

Situating adherence to medicines: The embodied practices and hinterlands of HIV antiretrovirals

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Abstract

Adherence to medicines tends to be envisaged as a matter of actors' reasoned actions, though there is increasing emphasis on situating adherence as a practice materialised in everyday routines. Drawing on the qualitative interview accounts of Black African women living with HIV in London, UK, we treat adherence to HIV medicines as not only situated in the practices of the immediate and everyday but also relating to a hinterland of historical and social relations. We move from accounts which situate adherence as an embodied matter of affect in the present, to accounts which locate adherence as a condition of precarity, which also trace to enactments of time and place in the past. Adherence is therefore envisaged as a multiple and fluid effect which is made-up in-the-now and in relation to a hinterland of practices which locate elsewhere.

KEYWORDS

adherence, antiretroviral drugs, hinterland, HIV, migration, women

INTRODUCTION

In this paper, we draw on the qualitative interview accounts of Black African women living with HIV in or near London, UK, to explore practices of adherence to HIV antiretroviral drugs (ARVs). Our aim is to draw attention to how adherence to medicines is not only situated in the practices of the immediate and everyday, but also relates to a 'hinterland' of broader historical, political and geographic relations (Law, 2004). Most health research approaches adherence as a matter of knowledge, belief

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and reasoned action (Donovan & Blake, 1992), which is shaped in relation to material disruptions, usually theorised as ‘barriers’ (Roberts & Mann, 2000). We argue that ‘reasoned action’ and ‘situated rationality’ models of adherence pay inadequate attention to the materiality of how adherence is made in practices. While the delineation of ‘practical barriers’ draws attention to adherence decisions and actions as effects of how individuals navigate their immediate social environments, it neglects attention to the wider complex of human and non-human elements which entangle to make-up adherence potentials, including how the immediate adherence present locates to a broader hinterland of history, geography and politics.

By drawing on thinking from Science and Technology Studies (STS) literatures, we therefore treat adherence as a practice assembled out of all kinds of human and non-human elements (Latour, 2005). Our focus is not only individual human subjects, and their reasoned or situated actions, but also the material relations which bring various elements together in the adherence assemblage (Duff, 2014; Fox & Allred, 2017). We are interested then, in the various ‘heterogeneous materials, forces, spaces, signs and bodies’ (Duff, 2016: 17) making-up adherence. As such, we theorise adherence as not only shaped in relation to the present but also shaped by broader historical and political relations, with these relations acting in, and thus making-up, the present. We attend, then, to how the adherence that is embodied in-the-now of the everyday also locates elsewhere (Callon & Law, 2004).

There are three paths our analysis follows. First, we attend to the embodied aspects of adherence; that is, the ways in which bodily experiences, and the felt sense of health, illness and side effects, come to participate in adherence practices, and ask of adherence to be remade anew. We shift away from singular or stable imaginations of adherence, to foreground the ways in which adherence is a process of tinkering, which is materialised differently, and multiply, in relation to what matters in emergent situations (Mol, 2008; Mol et al., 2010; Rhodes et al., 2019). We thus see adherence as contingent on its network of relations (Laet & Mol, 2000). This accentuates the active work that goes into making and maintaining a routine to enable adherence, given the temporal and material limits afforded by its assemblages. This moves us to our second analytical theme of precarity, where we address the ways this capacity to tinker maps on to broader patterns of inequality and disadvantage, particularly in the context of a history of migration. Precarity describes the fragile and unpredictable access of some populations to what is needed not only to survive, but also to flourish (Butler, 2009; Tsing, 2015). Here, we address how precarious relations, including those of the past, fold into efforts to sustain adherence routines in the present. This leads us to consider how adherence relates to a ‘hinterland’ (Law, 2004), in which embodied adherence locates to a broader set of relations from different times and places. For instance, differential access to pharmaceuticals, and memories of living with side effects and treatment, from different times and locations, folds into adherence as it emerges in the here and now. For Law, the hinterland is a ‘bundle of indefinitely extending and more or less routinised’ relations that inscribe by enacting a ‘topography of reality possibilities, impossibilities and probabilities’ (2004: 160). The idea of the hinterland helps situate what is possible in the proximal in relation to a wider, and more distant, network of practices, thereby also locating adherence events in relation to the absent presence of past and more distant relations (Callon & Law, 2004; Law, 2004).

Adherence beyond belief

Strict adherence to medication schedules is of particular importance for those who are living with HIV and taking ARVs, as ‘suboptimal’ adherence can lead to viral resistance (Bangsberg, 2008). Although in many cases, these drugs come with fewer and less severe side effects than earlier treatments, most people will have ‘imperfect’ adherence at least some of the time (British HIV Association, 2016).

With transformations in the use of ARV medicines for treating HIV have come new configurations of patient responsibility in relation to public health. Treatment as prevention (TasP) approaches in particular entangle individual responsibilities to adhere with community and public health concerns. TasP is founded on the theorised calculation, now evidenced in trials, that if there is sufficient ARV treatment coverage of, and adherence among, people who are living with HIV, there is an onwards prevention effect through reduced HIV transmission at a population level (Cohen et al., 2011, 2016). TasP transforms ARVs from an intervention of viral control within the individual body to a technology of public health and population governance. Adherence thus also transforms in its meanings and effects, shifting from an enactment of self to social responsabilisation (Lloyd, 2018; Young et al., 2019). Recent evidence demonstrating that most of those who adhere to treatment can achieve an undetectable viral load and thus become unable to pass on the virus to others (Eisinger et al., 2019; Prevention Access Campaign, 2016) accentuates the public health imperative of optimal adherence. The management of HIV is thus not merely a responsibility one has to oneself but a responsibility shared in relation to others (Nguyen, 2005; Papparini & Rhodes, 2016).

Considerable attention has been paid to understanding psychological and other individual-level 'barriers' shaping adherence to HIV medicines. For instance, a recent study among Black African and Black Caribbean communities in the UK identified a series of perceptual barriers to adherence, including doubts regarding effectiveness or that ARVs are necessary for those without symptoms, religious beliefs, the risk of accidental disclosure and concerns about long-term use (Glendinning et al., 2019). Although including some recognition of the materiality of ARVs and of adherence – for instance, identifying the physical characteristics which make them either conspicuous or difficult to swallow (see also Spiers et al., 2016) – such studies reflect what Rosenfeld and Weinberg (2012) have described as a tendency within the adherence literature, 'to focus analytic attention on thought processes, knowledge and belief so as to dislocate these broadly intellectual processes from the locally orchestrated practical activities within which, and with respect to which, they tend to emerge and evolve' (pg. 44). Such a focus on beliefs 'assumes that health-related beliefs are the most significant aspects of subjective experience and that compliance is a rational decision based on these beliefs' (Conrad, 1985: 30).

The limits of theorising adherence as reasoned action have foregrounded investigating adherence as a matter of situated rationality made-up in practices in particular contexts. Practice oriented interpretations accentuate adherence capacity and action as matters of agency–structure relation, cultural logic and habit (Blue et al., 2016). A focus here, for instance, is situating adherence as a matter of the mundane, incorporated as everyday routine. As McCoy (2009) has pointed out, it is rare that the 'work' of adherence is attended to as, 'the activity is conflated with the outcome: the pills are taken, a high degree of compliance is achieved, the schedule is followed' (pg. 129). Seeking to understand how patients do adherence, McCoy describes the need to align clock time, inner experience and medication schedules, sometimes relying on external reminders (such as alarms), as well as the spatial co-ordination required to ensure one is close to their pills at the right time. Adherence, in this account, is worked into the proximal and mundane as an effect of various human and non-human entanglements.

Focussing on unintentional non-adherence, Huyard et al. (2019) similarly foreground the necessary spatial and temporal co-ordination involved in adherence, but this time in terms of routine. Attempting to move beyond a framing of unintentional non-adherence as 'forgetfulness, carelessness or practical barriers' (pg. 15), the authors identify five dimensions of 'accidental' non-adherence: schedule disruption, external pressures, the positioning of medications and individuals, an inability to correct missed doses due to a lack of a 'backup' and forgetting whether one has taken their medication and having no way to verify. Their study shows how the work of adherence practices is an emergent and complex doing, involving the juggling of many interacting elements. Adherence is here materialised

as a matter of proximal relations which help to routinise it. Routinisation thus standardises adherence by creating a package of practices which hold together, more or less, to enact reoccurrence or stability (Law, 2004).

Adherence beyond the proximal routine

While lending support to the above with regard to adherence as a materialised practice, actively worked into routine, our interview material also brings into view some of the limits of this framing, especially as it relates to how a hinterland of practices affects the routinisation of adherence. The making and protecting of routine, by 'fitting bits and pieces together to produce more or less stable traces is a precarious business' (Law, 2004: 33). The precariousness of routine, as we will show, also maps on to a precariousness of a more political kind. Here, precarity describes a 'politically induced condition in which certain populations suffer from failing social and economic networks of support' (Butler, 2009: 25), and are thus 'differentially exposed to conditions that jeopardize the possibility of persisting and flourishing' (pg. 28). This can also be theorised as a form of 'structural vulnerability', wherein social, political and economic forces 'constrain decision making, frame choices, and limit life options' (Quesada et al., 2011: 342) and describes not only differential access to resources but also the patterns and experiences of uncertainty and unpredictability (Whittle et al., 2020).

Black African people in the UK are disproportionately affected by poverty, often related to immigration status but also because of low employment and pay (National AIDS Trust, 2014). Research on the experiences of Black African women living with HIV in the UK has also described high levels of uncertainty relating to migration status and financial issues (Anderson & Doyal, 2004). The experiences of the women included in our study reflect this, with many having difficult, complicated and fragile lives, precarious migration status and experiences of poor living arrangements. The analysis we present below accentuates how the work of everyday routine becomes noticeable in situations of precarity, when routine is disrupted or difficult, and when the elements which hold routine together become disconnected or torn apart from one another.

Whereas most work exploring adherence as a matter of practice accentuates the proximal, in the work that is done to establish adherence routines in the immediate environment, we also draw attention to how these elements relate to a hinterland (Law, 2004). Accordingly, we re-assemble the immediate 'practical barriers' to adherence as broader social and material concerns. This does not detract from the tinkering work that goes into making routines of adherence happen (Huyard et al., 2019; McCoy, 2009), but rather accentuates how this work is situated in, and affected by, broader trajectories of historical, social and political location. This is important because it helps notice how everyday routines are far from mundane or stable, nor completely of their moment, but contingent on how past events fold into, and make, the capacities of the present. As noted by Law, 'there is a backdrop of realities that cannot be wished away' (2004: 31). And as we will see, for those living with a situation of precarious migration, the past is never far away and is often located in the present.

METHODS

This article forms part of a broader project which sought to understand the experiences of people living with HIV engaging with and navigating care. The study was initially intended to focus on the experiences of Black African and Black Caribbean men as, following consultation with community and other experts, this group was felt to be underrepresented in research while also being particularly

vulnerable to disruptions in care. Around half of the men interviewed had been recruited via the lunch club of a community-based organisation (CBO) where the interviewer had regular presence. While there, the interviewer (SE) found herself regularly approached by women who asked why they were not being included, feeling that their experiences as women living with HIV were different to those of the men and that they too should have their stories heard. Following further consultation with the study advisory board, a decision was made to also include women in our research. As such, this article draws on the analysis of 29 qualitative interviews with Black African migrant women living in or near London, UK. These interviewees were primarily recruited from the lunch club mentioned earlier ($n = 20$), but some were also recruited from specialist HIV clinics ($n = 5$) or by referral from other participants ($n = 4$). Recent demands from the field for academic research to centre the experiences of women living with HIV (Sophia Forum & Terrence Higgins Trust, 2018) motivated us to focus only on the experiences of the women for this article. Thirty interviews were conducted with men, and these have been written up elsewhere (Rhodes et al., 2019).

All interviews were conducted by the third author (SE) in April and May of 2017, and interviewees were aged between 36 and 69 and with a mean age of 50 (two interviewees did not give their age). Using a narrative approach to interviewing (Riessman, 1993), interviewees were initially invited to tell their story of living with HIV, beginning wherever felt the most meaningful to them. The interviewer then followed a topic guide which included questions designed to foster participant-led accounting in relation to HIV diagnosis, adherence to medication, engagements with clinical and informal care, and experiences of community-based support. Interviewees received a cash payment of £20 for participating, and travel expenses were reimbursed.

Following the interviews, sound recordings were transcribed verbatim and analysed thematically using NVivo 12 in order to identify emergent and recurring themes across the interviews. This coding process moved from open coding to broader categorisations of data mobilised for thematic analysis (Charmaz, 2006), across all 29 interview accounts. Key categories of emergent analytical interest included the following: adapted and fragile adherence, self-care, felt-illness, care beyond the virus, social support, citizenship and community, home and family relations, testing and diagnosis, precarity and migration (see also Rhodes et al., 2019). Here, we adopt a case study approach to our analysis by selecting for attention particular participants and their narratives to exemplify adherence to medicines as an embodied and socio-material entanglement. Our aim is not to synthesise across the study thematically but to pull out for attention the stories of three women, whose experiences illustrate how embodied HIV, precarity and migration folded into stories of adherence. We thus avoid claim to a full and 'objective' account, opting instead to select specific instantiations of adherence in order to draw attention to the ways it is made-up in practice (see Singleton & Mee, 2017 for a similar approach). The accounts we have elected to focus on illustrate the broader themes we identified across the sample, which we describe in more detail in the opening section of our findings below. We take this approach in an attempt to offer 'enough stories at sufficient length to allow the storytellers to become not sources but actual presences' (Frank, 2009: 108). Our intention is to give a sense of the lives of the women we interviewed through the narratives they told with a view to exploring how these narratives enacted adherence as a matter of contingency.

We note that accounts of adherence to medicines themselves relate to their social contexts of production and that adherence to HIV treatments is a highly responsibilised field (Paparini & Rhodes, 2016; Young et al., 2019). Accounting does performative work (Riessman, 1993), enacting the presentation of self in relation to social and cultural expectations, and in this case, scripts of 'good' adherence and citizenship (Rhodes & Cusick, 2002). We therefore appreciate interview accounts as performative in how they constitute adherence. While we are interested in treating adherence as a

story told, that is, as an effect of narrative social construction, we are also interested in tracing the materiality of adherence in situated practices. This means we also pay particular attention to how accounts perform as material enactments of adherence (Fox & Alldred, 2017). Our focus here is less on interview talk as a resource to meaning, and more on interview talk as an event which materialises adherence as an object and reality in particular ways (Rapley, 2001). We pay attention then, to the things said about adherence in terms of 'what they produce, or constitute' as well as in terms of 'the practices that give rise to them' (Bacchi & Bohnham, 2016: 116–118). At the same time, we are making our own story through the particular attention we are giving to analysing adherence as a matter of contingency made-up in material practices (Law, 2004).

This study received approval from the London School of Hygiene and Tropical Medicine and Camberwell and St Giles' Ethics Committees. All names are pseudonyms. In order to maintain confidentiality, we do not include the country of origin of our interviewees and have removed or obscured any additional details which may identify them.

ANALYSIS

Our analysis below traces, through the accounts of Joyce, Ayo and Florence, adherence to HIV medicines as matters of embodiment and precarity, situated in relation to time and space. We have chosen these accounts as they reflect broader patterns and experiences across the interview set. Although specific in their particular articulations, these stories echoed other interviewees' lives and exemplified common threads across the interview sample. Thus, although Joyce, who we describe in the first section of our analysis, could be described as a 'deviant case' as she was the only interviewee who had made the decision not to take antiretroviral drugs, her account brings to the fore the tensions many interviewees experienced in making sense of their health and a need to take medication in the long term and also how bodily experiences came to participate in adherence. Our second analytical theme is precarity. Here, we discuss Ayo and how her precarious circumstances inhibited her ability to adhere to medicines. This precarity, we will argue, maps on to a longer trajectory of inequality which was materialised through her precarious migration status and housing situation. A great many of the women interviewed as part of this work similarly had very fragile social support (if any), and thus, her case is one articulation of a common experience across the sample. Finally, drawing on the story of Florence and others, we discuss adherence in relation to time and place, as relations with 'home' come to participate in adherence in the here and now.

Embodiment and adapted adherence

Joyce, who was in her late forties, was the only interviewee who had stopped taking her HIV medication in the long term, although some other interviewees had taken medication breaks or stopped medication for periods of time. When she first began taking medication, she had experienced terrible side effects: her dizziness was such that she had to hold onto walls as she walked. She was also diagnosed with a deficiency in her blood, and, although unsure of whether the side effects had been so bad because of the deficiency, her HIV consultant suggested a medication break in order to see whether treating the deficiency and then returning to the medication would help, or whether her medication would need to be changed. However, and although tacitly agreeing to his terms, Joyce knew then that she would not start treatment again, or indeed return to HIV specialist care:

So he [HIV consultant] said, “Let’s do that for you, for a month or two,” and I thought, “I’m not coming back,” but I didn’t say that... “Let’s do that for a month and see how your body reacts, and see if your body calms down, and then we might try you on a different medication.” So when they did that, I went back to my GP and I said, “I’m not going back.” And he said, “Are you crazy?” I said, “I feel better, and I’m not taking any ARVs, and I’m not feeling sick and I’m not feeling dizzy, so there must be something not right.” He said, “Why don’t you let us try some...” I said, “No, I’m not doing it.”

(Joyce)

Joyce enacted a relation with ARVs which is suggestive of how a body is sensed or felt beyond rational calculation. Although certain about her decision in the present, she left open the possibility of taking medication again in future, including the possibility of restarting treatment should the option to take ARVs intravenously become available, or should the situation change with regards to her wellbeing. One of the reasons for this was that regular medication did not fit with her bodily experience or her felt sense of what constituted health or illness:

In my mind, I feel like, “I’m not sick.” And I associate taking medication on a daily basis, and lots of it, to old age. So, when I see that, I’m just like, I am not yet there.

(Joyce)

Considering how ARVs might be better made to fit her life and self, she also felt that a monthly injection would be more favourable, as one of the problems with the pills was that she had a busy life beyond HIV and, as such, could not be planning around medication schedules. A resistance to long-term regimented adherence has been reflected in other studies (McCoy, 2009; Mills, 2017). What is interesting in Joyce's account, though, is that it functions narratively to remind us that there is more to her than her HIV (something she asserted as soon as the interview began) and that she materialises not *her* failure, but a failure of the *drugs*, to meet her situated embodied needs. When considering the possibility of intravenous medication, she did, however, not commit to an ongoing engagement:

I think if it probably goes to a point where it’s being done intravenously or something like that, I may probably just take it for two or three months, and not bother going back, because I don’t like taking medication on a daily basis.

(Joyce)

Joyce's story articulates some of the ambivalences of attempting to reconcile ones' own experience of their body and wellbeing with medicalised expectation (c.f. Rhodes et al., 2019). As Persson et al. (2016) have also noted, it should not be assumed that those who choose not to take medication do so because they are uninformed or disengaged from medicine, a tendency of non-adherence analyses which emphasise ‘patient failures and deficits’ (pg. 364). Although at odds with the advice of her HIV consultant and GP respectively, Joyce does not narrate herself as disengaged from clinical care, but rather as adapting medicine to make it congruent, and thus work, in relation to her bodily experience. This is a ‘practical tinkering’, an ‘attentive experimentation’ (Mol et al., 2010: 13), where adherence is remade in ways which afford an emergent care in a particular material situation (Mol, 2008).

Joyce then materialises her health as a situated bodily entanglement which partially connects with biomedicine as well as notions of responsabilisation regarding adherence and care. Indeed, she takes care of her health and self in alternative ways: by exercising, taking herbs, vitamins and iron tablets, drinking water and eating fruit.

I'm so lucky, because I study my body like 24/7, it's crazy, to the extent that from the beginning of the month, I know exactly how my body functions. I know it has a certain point, like, when I get bloated like this, I know that I'm ovulating, I know exactly when I'm ovulating, I know exactly when my periods are coming. Because that was the only way, I needed to know what's normal to my body, and then if something happened that I wasn't sure, I was down straight at my GP like, "I don't know what's going on, this is a bit out." So I think that's what I've done, because I'm not taking the medication, I thought to myself it's better to take control of this body, know how it functions, and how to keep it healthy.

(Joyce)

In her account, Joyce leaves open the option to recommence medical treatment should new delivery options emerge (while also leaving open the option to again halt treatment), potentiating treatment again in the future (regardless of delivery method) should her health and body call for it. Her adapted adherence is not a singular or fixed rejection of medicine on offer, but is a fluid, contingent and bodily entanglement. As she says of the emergent care that she is becoming-with:

I will do whatever it takes to keep myself healthy. But yes, I think one of the key things about me, it's really knowing how my body functions, and what my body likes, and what it doesn't like, and, you know, I think I'm just lucky to have that.

(Joyce)

Adherence to medicines and medical services become fluid engagements or potentials but not a matter of routine. Her doctors were apparently unhappy, but adapted to her terms: she did not go to the clinic as it was located in a hospital; instead, she got her blood (CD4) counts checked by her GP, who had also referred her for counselling and to see a nutritionist.

To suggest that Joyce was 'disengaged' from care would not be accurate, and since she was treating her blood deficiency with medication, to refer to her as non-adherent to medicines would also elide her active engagement in caring for her health. As Persson (2004) has noted of situated HIV care, 'therapeutic efficacy' is not simply a matter of viral suppression, but of 'overall well-being', with antiretroviral drugs sometimes enacted 'as inimical to, and incompatible with, this state' (pg. 59). As Joyce commented of the side effect potentials of the antiretroviral drugs she was holding back from taking for now: 'If I can't walk down the street and not think I'm going to pass out, that's not right.' Joyce locates adherence in the everyday, as a contingency in relation to being able to walk down the street, and in her body, as a sensed and situated need rather than universal prescription. Joyce's narrative is not so much one of non-adherence but a materialisation of *adapted adherence*, enabling her to get on with, as well as care for, her body in its situation without feeling unwell. Adapted adherence accentuates an adherence made multiple (Mol, 2002), leaving open the possibility of returning to ARVs alongside other alternative configurations of adherence according to material situation and felt need.

Precurity and fragile adherence

Of the 29 interviews, four women had spent time in immigration detention centres and two of these had missed doses because they had been taken there without their medication. One interviewee described how, even once reunited with her medication, taking it regularly was not possible given shared accommodation arrangements and concerns of HIV disclosure (see also Doyal & Anderson, 2005;

Spiers et al., 2016). While removal to detention centres might be considered a particularly dramatic break from efforts to maintain an everyday life routine, it locates to a hinterland of precarity in the lives of migrant women in relation to their experiences of HIV care. The capacity to tinker, to manage a situation, to maintain adherence as routine, is affected by elements which extend beyond and yet materialise the adherence moment.

There were, however, other ways in which histories of migration inhibited the ability to make a routine. Ayo was in her late thirties at the time of interview and had been diagnosed with HIV over a decade earlier following a minor stroke. Concerned for her daughter – who was living with a family member in her home country – she had requested that the family member take her daughter for an HIV test. The test had come back negative and since then,

I just concentrated on myself, made sure that I take medication, it's very important because if you take the medication, you can live long, you cannot have too much complications. There was a time I was in denial, not taking medication, I felt ill so many times. It's very important that people who are on ARVs they take their ARVs, they don't miss
(Ayo)

Here, Ayo frames adherence as part of her decision to concentrate on herself, echoing a common thread across the interviews, in which many of the women connected adherence with living well. While Ayo identifies events of non-adherence with what she describes as 'denial', throughout her interview she also relates not taking her medication to her emergent and precarious circumstances, which work against her efforts to routinise an adherence to medicines. Part of the unpredictability of Ayo's situation relates to her living with a series of violent and controlling partners, some of whom she had not felt able to disclose her HIV status to, or in front of whom she had not felt able to take her medication.

A couple of years prior to the interview, Ayo's visa had expired and, having attempted to apply for leave to remain in the UK, she later learned that the solicitor she had instructed had scammed her, stealing her money and passport. Having previously helped her to flee an abusive partner, her partner at the time became violent and controlling, particularly in relation to her inability to work as a result of her migration status. Wanting to leave, she had asked for help with housing but had not received any, and, since she had no other social connections she could call upon for help, she found herself homeless and living on buses.

Having been picked up by police and an ambulance, Ayo was put under section on mental health grounds, and she remained within a psychiatric hospital at the time of interview. She did not take her medication during this period of homelessness and of moving from one bus to another. As she put it, 'I didn't remember because I was tired, night bus, day bus'. She had started treatment again while in hospital and was positive about the future, although she commented she had not been able to leave hospital because she had no friends or social connections to help her: 'I've lived in the country for [over ten] years, I should have great friends who can be able to help me with accommodation'.

Similar to the women who were unable to access their medications, or who felt unable to take medications while in immigration detention centres, Ayo's narrative materialises adherence as a matter of living with precarity, which links with a history of migration. The capacity to make and maintain a routine, as a basis for stabilising adherence, is incredibly fragile. For Ayo, capacity to adhere to medicines, and for self-care, locates to a past–present of precarity, which enacts a lingering structural vulnerability.

The precarious experience of migration narrated by Ayo is familiar to the narratives of others we interviewed. Accounts of adapted and fragile adherence in the situated present are told in relation to a past, as stories of movement and of travel as well as entanglement. One common narrative device of

translation here is 'home', and of relating the experiences of here and now with that of a previous time 'back home'. The HIV and treatment of the situated present is materialised in relation to that of HIV and treatment in a different time and space.

Florence, for example, was in her mid-fifties at the time of interview, but had been diagnosed with HIV over a decade earlier when she fell ill while at university. As she was very unwell, her studies were paused. As she was preparing to return, her brother, who still lived in her home country, died of illness related to HIV. This was only a few years after her other brother had died, also of HIV related illness. Although thousands of miles apart, Florence understood her own HIV and relationship with medication in relation to that of her brothers as well as to the back home of Africa. Speaking of the death of her second brother, she said:

In [my country], African countries, medication is not that, you know, accessible really easy. So we were so close and then as soon as he passed away, I just lost hope and then I thought, "What if it was me, you know, who was going to follow?" Because it was the same, you know, illness.

(Florence)

Florence's narrative of lost hope in relation to her brothers back home affected her own fragile adherence. She felt there was little point in continuing to take her medication, and indeed, did stop for a time. Her adherence is located in a time and space elsewhere. Florence explained that her HIV doctor of the time reminded her of her own daughter, living in the here and now of the UK, who would suffer great loss were she to be without a healthy mother should discontinuing her medication cause illness. Florence's narrative of her HIV and adherence to medicines is thus also a materialisation of her migration, of her movement in time and space, between Africa and the UK, and between her social networks here and there. The adherence of the situated present connects with a past in these accounts of migration, acting as a site of translation.

Approximately ten years after the death of her first brother and her own diagnosis, Florence returned to her home country in Africa. Many participants in our study were fearful of telling even close family members of their HIV status. For Florence, this concern was especially acute because of the loss of her brothers. On her visit back home, Florence presents her adherence to medicines and health as a matter of good fortune, enabled by her migration. Speaking of her disclosure to her mother, she recalled:

I thought that she was going not to take it because she had lost two sons with the same illness and she has been caring for them. If I tell her, it was going to make matters worse. So then when I told her, she said, "Oh, I'm happy for you because you are there, you are getting good treatment there compared to here." And then, when she saw me, when I arrived, she was so happy to see me and that I was looking fit and strong

(Florence)

Personal and family histories, global disparities in drug access, and relationships with those back home and in the UK shape what HIV, ARVs and adherence become in-the-now. For Florence, migration is a good fortune story in relation to adherence and health. For others we interviewed too, access to medicines in the here and now was expressed as a 'gratitude', 'especially when you hear about people who were diagnosed some 20, 30 years ago'. Access to medicines, and the capacity to adhere, was described by Betty, for instance, as 'given on a silver plate' when contrasted to stories of others in a time and place elsewhere. As she commented: 'I have never suffered, I never went through that'. Other studies have noted that stories

of adherence in the context of migration may invoke the ‘luck’ of having moved time and place and that this good fortune is mobilised as a resource or motivation for maintaining adherence (see also Doyal & Anderson, 2005). Adherence opportunity is materialised differently here than back home: ‘It’s not like back home where people don’t even have food to support their medication, and I’ve got charities which help me’ (Mary).

Yet, as illustrated by Ayo’s account, ‘back home’ may also fold into the experience of fragile adherence in the situated present as an extended precarity linked to the uncertainty, as well as hostility, of migration. A common theme here was how memories of past times and relationships back home instilled uncertain affects in relation to ARVs in the present. Past experiences, for instance, of the toxic effects of medicines on people that participants had known or seen back home made them fear taking medication themselves. For instance, despite being told, when in the UK, that ‘if you start the medication you’ll be fine,’ Faith ‘located’ to her home country, immediately recalling what she had seen of ARVs there:

the person, all the bones, all the ribs of everything would be out, he would be hungered, he would be like a skeleton, is this how I’m going to look like, what is it you are telling me about, so from now I’m going to die, oh my God! I start crying

(Faith)

Others too materialised their adherence with medicines to a sense of back home, and to past times and relations: ‘I still had that mentality, I said oh no, I’m going to take this, I’m going to die, I’m going to get the side-effect. People used to die back home, you know’ (Sophia).

Previous analyses have noted how past experiences shape present ones in relation to HIV treatment and adherence. Lessard et al. (2018) have referred to this as ‘imprinting’. They identify one of three temporal categories as ‘a linear temporality in which unpleasant events have lasting impacts on adherence’ (pg. 3). These ‘unpleasant events’ include witnessing or having personal experiences of side effects. Our analyses suggest, however, that these affects, between pasts and presents, are not singular nor linear, but multiple and recursive. Adherence adapts in an emergent present, through entanglement in relation to a hinterland of past times, places and social relations. Narratives of adherence in contexts of migration materialise adherence not merely in relation to the local and the here and now, but also in relation to what has gone before.

CONCLUSIONS

Our analysis has situated adherence to HIV medicines at once as a matter of practice in relation to the immediate and everyday situation and as an effect of a hinterland of socio-material practices which enfold the past, through elements of time and place, into the present. We have made this analysis through the stories of three women, whose accounts we use to illustrate how broader themes of embodiment, precarity and migration entangle in relation to adherence practices. Our aim is to attend to adherence as matter beyond reasoned action to accentuate the materiality of doing adherence in-the-now, illustrating how embodied adherence locates in relation to the time and place of the present as well as in relation to a hinterland of precarity linked to migration. The accounts of the three women we draw upon in this analysis instantiate a broader theme of embodied precarity described among people in the study as a whole (see also Rhodes et al., 2019). By focusing on the particularities of three adherence stories, made in their specific situations, we are able to trace how precarious adherence to HIV antiretrovirals is lived and navigated locally.

We first attended to adherence materialised as a matter of embodied affect. Here, we described Joyce's relation to ARVs and her bodily experience. Joyce's account accentuated the importance of accounting for the felt sense of health and illness within the body and its active participation in what adherence comes to be. This necessitated an attention to the everyday – the ability to walk down the street without feeling dizzy – but also the ways drugs interact and have effects on bodies and the felt need to adapt adherence to become-with situated needs. Joyce's enactment of adaptive adherence and HIV care constitutes adherence as fluid, and she is open to adhering to medicines in variable ways in the future. Adapted adherence is contingent to its bodily entanglements in context and thus stands in contrast to the singular versions of adherence scripted through biomedical discourses. Most importantly, adapted adherence, as Joyce's narrative tells, is not to be conflated as 'non-adherence', a category commonly associated with the 'failure' of individuals to maintain narrowly defined biomedical adherence expectations (Donovan & Blake, 1992; Paparini & Rhodes, 2016). Joyce's account hits home the need to move beyond an all-or-nothing binary of adherence, accentuating instead a *tinkering* of adherence as a matter of situated and embodied care (Mol et al., 2010).

While Joyce's account draws attention to adherence to medicines as an embodied affect beyond reasoned calculation, our analysis also accentuates adherence as a matter of contingency which relates to a broader hinterland of practices. Precarity emerges as a critical element of the adherence hinterland shaping the efforts of many Black African migrant women to navigate HIV care. We saw this in Ayo's account, where the capacity to establish and maintain an adherence to medicine routine was made precarious by multiple elements – including migration processes, gendered violence and weak social connections of support – which created a condition of pervasive indeterminacy. Adherence capacity does not simply reside in reasoned action, and nor in human bodies and their affects alone, but in an assemblage of entangling elements, which also has a socio-material trajectory, a hinterland. Our analysis notices the enfolding of past times and places into the now of adherence events. The materiality of adherence as an event does not merely relate to establishing or sustaining everyday routine in the immediate present but relates to a 'backdrop of realities' (Law, 2004). For the women interviewed who are navigating HIV care in a context of migration, the past is never far away. Florence's account, for instance, locates her HIV care and adherence of the present in relation to her past, her home, her family, her relation with the Africa she left behind. This invites an approach to adherence to medicines as an assemblage of human and non-human elements, entangling across times, locations and scales. Adherence to HIV medicines becomes more than a matter of belief or reasoned action, and more than a matter of bodily affect in the present, but is an affect made-up of personal and political histories of toxicity, displacement and uneven access to care. Adherence in-the-now is a matter of a present–past made-up of enduring connections with times and places elsewhere. We therefore appreciate adherence as a coming together of bodily entanglements in relation to a hinterland of social relations.

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AUTHOR CONTRIBUTION

Emily Jay Nicholls: Formal analysis (lead); Writing-original draft (lead); Writing-review & editing (lead). **Tim Rhodes:** Writing-original draft (supporting); Writing-review & editing (supporting). **Siri Egede:** Investigation (lead); Writing-review & editing (supporting).

DATA AVAILABILITY STATEMENT

Research data are not shared.

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