

# Unstable rights

## Multidrug-resistant tuberculosis and access to rights in Rio de Janeiro, Brazil

Oriana Rainho Brás

### Abstract

People with multidrug-resistant tuberculosis in Rio de Janeiro accessed basic rights of citizenship, including socioeconomic rights and even formal citizenship, through their use of the public health care system. Access to those rights, however, was unstable and this had life-and-death implications. I argue that patients could only fulfil their right to live after it had been jeopardised by the absence of basic socioeconomic rights that rendered life precarious. Thus, the right to live is not a prerequisite of other rights, but rather cannot be fulfilled without them. I discuss the politics of life in this context based on ethnographic fieldwork in an outpatient clinic for multidrug-resistant tuberculosis and interviews with patients, health professionals, and activists, all conducted in 2009 and 2010 in Rio de Janeiro.

### Keywords

rights, citizenship, multidrug-resistant tuberculosis, Rio de Janeiro

### Introduction

In 2010, the state of Rio de Janeiro had the highest incidence of tuberculosis in Brazil, almost double the percentage in the rest of the country at 70.7 per 100,000 inhabitants (PCT/SES/RJ 2011). At 5.1 per cent, Rio de Janeiro also evinced the highest death rate for tuberculosis in the country, totalling between 800 and 900 deaths per year (PCT/SES/RJ

2011). Cases were concentrated in the city of Rio de Janeiro (Secretaria Estadual de Saúde e Defesa Civil 2011), which reported an incidence of 95.3 per 100,000 inhabitants. However, in certain neighbourhoods, the tuberculosis incidence was much, much higher: 696.4 per 100,000 in the Saúde neighbourhood; 464.4 per 100,000 in Bonsucesso; and 425.2 per 100,000 in Jacaré (PCT/SES/RJ 2011). Rio de Janeiro state also presented the greatest number of cases of multidrug-resistant tuberculosis (MDR-TB) in 2010 (PCT/SES/RJ 2011).

Both the seriousness of these numbers and the discrepancies they revealed among different neighbourhoods in the city fuelled my interest. To investigate how health care took into account the social contexts of tuberculosis, I conducted ethnographic fieldwork in the outpatient clinic for MDR-TB at the Reference Centre for Tuberculosis Professor Hélio Fraga (hereafter, 'the clinic') from July to December 2009 and from May to August 2010. The clinic served most of the people with MDR-TB in the state of Rio de Janeiro. At the same time, I conducted interviews with health professionals and activists working with tuberculosis patients in Rio de Janeiro.

Despite the state's free provision of drugs, having MDR-TB had direct and serious consequences for patients' ability to provide for themselves. To care for MDR-TB, and other diseases frequently associated with it, and to avoid transmission, many patients had to stop working. The situation was more difficult for people who worked without a formal contract and were not entitled to receive support from the welfare system. Indeed, a special committee of the Chamber of Deputies of Brazil studying the government policies on diseases affected by poverty concluded that many tuberculosis patients were not benefiting from the Brazilian welfare system (Subcomissão Especial 2013).

Generally, health professionals and patients recognised that care for this disease required social and economic support beyond access to drugs and medical exams. In the early 2000s, the Brazilian government created a revenue transfer programme intending to reduce poverty in the country. Many patients only became aware of or could access this programme and other such programmes when they began treatment at the clinic; in this way, their interaction with the health care system allowed them to begin to access basic socioeconomic rights. The fact that they had not had those rights previously, or known about those programmes, was a factor in their becoming ill. Mobilising biologically and biomedically defined conditions as a basis for claiming rights, these patients' stories point at the continuous redefinition of the state's margins (Das and Poole 2004) and of citizenship, specifically concerning the relations among the politics of health, life, and death.

## Social and economic support for patients with MDR-TB in Rio de Janeiro

Biehl (2007, 283) has emphasised the importance of studying the forms of care that take place in contexts where medicines and scarcity coexist. In Rio de Janeiro, the availability of treatment for tuberculosis, the frailty of the national health services, and the extremely precarious life conditions of many patients combined to create bacterial resistance to medicines. The situation affirmed what Farmer (1999) has pointed out: social inequality encourages the spread of drug resistance among tuberculosis bacteria. Vulnerability is thus produced by a matrix of individual and collective factors that lead to a greater susceptibility to infection and disease, on the one hand, and, on the other, the relative availability of resources that can protect individuals from infection and disease (Ayres et al. [2003] 2005, 123). With tuberculosis, the precarious life conditions that increase patients' vulnerability frequently persist while they undergo treatment, making it extremely difficult to complete treatment and be cured. Indeed, hospitals specialising in tuberculosis treatment reported that patients stayed at the hospital even after their clinical condition ceased to justify it, because they lacked adequate resources to complete treatment outside the hospital, meaning that they did not have enough to eat or sufficient support.

Tuberculosis occurred frequently alongside other health problems, such as HIV/AIDS, hepatitis, and diabetes mellitus, that also demanded care. An epidemiological study of the patients of the state hospital for tuberculosis in Rio de Janeiro, Hospital Estadual Santa Maria, revealed that 30 per cent of the patients with tuberculosis also tested positive for HIV/AIDS, 16 per cent for hepatitis, and 15 per cent for diabetes mellitus (de Oliveira et al. 2009). Additionally, most of the patients were incapacitated to some degree by their tuberculosis, either temporarily or permanently, especially from reduced breathing capacity. Treatment also frequently resulted in hearing and memory loss, and other side effects included nausea, stomachache, drug-related hepatitis, joint pain, and neurological changes.<sup>1</sup> Indeed, in interviews, patients detailed daily routines wholly dedicated to health care. The intensity of the treatment programme and the desire to avoid transmission combined to prevent patients from working, thus worsening their social and economic situation. And those who had been working informally – a considerable proportion of the total number of tuberculosis patients – faced a more serious situation because they were not eligible for

<sup>1</sup> The Health Ministry of Brazil's recommended MDR-TB treatment is a regimen of five drugs: one bactericidal (amikacin) for twelve months, three bacteriostatics (terizidone, ofloxacin, and ethambutol) for eighteen months, and one bacteriostatic (pirazinamide) for six months (Rocha et al. 2008).

disability payments. The number of tuberculosis patients receiving support through the state's disability allowance was far too low given the rate of infection (Subcomissão Especial 2013).

In 2004, the government of Partido dos Trabalhadores (the left-wing Workers' Party) created Bolsa Família, an economic aid programme that aimed to reduce poverty and inequality in Brazil by complementing the monthly income of families in socioeconomic need who agreed to some conditions, such as enrolling their children in school and attending health services (Ministério do Desenvolvimento Social 2015). Another important federal state programme is Benefício Assistencial de Prestação Continuada, a monthly financial grant to anyone who does not earn a livelihood, either independently or from family support (Ministério do Trabalho e Previdência Social 2016); this programme is especially important for elderly and disabled people. Prior to the establishment of these programmes, the Rio de Janeiro municipal programme for tuberculosis control distributed a food parcel to tuberculosis patients, according to my interview with its coordinator in 2009. When Bolsa Família began, it replaced all state and municipal economic support to people in need. It was intended to end the proliferation of targeted social programmes and to improve the organisation of public services. However, the coordinator explained, many tuberculosis patients, despite their precarious work situations, were often just over the income threshold and thus ineligible for the Bolsa Família programme.

During the fieldwork period, some additional measures were in place to provide economic support to patients during treatment. Patients with MDR-TB needed to go to the clinic for a monthly appointment with a physician specialising in the respiratory system or in infectious disease, a nurse, and, in some cases, a social worker. The Global Fund Project for Tuberculosis in Brazil covered patients' travel expenses to their monthly clinic appointments, as well as to examinations and other appointments, by providing them with a public transportation card. The clinic's health professionals also collected private donations to offer a monthly food parcel to every patient who needed it.

Health professionals played another important role by informing patients of their possible entitlement to state programmes and in preparing documents for their applications, such as reports of their social and medical conditions. At the Hospital Estadual Santa Maria, a social worker explained to me that health teams – made up of physicians, nurses, social workers, psychologists, and spiritual counsellors – assessed newly admitted patients with regard to their personal, social, economic, and clinical situations. During a patient's hospital stay, the team would prepare for the continuation of treatment by contacting local services to which the patient could be referred, together determining whether the conditions were right for the

patient to carry on their treatment outside the hospital. Like these hospital health teams, the clinic's health professionals were the mediators of patients' relations with the welfare system.

## Disease and health care: Pathways to access rights

I met Marta in July 2009 in the waiting room of the clinic. She was a thin, smiling, communicative woman who came in accompanied by her daughter. She had knocked at the door, and, when she talked to the health professional who opened it, she confirmed, relieved, that she had all the documents needed for an appointment: an X-ray and a bacilloscopy. The social worker spoke with Marta and obtained her consent for me to be there as well. Marta said she had previously received treatment for MDR-TB at the same clinic. The social worker had her medical record and read out loud that Marta had followed her treatment regularly for a year and then, because of financial problems, stopped going to the appointments for some months, and then resumed them. Marta said she had returned again because she once more had symptoms of tuberculosis. She was feeling tired and ate little. Her first treatment in that clinic had been in 2001, shortly after she gave birth to her youngest daughter. Now forty-eight years old, Marta had three daughters to take care of and a granddaughter whom she avoided kissing because she was afraid of infecting her.

Marta and the social worker talked about the development of drug-resistant bacteria, and the social worker emphasised that Marta should go to her appointments and follow the doctor's advice. She also informed Marta of the services and support the clinic gave to patients. Marta asked what she should do to receive disability payment, since she had lost her job as a domestic cleaner in the last month. After asking to see her work permit, the social worker assured Marta she was entitled to disability payment and instructed Marta to get a medical statement confirming her illness. Marta had also recently lost her Bolsa Família stipend and wanted to know what she should do to get it back. The social worker confirmed that she was entitled to it because she was unemployed and her three children were in school.

Later that day, the pneumologist saw Marta; afterward, she reported to the social worker that while Marta had many complaints, her X-ray showed only aftereffects and not active disease, and her two bacilloscopies tested negative. Based on the exams, the pneumologist was convinced that Marta did not have tuberculosis, and she further thought Marta had come to the clinic to get economic support now that she had become unemployed. In her view, Marta's MDR-TB had been cured in 2001, although she had not been formally discharged because she had missed the last appointments. The pneumologist declared she could not write a medical statement affirming that Marta had tuberculosis. The social worker responded that Marta was complaining of tuberculosis symptoms and emphasised that she

would not have come to the clinic unless something was wrong. The pneumologist agreed. She referred Marta to the pneumology department at the hospital for an appointment, and wrote a medical statement declaring Marta had residual tuberculosis and chronic obstructive pulmonary disease that should be further investigated.

The return of tuberculosis symptoms could be related to a relapse or caused by the severe aftereffects of treatment. Difficulties in distinguishing between these two possibilities led to clinical uncertainty, which the pneumologist could solve only partially through further exams and a vague diagnosis, such as chronic obstructive pulmonary disease. In this case, however, the interpretation of the pneumologist was that other needs motivated the search for health care, such as the need for social and economic support and some mediation to help get it.

Another former patient, Júlio, came back to the outpatient clinic after treating and curing MDR-TB. He asked the social worker at the municipal shelter where he was staying to call the clinic because he felt ill, and the clinic's social worker received the call. I was there when she approached the coordinator, a pneumologist, to discuss the subject. The pneumologist exclaimed, 'Is that patient not dead yet?' The social worker asked the pneumologist to mind her words, and the latter excused herself, saying he was a 'very difficult patient'. She told us he had once moved his bed out of the hospital ward and that one of the specialised tuberculosis hospitals would no longer accept him, claiming he had attacked a doctor. Despite consistently testing negative for HIV, he always declared that he was HIV positive, and she believed he did so in order to receive economic support. I asked her if there was any chance that a person with HIV could present negative results, and she answered that it would be a very rare situation.

The pneumologist could not admit him to the hospital as an MDR-TB patient without a sensitivity test. The social worker was anxious to act because Júlio lived with one hundred other people in the shelter and she wanted to prevent transmission. They agreed that the social worker would ask the professionals at the shelter to send Júlio's HIV test and bacilloscopy to the clinic. The pneumologist told me that while Júlio had completed MDR-TB treatment at the clinic, the pulmonary aftereffects were severe and could be the cause of his current complaints. It was possible that he was ill again, although the pneumologist did not believe it and wanted to avoid an appointment with him. The social worker described Júlio as a patient who knew his rights well and demanded they be observed. He had once written to the ombudsman's office to complain about having stayed a whole day waiting for an appointment at the clinic.

Marta's and Júlio's cases reveal a demand that surpasses strict biomedical definitions of eligibility for tuberculosis care. They also show how patients with MDR-TB, or still troubled

by its aftereffects, utilised their disease to access state support through the health services, thus exercising their basic rights. For many people with MDR-TB in Rio de Janeiro, their ‘injured biology’ (Petryna 2002, 5) opened the way to basic rights, because it was in the context of their treatment that they received socioeconomic support from the state. Many MDR-TB patients came to know they were entitled to state support programmes through their contact with health services, and health professionals acted not only as care providers but also as expert witnesses. Medical reports, social worker reports, and the assessment of a medical board played crucial roles in the application process for both federal programmes, but especially in the case of *Benefício Assistencial de Prestação Continuada*. Although in a different context, these processes resemble the cases described by Petryna (2002) in her study of people affected by the Chernobyl disaster, where specific medical, scientific, and technical processes were in place to prove to the state that people were entitled to certain socioeconomic rights. What we see at work here is a specific form of what Petryna (2002, 6) named ‘biological citizenship’: ‘the massive demand for but the selective access to a form of social protection based on medical, scientific and legal criteria which recognise and compensate for biological damage’. Similarly, Biehl (2007, 121), working in Salvador, Brazil, found that for many poor and marginalised people living in a highly unequal urban context, HIV/AIDS opened the possibility of economic survival as ‘diseased citizens’.

## Disease and health care as doorways to formal citizenship

While the stories of Marta and Júlio reveal trajectories from disease to citizenship rights, other stories show the trajectory from disease to formal citizenship. I met Sérgio at the clinic in 2009. I was present while he and the social worker were talking one evening after his appointment with the pneumologist. He had been engaged in antiretroviral therapy and MDR-TB treatment for six years. He was middle-aged and did not know how to read or write, and this made him sad. ‘I do not know how to read, but I know how to talk to people’, he told me. He said that in the past he had been addicted to drugs and ‘vegetating in the bad things of the world’. Fragility and suffering were visible in his body and his face. His limited breathing capacity made difficult even the simplest domestic tasks, such as hanging clothes out to dry or washing the dishes. He often spent the day at the house of an old woman who he said was like a mother to him. At the moment he was squatting in a house and living off of donations.

Sérgio told the social worker that he was happy because a worker at a nongovernmental organisation had given him a document so that he could take two witnesses to an office of

public records in Rio de Janeiro to obtain his ‘late birth certificate’.<sup>2</sup> When Sérgio had started his antiretroviral treatment at the municipal hospital in 2003, he did not have a birth certificate. In order to issue it, the court ordered that information about Sérgio be gathered in his birth town in northeastern Brazil. The same court made sure that his rights to health care were observed. The day I met him, Sérgio was about to get the *Benefício Assistencial de Prestação Continuada*, which would guarantee him a monthly livelihood. This, in turn, would free him from the unwelcoming atmosphere of his house. He told me that he came from a dangerous world and lived ‘amid caimans’. About a month and a half later, the social worker told me that the clinic received news that Sérgio had died in the hospital after being severely burned. The clinic professionals suspected he was a victim of violence in the house where he lived.

Another patient, Caio, had not been able to work regularly since he had started suffering from tuberculosis in 1995. He got involved in drug trafficking and was arrested in 2002. In prison, his tuberculosis manifested again, and he pursued treatment. But he could maintain it only for a few months because of the violence in the prison. After being released, he worked selling sweets at a crossroads. He was married and had a four-year-old son from that marriage whom he had raised for three years, and five other children from other relations whom he had not raised. However, his marriage ended which made him sad. In 2007 the disease manifested again and proved to be drug resistant. This time, he started his MDR-TB treatment at the outpatient clinic.

As he did not have a work contract, he could not receive disability payments. He lived in a room outside his mother’s house, and he described his living conditions as poor: he had no electricity, and on rainy days water came pouring into his room. His relationship with his mother was poor but he had no means to move out. During his MDR-TB treatment he obtained his identification documents. In 2009 he applied for the *Benefício Assistencial de Prestação Continuada* by presenting a medical justification signed by his pneumologist and a social justification signed by the social worker. The application was approved and in 2010, when I met him again at the hospital where he was admitted, he was already receiving his monthly financial support. His son had called Caio to ask Caio to live with him, and complained that his mother beat him. His ex-wife had been to the hospital but he did not want to resume their relationship, he said, because she was taking ‘crack’<sup>3</sup> and destroying

<sup>2</sup> A person may request their own ‘late birth certificate’ at the public records office in their place of residence by presenting two witnesses who sign the formal request (Apa 2009).

<sup>3</sup> ‘Crack’ is the name of a substance derived from the production of cocaine. It is very cheap when compared to other drugs. In 2009, in Rio de Janeiro its use was relatively recent, when compared to São Paulo, for example; however, it was already a very serious public health problem.

herself and harming the child. The possibility of having his autonomy guaranteed, providing for his son, and the prospect of a better life were important encouragements for his treatment.

Brazilian public health services are free of charge, and the state provides health care to all patients, whether or not they have identification and, in fact, whether or not they are Brazilian citizens. Sérgio and Caio received health care even though they did not have identification documents. But they did not exist in state records; it was only through tuberculosis treatment and the health services that they were entered into the state system. To access shelter and food to support their MDR-TB treatment, patients without a livelihood and without identification in the state's registry, like Sérgio and Caio, had to be 'counted'. It was disease that allowed them to become people whom the state formally took into account beyond providing them with free health care. Sérgio's and Caio's stories show that those who did not figure in the state's tallies when healthy could eventually enter official rolls when they fell ill. MDR-TB was the doorway to formal citizenship. While these men lived at the state's margins (Das and Poole 2004) before becoming ill, their use of health services and consequent formal citizenship and access to a monthly state support redefined those margins.

Yet formal citizenship did not guarantee Sérgio and Caio automatic access to basic rights, which we also observe in the stories of Marta and Júlio. Instead, those rights were constantly under threat: they were intermittent, unstable, and the patients needed to reinforce them continuously through their relation with the health services. Indeed, the absence of basic socioeconomic rights hinders life by making it extremely precarious, thus increasing the risk of contracting tuberculosis, and making it extremely difficult to cure when it occurs. When, however, people do have tuberculosis, their access to health care may be an important doorway for the fulfillment of those rights. As paradoxical as it may seem, the disease that could kill them was also the one to potentially guarantee them the rights necessary to support their lives. The specific role of health in citizenship and the definition of rights, and the contradictions it reveals seems to be common to other contexts, as Petryna and Follis (2015, 408) note: 'From local systems of mutual aid to international humanitarianism, anthropologists have explored health as a key fault line in which the paradoxes and prospects of citizenship find their most powerful expression'.

For MRD-TB patients, being in or out of citizenship has very high stakes: life or death. This very much resonates with Petryna and Follis's (2015, 407–08) remark that the boundaries of citizenship' today pose risks that act as fault lines of survival:

Yet the much-invoked Foucauldian question of "who lives and who dies" requires a less atemporal view of the kinds of lives that are peopling these dynamics and deploying difference (Fassin 2012, Fischer 2014, Jackson 2005), as well as a more

durable perspective on inequality, not just how lives are exposed but how they are left exposed. Moreover, what are the politics of rescue or nonrescue (Calhoun 2008, James 2010, Redfield 2013, Stevenson 2014, Ticktin 2014), and what is the responsibility of the citizen to the exposed not-yet or never-to-be citizen? In addition to grounding abstractions in their human consequences and realities (Nelson 2015), the nature of such boundary maintenance is increasingly central to a new anthropological study of citizenship. Efforts of self-preservation among migrants and noncitizens are indicative here, as are those among patients and environmental victims. Caught up in life-threatening conditions whose scope and needs exceed systems of response, they enter into a twenty-first-century risk-citizenship nexus in which a potential for dehumanization can widen.

## From citizenship rights to human rights

When I first arrived in Rio de Janeiro in 2009, health professionals and health managers emphasised that following treatment correctly was the best way to avoid transmission. The municipality was investing in expanding Directly Observed Treatment-Short Course (DOTS), in which patients must take medications in the presence of a health professional, and increasing the number of health agents in the community performing such direct observation in people's homes. The clinic had arranged for a few patients to follow a DOTS regimen, but most of them took the treatment on their own and were counselled by health professionals on how to prevent transmission among the people close to them.

Harper (2010) reports that a relevant discursive shift in language occurred at the international level, expressed in the WHO's guidance, which moved from an emphasis on 'patient compliance' and direct observation of treatment, to an emphasis on 'patient support' and human rights, which was underlined in the more encompassing STOP TB Strategy. However, this shift did not resolve relevant tensions between the two approaches. As Harper (2010, 210) writes, 'Central to these debates and policy formations has been a tension between a public health concern with protecting the public and preventing the spread of "untreatable" infection [that is] increasingly at odds with a rights-based and patient-centred approach'.

When I returned to the field in 2010, these debates were starting to take place, and I was able to follow them through the Forum of NGOs Fighting Tuberculosis in Rio de Janeiro (hereafter 'TB Forum'), which aimed at putting TB on the political agenda and advocated for patients' rights. In 2009, the TB Forum comprised around 100 institutions and individuals. As part of fieldwork, I participated in the TB Forum's meetings and received its mailing list. The history of the TB Forum dates back to 2002 when a restructuring of the Rio de Janeiro

state programme for tuberculosis control brought in a coordinator experienced in HIV/AIDS. Health managers as well as activists and researchers felt that the involvement of social movements in fighting HIV/AIDS in Brazil was a good practice and should be replicated. This coordinator (who was no longer in charge when we spoke in 2010) argued that in order to reach a true commitment of the state government towards tuberculosis control there should be a strong social movement supporting it, and she brought in an HIV/AIDS activist to work towards that goal. At that time, not even HIV/AIDS activists spoke of tuberculosis, this activist told me. Instead, they organised meetings with local NGOs dedicated to HIV/AIDS, teenagers and youngsters, sex workers, people living in the street, and also representatives of religious associations, providing them with information about tuberculosis in the state of Rio de Janeiro, and urging them to address it in their work. According to a representative of the TB Forum, participants were surprised by the scale of spread of the TB problem in Rio de Janeiro, and several of them decided to create a second organisation dedicated to this disease, the Forum of NGOs Fighting Tuberculosis in Rio de Janeiro, mimicking the already existing Forum of NGO for HIV/AIDS in Rio de Janeiro.

One of the emergent debates at that time concerned the mandatory hospitalisation of people with TB. In August 2010, the National Programme for Tuberculosis Control and the Pan-American Health Organization organised a meeting titled 'National Seminar on Tuberculosis, Citizenship, and Human Rights: Reflecting on the Duties to Affirm the Rights of People with Tuberculosis'. The TB Forum was invited to speak at the seminar. According to the report delivered to TB Forum members by their representative at the seminar, several physicians defended the compulsory hospitalisation of patients, arguing that it would avoid any interruption of their treatment, and justifying it by the primacy of collective over individual rights.

Along with this report, news of compulsory hospitalisations of MDR-TB patients in Brazil circulated on the TB Forum's mailing list. One of these cases concerned a man living in the state of Rio Grande do Sul who had undergone irregular treatment for TB for four months in a health centre; later, health-surveillance professionals had seen him living with other people in a house with no windows or ventilation (Ministério Público do Estado do Rio Grande do Sul 2008). The health-surveillance professionals informed him of the treatment options and the possibility of a cure. He refused to follow treatment, and the Public Ministry ordered his compulsory hospitalisation.

The TB Forum argued that such compulsory hospitalisation was a violation of human rights, and its representative affirmed this stance in an email to the TB Forum's mailing list:

Compulsory hospitalisation and treatment are unacceptable, as it is a cruel harm to patients, and a clear violation of Human Rights by public authorities who fail to keep

with their responsibilities to provide the necessary means and to break barriers so that patients have access to decent and human treatment. (4 September 2010)

The TB Forum invited a law professor to its September 2010 meeting who reinforced the group's position:

How do we attribute the abandonment [of treatment] to an individual who does not possess a house, information, or food, which are the basic rights of every citizen? Before determining that the patients should be compulsorily hospitalised, it is the state's responsibility to solve the historical social problems related to the disease.

Members of the Public Prosecutor's Office of the state of Rio de Janeiro met several times with the TB Forum, and, in November 2011, the office's coordinator of human rights asked the TB Forum to provide all available information on the matter in order to consider whether compulsory hospitalisation might represent a violation of constitutional rights.

Thus, compulsory hospitalisation was both rejected and justified with arguments based on human rights. However, in each case the focus was on a different set of rights holders: those who rejected it considered the rights of tuberculosis patients (both before and after they got the disease), and those who argued for it prioritized the rights of the healthy population who risked becoming infected. But they all realised that the state provided insufficient support for their arguments and scaled up by mobilising a discourse on human rights, a strategy that affirmed Petryna and Follis (2015, 404) in their conclusion that 'post-war human rights were intended to operate where the protection of citizenship failed or did not reach'.

According to the TB Forum, the basic citizenship rights of people who contracted tuberculosis took precedence over the possibility that they might transmit the disease through treatment interruption or noncompliance. TB Forum activists argued that citizenship in Brazil was unequal and resulted in precarious life conditions that led to tuberculosis outbreaks, under which following treatment was a daily struggle for survival. In doing so, they framed tuberculosis as a deep social and political issue. As such, they were undoing the 'translation of social realities into sanitary language' (Fassin 2000, 28) and arguing that the right to health implies respect for the social, economic, and civic rights of people with tuberculosis, and insisting that all these rights are inseparable.

Biehl's (2007) ethnography of HIV/AIDS in Bahia, Brazil, also demonstrates how the right to health is dependent on the realisation of other basic rights. In a global context of neoliberal economic principles that favour large multinational corporations like pharmaceutical companies, the Brazilian government had approved an AIDS policy of

universal access to antiretroviral treatment. This equated the right to health with the right to medicines and had a crucial role in configuring what Biehl (2007) calls ‘pharmaceutical citizenship’. However, one of the main features of this turn was that all other components of health care were left out. Biehl (2007) shows that access to HIV/AIDS medicines and treatment followed race- and class-based lines of exclusion and discrimination that already existed and were aggravated by the disease, and that no policies were in place to guarantee poor people living with HIV/AIDS housing, employment, or economic security. Instead, Biehl (2007, 400–401) describes ‘local economies of salvation’, in which life was dependent on a patient’s ability to create a ‘manufactured will to live’ and on their having a house, a stable income (even if small), a social network, and someone to live for.

## Conclusion

The stories of MDR-TB patients in Rio de Janeiro raise important questions about the contemporary politics of life. MDR-TB patients gained access to basic rights they did not have before they became ill, through their use of health care services. Health care, in this context, acted as a mediator between patients and the state’s socioeconomic support, and the effects of their disease were an argument for their eligibility for state support. I interpret this as the workings of the principle of ‘biolegitimacy’, which Fassin (2000) considers an important moral foundation of the contemporary world, whereby politicians are readier to recognise and support the bare right to live than civil rights in the aggregate. However, the stories of Marta, Júlio, Sérgio, and Caio reveal that the right to live is not so much a prerequisite for other rights as it is composed of them; it cannot be fulfilled without them. While the right to live was supposedly guaranteed through universal and free health care, other basic rights of citizenship remained unfulfilled. Ethnographic data demonstrates that access to basic rights, beyond access to medicines, had a clear effect on treating and curing tuberculosis. It is a deep contradiction that socioeconomic rights, whose absence is causally related to tuberculosis, are only granted to people after they become ill. Thus, I argue, in Rio de Janeiro, people could only fulfil the right to live after it had been jeopardised by the absence of basic socioeconomic rights, which rendered life precarious.

Activists advocating for the rights of TB patients in Rio de Janeiro clearly highlighted the connection between the right to health and other basic rights, and they claimed that the state is responsible for not granting the latter in the first place. This is considerably different from the trend toward the legal equation of the right to health with access to medicines that HIV/AIDS patients started and that is now argued for in other health contexts (Biehl and Petryna 2011).

Das and Poole (2004) note that the relation between biopolitics and thanatopolitics, while being constitutive of the state, is much more visible at its margins than in its centre. The precariousness and inequality of life in many contexts of Rio de Janeiro, where the state is almost absent, determines the instability of the rights that patients with MDR-TB can access, with life-and-death implications. Patients such as Marta and Júlio needed to come back to the health services after being cured of MDR-TB not only to secure further treatment but also to renew their access to socioeconomic rights because their living conditions did not improve with their cure. Moreover, people who suffer from MDR-TB and do not follow treatment or interrupt it may now face compulsory hospitalisation, and see more of their civil rights taken away. While many official perspectives involve a ‘radical decoupling of citizenship and biological preservation’ (Petryna and Follis 2015, 401) that prioritize the latter (Fassin 2000), local contexts such as MDR-TB in Rio de Janeiro continue to reveal the full political content of matters of health and life.

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## About the author

Oriana Rainho Brás is a researcher at SOCIUS-Research Centre in Economic and Organizational Sociology, CSG-Consortium of Social Sciences and Management, ISEG-School of Economics and Management, University of Lisbon, Portugal. She finished a degree in anthropology at the University of Coimbra and a PhD in sociology at the same university. She currently focuses her research on health, socioenvironmental issues, science and technology studies, and public participation in water management.

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