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Infant feeding as a transgressive practice in the context of HIV in the UK: A qualitative interview study

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ABSTRACT

HIV transmission risk via breastfeeding is greatly reduced by antiretroviral therapy but is not zero. Current UK guidelines recommend exclusive formula feeding; however, women can breastfeed if they meet certain criteria. We examine the narrative accounts of mothers with HIV (pregnant or recently given birth) who navigated divergent cultural and national policy norms regarding infant feeding.

Mothers with HIV, the majority of whom in the UK are of Black African ethnicity, face a complex decision regarding infant feeding, which has implications for their sense of identity, belonging and citizenship. While the UK has one of the lowest breastfeeding rates globally, breastfeeding is normalised across African and Asian cultures. However, HIV remains stigmatised and formula feeding could signal one's HIV-positive status. Our participants made difficult trade-offs to mitigate the variety of threats they faced, and both feeding options (breast or formula) felt transgressive, with immense hazards involved for these intersectionally-disadvantaged women.

1. Introduction

This study explores how women¹ living with HIV in the UK navigate powerful and contradictory medical and social discourses regarding motherhood and infant feeding. UK clinical guidance ([British HIV Association, 2020](#)) recommends formula feeding of babies born to mothers with HIV, but this policy position exists alongside multiple cultural and social discourses that promote breastfeeding. We use the concept of transgression (the idea that people act in ways that breach existing authoritative social or legal codes of behaviour) to understand this phenomenon. When conceptualising 'sexual transgression,' anthropologists [Donnan and Magowan \(2009: 3\)](#) describe how "transgressive nonconformity allows us to see through issues of power and control that are variously public and private, implicit and explicit, verbalised and embodied across a range of diverse social structures and cultural forms."

Through a feminist lens, we explore how structural and social forces that surveil and control new mothers with HIV push them into transgressive spaces, *irrespective* of how they feed their babies. We show how the divergence between national and international policies, in combination with the social position occupied by new mothers with HIV in the UK, makes their infant feeding choices (whether breast- or formula) appear transgressive and non-normative. We start by presenting a brief description of the clinical and socio-demographic contexts for this research.

1.1. HIV and infant feeding

HIV prevalence in the general population in the UK is very low at <0.15% ([National AIDS Trust, 2019](#)) and while HIV remains prominent within public health discourse in high prevalence countries, this is not

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¹ We use the terms 'women', 'mothers' and 'breastfeeding' instead of 'birthing parents' and 'breast/chest feeding' in this paper. Although our study was open to gender diverse participants (they could be anybody living with HIV and either pregnant or recently given birth), and we used gender-inclusive language in our recruitment materials, we only heard back from cisgender women. We recognise that there will be additional nuanced experiences for transgender or non-binary birthing parents living with HIV and deciding how to feed their babies while also navigating the wider healthcare environment.

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the case in the UK. However, the enduring association of HIV with perceived 'transgressive' sexual and/or injecting drug use behaviours, and with the early epidemic of the 1980s when HIV was almost universally fatal, leads many people living with HIV to maintain secrecy about their HIV status (Hedge et al., 2021; Hutchinson & Dhairyawan, 2018; Rai et al., 2018).

The potential for HIV to be transmitted during pregnancy, childbirth and breastfeeding, was recognised early in the HIV pandemic. However, as a result of routine HIV testing in pregnancy, antiretroviral therapy (ART) and pre-conception counselling, the UK rate of vertical transmission (to the infant during or after pregnancy) is low at 0.22 % (ISOSS, 2021). Approximately 700 women living with HIV give birth in the UK each year. Despite the excellent clinical outcomes of pregnancy, mothers and pregnant people living with HIV commonly report emotional distress, fear, anxiety and isolation as a result of HIV-related stigma; this is especially pronounced during pregnancy and early parenthood (Greene et al., 2016; McLeish & Redshaw, 2016; Sanders, 2008).

In the UK, any person living with HIV who has <50 copies of HIV per millilitre of blood (<50 copies/mL) is clinically regarded as having an "undetectable" viral load. Virological suppression (having a sustained undetectable HIV viral load) is achieved through access and consistent adherence to antiretroviral therapy (ART), which is available free of charge to all people in the UK with an HIV diagnosis). In one of the most triumphant medical achievements in HIV history, there is now unequivocal evidence that a person on ART with an undetectable HIV viral load cannot pass HIV on to sexual partners (Rodger et al., 2016; Rodger et al., 2019). This is known as "U=U" or "Undetectable Equals Untransmittable" (Eisinger et al., 2019), and is a status recognised globally by most major HIV organisations (NAM Aidsmap, 2017).

Unlike sexual transmission, there is currently no consensus on whether U=U applies to breastfeeding, partly due to limited data (Waitt et al., 2018). The risk of HIV transmission through breastfeeding is estimated to be 14 % when the breastfeeding parent is not on ART (Dunn et al., 1992); it is greatly reduced when the breastfeeding parent is on ART, but it is not zero. The largest clinical trial to date, conducted in several African countries and in India, demonstrated a 0.3 % risk of HIV transmission after six months, and 0.6 % risk after one-year of exclusive breastfeeding by mothers on ART (Flynn et al., 2018). While these are population estimates, for an individual case, transmission risk via breastfeeding will depend on maternal viral load, as well as other clinically-relevant factors such as maternal HIV seroconversion and breast conditions such as mastitis. Notably, there is a lack of research on HIV transmission through breastfeeding in resource-rich countries such as the UK (Waitt et al., 2018), where healthcare infrastructure and availability of medication differs to resource-limited settings.

1.1.1. Clinical guidelines regarding infant feeding with HIV

Prior to 2010, UK guidelines stated that breastfeeding by mothers with HIV was grounds for referral to child protection services (British HIV Association & Children's HIV Association, 2010); it continues to be a criminal offense in Canada and some states of the US (Whitbread & Greene, 2020). While this is no longer the case in the UK, the continued absence of studies from resource-rich settings and the existing evidence suggesting a low-but-not-zero transmission risk have led to a cautious approach: parents with HIV are advised to abstain from breastfeeding completely, even if they are on ART and with undetectable viral load (British HIV Association, 2020).

However, recognising the potential negative emotional and social consequences of not breastfeeding for some women with HIV (Tariq et al., 2016), UK guidance was changed in 2018, such that exclusive

breastfeeding² for up to six months should be supported by clinicians, provided certain biomedical criteria are met and the feeding parent agrees to additional clinical surveillance for both themselves and their baby. This includes presenting for monthly blood tests for both feeding parent and baby or if the feeding parent's viral load becomes detectable (British HIV Association, 2020). Parents who choose to breastfeed against medical advice e.g. who are not on ART, or have a detectable viral load, are considered a safeguarding concern, and may be referred to social care services because of the risk of transmission of HIV to the baby.

A vital issue is that these UK HIV infant feeding guidelines (and those of other resource-rich countries, like the US and Canada) contrast sharply with the World Health Organization (WHO) guidelines which recommend exclusive breastfeeding for the first six months of life (even if the feeding parent is not on ART), and continuing complementary breastfeeding for the first 24 months of life (WHO, 2016). The WHO guidelines are intended for resource-limited settings, where infant survival is estimated to be greater if babies are breastfed, regardless of whether the baby acquires HIV, because of increased risk of malnutrition and infant diarrhoeal illness. Furthermore, the UK HIV and infant feeding guidance also diverge from the unambiguous "breast is best" messages promoted more widely in society and by public health bodies (NHS, 2023 (webpage); UNICEF, 2023 (webpage)).

We are confronted with the paradox that breastfeeding by women with HIV is rendered transgressive in resource-rich countries but strongly encouraged in resource-limited settings. This important tension in global public guidance calls for a feminist critique in order to understand and interrogate it, and shine a light on how it actually plays out in the lives of people affected by it.

1.2. HIV, infant feeding and mothering 'morals'

Infant feeding decisions among women with HIV are also situated within wider medical and public discourses about motherhood and parenting. Despite the extensive promotion of breastfeeding as the 'best' infant feeding choice, and a high proportion of new mothers in the UK (81 %) initiating exclusive breastfeeding, this drops to only 1 % at six-months postpartum (McAndrew et al., 2012). The decision to end breastfeeding is often perceived by women themselves as transgressing social and moral expectations of motherhood (Harrison et al., 2018), and much has been written about maternal shame and guilt in this context (Jackson et al., 2022). There are also ethnicity-based differences in infant feeding practice, such that Black and Asian women in the UK are more likely to breastfeed than White women (Kelly et al., 2006; Odeniyi et al., 2020), and for many racially minoritised groups, particularly Black African women, breastfeeding is culturally valued.

Moralising narratives about 'good' mothering abound and many scholars have noted (Johnson, 2000; Schmied & Lupton, 2001) how pregnancy pushes women's bodies into a period of intense public scrutiny and surveillance (Mykitiuk & Scott, 2011). This surveillance is especially extreme if a pregnancy is identified as 'risky', with a consequent shift in focus from the maternal body to that of the foetus (Lupton, 2012). In order to gain 'reproductive citizenship' (Salmon, 2011), mothers are expected to conform to expert biomedical advice, acting in the best interests of the foetus/child 'while subduing any bodily urges that might counteract this advice' (Lupton, 2012: 337).

Williams Veazey (2015) argues that epistemologies of mothering – mothering practices and ideologies are not static or universal, but instead are spatially and temporally dynamic, altering in response to social and historical processes such as migration (Williams Veazey,

² Exclusive breastfeeding is defined by the World Health Organization as when "an infant receives only breast milk, no other liquids or solids are given – not even water, with the exception of oral rehydration solution, or drops/syrups of vitamins, minerals or medicines." (WHO, 2023).

2015). Most mothers with HIV in the UK also happen to be first or second generation immigrants from resource-limited settings, with 70 % identifying as Black African. They are part of what McKnight (2022) terms, the 'HIV diaspora', a cohort of racialised people affected by HIV who have migrated from locations where ART is not readily accessible to resource-rich locations where ART is available and where HIV is thus rendered a long term, manageable health condition. However, despite access to ART, women living with HIV in the UK are often socioeconomically marginalised (45 % live below the poverty line), and endure significant HIV-based stigma and discrimination (THT and Sophia Forum, 2023 (webpage)). Not breastfeeding among women from the HIV diaspora serves as a potential signifier of HIV status to others, and this is a well-documented source of anxiety (Boucoiran et al., 2023; Tariq et al., 2016). Formula feeding may also incur negative social judgement from their diasporic communities, along with personal disappointment and shame (Greene et al., 2015; Tariq et al., 2016).

In addition to the particular HIV stigma-related disadvantages experienced by women with HIV, Black and other racialised mothers continue to be pathologised as 'other' and 'deviant' in white majority countries such as the UK (Erel & Reynolds, 2018; Reynolds, 2020). They face racism and discrimination when accessing healthcare, including maternity care (Birthrights, 2022; MacLellan et al., 2022; Women and Equalities Committee, 2023), which contributes to disproportionately high levels of maternal and child morbidity and mortality (Knight et al., 2020). Later on, when Black children suffer poor outcomes (school exclusions, or disproportionate criminalisation), public narratives frequently blame parenting (or more often mothering, and absent fathers), rather than deeply embedded structural racism that has driven social and material disadvantage over several generations (Perera, 2020). In 1990, Patricia Hill-Collins used the term 'other mothering' to describe how Black women as teachers or healthcare workers, do "kin-work" providing care for Black children in their communities that "nurtures black children in society that position these children as second-class citizens" (Reynolds, 2020). This kin-work is also common among Black and Brown mothers in the UK (Erel & Reynolds, 2018). Later we will explore how infant feeding in the context of HIV unsettles the ability of racially minoritised women to benefit from kin-work, particularly in the often lonely and overwhelming first few months of new motherhood.

McKnight (2022: 4) proposes that there are 'ontologically multiple HIVs' and argues that "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". Our study exploring the experiences of infant feeding among mothers with HIV in the UK sought to pay particular attention to these kinds of racialised identities, and the complex trade-offs between clinical risk, moral identity and sociality made in the period before and during early motherhood. We are also informed by intersectionality theory (Crenshaw, 1989) as applied to health, which recognises that "intersections of individuals' multiple identities within social systems of power [...] compound and exacerbate experiences of ill health" (Heard et al., 2020) as well as Williams Veazey's argument that motherhood should be seen as an important social location in intersectionality (Williams Veazey, 2015).

We explore how complex and conflicting discourses from competing stakeholders of governance are negotiated and resisted, how interlinked components of positionality cast mothers as transgressive regardless of infant feeding experience, and how these transgressions are pathologised, medicalised and surveilled resulting in multidimensional burdens for women.

2. Methods

Between April 2021 and January 2022, we conducted 36 semi-structured interviews with women living with HIV from across the UK,

who were either pregnant ($n = 8$) or had given birth recently ($n = 28$). Although we attempted to recruit gender diverse birthing parents for our study, our sample only includes cisgender women. Ethical approval was obtained by Berkshire Ethics Committee REC Ref 12/SC/0495.

We recruited participants via HIV clinics, HIV charities and third sector organisations, and through social media and snowballing. Participants were compensated with a £20 shopping voucher. Co-author BK conducted the majority of the interviews (she is a Black woman living with HIV with links to several HIV clinical and third sector organisations as an HIV scholar activist). We feel that BK's name and positionality as a Black woman (evident in conversations preceding interviews, and appearance if on video call), contributed to the diverse recruitment and rapport between participant and researcher.

As a result of the COVID-19 pandemic all interviews were conducted remotely by telephone or online using Microsoft Teams. During the interviews, we invited women to tell us about their family and living situations, how and when they found out about their HIV status, about previous pregnancies (if applicable), their interactions with healthcare providers, and experiences of their most recent pregnancy, childbirth and infant feeding decisions. All participants were given the option to review and redact sections of interviews, if they wished.

Data were analysed thematically using a coding structure derived both from our topic guide and developed inductively during the analysis. TR and BK familiarised themselves with the transcripts and then coded excerpts, which were then analysed using the 'one sheet of paper' (OSOP) mind mapping method (Ziebland & McPherson, 2006) which ensures all relevant data are included and supports critical, reflective analysis. TR and BK developed mind-maps independently and then discussed them to reach consensus. Data were managed using NVIVO v1 software.

Our study team of social scientists, clinicians, a community activist/educator with lived experience of motherhood and HIV are all cisgender female, and the majority are from racially-minoritised groups. We also convened a patient and public involvement (PPI) panel comprising four mothers with HIV (all Black), part of a larger Advisory panel which also included HIV healthcare providers, academics and representatives of HIV professional organisations, advocacy groups, policy groups and food and milk banks.

2.1. Sample details and the context of our participants' lives

We interviewed 36 women living with HIV (Table 1), aged between 23 and 44 years, of whom eight were currently pregnant at the time of interview. The majority ($n = 28$) were in a relationship; two reported their partners being unaware of their HIV status. Five women had received their HIV diagnosis during their current pregnancy, the remainder had been diagnosed prior to conception.

For most participants, their HIV status was known to their HIV clinicians, sexual partners or other family members, and sometimes, also one or two trusted friends. Women described positive and close relationships with their HIV-specialist clinicians, who had typically supported them for several years. Pregnancy increased the frequency of clinical contacts with HIV and maternity care services. Many women described having supportive conversations with their HIV clinicians about infant feeding options, but there was wide variation in how much detail they recalled receiving, at what stage in pregnancy these conversations were initiated and by whom. Additionally, many had found it challenging to navigate care from multiple different healthcare services during their pregnancy. Women experienced maternity care teams as highly knowledgeable about pregnancy but less knowledgeable about HIV. This placed the onus on women to 'educate' non-HIV specialist midwives and nurses about HIV. Decision-making about infant feeding sometimes extended beyond the confines of the clinic, and a few participants described discussing options with partners or close family members (who knew about their HIV status), and/or drawing upon information on the internet and HIV support organisations.

Table 1
Participant characteristics.

Characteristic	N
Participants (n = 36)	
Age (years)	
18–24	2
25–29	6
30–34	8
35–39	10
40–44	10
Ethnicity (self-described)	
Asian	3
Black African	20
Black British African	2
Black Caribbean	2
White British	6
White other	2
Not stated	1
Country of birth	
Africa	21
Mainland Europe	2
UK and Ireland	11
Elsewhere	2
Diagnosed during most recent pregnancy	
Yes	5
No	31
Relationship status	
In a relationship	28
Single/separate	8
Basic expenses met	
All/most the time	16
Recruited from	
London	10
Northern England	6
Southern England	15
Scotland	5

3. Results: creating a transgressive practice

Below we describe how UK guidelines on HIV and infant feeding create tensions and contradictions, particularly for new mothers belonging to the HIV diaspora. We then demonstrate how both formula feeding and breastfeeding force women into multiple transgressive spaces, resulting in heavy social, emotional and physical burdens.

3.1. Contradictions in medical guidelines

The stark contrast between UK guidelines and WHO guidelines on HIV and infant feeding was confusing and troubling for many of our participants, especially those from the 'HIV diaspora'. Pauline, a first generation immigrant from West Africa asked:

I understand that people in in Africa and those parts, that part of the world they are being advised to breast feed whereas if you're here they give you the option to formula feed. So what is the difference between this part of the world and that part of the world?

Participants had questioned healthcare providers about the divergence in guidelines but found their responses to be inadequate and lacking in depth. One breastfeeding participant narrated her incredulity about how breastfeeding her baby was considered risky in the UK, but best practice if she went 'home' to Kenya on vacation. Similarly, Nozi-pho, originally from Southern Africa, recalled her frustrated attempts to get more detailed explanations from her healthcare providers, and how her own concerns were neither acknowledged nor addressed:

what the midwives were telling me at that time that [um] because here the water is good and they will give you free milk and free bottles, but [...] I did not want to bottle feed. I didn't care about they are free bottles, I didn't care about the free milk. For me I just wanted to have that bond with my child.

Many women described explanations based on broad differences between resource-rich and resource-limited settings in terms of environmental hazards, without acknowledgement of their own diasporic family ties in those countries and their knowledge of friends and family members with HIV who had breastfed without HIV transmission. This disregard of participants' experiential knowledge made some participants feel undermined and patronised, as well as raising doubts in their minds about the UK guidelines, as one who asked: *'is it because of water or is it because the risk of transmission is low anyway?'*

Changes in the UK guidance added to this ambiguity. The 2018 UK guidelines on HIV and infant feeding (British HIV Association, 2020) invite women with HIV to make an informed choice about whether to formula-feed or breastfeed, however formula feeding is still the clinically-preferred option. The wording used in accompanying patient leaflets (Freeman-Romilly et al., 2018) reinforces formula feeding as the safest option (echoing the clinical priority to the eliminate vertical transmission (BHIVA, 2015; British HIV Association, 2020)). So although breastfeeding is an option authorised by those with epistemic authority (i.e. the British HIV Association), the information provided to support decision-making demonstrates a less-than-complete commitment to this position. Such inconsistencies in clinical messaging make it difficult for women to identify whether (or not) it is a biomedically transgressive choice, as well as undermining their ability to communicate preferences during clinical encounters.

Although we did not observe clinical consultations, our data suggest that the medical ambivalence in the guidelines may have been amplified in the ways in which healthcare providers advised our participants about infant feeding. For example, when Deborah (originally from Southern Africa) who had consistent adherence to ART and undetectable HIV viral load, shared her intentions to breastfeed, she remembers being told by her clinical team: *"Okay, that is good. But if something goes wrong, it's your own fault because we told you so."* The discomfort felt by healthcare providers may reflect a lack of clinical experience of supporting breastfeeding mothers with HIV, however it served to shift the burden of responsibility for this possible transgression, and the potential consequences of a 'wrong' choice (i.e. transmission of HIV to the baby) onto the woman.

Kay, a White American, pregnant for the first time, was planning to breastfeed. On becoming pregnant she extended her stay in the UK, because breastfeeding with HIV is criminalised in her US home state. Although grateful for the option to breastfeed, she still felt that the UK guidelines shifted responsibility onto the mother.

I am just worried that like, well I get scared that, you know, there will be the one case where like the undetectable mother passes the virus on to her new born infant and then what ends up happening is that every mother regardless of how negligible that risk is will then internalise the fact that like this choice could still somehow lead to that [...] many, many mothers they would hold themselves to like such a high, like I feel like they'd be punishing themselves for the rest of their life if that happened [...] To expect that HIV-positive moms – who are already under a great degree of pressure [...] It piles on the mother, and only accounts for the costs of breastfeeding via transmission risks, without also factoring in benefits from a mental health or bonding, immunity, or financial standpoint.

We can see how ambivalence within clinical guidelines and recommendations about infant feeding create significant challenges for mothers with HIV. Far from being neutral, value-free documents they held substantial social and moral significance, with potentially deep and enduring consequences. The lack of nuanced and robust explanations left several participants feeling confused and ill-prepared to make decisions about infant feeding. Both feeding options appeared to transgress norms and rules for these transnationally-connected mothers and they were overwhelmed by the assigned responsibility to prevent potentially serious outcomes for themselves and their babies. The structural and systemic forces that surveilled them meant that not only did they have to manage the enormous and constant fear of potentially passing on HIV to

their babies, they also internalised the feeling that they are being transgressive themselves.

We now describe how these anxieties played out for mothers who formula-fed and those who breastfed. We also consider how transgressions were inherently relational – decision-making was not situated solely in clinics but extended into family and communities, and was underpinned by their own personal, moral and emotional expectations. These relationships and interactions shaped not just the nature of their transgression, but also the burdens entailed.

3.2. Formula feeding as transgressive practice

McKnight (2022) has described how even if mothers do not transmit the HIV virus to their babies the practice of formula feeding may signify mother and baby as 'HIV positive', especially within the HIV diaspora. Our participants' experiences of formula feeding, especially those from the HIV diaspora, resonate with previous research from the UK and other resource-rich countries (Greene et al., 2015; Greene et al., 2017; Tariq et al., 2016; Yudin et al., 2016). It describes the lengths to which formula feeding mothers with HIV go in their attempts to either "conform to or resist technologies of normalisation that are both stigmatising and paternalistic" (Greene et al., 2017: 2093). Some participants remarked that social distancing during the COVID-19 lockdowns helped avoid unwanted questions about their feeding decisions because it minimised their visibility as formula-feeding mothers. Echoing responses from a variety of global settings (Greene et al., 2015; Van Hollen, 2011), when asked they improvised medical reasons for formula feeding, or they aligned themselves with White women in the UK who often do not breastfeed (regardless of HIV status). A few participants would claim they had breastfed during the national lockdown phases, or only at home, in their attempt to explain to friends and acquaintances who had not observed them breastfeeding.

The majority of those interviewed post-partum had formula fed their babies. Previous experience of successful formula feeding often fostered confidence in the decision to formula feed. However, the most common reasons cited were to remove all risk of HIV transmission to their baby, a wish to adhere to guidance, and/or to stay in favour with their HIV clinicians. The perception that HIV had rendered women's breastmilk as 'tainted' was palpable. Amina, a South Asian woman in her 20s, living with her extended family, had been diagnosed at the same time as finding out she was pregnant. In accordance with guidelines, she commenced ART immediately in her pregnancy. Her HIV clinician had informed her about the possibility of breastfeeding, but she decided against it:

Like if I think of it in a spiritual way or like away from science way [er] it's like milk, I produce milk to be a nutritious and food for my child. If there is a possibility that that could be tainted or [um] not give the child, the nutrients, or alongside giving the nutrients give something else, it's not a risk that I personally would want to take.

Pauline, a Black African woman with West African origins, was married and lived with her parents; her husband lived abroad. Her parents were unaware of her and her husband's HIV status. She and her husband jointly made a decision to formula feed their baby, and felt enormously gratitude for healthcare in the UK that enabled them to have an HIV-free baby: "She's doing really well, yeah. With the help of doctors and others you're able to have a negative baby". However she described how her: "African parents were all over me – 'Why aren't you breastfeeding?'" She recalled a family holiday to West Africa where her formula feeding became a "huge problem", such that she had to constantly explain to her family why she was not breastfeeding. In particular, her mother's unhappiness about the formula feeding was an enormous source of stress for Pauline as she had heard her mother say hurtful things about people who have HIV.

Another participant, Rachel felt guilty about not breastfeeding several months after giving birth. A Black African first generation

migrant woman and single parent experiencing significant financial hardship, she imagined how her diasporic community would judge her for not breastfeeding:

Because it's really bad for us having babies and they're not having breast milk but for me, I look at it that this is all my fault and has nothing to do with my baby. It's something that I'm guilty of. It's something that I've put my baby through and for me, it's not something that I have on purpose that I did it on purpose, sometimes you can just have a one night stand. Sometimes you can just you could, there are things can really happen. It's not just through sex it can happen. You can have it in different ways. So it's something that you can't, it's just like flu when you don't know where you caught it from and that kind of thing.

So it's really, really sad for them, for the babies as well and for mums as well when people want to stigmatise with that, "You want to have sex, you want to be sleeping around, that's why you don't want to breast feed your child."

The complex interplay of HIV-related shame and stigma (Hutchinson & Dhairyawan, 2018), precipitated guilt about not only about choosing to formula feed, but also for acquiring HIV. In this imagined social commentary about her behaviour, Rachel invoked her transgression from being a good mother, and cast herself as deviant, even whilst trying to resist this narrative by citing the "different ways" HIV is acquired.

In the accounts of our participants formula feeding was experienced as transgressive on several levels. It violated moral, social and physical boundaries – potentially impacting mother-baby bonding, contravening family and community expectations, and physically transgressing the postpartum body by suppressing lactation with medication or disposing of their breast milk.

Rachel (mentioned earlier) had intended to breastfeed and her HIV clinicians had been supportive. However, her baby was born prematurely and hospitalised for the first three months. She brought expressed breastmilk to feed her baby in hospital, but the (non-HIV) specialist nurses in the neonatal intensive care unit (NICU), having heard that she had HIV, discarded her breastmilk and prescribed her medication to stop lactation. Rachel felt unable to challenge the authority of these healthcare staff. She lost the opportunity to fulfil her own expectations of motherhood, and instead felt marked out as someone with HIV. In the NICU setting, this takes on additional potency as the infant is largely cared for by medical professionals, and breastfeeding is the one mothering act mothers can perform (Mörelus et al., 2020). The contrast with 'other mummies' on the NICU further contributed to her sense of failure:

I felt really disappointed in myself that I put her through this and I let her go through this when you see other mummies there expressing and taking it for their babies, put their stickers name on them, put them in the freezer and for me I can't do it.

Thus mothers who conformed to guidance to formula feed, did so at the cost of transgressing their own bodily urges and desires, as well as culturally prescribed ideals of good mothering. We now explore the experiences of the (smaller) set of participants who breastfed their babies.

3.3. Breastfeeding as transgressive practice

Only six of the women we interviewed postpartum had breastfed their babies. They had been supported by their HIV clinicians, however they described non-specialist healthcare providers (outside HIV services) as being unsupportive. Two further participants had planned to breastfeed and had the support from their HIV team. However, they did not receive post-natal breastfeeding support from maternity care staff on the ward who believed an HIV-positive status precluded breastfeeding.

For the participants whose social contacts were unaware of their HIV status, breastfeeding meant that they did not need to isolate themselves from their support networks, or improvise explanations to explain

feeding choices. Eriife, originally from East Africa, had breastfed her older child and was doing the same again this time. While support from her HIV team reassured her, the monthly blood tests made her anxious and upset about the pain it caused her baby. She persevered however because “*breastfeeding [is] all I've ever seen from aunties, cousins, family, that's all I've ever seen*”.

Eriife had shared her HIV status only with her husband (who did not have HIV), mother (who lives with HIV) and brother. While socialising within her diasporic community and participating in ‘kin-work’ (Reynolds, 2020), she had to maintain secrecy about her HIV status. Although breastfeeding allowed her to openly conform to cultural and personal expectations of motherhood, it did not remove the need for secrecy and caution about her HIV status, including avoiding HIV peer mentor groups, known to be immensely beneficial to new mothers with HIV (McLeish & Redshaw, 2016).

Eriife's experience was different to Marella's, a 30 year old Black British woman, who is open about her HIV status and works in HIV advocacy. Her White husband does not have HIV, and at the time of interviewing she was pregnant with her second child. They had formula fed their older child, but this time Marella wanted to breastfeed. Reflecting on her experiences with her older child, she said:

it sounds so silly or it sounds so selfish I know, but like I think it does affect that sort of initial bonding process. Because anyone could feed him like he wanted milk and anyone could give that to him like it wasn't just me, [...] he wouldn't even know that I was him mum. That's what it felt like, I know.

It was not uncommon for parents' decision-making process to change as they had more children or as UK guidance changed. Interestingly, in Marella's case the latest guidelines were introduced when she was pregnant with her first child, but she had felt like “a paranoid first time mum” and decided to formula feed. This time, however, she and her husband poured over the latest published evidence, and hired a lactation consultant in preparation for breastfeeding. Time and experience had influenced Marella's response to the *same* clinical advice. Yet her choice did not go unchallenged; while her HIV team supported her, she met resistance from other healthcare providers:

During my meeting with the paediatrician, [...] she had actually said to me that, you know, “If this doesn't work out you need to not be very stubborn with it.” and I said, “What do you mean by stubborn?” and she said, “Well because for a lot of people, even, you know, those without HIV, breastfeeding doesn't work out and, you know I even have babies who come into my clinic that are malnourished because they have mums who just didn't wanna [um] give in to giving them formula.” [...] I said, “I've done my research, I know that things, it's not easy but I'm prepared to sort of try my best and of course I'm not gonna [um] I I don't-,” I said, “I-“ well I said, “I would-“, I don't, don't think I even responded to the comment about not being stubborn

There is a particularised grammar of transgression in this example. The clinician's use of the word ‘stubborn’ seems to indicate where ‘good’ mothering (i.e. breastfeeding, as per UK (non-HIV) recommendations) overstretches into possible transgression (for mothers with HIV). Marella's intersectional advantages, which include having a supportive (White) partner, a university education, financial security, and experience in HIV advocacy, enabled her to respond to this clinician, and she eventually breastfeed her baby. This stands in sharp relief with Rachel's experience described earlier.

We therefore see that although breastfeeding mothers with HIV achieved valorised personal and cultural ideals of motherhood, this entailed repeated reminders that they were transgressing medical advice (e.g. by increased surveillance or comments from other healthcare professionals), once again pressing onto them the charge of poor choices and irresponsible motherhood.

4. Discussion

Our participants' perceptions of the medical guidelines were entangled within concerns regarding the nutritional differences and the long-term health consequences of feeding choices. Concerns regarding formula feeding included poor physical, immune, and emotional development in the short-term, as well as increasing risk of longer-term health problems. Simultaneously, they worried about the material risk of HIV transmission, and the bodily and social consequences this could have for them and their children. In navigating infant feeding decisions, mothers with HIV faced a series of paradoxes: both breastfeeding and formula feeding potentially resulting in health consequences for the baby, historical and ongoing discourses stigmatising motherhood with HIV (Greene et al., 2016) alongside a ‘breast is best’ medico-social culture, and the ambiguities of HIV infant feeding guidelines. Participants negotiated these paradoxes, aware that they could not deliver the expected nutritive properties through “tainted” breastmilk or formula, and ultimately, the responsibility for transgressed maternal norms remained securely situated with the mother.

Many of our findings resonate strongly with those from other resource-rich settings, especially Canada and the US, where the guidelines are similar to the UK. For example, the risk of inadvertently disclosing one's HIV status when formula feeding a baby continues to be cited as a significant concern for women (Boucoiran et al., 2023; Ion et al., 2017; Tuthill et al., 2019). Likewise, mothers' sense of failure when they cannot breastfeed, and how their mothering ideals are shaped by personal and social expectations has also been described before (Greene et al., 2015; Tariq et al., 2016). However, our analysis provides a fresh and important discourse situated in the context of HIV, about how, when, where and for whom infant feeding (both breastfeeding and formula feeding) become identified as a transgressive practice.

The divergence in UK and WHO guidelines on infant feeding and HIV is problematic. There are medically-sound and essentially pragmatic reasons for the WHO guidelines advocating breastfeeding, reasons that are a consequence of colonial history and subsequent economic and geopolitical processes which have created much greater threats to infant survival than HIV in resource-poor settings. Nonetheless, the ‘WHO’ guidelines are positioned as a ‘world’ or *global* public health position, such that it is in fact resource-rich countries such as the UK that could be seen as *transgressive*. However, as we have shown, the responsibility for and consequences of this transgression fall almost entirely on mothers with HIV, and especially those from the HIV diaspora, who have a transnational identity and face multiple disadvantages and hostility in their host country.

A pregnant woman with HIV presents a potentially clinically ‘risky’ pregnancy because the mother's bodily fluids (blood, vaginal secretions or breastmilk) are understood to pose a risk of HIV transmission to the foetus. Extending Mary Douglas' (1996) conception of pollution, we suggest that the ‘pure’ womb represents a physical boundary, which must not be transgressed if the baby is to be protected. When a baby is born to a woman with HIV, an anomaly presents itself: breastmilk, although normally viewed as protective and nourishing (Knaak, 2010; Odeniyi et al., 2020; Williamson & Sacranie, 2012), is reconceived as polluting and transgressive. Formula feeding provides a means for ‘dirt avoidance’ (Douglas, 1996), as well as of aligning with clinical ideas of ‘safe’ parenting, and is set against the threat of surveillance and intervention. This rendering of breastmilk from a mother with HIV as ‘risky’ to the baby in resource-rich countries ignores other potentially significant ‘risks’ that might come from not breastfeeding, such as from poor maternal mental health or the financial impact of having to purchase formula milk (Tariq et al., 2016). It also distracts attention away from the impact of other socio-structural and material constraints faced by many mothers living with HIV globally (Gross et al., 2019; Van Hollen, 2011).

Just as human bodies migrating across national borders can be rendered illegal in one geographic space and legal in another,

breastfeeding by women with HIV is rendered transgressive in resource rich settings, but is encouraged in resource-poor settings. In her book, *Viral Mothers*, Haussman warns us that we should examine risk as a “cultural construction that needs consensus to be established as real” (p.60) and also that “the cultural context creates a consensus of ‘sense’ that dictates what will and will not be perceived as dangerous” (p.87) (Haussman, 2010). A parallel could be drawn with Ulla McKnight's concept of ‘ontologically multiple HIVs’ (McKnight, 2022) to also consider ‘ontologically multiple risks’ whereby, depending on the geographical location, some ‘risks’ will be elevated while others are diminished or even disregarded completely. These phenomena co-constitute each other and mothers with HIV are caught in the middle, forced into transgressive places (whichever choice they make) that predestine them to fail to do what is ‘best for their baby’.

Although the UK's infant feeding guidance is presented in a way that aims to facilitate an informed choice, it is also laced with a moralising message that communicates: “Good mothers don't put their babies at risk” which the mothers in our study could see clearly. In the US context, Gross et al. (2019) point out that if clinical recommendations are clearly against breastfeeding then they fall short of true clinical equipoise, and mothers cannot really make a ‘free’ choice when they are being “intensively counselled” against breastfeeding (Gross et al., 2019). The assumption of having autonomy and being positioned to make a freely informed choice felt incongruous for some of our participants as they negotiated infant feeding decisions within a wider context of racialised inequalities they lived with every day. Their multiple intersectional disadvantages were evident from their accounts of racism and discrimination (including in their healthcare interactions), immigration-related concerns and insecure personal and financial circumstances. Several of our participants appeared not to have received the UK's full guidance regarding infant feeding from their clinicians and the clinician-patient power inequality prevented them from advocating for themselves even when aware they had not been listened to.

In the context of the HIV diaspora, the practice of formula feeding risked marking both mother and baby as ‘HIV positive’ (McKnight, 2022). While breastfeeding enabled mothers to achieve a culturally sanctioned version of motherhood, the extra surveillance and moralising medical interrogations, combined with their already heightened concerns about HIV transmission left them feeling like irresponsible (transgressive) mothers. Our data show that mothers with HIV carry this transgressive ‘work’ in different ways, at different times, depending on their own intersectional identities, the particular interactions they face, and the distribution of power within these interactions. Half of our participants were financially insecure, most were from racially minoritised groups. The support of a community in diaspora was essential for their survival in the UK's increasingly ‘hostile environment’ (Erel & Reynolds, 2018). And yet, community acceptance relies on sociality and reciprocity, as well as being seen to follow cultural norms and expectations. We have demonstrated that when the practice of infant feeding (either formula or breast) becomes transgressive it distances new mothers from their communities while requiring them to work harder to display moral motherhood.

Rates of breastfeeding among women beyond the initial few days after giving birth are low in the UK (McAndrew et al., 2012). The BHIVA patient leaflets refer to this in order to normalise formula feeding choices, however they fail to acknowledge how breastfeeding is encouraged in wider medical discourse, or that infant feeding is racialised, with Black and Brown women more likely to breastfeed than White women (Kelly et al., 2006). The ‘performance of colour blindness’ (Younis & Jadhav, 2020) in health messaging ignores variation in cultural norms and expectation and is symptomatic of a failure by key societal stakeholders to recognise the diversity of its population or fully understand the social and cultural needs of all (FitzGerald & Hurst, 2017).

Finally, there is a wider question regarding the creation and legitimation of knowledge. There is a wealth of robust evidence from studies

conducted in Africa that show very low HIV transmission from breastfeeding. Although we acknowledge concerns about generalisation of data from different settings, the continued response from the UK and other resource-rich countries that more evidence is required from resource-rich settings risks ‘scholarly colonialism’ (Meekosha, 2011), whereby evidence from particular sources is privileged over others and knowledge only flows in one direction.

5. Conclusion

For mothers with HIV in the UK, navigating decisions and dilemmas around infant feeding involves difficult trade-offs and immense potential hazards. This is partly driven by the incongruence between national guidance and cultural and personal expectations, but also an acute awareness of the surveillance and censure women encounter in interactions across many domains, which is intensified for those occupying intersectionally-disadvantaged positions in UK society. At the time of data collection the UK's National Health Service was experiencing severe under-staffing and pandemic-related pressures. This provides an additional layer of explanation for the lack of adequate support felt by many of our interviewees. However, the suffering that results from the felt ambiguity between UK and global guidance needs to be acknowledged and we have shown that feeding an infant while living with HIV (whether by breast or formula) is experienced by some as a transgressive act. Improved and more nuanced counselling is required for parents living with HIV that accurately and clearly acknowledges the contradictions within existing scientific evidence. Additionally, more personalised support is needed that is responsive to the specific contexts of new motherhood, when different elements of women's intersectional identities (race, migration history, HIV status, social class) impact on their infant feeding choices. Parents may need ongoing emotional as well as practical support during their entire infant feeding experience, regardless if they formula feed or breastfeed.

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