkward if I say, 'oh I haven't took my medicine', it's kind of awkward saying that to a doctor.

Q. Tell me why.

Because the doctor thinks you're taking it but it's actually not, you're not taking it.... They'd probably go on a speech saying, 'you have to take it, do that, do this'.

Q. Do you think that would make any difference?

No it won't make a difference from my point of view ... they'll say 'you have to take it, it's good for you' and if you don't tell them you can keep it quiet, they don't ask no questions. (Lenny, 12, UK&I, Continuous Therapy arm)

The majority of the young people found it hard to admit to problems with ART unless it was to someone who they trusted and would be compassionate. Maya advised how healthcare workers should treat young people to encourage them to disclose non-adherence:

Let the healthcare workers handle them patiently. Leave them, let them be what they want to be. And slowly by slowly ask them. You have to be patient with a patient; you ask them in a manner that is so humble. (Maya, 21, Uganda, Short Cycle Therapy arm)

Some did tell their clinicians about episodes of non-adherence because they had been "caught," for example, through pill-count monitoring or diagnostic tests. In such cases and for those young people who told clinicians voluntarily, the "real story" was nonetheless often edited to something they perceived to be less shameful. It is of course possible that such editing was also happening in their interviews with us, a point to which we will return later.

Viral monitoring, legitimate slippages, and "getting caught"

Blood tests were often approached with trepidation, as these were means by which any missed doses might be identified. Therefore, participants were relieved when their viral load (in particular) had come back undetectable or unchanged, when they had missed doses:

I'm really scared of disappointing them and making them upset so sometimes I will have times ... where I wouldn't say anything especially if I know it's more than the usual ... I'm scared of getting caught up in my lie and saying 'oh, well, I haven't missed any this month' and my VL and my CD4 comes back terrible, you know? (Mike, 20, US, Continuous Therapy arm)

However, the relief of an unchanged viral load also reinforced their notion that there was no need to tell anyone about any challenges with treatment:

I try not to hide anything, it's just that I probably feel like a smidge ashamed.... It hurts me to hurt or disappoint anyone so that's where the shame and the worry of telling somebody comes from ... I have told them if they asked, but if they didn't ask then and I find out my viral load was undetectable then I just let out a sigh of relief and just keep going. (Eddy, 22, US, Continuous Therapy arm)

Thus, participants relied on monitoring to pick up any problems rather than initiate a discussion about it and avoided seeking help if their blood tests indicated that no help was needed. This behavior could be especially problematic for those in resource-constrained settings who would not routinely have access to such tests outside of the clinical trial.

Participants deciphered what they felt could be safely "recounted" in the clinic. They sought to align their stories with legitimate scripts that could help rationalize their "personal deviation" from expected ART behavior. For example, they described what they perceived to be an acceptable amount of missed doses and talked about the number of pills they considered safe "enough" to miss, at least without telling anyone. Most young people appeared to have settled for the safety of an amount of "two"—two consecutive doses, two days, twice a week, or twice a month:

If I miss one then I might not say nothing, but if I've missed two then I'm like, 'hey, I missed two out of this, that month'. (Omar, 21, US, Short Cycle Therapy arm)

In the case of the BREATHER trial, this use of 'two' likely came from the research testing the safety of skipping two days of treatment out of seven in the intervention arm. Participants then applied this metric to skipped doses in general, whether before or during the trial, and regardless of the arm to which they were randomized:

Since I learnt about my status I only miss unintentionally and I resume. But I cannot miss for three consecutive days; it is possible to miss two days (Jana, 12, Uganda, Short Cycle Therapy arm)

Even though in most cases young people still kept quiet, they did at times talk about having skipped doses if they could ensure there were "extenuating circumstances":

Q. Have you ever missed to take your drugs?

Yes I have ... We went for a school trip that was a week long and remember we were many including my friends in school so you don't feel comfortable when they see you taking drugs ... I was very worried that is why I was able to tell the health care workers so that they can check and see if they were any changes in me. (Jana, 12, Uganda, Short Cycle Therapy arm)

The responses they received in the clinic to what was "acceptable disclosure" could, however, serve to reinforce how only accidental or inevitable slippages, rather than more systematic and long-term adherence struggles, would be tolerated. Sticking to this adherence script made it even harder to reveal substantial and sustained adherence problems.

Reflections on researching stories of non-adherence

Far from wishing to engage with a "confessional imperative" that sees talk as automatically generating inherent benefits (Nguyen 2013; Mazanderani and Papparini 2015), our findings underscore rather than non-talk also has challenges and ramifications. Despite the absence of discussion in many of our participants' experiences of growing up with HIV, they could and did talk about these at length in interviews. Investigating "the absence of talk" with a qualitative interview-based approach clearly presents particular challenges, but opportunities were created by our longitudinal approach and the young people who participated in our study seized them.

Initially, the idea of a research interview was unfamiliar to the young people. Yet by the time of the second interview, participants had gained confidence that there were no "right" answers to our questions and there would be no judgmental response to what they said. This was especially important when investigating disclosure of non-adherence. As no repercussions came from what they told us in the first interview, participants were able to test and confirm the confidentiality of what was said, which meant that they could to some extent trust us in subsequent meetings.

Also, through ongoing iterative data collection and analysis, we were able to reflect back to participants what other young people had been telling us. This validated their own perceptions and experiences as something their peers shared. For many participants, this appeared to be a first glimpse into the issues faced by many people living with HIV. For the young people in the UK, Ireland, and US, peer support was available but very rarely or only briefly taken up. In these sites, as patients in mixed clinics, young people did not know (but wondered) why other clinic attendees were there. The Ugandan clinic was an HIV specialist service, and many participants' lack of experience of peer support activities surprised us, especially given the local prevalence of HIV. This suggests that young people with HIV remain isolated at a time when much of the discourses in the epidemic moves toward normalization, chronicity, and manageability (Moyer and Hardon 2014).

Another value of the longitudinal approach was the difference in adherence accounts in phases one and two of our fieldwork, whereby we witnessed narrative "movement" from discussions of adherence "perfection" (in phase one) to adherence "slippages" (in phase two and also in the third interview in Uganda). Changes in the style, as much as their content, revealed the disciplining discourses surrounding

adherence. Young people told us in the first interview what they anticipated that we wanted to hear and what was expected of them as trial participants and “good adherers.” This is a useful example of the extent to which young people reason their way out of adherence issues and grapple with “truth economy.” Substantial time, patience, lack of judgmental attitudes, and clarification about the separate role of our study in relation to the clinical trial were required to shape communication where young people felt they could open up about (at least some?) missed doses.

Finally, the “style” of discussions, particularly with younger participants, offers a valuable example of how communication in the clinic can be complicated. As the extract from Jade below exemplifies, to ensure we understood young people’s answers as fully as possible, it was often necessary to ask many questions, from different angles and at greater length than what might usually be the case in a clinical appointment:

Q. Would you tell her [doctor] then [that you are missing doses]?

No, because I don’t think there’s any need to ... If that’s what she’s asking me about then I would tell her, but if she’s asking, how is it going in general, I wouldn’t tell her.

Q. So is the key thing how specific people’s questions are?

Indicates agreement

Q. So in a way does, like whether you tell them or not, it just doesn’t come up?

Only if they ask me specifically because I get really confused easily, so I’d need to know specifically what you’re asking me. (Jade, 15, UK, Short Cycle Therapy arm)

While HIV may provide an extreme case, similar communication challenges may emerge across areas of pediatric care. Young people appreciated the opportunity to talk in the qualitative study because it was a novel situation they told us they enjoyed, but some also saw it as a means to help others “understand the emotional side of what we’re going through, rather than just the physicalities of taking the treatment” (Brad, 17, UK&I, Continuous Therapy arm).

Conclusions

The place of the clinic, dependency upon it and relationships within it are marked in the lives of young people who have grown up with clinical care as a constant feature. For those in HIV pediatric care, there is a fundamental interconnection between the care that they receive and the fact that they are living with a chronic, controllable yet still potentially terminal condition, for which many young people in their same situation cannot access therapy. And beyond the clinical necessities of sustaining “good” relationships with health care workers, the centrality of the HIV clinic as a social space where HIV is not a secret is underpinned by the otherwise widespread stigmatization of HIV in many of the communities young people grow up in.

Young people partly forge their identities within those restricted social spaces in which their status is known, which reinforces the need to maintain inherent relationships and avoid “spoiling” them by deviating from the medical script they are given. Such a script invariably involves perfect adherence to ART, with no margin for error envisaged or discussed. Our study suggests that “ART talk” is the only framework available for many young people to understand their own condition (see also Kajubi et al. 2014, Newman et al. 2016).

Our results illustrate that many young people in our study lack an appreciation of what HIV means for their present and future, and they sometimes also have limited understanding of how it has come to be part of their lives (Bernays et al 2015). They have been repeatedly taught not to disclose their status, which signals that there is something inherently “wrong.” Many cannot envision a time when they may be able to be open with others and imagine a possibly bleak future of isolation.

The absence of discussion does little to support young people’s adherence. Difficulties with taking medication and anxieties about talking to their clinicians about instances of non-adherence were common in the interviews. At the harsher end of the spectrum, participants describe significant fears of stigmatization, of being scolded in the clinic and even beaten at home for failing to take treatment. In Uganda particularly, where treatment access and options are restricted by a lack of resources, young people can be made to feel that they have to deserve their medicines, by adhering to them.

Any “failure” in adherence is a moral “failure,” a form of disrespect for those caring for them and disregard for other, less fortunate young people who cannot access ART. The more supportive end of this spectrum still involves complex relational dynamics. In some cases, this relates to a paternalistic system in terms of who controls access to treatment and other material support at home and in the clinic. But young people’s invariable desire to maintain “good” relationships with clinicians, to not disappoint them, and to be seen and recognized as “good” patients has moral dimensions which until now have received little attention (Mattes 2014).

Suggestions by some of our participants that blunt measures are needed to push patients to take ART are poignant. While strict enforcement of adherence does at times result in more consistent treatment-taking, the priority of ensuring ART adherence can cause dilemmas for providers who understand that young people face multiple pressures, yet feel responsible for ensuring young people stay on treatment to maintain their good health (Perrson et al. 2014). This may be even especially acute where resources and treatment options are limited.

For the young people in the BREATHER trial, this was likely influenced by their participation in a clinical study that included only “successful” or “exemplary” adherers to test the intervention. This may have affected their initial accounts of “perfect” adherence in the first phase of interviews, along with a common desire to impress researchers. Participants very often admitted to missing one or two doses of ARVs at a time, rarely more than two. Given that the intervention tested in the BREATHER trial focused on whether it was safe to miss precisely two days of ARVs out of every seven, it is probably significant that participants were willing to disclose a similar figure, especially after claiming to never miss a dose in the initial interview. Important questions remain with regard to the effects of trials in shaping clinical relationships, particularly where trials are addressing adherence issues, as in the case of BREATHER. In settings where clinical care in a trial surpasses standard HIV care, as in our Uganda site, the even more urgent need to perform “deserving” patienthood to avoid losing care access has been established by many others (Petryna 2009; Lock and Nguyen 2010). However, this spectrum of stigmatization is unlikely to be unique to this sample of young people in this trial or in our study, despite the significant and shared emphasis young people placed on their gratitude to the clinic and investment in wanting to be seen to be doing well.

As young people worry about what might happen if and when they talk about HIV and ART, about their challenges and their preoccupations, they also (consciously or unconsciously) put strategies in place in relation to what they disclose and to whom. These include not reporting any missed doses (or reporting less than what they actually missed), not discussing changes they make to how they take their medication, and underreporting of medication side effects. In most cases, young people do not consider, or avoid, seeking help with any of the obstacles affecting them and their treatment taking.

The overall result of “truth economy” strategies in the context of near-absolute silence is a difficult and isolated experience of non-adherence, in which young people cope on their own with their anxieties about failing a moral script and about the possible damage of not taking ART to their health. Assuming that young people, even younger children, are “unaware” of their health is unhelpful. It may be useful instead to consider how more or less subtle processes of stigmatization of non-adherence to ART might be compounded by a wider spectrum of silence about HIV and produce a particular clinical environment where responsibility is constituted relationally, but “failure” and its consequences are experienced individually by children and young people growing up with HIV the world over.

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