Replacement feeding and the HIV Diaspora: a case of ontological multiplicity and fluid technologies

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Breast milk is a transmission source of HIV. Therefore, mothers living with HIV are able to avoid exposing their infants to HIV-contaminated breast milk if they replacement feed them. This article draws on an ethnographic study of an acute National Health Service HIV specialist antenatal clinic in London and explores the ontological multiple HIVs that the practice of replacement feeding takes part in enacting within the fluid space of the HIV diaspora. The term articulates the circumstances of racialised people affected by HIV who are originally from countries where access to life sustaining medication, care and resources – that enable a decoupling of the illness from death – are not readily accessible, and who have (temporarily) relocated themselves to geographical places where these resources are on offer. Arguing that Black African and Caribbean migrant women’s ability to benefit from the technologies and care that have turned HIV into a chronic illness in England is delimited by race and their diasporic positionality. In so doing the article contributes to Sociology by showing how race is part of practice - ethnographic research and medical care even when it is seemingly absent.
feeding — all of that is the opposite of what you’re wanting when people are pregnant. You’re saying don’t take medicines, breast is best, you know, normal and natural and that’s what they want mostly from their cultures and it’s quite an adjustment and it’s a short time span so we have to work with where we are at (Ellen, HIV specialist midwife 2009).

Well, to be honest with you, I actually have issues with breastfeeding [in South Africa] because it’s really difficult when you know that this woman is positive and she’s been given that choice, but actually the choice is really more to do with what’s best for the child. So if they’re coming from an area [in South Africa] where there’s no clean water and they can’t clean, sterilise the bottles and all that, the chances [are] that the child is going to die of gastro-enteritis or some other problem much quicker than HIV, so in that way it makes sense that they breastfeed. But it is hard, isn’t it? Because you know that actually we are trying to reduce the risk and you are breastfeeding! (Laura, HIV specialist paediatric nurse, 2009).

Drawing on Science and Technology Studies (STS), this article argues that HIV is a terminal illness for Black (African and Caribbean) migrant women in London despite having access to advanced care and biomedical technologies that have successfully turned HIV into a chronic illness. Breast milk is a transmission source of HIV. It is possible to avoid exposing infants to HIV-contaminated breast milk by replacement feeding (RF) them (WHO 2010). While RF may seem like the most straightforward HIV prevention technology on offer to mothers living with HIV, who are located in geographical locations where it is advised, it is in fact a highly complex practice for these women. The article uses the concepts of ontological multiplicity and fluid technology to explore how the practice of replacement feeding becomes enacted as an HIV prevention and detection technology for Black African and Caribbean migrant women in London, with the latter having both harmful and beneficial effects. This
exploration illustrates how different relational configurations associated with race and
(previous) geographical space led to the enactment of different diseases rather than
different experiences of the same disease. In other words, RF takes part in enacting
ontologically multiple HIVs if and when the woman that engages in the practice is
incorporated into a fluid space that I call the ‘HIV diaspora’. The concept articulates
the circumstances of racialised people affected by HIV who are originally from
countries where access to life sustaining medication, care and resources – that enable
a decoupling of the illness from death – are not readily accessible, and who have
(temporarily) relocated themselves to geographical places where these resources are
on offer and HIV is consequently a chronic illness.

Premised on an ethnography of an HIV specialist antenatal clinic housed in an acute
National Health Services (NHS) Research Hospital in London, the article contributes
to Sociology by illustrating the relevance and usefulness of the STS concept of
ontological multiplicity and fluid technology with the addendum of the significance of
race and the (previous) geographical place of the researcher and her subjects. In so
doing the article also contributes to discussions of ontological multiplicity and fluid
technologies within STS by arguing that race is part of practice (ethnographic
research/medical care) even when it is seemingly absent. In what follows I set the
stage by providing a truncated history of HIV prevention efforts and HIV (antenatal)
care which have decoupled HIV from death, before introducing the theoretical
concepts that will be used in this article.

HIV as a chronic illness and a death sentence
Towards the end of the twentieth century, the use of a combination of antiretrovirals (ARVs), known as antiretroviral therapy, or ART, drastically altered the course of the HIV pandemic (Detels et al. 1998), changing the prognosis of a person living with HIV from almost certain death to life with a chronic illness (Siegel & Lekas 2002). The ability to reduce the vertical transmission (VT) rate of HIV-1 (where HIV is transmitted antenatally at birth, postnatally or through breastfeeding) is considered to be one of the most successful achievements in the use of ARVs (Anderson & Doyal, 2004). In England the VT rates have fallen well below 1% (Peters et al. 2017, p. 527), through the provision of an advanced care regime involving the universal offer of an HIV test as part of antenatal care, the management of a pregnant woman’s viral load with ART; at birth through a managed delivery – and postnatally by the administration of Post Exposure Prophylaxis to the baby and by exclusive replacement feeding (BHIVA 2020).

However, despite being a crucial and effective way to prevent HIV transmission through breastmilk (Townsend, et al 2014) the materials needed to RF are not provided as part of NHS HIV care and are thus not free of charge in England (NAT 2017). This omission increases the hardships faced by Black African migrant women living with HIV in England. This group are at highest risk of HIV-1 infections, compared to other women (Dhairyawan et al, 2021; Nicoll et al. 1998, p. 257) and have consistently had the highest HIV prevalence (The UK Collaborative Group for HIV and STI Surveillance 2007, p. 90) – representing a little more than 70% of the women living with HIV that gave birth between 2012 – 2014 (Peters et al. 2017, p. 527). Further to this, pregnant Black women living with HIV are more likely than white women living with HIV to be late in booking their first antenatal appointment (Tariq et al. 2012, p.
This increases the risk of VT and other adverse health outcomes for mother and baby (Tariq et al. 2012, p. 978).

UK based researchers have usefully started to explore the significance of the HIV care on offer to patients. When care of Black migrant patients’ fails the fault is understood to lie with the social - in particular with the complicated issues patients experience as a result of their position within an “African diaspora”, which may lead patients to reject care (Tariq, 2013, p. 300) - and not the biomedical (Dhairyawan et al., 2012; Peters et al, 2017, p. 527; Tariq et al. 2012; Tariq et al., 2014). This is particularly true in relation to infant feeding practices - wherein breastfeeding is understood as having a significant cultural meaning for African women (Tariq et al. 2016; Treisman et al. 2014), to the extent that Black African mothers living with HIV fear that RF will be used as a proxy for their HIV status, and thus their status will be revealed if it becomes known within their communities that they are not breastfeeding (Tariq 2013, p. 270). Barriers to preventing VT are understood as having to do with access to formula and cultural meanings and understandings of HIV that stigmatise women from Black African migrant backgrounds who opt to replacement feed their infants.

It is important to acknowledge that women living with HIV in sub-Saharan Africa, the most affected region in the world (WHO 2021) are advised to exclusively breastfeed for six months after birth and to continue to offer breastmilk till the child is at least two years old (WHO 2021), notwithstanding a transmission risk ranging from 13 – 48% (Bansaccal, et al, 2020; Coovadia, et al, 2007; Nduati, et al 2000, Nguefack, et al, 2016). Babies in these regions are more likely to die from a water-borne illness before they have a chance to die from an HIV related illness (Overgaard, 2021; WHO, 2018,
2021). Risking transmission through breastmilk is understood to be preferable to the more immediate risk of mortality from a water born illness. Additionally, mothers and/or baby are advised to take ART throughout the breastfeeding period (WHO 2021). However, despite being home to approximately 25.6 million people living with HIV out of an estimated global total of 38 million, less then 17 million people living with HIV in the region were accessing treatment in 2018 (UNAIDS 2019). Mothers and their babies in this region are thus doubly disadvantaged by public health considerations undermining HIV protective replacement feeding and a lack of recommended medication.

Hence, while HIV is undoubtedly a global issue, what HIV *is* is different depending on the practices that enact HIV. What these practices *are* - varies and is contingent on where the person living with the virus *is*, comes from, moves to, and how she is racialised in the spaces she moves within and between. Flowers and colleagues remark on the way the expense or unavailability of HIV treatments in some countries means that an HIV diagnosis in those locations is tantamount to a “prognosis of death” (2006, p. 110). Furthermore, they argue that even in geographical locations where treatments and care are available, the consequences of an HIV diagnosis are variable given the risk of deportation that many people living with HIV constantly live with and the complications that may arise from living with a chronic illness (2006, p. 118). These observations ask us to pay attention to the differing practices that enact HIV in the same geographical locations depending on how resources and privileges (access to public funds, permanent residency and citizenship) are negotiated, allocated or denied. Therefore, if we are to better understand the experiences of Black migrant women living with HIV in England, we should attend to the practices that enact their
HIV while also attending to the ways in which ‘race’ and ‘migration status’ are part of these practices. Thus, in this article I attend to the ways in which race and a person living with HIV’s previous and anticipated geographical locations participate in the enactments of HIV. I have coined the term HIV diaspora to refer to the fluid space that encompasses people that (are forced to) move between geographical places wherein HIV is linked to almost certain death, and places wherein HIV is a chronic illness. The concept enables a way of assessing the experiences of Black African/Caribbean migrants that takes into consideration their complex positionality and the unequal global distribution of ART, and advanced HIV care without reducing their experiences to issues related to their “culture” and/or (lack of) access to resources (Nguyen et al., 2011, p. 292). In this way, I use the concept as a lens through which to challenge the notion that improving the lives of Black African/Caribbean migrants living with HIV in England primarily concerns the meanings attributed to HIV (M’charek 2013, p. 424) and their access to resources and HIV technologies. Hence, the HIV diaspora is a valuable conceptual tool that may be used to better understand the contingencies of the experiences of being or caring for racialised (pregnant) women living with HIV whose current care location is different to where they came from - and wherein HIV and death may not be decoupled. While the London clinic reported upon here is located in a geographical place where HIV is a chronic illness it caters mainly to women who are originally from places wherein HIV is life-threatening and/or life-limiting. By ethnographically attending to the practices used to prevent VT in England – specifically RF – I will show how these women’s HIVs are done differently.

Ontological multiplicity
Fluid technology is a concept developed by Annemarie Mol and John Law, which reflects the way that medical practices and technologies enact ontological multiplicity (1994, 2002). While I bring the term to the study of HIV, in their case they focused on anaemia, and the idea was later extended by de Laet and Mol in relation to the ‘Zimbabwean bush pump’ (2000). They write that:

“…this piece of technology, so advanced in its simplicity, is fluid in its nature.’

The Zimbabwe Bush Pump is solid and mechanical and yet … its boundaries are vague and moving, rather than being clear or fixed. Likewise, the question as to whether or not the Bush Pump actually works, as technologies are supposed to, can only rarely be answered with a clear-cut 'yes' or 'no'. Instead, there are many grades and shades of 'working'; there are adaptations and variants. Thus the fluidity of the pump’s working order is not a matter of interpretation. It is built into the technology itself (de Laet and Mol, 2000, p. 225).”

For de Laet and Mol the boundaries of the bush pump are multiple and each of the boundaries of the pump “define a limited set of configurations” (2000, p. 237). “They each, one might say, enact a different bush pump” (2000, pp. 237-38). Thus, like de Laet and Mol, who refer to the bush pump as a fluid technology, I think of RF as a ‘conglomeration of the various instruments that are used to facilitate RF’, i.e., are needed to get replacement milk (formula) into a baby (2000). These instruments could include bottles, kettles to boil water and so on. Important, however, is the fact that while what these instruments are and how they may be used can vary, the final product would be the same: namely an object that is able to make and convey replacement
milk into a baby. RF is thus both a stable object and a process that involves multiple contingencies. Of particular interest to me are the different HIs that RF takes part in enacting within the HIV diaspora.

Mol and Law consider how the diagnosis, problems, prevalence and the methods of diagnosing anaemia vary within and between the Netherlands and Africa (1994, p. 644). They point to the varying methodological decisions that are part of the way in which boundaries around regions are drawn, methods and technologies are used to detect, diagnose and treat anaemia. Following this they argue that anaemia may be enacted differently in different geographical spaces (1994, p. 646-47). In their example, a Dutch doctor flowing between the Netherlands and a clinic in Zimbabwe takes with her ‘her’ anaemia which may transform as it moves. For them “…fluidity generates the possibility of invariant transformation (Italics in original) (Mol and Law 1994, p. 658)”. They argue, the anaemias found in Africa and the Netherlands exist within a fluid space (Mol and Law 1994, p. 658). This space does not have clear boundaries, nor does it generate well defined objects or identities (1994, p. 658-60). The way in which anaemia may flow between geographical regions is an empirical question: “[it] may flow in people’s skills, or as part of the attributes of devices, or in the form of the written word – any or all of these may carry anaemia 1994, p. 664).

Following this work, Mol famously argues that the object does not pre-exist its own enactment. As a result of disease being enacted in practice, it is possible for the same disease to be done differently in different environments (2002, pp. 35-36; Law 2009, p. 152). In other words, the same diseases are ontologically multiple (Mol 2002, p. 46) if and when they are enacted differently. Thus what HIV is, and the effects that it has,
are particular to the environment wherein HIV is enacted. In other words, a patient’s body and disease may be *done* differently. Furthermore, her arguments suggest that a patient’s virus would *not* pre-exist its enactment through practice. Importantly, Mol would not say that HIV becomes a material reality only if and when it is enacted. For example, a person with undiagnosed HIV will still be subject to the progression of the disease, although the pathologies experienced may be attributed to some other malady.

Drawing on Mol social scientific researchers have considered the way in which HIV (biomedical) technologies are developed and used in different and unexpected ways (Rosengarten and Michael 2009; Montgomery 2012). Like this, Rosengarten and Michael consider the potentiality of pre-exposure prophylaxis (PrEP) - an HIV prevention technology - as both stable object and process involving multiple contingencies (2009). They illustrate how PrEP is connected to multiple futures which in turn relate to multiple presents that are the conditions on to which the futures are possible (2009, p. 1049). They suggest it becomes conceivable to extend the possibilities of HIV technologies by centring their expectation (2009 p. 1049). Relatedly, Montgomery explores the way in which the vaginal microbicide was imagined as having the ability to empower African women and prevent HIV transmission (2012). Montgomery’s case demonstrates “… how scientific practice is intimately bound up with prevailing social norms and political agendas (2012, 925).” Consequently, the *success* of an HIV prevention technology is not straightforward – and does not only concern the technologies’ ability to prevent HIV transmission (2012, p. 939). Influenced by this work I contend that HIV, expectations of HIV and HIV technologies are ontologically multiple. However, this article’s main focus is on the
ontological multiple HIVs that RF takes part in enacting within the fluid space of the HIV diaspora.

Race and geographical movement

One of the main criticisms directed towards Mol’s work is that it fails to adequately acknowledge the researcher’s role through the act of conducting research and how it is an integral part of the “intervention” that is being observed (Gad & Bruun Jensen 2010). Thus, while Mol and Law are white Europeans researching the relations between the Netherlands and Africa – an engagement with their positionality, (the effects of) colonialism, race and racism is conspicuous in its absence. Mol and Law do not question the conditions that allow (white) Dutch practitioners to work in Africa; flow over borders; compare the Netherlands to Zimbabwe; take pleasure in discrimination; or describe (Black) African technicians as not meeting European standards (Mol & Law 1994, p. 651). Moreover, while they limit their analysis to the movement of European professionals - we can safely assume that anaemic Africans (be they professionals or not) may also flow across borders taking with them their anaemia which may likewise transform as it moves. Following this, the ‘anaemic African’ (and people connected to her) would also contend with ontologically multiple anaemias in disparate locations. However, the experience of this ontological multiplicity would presumably be different for them. Here, the significance of the researcher and her positionality, the locations wherein empirical material is gathered and what that material is becomes clearer.

An integral and overlooked aspect of the researcher is the way in which she is racialised and her geographical location(s). As such, race and place are part of every
aspect of a researcher’s research; the methods and methodological approaches she chooses, the interventions she observes, how she makes sense of them and the geographical spaces she observes them in and from; the way in which she is treated in these spaces and the way she imagines and communicates with her audience. In other words, race and racialised bodies are part of every aspect of Mol and Law’s research – despite remaining unnamed. Importantly, the failure to name and explore race, and the way in which it took part in their research and in the enactment of the anaemias they observed, in their disseminated materials, means that race and its effects may continue to remain invisible.

The (ethnographer’s) ability to see the practices that enact race is perhaps a skill that must be learned. Much like the (white) Dutch physician who “discovers that there are pallid skins” in her Zimbabwean clinic, but relies on the (Black) local nurses to help her “see” that the (highly-melaninated Black) “skins” are in fact “pallid” (Mol and Law, 2000, p. 658). Similarly, and drawing on Mol, Amade M’charek posits race as ontologically multiple (2013, p. 424). She argues: “…race does not materialise in the body, but rather in relations established between a variety of entities, including bodies” (M’charek 2013, p 434). The entities that enact race are not always or “inherently racialized” (M’charek 2013, p 434-35). Drawing on this literature I attend to the relations that materialise race – and explore the consequences of this for the clinic’s patients, myself and (this) research. In what follows I will describe the methods and methodological approach used to conduct this study.

Methodology
This article draws on a doctoral project that involved a nine months-long ethnographic investigation into a once-weekly HIV specialist antenatal clinic housed within an acute National Health Services hospital in London. The hospital is home to one of England's busiest HIV centres. The research investigated the way in which HIV was enacted in social, clinical and technical domains. Thirty women were cared for in the clinic during the course of this project. Four of these women were born in the UK and were mixed race (either white British and Black Caribbean or African), while the rest of the women (n. 17) were Black African and from different countries in Sub-Saharan Africa.

My initial access to the clinic was negotiated with the help of one of the clinic’s consultant physicians, Anne. Members of staff were informed about the project via emails from Anne and Sophia, an HIV specialist doctor, and during meetings with me. I would seek verbal consent from members of staff to attend meetings, consultations and otherwise spend time with them. The process of recruiting patients was as follows: practitioners would tell patients about the project during their regular appointments, seek verbal consent to be introduced to me and offer them the Participant Information Sheet (PIS). If they agreed, the practitioners would introduce me to the patient during her next appointment. I would join the practitioner and patient in a consultation room where I would speak to the patient about the project and seek verbal consent to attend the consultation. Moreover, I would seek verbal consent from patients that had consented to be introduced to me, before I spent time with them in other areas of the hospital.

Sophia, a Black HIV specialist doctor told me that patients would often ask her where I was from before they agreed to meet me. The extract from my field notes below is
illustrative of the questions patients asked Sophia about me. The patient in question had seen me in the waiting room and knew that I was the person Sophia was referring to.

… the last patient had asked if I was from here: “is she from London”; as soon as Sophia had told her that I was from the US and Sweden she was ok to have me sit in. Sophia said that she felt that my [North American] accent worked to my benefit; people did not “read” me as being from “here” (2008).

Not mentioned in the notes above is the crucial fact that I was not read as a Black woman from here, i.e., a Black woman of either African or Caribbean decent. Similarly, Anne, a white consultant physician, warned me that many Black African patients living with HIV preferred to speak to white professionals. However, she also said that it might be possible for me to gain some kind of insider knowledge because of my ethnicity and nationality: being Black but a different kind of Black. Moreover, two Black practitioners and I often discussed the status and effects of our Blackness/ethnicity and the reasons why many Black patients expressed a hesitancy to meet Black (care) professionals. They thought that Black patients that expressed a reluctance, did so because they feared that the professional in question might be connected to their lives outside of the clinic.

Being Black African has been quite interesting, because I’ve had patients not, actually, being quite wary of seeing me, because they don’t know where I’m from, I mean, I’ve lived here most of my life, but I’m still African, but I’ve had, you know, patients that have been quite wary of seeing me … but it’s also worked to my advantage, because I’ve had quite a lot of women saying to me
‘I quite like talking to you, because I feel you understand’, and I do, sometimes I suppose I do understand things that somebody, someone can say something, I can actually understand where they are coming from, even if I’m not from the particular culture, but I can understand it, I believe better, than somebody who isn’t African. (Laura 2009).

In my case a North American accent served to persuade patients that despite my Blackness I was not part of their group. Indeed, all of the patients that I interviewed broached the subject as well, usually to speak of my perceived “American-ness” as being one of the reasons why they eventually felt comfortable with me, despite my being Black. ‘American-ness’ turned my ‘Blackness’ into a tool that signalled the possibility of intimacy. Whereas had I been a different kind of Black – blackness would have indicated the possibility of disclosure of their serological status to other members of our group. Thus, my accent and race encouraged patients to share their experiences with me in more detail. I was sufficiently close but also sufficiently other. Whereas the Black practitioners assured patients that while their British African-ness included them into the groups – this inclusion could lead to greater intimacy rather than harm. The practitioners did this by eliciting intimate relationships with patients over a period of time. These relations allowed the practitioners to demonstrate their trustworthiness. In the extract below Sophia discusses how she thought her patients felt about her being a Black professional.

I think sometimes some people feel more empowered when they see that there is someone Black [in the clinic] and they feel: Oh ok, that there’s a kind of thing, feeling that you’re Black and you’re not a kind of a worthy part of society, but
when you see someone in that whole thing, that’s a doctor, it’s the kind of thing, oh there are actually Black people that are doing quite well, that kind of thing, and it’s very important to a lot of people, more than I will ever understand … it’s a kind of justification for their role in British society (Sophia 2009).

Race is an important part of (this) research. And the way certain things about me, and the patients and staff in the clinic — such as the colour of our skin, our accents, and our perceived nationalities, professions and our knowledge and understanding of one another — were part of the practices that enacted race. Incidentally, none of the patients ever remarked on the fact that I am also Swedish. I mention this because my ability to fund the research, *flow across borders* and live securely in the UK were enabled because of my Swedish nationality. Thus, this *variable* was part of the practices I observed in the clinic – in that my Swedish nationality was one of the components that enabled me to be in the clinic - while simultaneously remaining unnoticeable. I, much like Mol and Laws (medics), flowed across borders in a way that most of my patient research participants did not and could not.

Sophia asked some of the women who had consented to let me observe their consultations if I could interview them. If they agreed she would give them my contact information. Research participants only signed a consent form if they were interviewed. Interviews with practitioners lasted for about one hour while interviews with patients lasted between one to three hours. All of the interviews were recorded and later transcribed by me. Pseudonyms were given to all research participants.
In the course of my observations, I followed twenty-one patients through their pregnancies and had the opportunity to approach 13 patients for interviews of which 10 agreed. I excluded one woman because I had concerns about her voluntariness. Thus, I ended up interviewing 9 patients. The patients I interviewed were originally from Angola, Burundi, Cameroon, the Congo, Ghana, Jamaica, Malawi, Nigeria and Zambia. Three of these women described themselves as having secure migration status. Second interviews were held with three women and a third interview with one woman. Interviews were conducted with five practitioners; second interviews were held with the two practitioners who regularly met with patients in the clinic – Ellen, an HIV specialist midwife and Sophia. Three of the practitioners interviewed were white British, while Sophia, and Laura, an HIV specialist paediatric nurse, were Black women of African descent, one UK born, and one from South Africa. This paper focuses on the interviews with patients and staff which are offered to give insight into findings from my broader ethnography. The study received research ethics approval from Goldsmiths, University of London and the NHS research ethics committee (08/H0809/6)). Data analysis took place in NVivo, using an adapted Grounded Theory approach.

During initial coding I noticed the importance the practitioners placed on finding out a patient and her family’s immigration status. Moreover, all of the women whose pregnancies I followed that were born outside of the UK (n.17) frequently expressed apprehension over their own or their family members’ migration status and/or circumstances associated with HIV in their countries of origin. Following this, issues related to immigration permeated all of the data collected. Consequently, during data analysis I created the following codes in NVivo for “establishing immigration status”, “worrying
The significance of these initial codes became apparent as I collected and analysed more data, eventually leading me to create the theoretical code “diasporic issues” (Charmaz, 2006, p. 45, 63). This term signalled a theoretical direction that emerged from the data collection and analysis, and later, led to the theoretical concept of an HIV diaspora. In what follows, I attend to the way in which RF takes part in enacting ontologically multiple HIVs within the HIV diaspora. The findings section is divided into two main themes that (1) show how the practice of RF promises to prevent VT while also disclosing HIV and (2) the way in which (previous) geographical location came to matter and makes chronic HIV an impossibility for HIV diaspora women.

Replacement feeding - preventing HIV transmission and detecting HIV

Eleanor and I met during her second pregnancy. She was originally from Malawi and had been diagnosed in the UK before her first child was conceived. Eleanor was single and her asylum claim had been rejected. After having exhausted her right to appeal the decision she was no longer entitled to welfare provisions. She was therefore forced to survive on the financial assistance her infant daughter received. Eleanor had little hope of being able to legally remain in the UK.

Her mother, who lived in Malawi, warned her never to reveal that she was not breastfeeding. Eleanor’s mother explained that people in Malawi would begin to suspect there was something “wrong with [her]”, if they knew the truth (Eleanor 2009). This conversation led Eleanor to believe that her mother suspected her of being HIV-positive, although Eleanor had never directly disclosed her status. Eleanor thought her mother had begun to suspect the truth after she had found out she was RF. Eleanor’s
mother’s expressed distress concerns the likelihood that other Malawians would use RF as an HIV detection device in the same way she had used RF to detect HIV in Eleanor. In accordance with her mother’s advice, Eleanor came up with elaborate strategies to trick people (both Malawians and other Black Africans) into thinking that she was breastfeeding.

Author: So much of your problem with breastfeeding is with other people?

Yes, so when they are coming to see the baby, I have to feed her before they come; I like ask them what time are you coming, are you on your way now, I keep on calling them, so I can give her her milk before they come; and they think my breasts are small, so sometimes they say are you breastfeeding? I used to lie that there is no milk coming out (Eleanor 2009).

I was on the bus, [the new-born] was crying. I tried everything. I gave her a dummy. So this [African] lady, she wanted me to give her milk. I had milk, but it was too hot [...] so this lady says “the baby is crying too much, give her the breast, don’t be afraid of everyone; come sit here, give her the breast.” That’s what she was telling me, you know, “give her the breast, sit there, don’t be ashamed!” I looked at her and said, “no, she doesn’t want breast, I have given her food already”. One thing that lady kept saying to me, one thing I cannot understand, she kept on saying “my baby is crying” — I didn’t like it, I ended up insulting her. I told her I am the mum, I know best. Because she kept on insisting that I give the baby breast and that really just affected me and offended me [...]
I had to get off at this stop where I was not getting off because people were looking at me (Eleanor, 2009)!

Eleanor tried to avoid bottle feeding in front of her visitors and the woman on the bus because they were Black African. Eleanor thus extended the geographical reach of her mother’s warning to include all Black Africans and not just Malawians. In this way, her concern is not restricted to national boundaries per se – but to broader geopolitical locales and racialised peoples connected to them. By not publicly bottle-feeding Eleanor protected herself and her baby from a practice that would take part in the enactment of HIV positivity and lead to rejection. However, not publicly breast-feeding excluded Eleanor from significant social interactions. This was particularly upsetting for Eleanor because she was desperately lonely. She longed for the intimacy, with other Black Africans, she felt publicly breastfeeding would lead to.

All of the patients I interviewed also used RF as a way of identifying other Black African/Caribbean women living with HIV. In regards to this Eleanor explained to me how she met the Black African young single mother living with HIV that eventually became her house mate and close friend.

… [Social Services] took us to this hotel, the B&B, so I found that there were other mothers with babies there, small babies and everything. So how I knew, was I could tell no one was breastfeeding amongst ourselves. Cause you see, we’re like family, Oh there is this one in this room, that one in that room; Oh, let me see your baby … and I could not see anyone even breastfeeding … we could just tell, even all of us, all of us were going to get milk one place, and
people who get that, who are like HIV-positive. So we could tell ... that’s how I just knew, she is and afterwards we just started talking about it (Eleanor 2008).

While not being explicitly mentioned by Eleanor, in the extracts above, the woman on the bus and the women in the B&B were Black African. Thus, race and (previous) geographical place are part of the significance of their interactions. For Eleanor and the other women living with HIV that I interviewed the practice of RF becomes an HIV detection device, rejection is particularly painful and intimacy more meaningful when the practices that enact them materialise with Black African migrant. HIV is thus enacted through practices that promise the prevention of HIV transmission when these practices take place in England and are combined with particular enactments of race (i.e., Black and African but not I would argue Black and Northern American). In what follows I will show how RF is used as a device that can detect HIV in HIV diaspora women and their children.

Replacement feeding preventing VT of HIV while transmitting HIV

Elisabeth was originally from Zambia and had permanent residency in the UK. She had been diagnosed in the UK before conceiving her first child. We grew close during the course of her second pregnancy. She would often speak to me about her violent husband. Elisabeth and her son had suffered severe mental and physical abuse at the hands of her husband and they both lived in fear of him. Her extended family suspected Elisabeth of being HIV-positive and she feared they would try to find out if she was RF. Elisabeth thought they’d assume that she and her children were living with HIV if they found out that she wasn’t breast feeding.
Because they will treat [her son] differently, and I have seen it! At times, with some of the cousins, the way they will behave, and it’s because they know that I am, they figure: Oh maybe even the child? So stay clear of him, don’t move his stuff (Elisabeth 2008)!

I know [having the baby] [is] going to be another struggle again. ‘Cause they’ll be constantly watching me, my cousins thinking: oh, she’s not breast-feeding on this one as well! ‘Cause it was the same last [time] with [name of a relation] she hasn’t breast fed! … That’s how it started, checking up and seeing and sorts. Even after he was born, one of my aunts came to the house saying: Oh they’ve heard something, they have to ask me something, and one of my cousins had been saying I’m ill. I’m ill? What am I suffering from? She just told me I’m ill. She goes ‘well we hear you’ve got this disease that has come these days, this illness’. I say what illness has come nowadays? You tell me what you’re talking about! She says ‘Oh you’ve got AIDS!’. I say ‘I’ve got AIDS’? I say ‘well since the person that told you is my doctor, she’s got her facts right, then listen to her’! And she goes, is that what you’re saying? And I say yeah that’s what I’m saying, And if anything, if I’m going to die, if I’m going to die alone, I’m not dying with you! I’m dying alone! So you listen to whatever people want to tell you and take that! So they were like shocked. I don’t care at the moment, I just need to take care of the little one. At that time I think he was only two, two weeks old so they didn’t even care to say; Oh she’s got a little one we shouldn’t be depressing her or doing anything, they just had to come in, poke a little bit and see how the cookie crumbles! See how she crumbles and enjoy (Elisabeth 2008)!
Being associated with practices that are known to prevent VT discloses the HIV diaspora woman’s serological status and transmits HIV to their children. In other words, the practices mark both mother and baby as HIV-positive irrespective of the materiality of the virus as it may or may not be in the mother and babies’ bodies. As an important aside, Elisabeth’s husband maintained that he was HIV-negative and this claim was never questioned. I argue that concern over transmission risks pertain to ontologically multiple HIVs that are transmitted from mother to baby through the practice of RF – but not – in Elisabeth’s case, between husband and wife through sexual intercourse. It appears contradictions abound.

The women’s experiences as I have described them illustrate the complex ways a technology can simultaneously be helpful and harmful. Furthermore, as “a device installed by the community” one of the “boundaries” of this aspect of RF’s identity is firmly constructed around and generative of a hostile way of viewing HIV and mothers living with HIV (de Laet & Mol 2000, p. 252). Consequently, in this circumstance, and to continue to use de Laet’s and Mol’s terminology, RF as a fluid technology “contains”, as a “variant of its environment” (2000, p. 252), both the ability to protect an infant from HIV and also the ability to disclose its mother’s HIV status and expose her and the infant to censure and/or intimacy within the diaspora. Moreover, in what follows I will show how the process of gaining access to the materials needed to practice RF may also be harmful for HIV diaspora women.

The impossibility of chronic HIV for diaspora women

Laura, an HIV specialist paediatric nurse, explained the steps she would have to go through in order to procure formula for women who were not in the UK legally. Laura
would occasionally have to request financial assistance from Social Services for
women who did not have the funds to buy formula. However, for women who were in
the UK illegally, accessing these funds was conditional.

You can’t just say, well I’m illegal, I want milk! You know, you’re illegal, but we
need to get them to get to a point where maybe they’re trying to be legal, so
maybe in the meantime get them to get a solicitor; get them to start processing
them and their immigration because the fact that they are processing and they
are recognised, then at least, because children in this country have rights, any
child born here, so I use that as an argument to say ‘actually, this child has a
right to be HIV-negative’, because you know they need to get that chance
(Laura 2009).

The steps taken to procure formula evidences the complicated situation mothers find
themselves in. On the one hand, they need to procure formula in order to ensure that
their baby remained free of HIV. While on the other hand, exposing themselves to the
Home Office, especially if they felt their chances of being granted leave to remain in
the UK were slim, would pose a tremendous risk (DOH 2016). Therefore, the rights
that Laura says the child would have as a result of being born here, would ostensibly
protect the child from HIV for a period of time (the first six months of the child’s life
during which it will exclusively consume formula), but not after this. Such as after the
baby’s mother becomes unwell and/or dies as a result of both mother and baby being
deported to a country without access to adequate HIV technologies and care. To
reiterate, according to Laura the child is bestowed with legal protection from the
material real of HIV as it may be transmitted via its mother’s breastmilk for a period of
time. However, taking advantage of that protection may led to the mother and her
baby’s deportation. In other words, if the mother enacts the ‘child’s right to be HIV-negative’, she simultaneously exposes the child and herself to another kind of threat. This dilemma harks back to the choices mothers living with HIV in countries wherein RF is not advised, face i.e., ‘protect the baby from contaminated water by breastfeeding and risk transmitting HIV to the baby’ or ‘protect the baby from HIV transmission via breastmilk and risk killing the baby via contaminated water’. Moreover, as discussed above, in England, protecting babies born to HIV diaspora mothers from breastmilk exposes the baby, its mother and any other children she might (already) have to being marked as HIV-positive.

All of the women who had a tenuous immigration status expressed to me their fear of being “sent home”, which was for them synonymous with being sentenced to death. Women who felt themselves to be at risk of deportation realised that they would not have indefinite access to the kind of technologies and care available to them in the UK. Consequently, the way in which the women imagined their own and their children’s futures were intractably related to their ability to remain in a location wherein HIV is a chronic condition. Women thus positioned constantly attempted to negotiate and coordinate between these contrasting locations - with their ontologically different HIVs and their associated life trajectories – for both mother and baby.

Sophia summed up the essence of this during a medical consultation with a postnatal patient with an insecure immigration status, who was petrified of dying. She explained that the patient’s fear of dying would be appropriate if the patient were in Ghana, but as long as the patient was able to remain in the UK, she could expect to live if she adhered to treatment. Underlying Sophia’s discussion about the patient’s life
prospects depending on her geographical location was the fact that the patient was living in the UK illegally. So, while Sophia was offering the patient reassurance that her life was not in danger now, she was simultaneously acknowledging that the patients' life would be in danger in the future. Laura echoed this sentiment.

...having an HIV diagnosis where they're going to need treatment could mean that they have to stay in the UK to get that treatment and to, to live and therefore they're restricted in what their future might be, and there's also the issue of whether we will let them stay in the country (Laura 2009).

Like this, the Home Office took part in the practices that enacted HIV for the diaspora women. Eleanor was frightened of being sent back to Malawi. She explained that she had seen what the lives of people living with HIV were like there. After witnessing her sister’s rapid physical deterioration and suffering after being diagnosed, Eleanor believed a similar fate would befall her if she was forced to return.

I can’t go back home no matter what, honestly. If it means sleeping on the streets, I'll sleep on the streets ‘cause I can’t go there; it's like they are sending me to go and die [...] it’s a matter of life and death. So, I have to choose, if I’m going I have to choose, I’m going to die and I don’t want to die now (Eleanor 2008).

Originally from the Congo, Alegra’s fears for the future were similarly compounded by her immigration status. Her ability to live and to imagine a future for herself was dependent on being able to stay in the UK. Her solicitor had made an application on her behalf for permanent residency, citing her medical status as the incentive but the Home Office had rejected her case. I asked Alegra how this made her feel.
You living here illegally is not good! They can send you back to your country and what should happen to me? *Just die!* … If they send me back I’m not going to live, but if I’m here I will live, I can work also, I can do everything people are doing here but not in Africa (Alegra 2009).

Evelina had recently given birth when we first met. She was the only patient I interviewed whose pregnancy I did not follow. She was originally from Jamaica and reeling from the heartbreak she had suffered as a consequence of finding out that she was HIV-positive. She was almost certain that her ex had known that he was living with HIV and had knowingly put her at risk. Evelina ended what she considered to have been a near-perfect relationship and was consequently without a home or a means of support. She was living in the UK illegally but had been able to comfortably support herself and her young son (who was cared for by a relative in Jamaica) with the financial assistance of her ex-partner. She explained that despite not living with her son she had felt like a good mother for the duration of her relationship with her ex-partner. The life she had coveted before moving to the UK had felt within reach and she was in a stable relationship with a man she thought was wonderful.

Without explicitly saying so, Evelina implied that her relationship with her current partner and the father of her new baby was dependent on her being sexually available to him. Her living situation felt precarious and unsafe. However, the most devastating repercussion of the end of her previous relationship was that she could no longer send money back home to support her son. Evelina had not felt able to tell him why she had stopped calling and sending money. She was plagued with worry that he would feel unloved and would be abandoned by the family member caring for him.
Evelina felt that HIV was tolerable now, only because she had the support of the practitioners at the clinic and access to medication. She thought it would be very difficult, but just about manageable, to support two children and herself in Jamaica, if she were not living with HIV. Being HIV-positive made imagining a life there impossible for her. She expected to die if she was deported and she didn’t know how her children would survive without her.

I don’t really think about life — things that are in the world, because you’re just going to go away and leave [her children]. It’s just done me different. HIV just … I don’t have any hopes or dreams. Sometimes I don’t really bother (Evelina 2008).

She feared what people would think of her if she was forced to return and the effect that this would have on her and her children’s lives. Evelina felt that people would be less inclined to help her if she needed it because they would consider her a person who had squandered a coveted opportunity.

They would think that I made a whore of myself … They’d think I whored all over the place. That’s what they’d think … they have a thing like this if you went away … you went somewhere where the money was given away so you should have come back with a lot of it (Evelina 2008)!

Evelina fears being excluded from a collective that would normally protect her and her children. Her rejection would result from the fact that people in Jamaica would think she had failed to take advantage of the privileges that she was assumed to have had access to. Therefore, from Evelina’s perspective, failing to be appropriately enhanced by the resources thought to be available in a privileged geographical location — and even worse, becoming HIV-positive — would make any re-admittance and acceptance
into her previous home an impossibility. She is thus in limbo, as are her children. Consequently, she is unable to secure decent lives or futures for herself or her children in either location.

Most of the women I interviewed had relocated to the UK only after their families and communities had made tremendous sacrifices. They had expected to prosper in the UK, repay debts and support children and extended family networks. The women were often the sites onto which they and their families’ placed dreams of future prosperity. The fantasy of this imagined future ended as a result of their HIV diagnosis. Instead, the women spoke of themselves as having changed from being full of potential to becoming liabilities for their children and family members (Kelly et al., 2012; Tariq, 2013).

Discussion

Through the accounts of my research participants, I have explored how within the fluid space of the HIV diaspora certain objects and practices – such as RF, race/ethnicity and migration from a geographical place wherein HIV is life-limiting - come together in specific relational configurations (M’charek 2013) and enact HIVs that are different from the HIVs enacted outside of the diaspora. The analysis suggests that when HIV diaspora women RF their babies, the practice takes part in the enactment of ontologically multiple HIVs while simultaneously being used to prevent HIV transmission. The HIV that is transmitted is gendered, in that it is transmitted from mother to baby but not between the mother and her male sexual partner(s) and it is also racialised and decoupled from the material real of the virus. Having said this, practitioners in the clinic are actively aware that HIV as it is displayed in the clinic by
the technologies that are used to come to know HIV - such as viral load assays that ‘read’ the amount of virus in blood samples - do not produce information about the material reality of the HIV in a patient’s body in real-time (McKnight & van der Zaag, 2015). Thus, the HIV displayed in the clinic is not “unaffected by technologies involved in [its] representation” (Rosengarten 2009, p. 24). Instead, the practices and technologies that are used to come to know HIV in the clinic become part of what HIV is. RF is particularly significant because it is used outside of the clinical environment to detect HIV in both HIV diaspora mothers and their babies.

Importantly, RF only becomes a device used to detect HIV when the objects mentioned above, ‘race/ethnicity’ and ‘migration from a geographical place wherein HIV is life-limiting’, are part of the configuration. This becomes clear when we consider that not all women in the UK who abstain from breastfeeding would be suspected of living with HIV, considering that according to the most recent Infant Feeding Survey, only one in one hundred mothers in the UK followed the NHS guidelines of exclusively breastfeeding their babies until six months of age (McAndrew et al. 2012, p. 4). Thus, the overwhelming majority of women in the UK RF their babies. Hence, RF only becomes a HIV detection device within groups that are already constituted as being potentially HIV-positive (Montgomery, 2012, p. 922), in this case Black African/Caribbean migrants. The combination of ‘Black African/Caribbean’ and ‘RF in England’ come together and enact HIV positivity for both mother and baby.

The practice of RF has the potential to forever subject the women and their children, to ontologically multiple HIVs. In other words, fulfilling NHS advice to RF means that HIV diaspora women will take part in practices that may prevent transmission of HIV
while also transmitting HIV. Thus, the women’s experiences illustrated how RF functioned as both an HIV prevention and a detection technology within the fluid space of the HIV diaspora (de Laet & Mol 2000; Tariq et al. 2016). In this way, the practice of RF for HIV diaspora women promises a life lived free of HIV for the baby, while simultaneously enacting the baby and its mothers HIV positivity.

As a detection device RF may lead to harm but it may also lead to more intimate relationships with other women who are also part of the configuration and are thus similarly positioned. Following this, race was used by HIV diaspora women as a signal that alerted them to the possibility that a racialised person might be part of the diaspora as well. The Black professionals in the clinic and I felt that this could work in our favour at times – but only after patients were assured that the shared experience of being racialised would not be harmful. For Laura, being African helped her understand the women better. And Sophia felt that being a successful black medical professional validated her Black African patients. In my case Black Americanness firmly indicated that I was situated outside of the HIV diaspora but also suggested the shared experience of being a racialised migrant in England.

This article has shown that different relational configurations – connected to race, migration and the unequal global distribution of advanced care and HIV prevention technologies – in particular RF - enact ontologically multiple HIVs. We should think about these (unwanted) effects of RF as being part of what RF is for HIV diaspora women. This would require a move away from the idea that it is the patient’s “culture” or family that would lead to the stigmatisation of RF and instead position the decoupling of HIV in some locations, but not in others, as being the real culprit (or source of the problem). The women’s predicament is not the result of different
understandings of HIV in different geographical locations. Instead, the issue concerns the HIV that is enacted within the HIV diaspora. This is important and shows that the issues this article raises cannot be addressed by educating affected individuals about the materiality of the virus or the effectivity of HIV prevention efforts. Therefore, what matters are the various technologies, (bio) medicines and care that are on offer and the socio-historical and economic contexts and positions of people living with HIV in a particular geographical location. Additionally, however, what is or is not on offer, and the socio-historical and economic contexts and positions of people living with HIV in other geographical locations, also matters. For example, as Tariq et al. have argued, a mother living with HIV in the UK who is strongly advised not to breastfeed may find it more difficult to adhere to her care practitioners’ advice because she knows that HIV-positive mothers elsewhere are advised to breastfeed their babies (Tariq, 2013, p. 275).

Preventing VT was a desirable goal for the HIV diaspora women I interviewed. However, even if they succeeded, their children’s lives were still under threat because of HIV. If the mother is deported, the mother’s potential or eventual death would be the most extreme effect of HIV on the baby’s life. Accordingly, being born free of HIV does not mean that the baby won’t suffer and potentially die as a result of HIV. Because she is aware of this precarious situation, an HIV diaspora mother living with HIV simultaneously negotiates her own and her children’s future expectations in multiple geographic locations – with their ontologically different HIVs. Fear of the future has a real and immediate effect on the women’s lives in the present. This fear is part of the practice of RF for HIV diaspora women in locations where RF is a practice used to prevent and detect HIV.
In conclusion the ontological multiplicity of HIV makes it possible to see that different HIVs may require different care regimes. Following this and considering that babies born in the UK have the right to live free of HIV and people living with HIV in the UK have the right to HIV care – the requirements of a life free of HIV and care for HIV would be different depending on what HIV is. In other words, the HIV enacted within the HIV diaspora would require different care then a chronic HIV. If we centred the expectation that HIV care in England should enact a chronic illness and prevent VT (Rosengarten and Michael, 2009 p. 1049), and positioned these expectations as rights – we could perhaps begin to rethink what would need to be done to ensure that HIV diaspora women could expect to live with HIV and continue to ensure that their children may live lives free of HIV.

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