Special issue: Practising refusal as relating otherwise: engagements with knowledge production, 'activist' praxis, and borders

Reading for refusal in UK maternity care: entangling struggles for border and reproductive justice

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Cassidy, K., Amiri, R. & Davidson, G. (2023) Reading for refusal in UK maternity care: entangling struggles for border and reproductive justice. *Fennia* 201(2) 199–214. https://doi.org/10.11143/fennia.127866

Research has shown that women with insecure immigration statuses in the United Kingdom (UK) are more likely to register later in their pregnancy with National Health Service (NHS) maternity care providers. This late engagement with healthcare services is framed in academic debates as one of the key reasons for poor outcomes for these women and their children during and after birth. Interventions, therefore, have focused on how to remove barriers to accessing maternity care for these women. In this paper, we argue that this approach fails to account for the agency of the women adequately, which needs to be understood in the context of state harms and violence towards women with insecure immigration statuses and, in particular, their reproductive lives.

We seek to shift these debates by framing this lack of early engagement with state-provided maternity services as a form of refusal that denotes an active disengagement by bordered women from intersecting structures of harm and oppression that are embedded in the UK's National Health Service, particularly through the charging regime. We argue that the politics of refusal in this case are embedded in struggles not only for border but also reproductive justice. Drawing on participant observation and data from secondary sources, we illustrate how refusal of early antenatal care opens pathways for bordered women to seek the care-ful conditions they need and want during pregnancy.

Keywords: bordering, refusal, reproduction, justice, care

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URN:NBN:fi:tsv-oa127866
DOI: 10.11143/fennia.127866

Introduction

Research has continued to highlight inequalities in maternal care and outcomes. Black, Asian and mixed ethnicity women are more likely to die or become unwell during birth, experience baby loss, and generally have poorer experiences of formal (state-provided/sponsored) maternity care (Guendelman *et al*. 2006; Howell & Zeitlin 2017). Racial inequalities in reproductive rights and justice are also linked to broader social inequalities (Roberts 2014) and approaches to population control intended to further 'development' in countries in the South (Hartmann 1995). In addition, struggles for reproductive rights historically have often failed to focus on issues affecting Black women (Roberts 2014). For bordered women, *id est* those subject constraints on their lives due to border and immigration regimes, these racial inequalities also intersect with border regimes and asylum-seeking women in the UK, specifically, are three times more likely to die in childbirth and four times more likely to experience postnatal depression than the general population (Asif *et al*. 2015; McKnight *et al*. 2019).

Women's reproductive lives have been specifically targeted by immigration and border regimes through "various biopolitical controls which penetrate their bodies in everyday processes" (Bagelman & Gitome 2021, 369). The reproductive harms that are caused by bordering can be arranged into three categories: direct harms perpetrated against women as part of border and immigration processes; the creation of violent conditions for women subject to immigration control that harm reproduction; connecting to other systems of gender-based oppression and violence to form a 'complex of violence' (Pain 2015) that is harmful to women's reproduction.

Analysis of direct harms perpetrated against women's bodies at sites of bordering reveals that this is a globalised phenomenon, which varies in terms of the intensity of the violence perpetrated but demonstrates continuity in these practices over time. Abuses against women that have formed part of formal state border regimes include the use of invasive virginity tests by a number of countries (World Health Organisation 2018). As Smith and Marmo (2014, 75) have argued, this practice "must be seen in the context of the overall highly discriminatory treatment of migrant women coming from the Indian subcontinent evident from the late 1960s to the early 1980s" in the UK, and is linked to the continuing legacy of empire within the UK's relations with its former colonies.

In addition to the harms perpetrated in the process of obtaining entry (or firewall bordering after Rumford 2008; Yuval-Davis *et al*. 2019), being subject to border and immigration controls when residing within a territory, results in harms, which are gendered and racialised, and particularly target women's reproduction (Canning 2017). Factors such as dispersal into housing away from any existing support structures (including partners) whilst awaiting the outcome of an asylum application, involuntary detention in centres and the length of time it might take to navigate the regularisation of their immigration status, also inhibit women's ability to pursue their reproductive lives as they might wish. These processes and practices produce the violent conditions (Laurie & Shaw 2018) that lead to refusal.

The violent conditions created by bordering regimes also leave women exposed to sexual exploitation. "[The] asylum system is…markedly sexist, denying refuge to many women who have experienced serious gender-based violence, and often forcing them into abusive and exploitative situations" (Dudhia 2020, 48). A joint report by HM Inspectorate of Constabulary and Fire and Rescue Services, the College of Policing and the Independent Office for Police Conduct (IOPC) published in 2020 judged that police should not share their information with the Home Office if they suspect that domestic abuse victims have insecure immigration status, as it discouraged victims of crime from reporting it to police for fear of having their information shared with the Home Office, leaving them vulnerable to further abuse (Grierson 2020). In some cases, police prioritised immigration enforcement over safeguarding victims of crime. Therefore, bordering regimes extend the reach of gender-based violence, exposing women to exploitation and protecting those who perpetrate gender-based violence by focusing the gaze of law enforcement on women's immigration status.

Our paper is inspired by contact with a group of bordered women on Tyneside in the North East of England through a migrant justice coalition. The women had founded a charity with a drop-in for other bordered women and their families in the area and were central to the driving campaigns within the coalition, particularly in relation to improving housing conditions for those seeking asylum. We analyse

the complex relationship the women had to state-provided maternity care and frame this within a lens of refusal. We argue that reading for refusal in maternity care turns our gaze upon how such 'care' is not only embedded in the harms and violence of the UK's border regime but actively creates the violent conditions that lead women to make agentive decisions (Newhouse 2021) to refuse care earlier in their pregnancies. In the UK context, the complex forms of refusal we elucidate are particularly linked to the harms created by changes to the National Health Service (NHS) charging regime and its impacts on bordered women living in the UK. Refusal of early antenatal care, as we show, is often incomplete or partial and interwoven with refusals of other state bordering institutions. However, it is also a standpoint from which women try to reform this care, as well as pursuing alternative arrangements in their communities in order to care for themselves and their unborn children.

Following an introduction to refusal as a concept and a short methodological note, we analyse this refusal in two sections: firstly, we explore how the UK's attempts to border the NHS materialise in the delivery of maternity care and create the specific conditions for the refusal of this care; secondly, we analyse the care-ful conditions that bordered women are seeking to enable them to care for themselves during their pregnancy.

Reading for refusal

Recent engagements with the politics of refusal have emerged from work undertaken by Black feminist scholars (cf. Collins 1986; Lorde 1997) across a range of disciplines, and the concept is increasingly being operationalised by scholars to analyse the agency of marginalised groups (Simpson 2007; Terrance 2011; Wood *et al*. 2020).

Refusals are 'agentive decisions' including a decision not to do something, *id est* to apply for asylum (Newhouse 2021) or engage with state-provided antenatal care. As Tuck and Yang (2014) note, refusal is not an end, but a beginning; a standpoint from which a different action or alternative path can be taken. Therefore, refusal is generative in the sense that it makes space for alternative possibilities to emerge (Tuck & Yang 2014; Bhungalia 2020). In addition to being generative, refusal has been conceptualised as social (after Mauss 1967/1925) and affiliative (McGranahan 2016); creating links to others through actions that may or may not be political. Consequently, refusal is not just one act but involves "an ongoing project of building other trajectories, other pathways to success, other affiliations and prioritizing other relations" (Newhouse 2021, 183). Hence, refusal is not only generative but can also be radically transformative (Campt 2019) by directing transformative efforts toward self-governance (Honig 2021). By refusing what is offered by oppressive structures, institutions and agents, marginalised individuals are able to draw attention to what is sought instead (Newhouse 2021).

Refusal can also be understood as 'opaque on purpose' (Shange 2019). These 'epistemic refusals' include a rejection of the terms on which someone in a position of authority is attempting to get to know someone from a marginalised group (*ibid*.). Analysis of refusal enables us to turn our gaze back onto the power/authority being refused, what Browne (2015) has called 'sousveillance', *id est* the act of gazing upon power from below. Therefore, in this paper, in reading for refusal, we turn our gaze on the specific ways in which bordering practices within antenatal care create harms and violence that lead to refusal.

There is considerable variation in the literature on how refusal might be linked to opposition and/or resistance. For some, refusal involves acts that are not oppositional, but simply refuse to recognise the authority of a particular power (Bhungalia 2020). "Refusal [...] is a kind of abstention, a disinvestment from rules of engagement" (Bhungalia 2020, 390). However, in the case of bordered people, refusal has been argued to be 'a subtle form of resistance', as it involves transgressing the orders that governmental and non-governmental authorities attempt to impose (Moulin & Thomaz 2016). This links to more expansive ideas of resistance that have recently been developing in human geography, which urge us to view resistance as a combination of incoherent and perhaps indiscernible forces. Hughes (2020) has argued that resistance may be ambiguous as actions and actors can be both resistant and compliant at the same time.

McGranahan (2016) has argued that refusal is, therefore, linked to but not the same as resistance. This link is quasi-dialectical; groups often oscillate between both strategies, which can increase the

efficacy of particular interventions (Prasse-Freeman 2022), but also the ambiguity of certain actions (Hughes 2020). Amongst bordered communities, 'everyday mechanisms of resistance' involve non-cooperation and non-compliance, and it is, therefore, at the everyday level that we can discern the nuance of these oscillations. Everyday practices of refusal are multiple and can expand possibilities for minoritized people (Franklin-Phipps 2022). These everyday politics of refusal evidence the ungovernability of certain people and their *decisions* not to be governed/treated in particular ways (Moulin & Thomaz 2016). In this paper, we draw upon the diverse practices generated from refusal of early antenatal care by bordered women to further our understanding of the relationality of refusal and resistance in everyday life.

Methodological Note

This paper draws upon participant observation carried out in the North East of England within loose coalitions made up of organisations and individuals campaigning for migrants rights and border justice between 2013 and 2023. These campaign groups were made up of people with lived experience of being subject to border controls within the UK as well as UK residents without this experience, who wanted to stand in solidarity with them and oppose practices and processes stemming from the UK's bordering regime.

To supplement this participant observation, the authors also collected secondary data from a range of sources including the Hansard, online news and other media, as well as reports published by professional bodies and VCS organizations, and policy documents produced by NHS Trusts. Collection and analysis of this secondary data in relation to health care began in 2016 and continued into 2021.

Everyday bordering through NHS charging

Bordering the public institutions constituting the welfare state or 'welfare bordering' (Guentner *et al*. 2016) is part of a wider shift from institutionalizing the perimeter of nation-states to multiple or transversal borderings cutting across the perimeter (Sassen 2015). The UK has introduced increasingly complex regulations to determine access to health care as part of this shift; creating practices of 'limited inclusion' that produce spaces of compromise (Su & Cai 2020). Decisions on eligibility for health care are made by workers in the healthcare sector, other UK residents, who restrict access for those with uncertain immigration status and other non-citizens, as well as settled populations unable to prove their status (Yuval-Davis *et al*. 2019).

As part of the 'hostile environment' policy announced in 2012, the UK government made changes to legislation that focused on tightening the UK's internalised border regime, including within the NHS. The 2014 Immigration Act changed the definition of who was deemed *ordinarily resident* in the UK from anyone legally living in the country to those with indefinite leave to remain, which requires five years of residency (Grove-White 2014). Anyone not meeting this requirement has to pay in advance for non-urgent care, and for urgent care, the costs will be recouped later on (Cassidy 2018). Bordering healthcare in the NHS, therefore, takes the form of a paywall, which has gradually been extended and whose impacts are felt more acutely by those with no means to pay such charges.

The change in ordinary residency was accompanied by a discursive reframing of some visa-holders from 'ordinarily resident' to 'temporary migrant' (Lonergan 2023). This shift enabled the UK government to introduce an Immigration Health Surcharge (IHS), which entitles holders of visas of over six months to free NHS care with some exemptions (including fertility treatment). The surcharge is compulsory and is payable upfront for each year of a visa at the time of application. Between 2015, when it was introduced, and October 2020, the cost of the surcharge tripled to £624 (US$770)/year. The main groups considered chargeable for care under the current rules – *id est* those people who do not either qualify for free treatment or pay the IHS – are tourists, holders of visitor visas, British citizens who are not ordinarily resident in the UK, and undocumented migrants. Women who are wives or partners of men with ordinary residence must pay for NHS care if they are in the UK on a visitor visa or have overstayed an earlier visa, even if they have since submitted an application for leave to remain.

According to UK government guidance (Department of Health and Social Care 2020), refugees, asylum seekers awaiting a decision on their status, and victims of modern slavery are exempt from NHS charges. Asylum seekers whose claim has been rejected and are in receipt of support from the Home Office (the UK government department responsible for implementing border and immigration policies) are also exempt, although this support is subject to stringent conditions; pregnant women whose claim for asylum has not been accepted can only obtain support on health and destitution grounds at 34 weeks' gestation (Maternity Action 2018). Therefore, immigration policies clearly frame only care later in pregnancy as being worthy of support. In most cases, the dependents of people who are exempt on these grounds, *id est* their spouse and any children under 18 years of age, are also exempt providing they are legally resident in the UK.

To add to the complexity around an individual's eligibility for charging, certain NHS services are also exempt: infectious diseases, including HIV and other sexually transmitted diseases; family planning (but not terminations); treatment for conditions resulting from sexual or domestic violence, torture, or female genital mutilation; and emergency treatment in Accident & Emergency departments (DHSC 2020). Consequently, migrant women experiencing problems in pregnancy may feel they are better off waiting to seek medical advice until the situation becomes an emergency and they can access urgent care free of charge (Shahvisi & Finnerty 2019), *id est* refusing early antenatal care.

Indeed, research has shown that the impacts of charging are highly gendered. A study published in 2022 (Dobbin *et al*. 2022) based on data for the 2016/17 and 2017/18 financial years for 64 of the UK's 135 NHS trusts showed that in spite of being the minority among the chargeable population (accounting for only 33% of the estimated undocumented migrant population) (Williams *et al*. 2018), women comprised the majority (63%) of those charged. In addition, 48% of those women (30% of all patients being charged) were of reproductive age (16–40 years) and women's health costs overall were significantly higher than those of men (Dobbin *et al*. 2022).

By the end of March 2020, 44,244 asylum seekers in the UK were receiving support under Section 95 of the Immigration and Asylum Act 1999; almost half of this population were women. Refugee and asylum-seeking women face significant challenges, which can significantly impact their health and wellbeing (McCarthy & Haith-Cooper 2013; Balaam *et al*. 2016) particularly due to the additional physical and emotional demands of pregnancy (McKnight *et al*. 2019; Garcia *et al*. 2015; Fair *et al*. 2020).

Recent border and immigration legislation in the UK specifically promotes decisions to refuse maternity care by creating unnecessary complexity. Limiting the use of NHS maternity (especially antenatal) services by bordered women is "necessary to discipline the arrival of 'unwanted guests' in the national home" (Lonergan 2023, 12). Maternity services are the most prevalent secondary care service in policy documents surrounding the 2014 Immigration Act (*ibid*.). Policies do not provide maternity care free to all women present within the UK, but create exemptions that are difficult to access and connections between indebtedness for care and processes of regularising immigration status. To better understand the politics of refusal in the context of maternity care for bordered women, we need to explore how the violence of bordering regimes emerges as conditions that frame women's encounters with healthcare settings and professionals.

Necessary but chargeable

Maternity care is designated 'immediately necessary', which means that it must not be delayed or denied because of a woman's inability to pay up front. The latest UK government guidance on charging for pregnancy care states:

> Due to the severe health risks associated with conditions such as eclampsia and pre-eclampsia, and in order to protect the lives of both mother and unborn baby, all maternity services must be treated as being immediately necessary. Maternity services include all antenatal, intrapartum and postnatal services provided to a pregnant person, a person who has recently given birth or a baby. No one must ever be denied, or have delayed, maternity services due to charging issues. Although a person must be informed if charges apply to their treatment, in doing so they should not be discouraged from receiving the remainder of their maternity treatment. [Overseas Visitor Managers] OVMs and clinicians should be especially careful to inform pregnant patients that further maternity healthcare will not be withheld, regardless of their ability to pay. (DHSC 2020, 66)

The guidance does not make it clear how Overseas Visitor Managers (OVMs) should manage the delicate balancing act of telling women that they need to pay for their treatment without discouraging them from accessing it. However, individual policies written by trusts attempt to provide staff with support on how to implement the policy.

> No woman must ever be denied, or have maternity services delayed, due to charging issues. *Although she will be informed if charges apply to her treatment.* In doing so, she should not be discouraged from receiving the remainder of her maternity treatment. All staff should be especially careful to inform pregnant patients that further maternity care will not be withheld, regardless of their ability to pay. [...] For those not entitled to NHS treatment free at source, maternity services are not exempt from charges. The patient remains liable for charges for treatment [..] and the debt will be pursued in accordance with the Trust's Standard Financial Instructions. Where a patient expresses severe anxiety over incurring charges the OVT [Overseas Visitors' Team] will liaise with and advise the patient on the process and where appropriate e.g. the patient advises they will not attend ante-natal care, will liaise with the safeguarding team. (Anonymised NHS Trust 2019, *emphasis added*)

The guidance provided by this NHS Trust clearly recognises the impact of charging on women's mental health and also indicate that those who advise them of their intention not to engage in antenatal care may also face further scrutiny by referral to a safeguarding team. Clearly, this may lead some to turn away or refuse to receive antenatal care, *id est* make an agentive decision (Newhouse 2021), and seek to care for themselves during pregnancy outside of NHS maternity services (Bhungalia 2020).

A recent report suggested that at least three women may have died between 2015 and 2017 after being deterred from accessing maternity care because of fears of charging and concerns about their immigration status (Knight *et al*. 2019). Shortall and colleagues (2015) interviewed two migrant women in the UK who had lost babies. One mother did not attend any antenatal appointments prior to giving birth, "[She] was referred to her local hospital for antenatal care but was too scared to go as she was worried about being found by the Home Office" (Shortall *et al*. 2015, 8). Her baby died after being born prematurely; she subsequently received a bill for £1,500 (US$1896) for maternity care. Another woman presented at hospital at 40 weeks feeling unwell, but felt she was not supported by the doctors. She lost her baby at 42 weeks, and was later billed £2,620 (US$3312) (*ibid*.). Research by Maternity Action (Bragg *et al*. 2018), an organisation dedicated to struggles for reproductive justice, found that migrant women were refusing antenatal, perinatal and postnatal care for fear of incurring debts that would lead to Home Office sanctions. We have suggested that charging for care, specifically leads bordered women to refuse early antenatal care in order to avoid incurring costs. Refusal is the only way to evade border violence embedded in maternity care through the charging regime.

(In)Accessible exemptions

Maternity care may be provided for free for a woman who would usually be chargeable, if her pregnancy is the result of sexual violence. However, this exemption remains inaccessible to many bordered women. The guidance states that exemptions are contingent on being able to provide evidence, which is difficult to obtain for a number of reasons. OVMs are advised that 'proof' of the violence may be found in patients' health records and/or by confirmation from a medical professional, "[T]hat the patient is a victim of sexual violence, and that the treatment being accessed is directly attributable to that violence" (DHSC 2020, 58). It is suggested that a general practitioner (GP) or staff at a Sexual Assault Referral Centre (SARC) should be able to identify the signs and symptoms of sexual violence during examination of the woman, although this is likely to depend on how recently the violence took place (and relies on the assumption that evidence of rape is distinguishable from that of consensual sex, which may not be the case) and also whether a woman has been able to register for GP services.

NHS charging increases women's vulnerability to domestic violence (Maternity Action 2018). Women whose immigration status is dependent on their violent partner lose their entitlement to free NHS care if they leave the relationship (Pellegrino *et al*. 2021) and many, therefore, choose to remain in the violent situation. Pregnancies may be even more difficult for undocumented women because

of unsafe living arrangements, as shown by the case of a woman in the UK who had had two miscarriages because of being beaten by her partner (Dudhia 2020). Many bordered women fear any interaction with the police may result in them being reported to the Home Office. Current Metropolitan Police Service guidance states that it is appropriate for police officers to contact immigration enforcement if the victim of a crime is suspected of being an 'illegal immigrant'. There have been increasing entanglements between policing, law enforcement and border regimes (Stumpf 2006), which have materialised as arrests and reports to the Home Office of bordered women reporting sexual violence and rape to the police (BBC 2018).

Similarly, policies in place to prevent further harm through immigration detention, are inaccessible or ineffective. The Adults at Risk policy was introduced to comply with section 59 of the Immigration Act 2016, on determining whether a person is vulnerable and should not be detained. The specific vulnerabilities it lists include having been a victim of torture, sexual or gender-based violence, human trafficking or modern slavery, or being pregnant. The approach depends firstly on women disclosing their previous experiences of violence, and secondly on them being believed. The violent conditions of the UK border regime lack the safety needed for such disclosures.

> I told him, 'Who says that, who just says they have been raped?' I couldn't talk about it before, I felt so ashamed. And nobody had asked me about it; how could I just tell them? (Lousley & Cope 2017, 13)

Although it is Home Office policy to provide same-sex interviewers and interpreters if requested, staff constraints mean that this is not always possible and asylum-seeking women who had asked for a female officer are often interviewed by male officers (Dudhia 2020).

In addition to feeling safe to disclose such information, women are also expected to know the correct procedure – a Rule 35 report prepared by a doctor – and have their disclosures dismissed on this basis (Lousley & Cope 2017). Even when the correct procedure is followed, women's accounts are rejected on the basis of a lack of evidence or 'inconsistencies' (Lousley & Cope 2017; Dudhia 2020). Such rejections form part of the border violence specifically directed at women in the UK.

Even when women have provided evidence and the Home Office believed them, changes to the way they are treated did not always result and they often remain in detention. Of 374 Rule 35 reports submitted by doctors in Yarl's Wood Immigration Removal Centre in 2016, less than half (45%) resulted in the release of the person being detained (Lousley & Cope 2017). Therefore, women's experiences of engaging in the rules set out by the British state are unjust. State rules intended to protect them do not function in practice because border securitisation is always prioritised over women's health and safety (Lonergan 2023). In these ways, exemptions intended to give women access not only to free care but also safe living conditions become inaccessible because of the barriers to providing evidence but also of being believed even when evidence is provided.

Entangling care and border violence through indebtedness

These violent conditions form the context in which bordered women are expected to access maternity care. The negative impacts on their health of not only being denied care but also potentially detained enable us to understand refusal as one way to protect not only themselves but also their unborn child. Therefore, it is not the provided care but the violent conditions within which such 'care' exists that is being refused.

If women are not eligible for free NHS care, they do have to pay, and if they do not respond within two months when invoiced for maternity care they have received (either by paying, or setting up a repayment plan), they must be reported to the Home Office, with potentially has negative consequences for their future residence in the UK. In 2019–2020, the cost of full maternity care (pre-natal, birth and post-natal) in the UK was £6994 (US$8882) for women from outside the EEA and pregnancy terminations cost £1353 (US$1718) (Shahvisi & Finnerty 2019). In order to incentivise NHS trusts to recoup these monies, the UK government permits them to charge non-EEA patients approximately 150% of the estimated cost of treatment (Department of Health 2017). A study of 35 migrant women who had given birth in the UK reported that ten of the women had been charged for their maternity care, with charges varying from £1500–£6000 (US$1905–7620). One woman who had

recently given birth said she was required to pay a sum of £300 (US$381) a month towards settling her bill (Shortall *et al*. 2015).

For women who have very low incomes, migrant and asylum support groups, as well as specialist maternity charities, such as Maternity Action, advocate for repayment plans for women that are as low as £1/month. One worker from a city council in the North of England explained to us that if women entered into such plans, however small the amount, they were able to avoid being reported to the Department of Health and Social Care by the NHS Trust.

> Debts of non-EEA nationals, over £500 in value and over 90 days outstanding are reported to the Department of Health on a monthly basis. This may affect a person's future visa applications and/or affect their entry into the UK. (Anonymised NHS Trust 2019)

The data on non-payment is reported to the Department of Health and Social Care and is accessible to the Home Office after three months. Thus, the bordering of maternity care through the charging regime is directly connected to future immigration status in a way that clearly could lead to a refusal of such care by those women whose lives are hyper-precarised by the UK's border regime (Cassidy 2018).

> Family planning services are exempt from charging, but termination of pregnancy is not and ineligible patients must pay. Meanwhile, the regulations class all antenatal services as 'immediately necessary', meaning patients must not be denied care because of an inability to pay. Instead, after the birth women whom the hospital finds to be eligible for charging receive a bill for 150% of the cost to the NHS of their care – potentially for thousands of pounds for even an uncomplicated delivery. This can leave women in an impossible position of being unable to afford either option – continuing with a pregnancy or terminating it. The contradictions in these policies take away women's control over their reproductive health, which is particularly concerning given the risks of sexual violence and exploitation that undocumented migrant women face. (Whelan 2019, n.p.)

The decisions of women to refuse care are complex (Collins 1986) and have to take these multiple layers of harmful state bordering processes and practices within healthcare-scapes into account. In the final section of the paper, we explore how some bordered women, who have been refusing early antenatal care, are endeavouring to secure alternative options for them and their families.

Refusing maternity care: securing care-ful conditions

In this final section of the paper, we explore the alternative pathways to care developed by bordered women refusing early maternity care in the North East of England. We do this through analysing the actions of some women living under border/immigration controls with whom we came into contact through various migrant and asylum justice campaigns in the region. As Newhouse (2021) concludes, refusal is but just one step that enables bordered people to forge new and alternative pathways instead. Here, we categorise the alternatives that refusal generates as: securing care-ful spaces, *id est* the creation of alternative spaces where women could come together to others with similar experiences and be heard; affiliative actions with diverse organisations that the women felt could have a positive impact on their efforts to secure their own lives and those of their children; directly advocating for improved conditions that would alleviate the harms of border and immigration regimes. What our analysis reveals is that although for some women these pathways were developed out of a refusal of NHS maternity or early antenatal care, yet others, who engaged in this care (sometimes in limited ways), were also involved in coming together to secure care beyond that provided by state institutions.

Securing care-ful spaces

One South Asian woman, who we have given the pseudonym Yasmin, that we spoke to frequently had set up an organisation to help and empower other women and families. The organisation originally focused on the mental health and wellbeing of women being dispersed via the asylum accommodation system into the North East of England. Yasmin thought this was necessary due to her own experience of arriving in the region with a small baby and without funds to provide for her baby or any information of where to locate any help or assistance. Without any information on how

to access help, she had presented herself at a local church, who helped her with the practical support that enabled her to care for her child.

The organisation she founded was originally a drop-in at that very church, which offered not only practical support – toiletries, nappies, food, clothes, pushchairs, and so on – to bordered women but also a space to talk to others who were or had been through similar experiences and gain knowledge and information. Importantly, it was a safe space in which these women also felt able to share their experiences and ask questions. We visited the drop-in on a number of occasions and beyond the core group of several women, there were always many others and their families in attendance. The noise of them talking and the children playing in the large hall was sometimes overwhelming. Conversations also took place away from the noise of the main hall in the kitchen and sometimes in smaller side rooms. This was an *accessible* space for two main reasons: the women were able to bring their families and children along (something that is not always possible within NHS maternity services); the drop-in was in the area where the women were living, meaning they did not have to pay to travel there.

In addition to the drop-in being accessible, the women came with their families as not only were they believed and their concerns taken seriously, but they were offered practical advice by the longer-term members and some volunteers that did not have lived experience of the asylum system. In this sense, the organisation and its drop-in performed a key function of maternity services: providing a space where women felt able to come and discuss any issues or raise any questions related to their pregnancy or the health of them and their child, but that they could also get direct help and support or be signposted to other services – and importantly – be given the tools to access them. Given the limited funds and, therefore, mobility of most of these women, being able to access all these things locally was clearly important to them.

> After my experience, I have been helping many pregnant women in my networks and I found out that many immigrant women don't receive the care they need while they are pregnant [...] Women who are migrants are not treated well; they don't count us as anything. (Kemi, Doctors of the World in Jones *et al*. 2022, 4)

As we see from Kemi, who works with the organisation Doctors of the World, actively seeking to support other bordered women as a result of poor experiences is something that extended beyond the group we observed. In terms of refusal, it suggests that bordered women are prioritising relations with others (Newhouse 2021) who are or have lived through similar experiences instead of with healthcare practitioners. For the women we spoke to, the space created by these networks enabled them to direct their labour and 'transformative efforts' towards self-governance (Honig 2021). However, although these spaces and the relations made within them were transformative in and of themselves, we also observed that they created the potential for further affiliative actions that could transform the women's capacity to care for themselves and their families.

Affiliative actions

From within the drop-in organisation, the women also pursued collaborations with a range of other groups, which we understand here as *affiliative actions*, in order to support them in securing care-ful conditions for them and their families. These collaborations included local authorities, voluntary and community sector (VCS) organisations, academics/researchers, and campaign groups. However, we observed that they particularly prioritised links to specific campaign groups because of barriers to working more closely with some of these other actors.

Although there was already a black women's organisation in the Tyneside area, Yasmin described having difficulties in accessing this organisation due to the limited funds available to her even for local travel. There was also an established group of VCS organisations that had been supporting and advocating for those subject to border and immigration controls since the 1980s. These organisations collaborated together with local authorities in Newcastle-upon-Tyne within the parameters of the 'citywide group' (Cassidy 2020). In addition, Middlesborough Council also hosted the North East Migration Partnership (previously the North East Strategic Migration Partnership -NESMP), which brings together VCS organisations with other stakeholders – local authorities, police, the Home Office. However, a number of the women we spoke to said they found that these were not safe spaces due

to the presence of the Home Office or the sharing of information by other organisations present with the Home Office even though some of these organisations had a specific focus on health. Therefore, in choosing which organisations to affiliate with, the women actively refused those which were associated with other institutions of state border violence beyond the NHS.

Instead, the women specifically sought to build collaborations with groups that were both beyond these more formal networks and who sought to shape their activities in response to the experiences of bordered people rather than be directed by state actors involved in the border regime. By refusing close affiliations with these formal networks in this way, the women were refusing pathways through the VCS that might be a means for authorities to get to know their experiences as a marginalised group (Shange 2019).

In research carried out by Maternity Action (Arrowsmith *et al*. 2022), pregnant women in the process of seeking asylum in the UK highlighted housing as one of the key structural conditions that would not only improve their health, but also could be a site to engage safely with community-based healthcare practitioners. During the period of our observations, one of the groups the women were most involved in was a loose coalition campaigning for border justice on Tyneside after 2015 (Cassidy 2020), who focused on housing conditions in accommodation for asylum seekers between 2015 and 2019 (*ibid*.). The founder of the drop-in organisation noted that she had "observed the positive effect of the [coalition]'s empowering campaigns on the mental health and wellbeing of local asylum seekers and refugees".

> My own suggestion to Home Office or whoever organisation, I'm pleading with them, we should have, nursing mothers or pregnant women should have a separate housing, that they should be placed in, and then they should make sure they have midwives, health visitors, to go there. (Anon cited in Arrowsmith *et al*. 2022, 21–22)

Care-ful conditions for pregnant women in this case relate to separate housing, limited to those who are pregnant or have recently given birth. However, where such separate accommodation has been provided, the style and poor quality has proved incompatible with the care-ful conditions sought.

> In some regions, Providers had created 'mother and baby' homes. [Non-governmental organisations] NGOs reported that these homes offered important support networks to women at a particularly vulnerable time in their lives. But, they could also be claustrophobic, with too many women and children in too little space, which created tension and led to arguments. (Bolt 2018, 12)

As well as the lack of space in such accommodation, which is a structural feature of asylum accommodation due to the use of private sector, for-profit contractors (Darling 2016), conditions in this type of accommodation were found to be detrimental to the health of women and their children.

> The children are sick every day because one gets a virus and it spreads round the building so quickly.
>
> Our children have no freedom, they can't develop or enjoy themselves because there's nowhere to play so they're more unhealthy than they should be.
>
> (mothers in dispersal accommodation in Newcastle-upon-Tyne cited in Seddon 2018, n.p.)

The women from the drop-in organisation facilitated connections between the coalition and women living in these types of accommodation. This led the coalition to develop demands for single-family housing within its campaigning, but also in assisting the women in getting immediate improvements to existing housing by putting pressure on the contractor and subcontractor. The evidence gathered by this group was used in a submission to a parliamentary inquiry into asylum accommodation and the work of the coalition was instrumental in the contractor losing out to another provider when the Home Office contracts were replaced (Cassidy 2020).

However, bordered women have also been demanding systems that are flexible enough to be able to respond to individual needs and circumstances in a way which centres the voices of bordered women.

> They should be asking that question, 'What do you need?' And the person will tell you. Because my need, will be different from [name's] need, yeah? (Anon cited in Arrowsmith *et al*. 2022, 22)

This assertion speaks to bordered women's agency in refusing early maternity care as it is currently offered to them. This woman recognises that not only is the basis on which care is offered flawed, but that to avoid epistemic refusals, any efforts to get to know bordered women and their needs must not be driven by the 'clinical gaze' – both institutional and individual – which is often trained on symptoms and the body rather than the wider context of a patient's life (Holmes 2012 after Foucault 1994). Therefore, in our final sub-section below, we argue that refusal and the relations with other women and affiliation with campaigning organisations also created conditions in which bordered women were able to move from self-governance to self-advocacy and, thus, (re)engage with the state on different terms.

Self-advocacy

Below is the text from an email sent to UK Visas and Immigration (UKVI) in January 2017 in the form of a freedom of information request. The correspondence comes from a pregnant woman, Asma, seeking asylum in the UK, who is housed in Initial Accommodation (IA), awaiting the outcome of an application that she and her husband have made for section 95 (housing and financial) support from the Home Office.

> Dear Home Office,
>
> Hi,
>
> I am 37 weeks pregnant with husband. We are in IA (initial Accommodation) provided by home office since two months. Since I am here, I am facing many food and nutrient issues which ultimately affected my physical and mental health.
>
> I am in a deep stress, depression and tension that our section 95 is still under consideration since 2 months. Then I made an application to disperse my in a separate house on temporary basis so that I can give birth to my new one in a peace of mind. The application has been refused because our case in still undecided.
>
> In the past, there are so many cases that pregnant women having health issues have been moved to temporary accommodation until their application has been decided and until she gives birth to baby.

In the extract from the letter above, Asma highlights several aspects of her current situation that are impacting on her health and that of her unborn child. She recognises clear deficiencies in the food being given to her in her current accommodation (which is temporary accommodation provided to those seeking asylum, who do not have the means to house and/or support themselves) and the impacts on both her physical and mental health. She also highlights the harms caused by delays in the processing of her claim for section 95 support by the Home Office and what she has done to try to get access to more suitable accommodation for her family. She clearly demonstrates knowledge of the process, indicating that she is aware that moves to more suitable (separate house) temporary accommodation have been arranged for other expectant mothers in the same situation. This highlights that in attempting to transform (Campt 2019) her own situation during her pregnancy, Asma is drawing on pathways developed by others that she has been made aware of through networks that she has developed with other women (Newhouse 2021). Asma's correspondence continues to draw on the path forged by these other women.

> Home office also made an other objection that I am under 6 weeks cover period. BUT also there are so many pregnant women who moved to their accommodation being more than 38 weeks pregnant. Therefore, I have also provided a consent letter that all the risk during my travel in this situation would be mine. But After providing all the responses and objection, I am still not unheard from Home office Asylum support team.
>
> I have also supplied a letter from nurse, midwife and doctor in my application support that I should be moved on URGENT basis as my health is not coping with the food and environment here.
>
> This situation is increasing my anxiety and depression which is seriously dangerous and risky during pregnancy, during my labor and my newborn during the delivery.

> Therefore I will held responsible to the home office, if anything is going happen to myself or my child during this situation.
>
> (Asma, January 2017)

Asma's narrative also draws our gaze back to the broader, structural harms to her and her baby through bordering practices and processes that lead to hyper-precarization (Lewis *et al*. 2015; Cassidy 2020). It is access to appropriate housing and nutrition that Asma wants; access to conditions that will enable her to care for herself and her unborn child. Her letter also reveals that she has engaged with healthcare professionals – a nurse, midwife and doctor. However, although they are supporting her request in the form of a letter, it is Asma who has to liaise with the Home Office – the only authority that can change her situation in relation to housing and nutrition.

Just as Asma's letter demonstrates how she advocated for and articulated her needs herself vis-à-vis the state, we found that the drop-in organisation was a key actor in enabling bordered women on Tyneside to gain the knowledge and skills for this form of self-advocacy. The drop-in organisation had developed a range of other initiatives over time to respond to the needs of women, including a food/catering service. The women used their connections to other organisations developed through collaborations and liaison to offer catering for events to generate funds for various community projects, including training on refugee women's rights, domestic violence, forced marriage and Female Genital Mutilation (FGM). This training and support enabled self-advocacy as an alternative to the model offered through engagement with early maternity care, where midwives (or other health professionals) would aim to detect these issues in appointments with a woman and then usually get other services involved in the woman's care if necessary. The women from the drop-in organisation had identified and were funding and delivering their own support and training around these issues, facilitating self-advocacy and self-care.

In this section we have argued that a reading for refusal directs our gaze to what bordered women are seeking in early pregnancy in the context of violent immigration and border controls that impact their reproductive lives. We find that the actions of these women direct us to three key pathways: firstly, that they value being connected to those who have had/are having similar experiences as this creates spaces in which they feel safe to share their experiences and also ask for help; secondly, they do want to connect and affiliate with organisations that are aiming to transform the system that is harming their reproductive lives, but that this relates to the wider conditions of their lives, *id est* housing, and also with organisations and groups who are not trying to get to know them on the terms set out by the UK state; finally, we found that refusal opened up possibilities for self-advocacy in relation to the state that acknowledged the limitations of being able to care for themselves and their child/ren without some form of state support. These women are actively transgressing the orders that governmental and non-governmental authorities are attempting to impose on them (Moulin & Thomaz 2016).

However, beyond maternity care, by attuning to the actions of these women through the lens of refusal, we also see important lessons emerging regarding the politics of care in the context of everyday border violence. In particular, the women on Tyneside started by prefiguring holistic spaces of care that were accessible and alleviated some of the violence of the UK's border regime within their own community. The space they created then formed a basis for affiliating with other groups and also challenging the institutions and organisations responsible for perpetrating this violence more directly. This raises questions around the forms and foci of resistance to and organising against border violence in the UK and elsewhere, but also the way in which certain types and aspects of care are prioritised within the UK's National Health Service.

Conclusions

In this paper, we have presented a reading of refusal to frame the experiences and actions of bordered women vis-à-vis early, state-funded antenatal care in the UK. Whilst existing literature acknowledges the harms created by border and immigration regimes and the ways in which these deter women from accessing care, current debates generally represent these harms as part of a

wider set of 'barriers' and focus policy-makers attention on their 'removal' (Higginbottom *et al*. 2019; McKnight *et al*. 2019). Reading for refusal, we argue, enables us to centre the agency of bordered women (Bagelman & Gitome 2021) and regard their lack of engagement in care as 'agentive decisions' taken to keep them and their children safe from harm.

Our case study of the UK draws attention to the specific ways in which the border regime has materialised within state-funded maternity care settings. We argue that designating women as chargeable for care that is deemed immediately necessary presents many women with no choice but to refuse care because of the impact charging has on not only their health and wellbeing, but also the possibility to stabilise their immigration status in the future. Similarly, offering to exempt care for those whose pregnancy results from sexual violence does nothing to alleviate the structural conditions of bordering regimes that make such sexual violence possible, but accessing such exemptions can also be harmful and indeed impossible for many women.

However, we argue that this reading for refusal also elucidates that in refusing early maternity care, bordered women open new pathways to secure care-ful conditions that will support their health and that of their child/ren during pregnancy. These pathways of securing care-ful conditions through forming their own networks and connections, affiliative actions with selected organisations, and building capacity for self-advocacy, enable us to further analyse refusal and its links to resistance. We can think through how these actions may be 'opaque on purpose', in that the women avoided directly challenging healthcare systems and healthcare professionals and instead draw attention to problems with the living conditions and lack of support that bordered women are subject to, particularly in the context of the UK's asylum system.

Refusal encompassed actions which are oppositional in consciousness (Katz 2004) and others that are not. For example, the establishing of the drop-in and the catering service were not oppositional but affiliating to and supporting campaigns to improve housing for asylum seekers were. Therefore, we see how refusal – and its everyday practices – are not only multiple, but how this multiplicity enables an expansion of possibilities (Franklin-Phipps 2022) beyond the oppositional and enables women to prefigure the care-ful spaces they seek within their communities.

Our reading for refusal highlights a number of key issues for policy-makers to focus on if they want to improve engagement in antenatal care by bordered women. Firstly, exemptions are not accessible for women and all care must be free entirely, so that women don't have to choose to delay treatment/care until it is urgent. Secondly, to alleviate fears of immigration enforcement, healthcare settings have to be safe and secure for bordered women and, therefore, there can be no links between healthcare services and the Home Office. Thirdly, women appreciate support from those who have similar experiences, within their local area and being able to access multiple types of support at once. Finally, effective health care cannot be delivered to women whose wider living conditions are so poor that they continue to harm them during their pregnancy. All women should have access to adequate housing and nutrition during their pregnancy, but this is particularly the case for women subject to immigration controls that make them dependent on the UK state to provide for these needs.

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