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# Everyday Political Economy of Human Rights to Health: Dignity and Respect as an Approach to Gendered Inequalities and Accountability

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## Everyday Political Economy of Human Rights to Health: Dignity and Respect as an Approach to Gendered Inequalities and **Accountability**

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#### ARSTRACT

Sexual and reproductive health needs and rights are one of the bleakest examples of (racialised) gender health inequalities in Brazil. This is so despite legal and constitutional specificity recognising the right to health as right of citizenship. In this paper we argue that a 'performance gap' is revealed in contradictions between what the right to health as a normative framework encourages states to do, and institutional arrangements and power relations that underpin everyday gendered inequalities in health delivery. The contribution of this article is two-fold. First, it contributes to feminist political economy accounts of the neglect of sexual and reproductive rights by adding a perspective of human dignity as an approach to gender inequalities. Second, it explores ways in which health inequalities manifest in everyday practices, and how divergent expectations of what the right to health means for professionals and for disadvantaged black women limit the capacity of healthcare to make a difference to their well-being. The article also underlines the importance of complementing legal accountability in health with mechanisms that account for prerogatives of gender justice, equality and dignity.

#### **KEYWORDS**

Gender inequalities; right to health; everyday political economy; dignity; rightsbased accountability; Brazil

The global development discourse on women's rights has substantially expanded from normative assertions in the Declaration on the Elimination of Discrimination against Women adopted in 1967 to specific commitments to reduce gender inequality through action on socio-economic rights and well-being in numerous international and regional agreements, most recently the 2030 Agenda for Sustainable Development (United Nations 2015), Gender equality became a goal in itself in the Sustainable Development Goals (SDGs) with specific targets to address the genderhealth nexus through sexual and reproductive health (SRH) and rights (Goals 3 and 5) (Winkler and Williams 2017). Studies in political economy and development have also acknowledged the premium that human rights place on just and inclusive development processes (Cornwall and Nyamu-Musembi 2004, Uvin 2007, Grugel and Uhlin 2012, Cornwall 2017). However, even in states where socio-economic rights are legally guaranteed, conditions such as violence, lack of education, harmful cultural practices, and differential exposures and vulnerabilities to diseases, are still all too common determinants of uneven development and inequalities within and across societies (Yamin 2019).

Scrutinising these tensions, critical scholars of social reproduction and feminist political economy have explored the ways in which everyday social interactions, often supported by policy and reproduced in institutions, affect the practice and lived experience of the socio-economic, political and civil rights of the most vulnerable (in particular, Elias and Rai 2015, 2019, Tanyag 2018, Nunes 2020). For them, if development is to leave no one behind as the SDGs proclaim, then it is vital both to diagnose the ways in which everyday social norms reproduce patterned structures of inequality with respect to the enjoyment of rights, and to identify mechanisms through which these norms can be contested and transformed.

This article builds on this feminist contention to highlight the centrality of dignity and respect as an approach to gendered inequalities in political economy. We focus on sexual and reproductive health rights in Brazil, where health is a recognised right of citizenship in the 1988 Federal Constitution, but rights regarding SRH are neglected to a great proportion of women, particularly amongst rural and black population (Caldwell 2017, Leal et al. 2017, PAHO 2017). We explore everyday tensions between the ways the right to health is enacted and performed in the practice of health services, and how those tensions affect lived experience of health and rights by disadvantaged women. We argue that deep injustices rooted in social norms, institutional arrangements and power relations underpin everyday practices that manifest in gendered health inequalities, often affecting women in already vulnerable socio-economic contexts. However, our analysis also extends the theoretical resources of this literature. It does so, first, by arguing that women's lived experiences of dignity are mediated by political economy of health service delivery. Theoretically, we claim that dignity is where everyday political economy and human rights intersect, and thus contribute with a perspective that places dignity as a measure of everyday accountability for women's SRH that intersects inequalities of gender, race, and class.

Empirical data were gathered during extensive fieldwork including workshops and focus groups with community health workers, women and health authorities in the states of Goiás in the Central West and Maranhão in the North East region of Brazil during 2018 and 2019. This research was led in the context of a Medical Research Council-funded project, 'Engaging Users for Quality Enhancement and Rights (EU QUERO): Strengthening the maternal and child healthcare system over the first 1000 days in Brazil'. EU QUERO ('I want' in Portuguese) that explores community health workers' everyday work with poor and vulnerable women, raising awareness, providing information about their rights to enable self-reliance and health-seeking behaviour.<sup>1</sup>

The analysis proceeds in four stages. The first section explores the place of dignity in feminist political economy accounts of the neglect of sexual and reproductive rights. The second section elucidates the historical context of the right to health and conceptualises gender and racial determinants of SRH inequalities in Brazil. The third section presents our empirical account of the ways in which inequality in respect of SRH rights is realised through everyday practices and how this is manifested in the experience of poor and black women as rights-bearers. The fourth section explores health accountability beyond legal frameworks to include mechanisms that account for prerogatives of gender justice, equality and dignity. The article concludes by discussing the implications of dignity and respect as social determinants of SRH and as an approach to gender inequalities in political economy.

#### The Place of Dignity in Everyday Political Economy

Feminist work in international political economy is remarkably vast, but a common concern relates to nuanced and often invisible gender-specific challenges that women and girls face in relation to their autonomy and well-being as a consequence of biased power relations and harmful practices affecting health; intra-household labour division; access to and distribution of economic resources; indicators of human well-being; gendered patterns in, and decency of, wages; unpaid care work (Waylen *et al* 2013, Tanyag 2018, Elias and Rai 2019). It also allows for an intersectional analysis that looks at gendered, raced and classed arrangements of social reproduction and gendered

injustices that maintain and reproduce a social order necessary to sustain those power relations (Elias and Rai 2019, also Caldwell 2017).

One of the major contributions of feminist political economy is that it locates power relations in the tensions between policy frameworks and the everyday private and public environments where social relations take place. The everyday experience of social relations draws attention to the ways in which constructions of subjects and subjectivities create and reproduce divisions and hierarchies in social, political and economic relations that may block (some) subjects from exercising their rights of citizenship. This is at the core of critical literature on social reproduction as well as feminist political economy accounts that provide insights into both agency of non-elite actors and mechanisms through which everyday life is governed through practices that reproduce particular forms of violation of rights in the form of, for instance, unequal access to productive and financial resources, labour exploitation, violence and bodily harm (for instance True 2012, Elias and Rai 2015, 2019, Elias and Roberts 2016, Nunes 2020). What the everyday approach suggests is that structural and deep injustices risk becoming routinised in ordinary interactions where conscious and unconscious practices reproduce bureaucratic hierarchies and cultural stereotypes underpinning 'normal' processes of everyday life.

A particular challenge of considering human dignity as an approach to gender inequalities lies in the fact that discussions about gender inequalities in political economy have rarely referenced human dignity. However, dignity is at the core of everyday social relations, struggles for emancipation and equality. As Waldron remarks:

A person's dignity is not just some Kantian aura. It is their social standing, the fundamentals of basic reputation that entitle them to be treated as equals in the ordinary operation of society. Their dignity is something they can rely on – in the best case implicitly and without fuss, as they live their lives, go about their business, and raise their families. (2012, p. 5)

Dignity in the debate of everyday political economy is enlightening insofar as it signals practices of reciprocal respect, and self-respect, in everyday relationships. The salience of the concept of dignity can be further developed by drawing on a distinction advanced by Michael Rosen (2012) between two modes of respect: 'respect as observance' and 'respect as respectfulness'. The former denotes observing human rights recognising the dignity of a person by not breaching those rights – that is being respectful to the law. The latter acknowledges dignity in, and engaging respectfully with, a person – that is being respectful to a person. Respect as observance demands of agents as duty-bearers (for instance, states, health systems, health workers) simply that they abstain from interfering with one's actions, that they exhibit 'respect' by not breaching the rights in question. However, in the case where the duty-bearer is required to provide the rights-holder with a good service, the situation is more complex and both modes of respect are required. In this case, there is an expectation of a right (to development, to health, etc.) to be anchored in normative and legislative obligations to create the opportunities for, and capabilities of, all citizens to equal enjoyment of human rights and, hence, to redress political and economic processes that may systematically block some individuals or groups from equal access to, and effective exercise of, human rights. This resonates global health scholars' call for harnessing the rule of law and sustainable development to redress structural drivers of inequalities such as gender relations (Gostin et al. 2019, Yamin 2019, Hawkes and Buse 2020).

But what would such harnessing require for tackling existing gender norms, dignity and gender inequalities? The subsequent analysis explores this question with respect to women's reproductive rights and inequalities in the delivery of SRH and rights.

#### The Right to Health as (Unfulfilled) Democratic Citizenship in Brazil

Despite declines in inequality over the past two decades, Brazil remains one of the most unequal countries in the world. For Hogan et al. (2018) gender inequalities in Brazil operate in subtle ways

and are inherently linked to a legacy of slavery and forms of patriarchal control which structured processes of uneven inclusion and development across society and within regions. Intersections of gender, race and socio-economic status also explain how women experience access to healthcare in Brazil (Caldwell 2017, Layton and Smith 2017). This is overwhelmingly significant in a society that has, according to the latest national census in 2010, the largest Afro-descendent population in percentage terms (50.9 per cent) in Latin America (ECLAC 2018).

Health has been a site of social activism and part of the social justice agenda in Brazil, and in Latin America more broadly, since the mid-1950s (Birn and Nervi 2014). But social demands around gender rights and the right to health unfolded as a real struggle for democratisation during military dictatorship in the 1970s–1980s (Nunn et al. 2009). The movimento pela reforma sanitária (health reform movement), also known as sanitarista movement, campaigned around the slogan 'salud es democracia' ('health is democracy') promoting the idea that health provision is a central element of meaningful and inclusive democratic citizenship (Melo 1993).

The sanitarista movement also played a role the country's universalist health reform that began in the 1980s. Democratisation created an environment in which political and advocacy actors dedicated to the defence of health as a citizenship right managed to occupy strategic spaces, from which they influenced policy as well as the 1988 Constitution. These developments seeded an innovative legal paradigm of citizenship that placed health as a fundamental universal and democratic right. A complex set of constitutional laws, policies, guidelines and practices has been expressly used to protect and defend citizens from abuses and to promote social programmes seeking socio-economic development and inclusion. Article 196 in the Brazilian Constitution states that 'Health is a right of all and a duty of the State and shall be guaranteed by means of social and economic policies aimed at reducing the risk of illness and other hazards, and at the universal and equal access to actions and services for its promotion, protection and recovery' (also Cornwall and Nyamu-Musembi 2004, De Mendoça et al. 2010).

The framing of health in terms of constitutional obligation, a duty of state and a recognition of health care as a right of citizenship was a significant step towards the recognition of women as subjects of rights. This is not surprising as many feminist non-governmental organisations and women's movements had advocated for the inclusion of gender equality, dignity and non-discrimination in the 1988 Constitution, as well as for legal instruments safeguarding those principles (Correa 2014, Caldwell 2017). The Constitution also establishes that the state must provide the necessary educational and scientific resources to make it possible for individuals to exercise their right to family planning (Law 9.263/1996) as well specific reproductive rights such as to have a companion during labour (Law 11.108/2005) or to know which hospital to be admitted for birth delivery (Law 11.634) (see Bustreo and Hunt 2013). Further laws have been enacted for the prevention and treatment of sexual violence against women and adolescents; humanisation of antenatal care and child-birth, contraception, reproductive rights for people with disabilities, and on abortion (Bustreo and Hunt 2013, p. 36).

Public health movement organisations and women's rights groups have been key actors in the advocacy and adoption of many regulations and the Comprehensive Women's Health Programme (PAISM) in Brazil (Victora et al. 2011, Caldwell 2017). Paradigmatic within this framework is the Family Health Programme, created in 1994 as Brazil's main primary health care strategy to provide a full range of quality health care to families in their homes, at clinics and in hospitals through the deployment of auxiliary health workers or agentes comunitarios de saúde (community health agents). In addition, Brazil has also implemented a number of initiatives to strengthen maternal and child health, including Bolsa Familia, a conditional cash transfer programme focused on health and education launched in 2003 Bolsa Familia has had a tangible impact on reducing poverty and health inequalities amongst children (Calvasina et al. 2018). The programme also increased the number of clinical visits by pregnant women and, in turn, generated a 14 per cent rise in the number of full-term births as well as improved child nutrition, infant mortality and access to vaccinations (Rasella et al. 2013).<sup>2</sup>

Despite progress, the realisation of inclusion and equal rights in relation to citizenship and health has not been achieved. There are two problems concerning the realisation of the right to health, particularly SRH rights. First, despite international and national legal frameworks ensuring a minimum set of rules and entitlements that uphold the right to health in terms of access and availability of services (including quality of services), discrimination on the bases of sexuality, socio-economic status and race still shapes forms of inequalities in terms of health access and the experience of rights. As put by Sonia Correa, a leading Brazilian feminist and sexual and reproductive rights scholar,

History in Brazil and elsewhere shows that realizing human rights in the realm of sexuality requires unending struggles within the social fabric itself. Progress also depends, importantly, in dialogues and solidarity ... to overcome class, race and other social hierarchies and inequalities that intersect with sexuality and human rights. (2014, p. 234)

Second, constitutional gains have translated highly unevenly into the everyday reality of health rights and healthcare. The effects of law and policy evolved across a spectrum of claims pertaining sexual and reproductive rights. However, as Htun (2003) and Htun and Weldon (2018) show, Brazil has historically adopted conservative family policies which have made debates about gender, sexuality and sexual and reproductive rights' divisive terrain. The voice of the Catholic Church and other religious or cultural organisations underpinning restrictive policies in relation to SRH and rights, fall heavily on, and often criminalise, the poor and the young (Htun and Weldon 2018, p. 215). 'Lingering conservatism' associated with influential religious and political parties, in Brazil and indeed across Latin America, has blocked legal changes to broaden rights in relation to sexuality, contraception and demands for legal abortion (Htun and Powell 2006, p. 83). Such a conservative approach has also worked to conceal the duty of the state to SRH rights, often shifting responsibility to women's behaviour, while disregarding the tremendous material and socio-cultural barriers that women face in terms of accessing contraception, safe abortion and healthcare more generally. All these disproportionately affect women from low socio-economic and Afro-descendent women (Caldwell 2017, Soares Leivas and Dos Santos 2018; also Wenham *et al.* 2019).

While Brazil has reduced the national maternal mortality ratio by approximately 57.7 per cent from 104 to 44 deaths per 100,000 live births over the past 25 years, stark health disparities exist between population groups, noting that black women are subjected to unsafe abortion to a greater extent when compared to white women, and contributing substantially to maternal mortality (WHO 2015a, Collucci 2018). A comprehensive study on inequalities, in health experience in Brazil led by Leal et al. (2017), found that black and brown women, particularly those living in the poor North and Northeast of the country, are subject to greater inequalities related to access and care received because of availability of human and equipment resources, geographical accessibility, and cultural sensitivity of service provision and acceptability of treatment. Compared to white women, Afro-descendants and brown receive less professional guidance, fewer consultations and examinations during prenatal and postpartum stages, and are less likely to be assigned to a maternity unit for childbirth therefore more likely to require longer journeys to neighbour states or regions before or while in labour (Leal et al. 2017, p. 10). Finally, for many women the realisation of human rights to health, and the effective enjoyment of SRH rights in particular, is also critically challenged by institutional violence associated with verbal abuse and insensitive treatment towards mixed-race or black women, and women with lower education (Marrero and Brüggemann 2018).

What this accumulated evidence reveals is that the linkages of SRH rights, the right to health, and citizenship, at the heart of a long yet fragmented continuum in Brazil's state-building project,<sup>3</sup> are at best only weakly realised for women from low socio-economic and ethnic minority groups.

#### **Everyday Gendered Indignities Undermining Rights**

The right to health codified in Brazilian Constitution is based on the international proposition that states should recognise the right of everyone to the enjoyment of the 'highest attainable standard'

of physical and mental health; and that steps should to be taken to achieve the full realisation of this right. To talk in terms of rights is to talk not only about normative frameworks underpinning policies and practices for social development, but also about everyday barriers that affect the lived experience of rights. To explore this, we turn to qualitative analysis based on extensive research conducted in the municipalities of Sao Luis and Alcântara in the state of Maranhão during 2018 and 2019, respectively. Maranhão is the second poorest state in the North East of the country and scores low in the Human Development Index (HDI). Maranhão's municipality of Alcântara, with a population of less than 22 thousand inhabitants, mainly black, poor and rural, has a low HDI (0.573) compared to the close-to-national value HDI (0.768) in the capital of the state, São Luís, with more than 1 million inhabitants (HDR 2019). Maranhão, and the North East region of Brazil more generally, is amongst the highest registers for maternal deaths amongst its poor, rural, and Afro-descendent women and children in Brazil (Leal *et al.* 2017).

Our research documented women, community health workers, and health system providers' understandings of the right to health, their perceptions, and emotions around its meaning; as well as the lived experience of healthcare provided. Fieldwork included focus groups, participant observations, and open discussions with 56 women of childbearing age (between 15 and 35 years old) and mothers of children up to 2 years old; all users of the Primary Health Care in São Luís and Alcântara. In Alcântara focus groups also involved community health workers across all nine Basic Health Units (UBS) in the municipality. In São Luís, workshops at the Universidad Federal de Maranhão (UFMA) involved around 60 community health workers and focus groups' discussions with women, community health workers, and health authorities. In both municipalities, community health workers and women shared, to a large extent, socio-economic and ethnic backgrounds that is predominantly poor and self-declared as black (preta) and brown (parda). As community health workers provide healthcare to the same community they are recruited from, they have a strong sense of community identification and of pivotal role as mediators between the community and other professionals in health teams. Community health workers are part of the Family Health Team or similar health models providing primary healthcare alongside doctors, dentists, nurses, and other professionals; yet they are significantly underpaid and underappreciated in their labour status, all of which affect not only their welfare but also fundamentally their views about what right to health in practice means (also Nunes 2020).

After seeking appropriate ethics approval and clearing with participants, they were asked to define (i) their awareness of the rights to health, as outlined in the Constitution and national guidelines from the Ministry of Health; (ii) what rights of health meant to them in their own experience, and (ii) how they would define barriers to their exercise of the right to health in the context of maternal and child healthcare. Data analysis, including demographic data, was supported by members of the research team who read through a subset of verbatim transcriptions of all audio-recordings to identify first-order codes, such as 'health rights'; 'health behaviour'; 'access to healthcare'; 'barriers to access'; 'respect'. The coding process was facilitated by NVivo software and by systematic team discussions for refinement of the coding process. The coded data identified patterns within and between the different groups.

In general, all participants were able to identify some specific rights provided in national laws and guidelines, and in the *Caderneta da Gestante* (pregnant woman's booklet) which provides information on healthy pregnancy, birth, breastfeeding, and women's rights during pre- and postnatal periods. Women, community health workers, and other health professionals (i.e. doctors and nurses) demonstrated a great deal of knowledge about the right to health of women. But their perception, about what defines health rights and what accounts for barriers to exercising those rights, was fundamentally different between the groups of respondents. Specifically, community health agents and women participants in the focus groups defined the right to health in terms of 'dignity' and the right 'to be respected'. That both community health workers and women highlighted this is not unusual given that the community health workers are vital in the everyday delivery of healthcare and also given the shared socio-economic hardships with the community they are part

of. Simas and Pinto (2017, p. 1868) show that about 70 per cent of the community health workers received a salary equivalent to 1–1.5 minimum salaries in the Northeast region – 73 per cent in Brazil – and that for 31.4 per cent of them their salary represents the only family income.

Amongst the main barriers to the enjoyment of health rights identified by both women and community health workers was the power that professionals exercise over decisions and autonomy of women and their bodies. At a focus group discussion, a nurse, by training and consultant to the Ministry of Health, highlighted an enduring claim from women regarding the 'right to be called by one's own name rather than 'mãe' recognising a systematic disregard of 'women as subjects of rights as individuals, not because of motherhood' (23/09/18).<sup>5</sup> Expanding the point, a female participant referred to a persistent 'dehumanised' treatment, and lack of respect, support, and care in critical situations related to pregnancy and birth. She went on to say, 'what's missing is respect. Sometimes the woman is in pain and the response is "Ah, mãe, here you are, I'll give you only five months for you to be here again" (SF, M4, 25/02/2019). Similarly, other participants recalled that 'even at the time of the pain, the nurse said – while watching her soap opera on her cell phone that night: "Ah, I will call one thirteen years old who gave birth here yesterday to teach you." Those kinds of jokes shouldn't happen' (SF, M2, 25/02/2019). Threatening and dominant attitudes were felt in commands such as 'stop screaming [during labour] otherwise you would be left on your own in the room' (M2P, M2, 24/ 04/19) or 'You can't make a peep! ... If you keep crying, you will be left there alone!' (M3RS, M4, 24/ 04/19).

Women and community health workers' participants also identified a relationship of power established over the woman's body, with the professional health team making decisions over issues such as childbirth position or whether to allow a companion during labour and birth. Studies in public health have identified this systematic neglect as a particularly burden for black women (Leal *et al.* 2017). This was recognised by participants at focal groups, self-identified as *preta* (black) or *parda* (brown) who recalled, 'I knew my mum could come in, but they didn't let her' (RS, M1, 24/04/19) and

If it is my right to get pregnant, then I must choose the maternity that I am going to give birth too ... and the position I am going to give birth. I must choose the person I want to attend my birth. But unfortunately, this is not so. Sometimes we are barred by the health professionals themselves. We are barred, understand? (ACS3O, 24/04/2019).

A humanised and respectful care in health units regardless of age, religion, sexual orientation, or race was reclaimed by many community health workers. One participant summarised their views as follows.

We have rights. Yeah ... For example, the right to free health care, SUS is everyone's right, and it's for everyone. And that is why it is universal. But we still find several taboos in SUS health services regarding some users ... Several obstacles, so to speak, difficulties for receiving the user in a humanised way ... We see that in some health units, they suffer discrimination, they go through very difficult situations. (ACS2RS; ACS14, 24/04/19).

Those situations also intersect socio-economic vulnerabilities as almost all participants declared to be unemployed and recipients of the cash transfer programme *Bolsa Familia*. In this context, some highlighted the right to know in advance the place (maternity ward) where the birth will be performed to avoid not only 'pilgrimage' but also incurring the costs of transport as they are sent from one maternity ward to another. One participant, a 16 years old, recalled that she

was sent to São Luís from Alcantara and was refused at the maternity ward. I really had to fight to be accepted. I almost had my daughter in the hall. Because the maternity said [they] didn't have a bed so I had to pay a taxi with my own money to go to another hospital. (ACS1CM, A2, 22/01/19)

This is significant in a population 'mostly dependent on *Bolsa Família*, and no jobs ... and if had to go to São Luís to have a baby may have no way to return from there because of the financial conditions' (ACS1CM, A7, 22/01/19). This is also significant not least because socio-economic determinants are barriers to health and to opportunities for sustainable human development.

The perception of opportunities as well as what defines health rights, respect, and dignity shifted to a focus on the 'behaviour' of women (as patients) at focus group discussions with health professionals. The emphasis turned to services that are available but unreached by women 'often because of cultural differences, language and lack of information about services available to them', as one nurse put it (P3RS, nurse P2, 24/04/2019). In effect, when defining the right to health, health authorities and professionals referred to 'existing laws, regulations and guidelines provided by the universal health system, SUS, that safeguard universal coverage' (P3RS, doctor P4, 24/ 04/19). Claims about barriers to the right to health were linked to modifiable 'behaviours of women' who are perceived, as 'resisting and not engaging with the available services' (P3RS, doctor P4, 24/ 04/2019). A doctor summarised the widespread shared view of 'resistance and negligent behaviour of women' by praising those 'who seek their rights, and are up to date completing their booklets' as opposed to those 'with the lowest education, who do not seek their rights, not even read the information provided' (P2SF, doctor P2,19/02/19). During focus group discussions, a nurse raised the concern that 'resistance happens because of the perceived lack of humanised treatment, some already experienced this in previous pregnancies and births ... which leads to complacency (acomodamento)' (P3RS, nurse P2, 24/04/2019). To which a doctor replied 'there are reservations for this issue of humanisation. Because there are techniques that are brutal, but that have to be done.... to save lives, the life of the baby' (P3RS, doctor P3, 24/01/2019).

We can explicate what is at stake in the divergent responses of local women and of medical professionals by considering the proposed concept of dignity. The discussions with the latter illustrate that they take their role to be the efficient provision of the service due to the rights-bearer in ways that they, as medical professionals who are sole possessors of the requisite knowledge, determine to be best for the patient. The point repeatedly made by local women and community health workers is that in operating in this way, and arrogating to themselves, on the basis of their medical knowledge, the right to determine how women are treated, the medical professionals may make healthcare and services available but fail to acknowledge the dignity of the rights-bearer. This is, in effect, a performance contradiction in rights delivery. This situation is compounded by the local women's perception that the denial of their dignity is shaped by conscious and unconscious class-based and racial biases, and hence that the mode of service provision amplifies the existing structures of disadvantage and inequities. As such, despite government and municipal efforts to implement public policies that promote social development and to strengthen maternal and child health, the lived experience of rights stands in tension with the actual provision of services.

This case illustrates that fulfilling health rights is, to a large extent, shaped by cultural factors and requires complex processes and efforts on the part of the health authorities and service providers to address social and state biases. Issues of ethnicity, education, poverty, and socio-economic vulnerability underpin forms of power relations and discrimination that harm the ways in which women are treated when seeking to access SRH services, particularly affecting the dignity and social standing of women as humans and as citizens of those whose conditions of agency are already circumscribed across several dimensions. The key point highlighted by this study is that the provision of services by a duty-bearer must, *in its performance*, acknowledge the basis of the duty, that is the dignity of a person. Unless it does so, it is liable to generate harmful effects that adversely affect the relations between community and service-providers in ways that undermine the enjoyment of the rights at stake.

How though is the agency of women and their dignity and rights to be secured in everyday health service provision? Our proposal is that what is required are accountability mechanisms that effectively identify problems and guide action towards the correction of performative failures.

#### **Everyday Problems of Rights and Accountability**

The recognition of community engagement, accountability, and people-centred provision of services alongside the rights of each individual are central to the 2015 WHO Every Woman, Every

Child, Every Adolescent strategy that aims to provide a roadmap for countries to achieve the SDGs (WHO 2015b). However, the attainment of health rights underscores the importance of having accountability mechanisms in place to ensure that appropriate actions can be taken to address both how the right is enacted through public health policies and practices, and how its operation is monitored, evaluated, and its failures redressed. Otherwise, the right to health remains nominal.

Comparative scholars in gender studies show how in Latin America different actors and institutional arrangements establish different possibilities of access to healthcare and to enjoy rights, as well as to generate different advocacy strategies (Caldwell 2017, Htun and Weldon 2018). Yet, the debate about health accountability has centred on the role of Courts (Biehl *et al.* 2016, Joshi 2017) and on indicators, indexes, and targets (Williams and Hunt 2017) neglecting social norms, beliefs, and practices that might prevent women from accessing health services in the first place. In response, we propose that to track progress in the promotion of the right to health it is important to recognise implicit social norms of dignity and respect that shape practices and the lived experience of women and that are axes for building sustainable and inclusive development in Brazil, and beyond.

The use of courts as a vehicle of accountability in health through litigation has been an effective mechanism to demand states to guarantee access to medicines and services that are denied or restricted by health care providers. This has served as an effective mechanism particularly in relation to HIV/AIDS treatment (Biehl *et al.* 2016). However, access to courts is typically affected by the socioeconomic and ethnic profile of litigants and it presupposes an awareness and understanding of rights by citizens and access to information and litigation mechanisms that are often missing in the case of the most marginalised.

Brazil created Health Councils to bring together civil society groups, health professionals, and government officials in the discussion of health policies and health system resource allocation. However, the effectiveness (in terms of inclusion and representation as well as the independent competence and influence on healthcare policy) of Health Councils has been severely questioned (Jerome 2018). Furthermore, a central problem is that many women, for example, can't effectively participate in the relevant forms of monitoring and public affairs because they are faced with barriers arising from violence, poverty, lack of access to a quality education or medical assistance (Hawkes and Buse 2013; also Marmot 2010).

Moreover, the value of legal reporting and monitoring mechanisms has been questioned in relation to its narrow focus on indicators, indexes, and targets (i.e. maternal mortality rates, coverage of health services, interventions for neglected diseases, etc.) as a proxy for progress in the promotion of the human right to health (Williams and Hunt 2017). While important, this focus on indicators, indexes, and targets risks masking the distinct health barriers that women face in attaining bodily autonomy and well-being that embedded in socio-cultural beliefs and practices (not least religious beliefs and practices) that may effectively prevent women from accessing services in the first place (Tanyag 2018, p. 664). The challenge for accountability in health is thus to account for prerogatives of gender justice, equality, and dignity that cannot be reduced to checklists of criteria; these are contextual factors of cultural and normative significance for how the provision of SRH rights functions in practice and how this mode of provision is experienced by rights-holders.

A human rights-based approach to accountability in heath requires ways of thinking about what health rights mean and what constitutes evidence beyond discrete instruments that measure accessibility and quality of services in terms that abstract from local contexts of practice. What is needed is an approach that is grounded in the challenge of providing human rights to health in a way that acknowledge the significance of how particular individuals in society and communities (poor women, minority groups, indigenous populations, etc.) understand it and live it, and accountability instruments that capture how they see and experience barriers to the use of available health services. Such an approach should build upon three main assumptions. First, for accountability to be effective it requires laws, policies, institutions, and administrative procedures as well as effective monitoring of human rights standards which avoids simply equating the fulfilment of rights to health with the

general availability and quality of existing health services. Second, for advocacy and accountability to be translated into information concerning dignity and respect in the practice of health provision, it is important to draw inputs from society about what the community perceives and experiences as the everyday problem of accessing and exercising rights. Third, for social audits and citizen reporting to be meaningful it needs to bring the voice of women and empower local community health workers who are best placed to serve as conduits of social accountability, mediating the relations of local women and medical professions, and alerting each to problems in their approach that may impact the effective enjoyment of health rights (also Lodenstein *et al.* 2017).

Assessing access to, and quality of, health services is undoubtedly a means to address diverse health inequities, but for the right to health to be more than a nominal declaration in global and domestic frameworks, accountability mechanisms should also be able to capture structural, symbolic, socio-economic, and cultural barriers that negatively affect or undermine dignity and choice of individuals and communities. Our study is a step in this direction assuming that accountability for the right to health, particularly for SRH and rights, needs to engage more critically with data that captures both the circumstances of daily life and 'everyday problems of rights' as experienced by women, and the structural and societal drivers of those circumstances.

#### **Conclusion**

The intersection of multiple structures of domination (political, economic, racial, or gendered) exerts a decisive influence on the social and economic position of Afro-descendent women in Brazil and in Latin American societies more broadly. These structures are manifested in everyday social relations and practices, and are given expression in the form of ethno-racial and gender-based discrimination. In Brazil, despite pioneering the codification of reproductive rights as constitutional norms since 1988 as part of the (re)democratisation process, deep-seated racial discrimination and inequalities continued to be the mark of the linkages between the right to health, SRH rights, and citizenship. Providing first-hand evidence, this paper has offered a novel contribution to scholarship on sexual and reproductive health and rights in Brazil to illustrate those linkages and expressions of socioeconomic and culturally determined barriers to the enjoyment of the human right to health of women. Given the greater challenges facing certain groups of women and especially women of African descent in terms of recognition and representation, it becomes clear that the enjoyment of the right to health and the experience of sexual and reproductive rights are a very different matter for some women than for others. As put by a participant, 'the right to health is everything that is guaranteed, but this right is not granted to us' (ACS1CM, A1, 22/01/19).

The paper contributes to feminist political economy accounts of the neglect of SRH rights arguing that advancing rights-based health policies, programmes, and practices is significantly dependent on eliminating structural and cultural barriers that affect individual dignity and the enjoyment of rights. The salience of dignity, as an approach to gender inequalities, brings new insights into barriers that are rooted in divergent understandings and expectations of what the right to health and respectful delivery of health mean across disadvantaged social groups and health professionals. Taking as its core focus the idea of the dignity and value of each individual, states and service providers are seen as having a duty to treat each person as a subject of rights, to acknowledge the dignity in their person, not merely as a 'beneficiary' of policies or services available to them.

Specific manifestations of discrimination and abuse of human rights to health explored in this paper expose deep injustices affecting some groups as a consequence of assumptions, reactions, and stereotypes in ordinary, everyday interactions where professional and bureaucratic hierarchies amplify already existing cultural and socio-economic barriers through gendered forms of rights violations. These processes occur at interconnected layers from discriminatory comments and practices that fail to respect women's dignity in the provision of SRH care, to restrictive family policies and conservative local understandings about reproductive health which have made gender and sexuality divisive terrain.

This takes us to a second point that women are most disadvantaged because of barriers to health that span a normative continuum of formal explicit legal frameworks and implicit informal social norms. The case of Brazil reveals that a 'performance gap' emerges as a consequence of how the right to health is enacted within these spaces. Brazil simultaneously harnesses a kind of 'health citizenship' based on legal provisions for gender equality, dignity, and non-discrimination in health services while routinising biased practices and power relations that privilege health professionals' power over women's decisions and bodies in ways that deny gender equality, dignity, and non-discrimination.

While gender equality is being mainstreamed across international development agendas, our analysis shows that fully addressing the root causes for health right failures requires transformations in how the provision of a duty, that is health services, acknowledges equal dignity of persons. In Brazil, as in many other places, women's lived experiences of dignity are mediated by political economy of health service delivery. In the absence of such acknowledgment, women as rights-bearers are likely to experience the right to health as itself enacting dignitary harms in ways that adversely affect their enjoyment of the right. These efforts are deeply intertwined with broader notions of social and gender justice bridging dignity into the debate and the practice of everyday political economy.

Finally, by making visible the lived experience of women, in situations of socio-economic deprivation in Brazil, this article also put forth a case for rights-based accountability as a foundation for redressing (racialised) gendered health inequalities. The underlying claim is that if a human right to health is to be given effective expression as citizenship entitlements and as part of inclusive political economies, then public mechanisms for determining the practical meaning of these entitlements and holding to account those who fail to discharge (or violate) those duties are required. This might mean creating more spaces where issues of SRH rights are made visible within health frameworks and codes of practice, moving beyond monitoring access and availability of services, to account for practices and the social power relations that reproduce respectful care and dignity in service delivery.

#### **Notes**

- 1. MRC Grant MR/R022933/1. For information about the project, see https://gtr.ukri.org/projects?ref=MR% 2FR022933%2F1.
- 2. For information about Bolsa Familia, see http://saludentodaslaspoliticas.org/en/experiencia-amp.php?id=13.
- 3. I am thankful to an anonymous referee for raising this point.
- 4. International Covenant on Economic, Social and Cultural Rights, 1966 (art.12).
- 5. The right to be called by one's name, avoiding terms such as 'mum' 'mummy' or 'miss' is recognised by the Ministry of Health as central to a humanised treatment of women during birth. See https://bvsms.saude.gov.br/bvs/publicacoes/cd04\_13.pdf.

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