Reactions to institutional violence: patient strategies for facing infringements of the right to health in Brazil

Reacciones a la violencia institucional: estrategias de los pacientes frente al contraderecho a la salud en Brasil

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ABSTRACT In this article we identify evidences of inequalities, prejudices and discrimination in the access and utilization of public health services belonging to the Brazilian Unified Health Care System, considering them to be institutional violence and a negation of rights, in order to look at the reactions of the subjects victimized by this process. This research study utilized different methodologies, articulating participant observation, semi-structured interviews, focus groups and dramatization. The results highlight the trajectory in seeking health care as the main expression of inequalities, strengthened by structural factors such as the precarious condition of health care services, which potentiate power asymmetries, and the presence of discrimination derived from stigmas and prejudices. Most patients' reactions to the situation of institutional violence seek an individual solution to the problem, often reaffirming the conditions that generate rights violations. Few patients' reactions question the systemic conditions that determine the continued discrimination.
KEY WORDS Healthcare Disparities; Social Discrimination; Professional-Patient Relations; Patient Rights; Brazil.

RESUMEN Este artículo se propone identificar evidencias de desigualdades, preconceptos y discriminación en el acceso y utilización de los servicios públicos del Sistema Único de Salud de Brasil, consideradas como violencia institucional y denegación de los derechos, con el fin de abordar las reacciones de los sujetos perjudicados en este proceso. La metodología utilizada articuló observación participante y entrevistas semiestructuradas a las técnicas de grupo focal y talleres de dramatización. Los resultados señalan la peregrinación como la mayor expresión de las desigualdades, acentuada por factores estructurales como la precarización de los servicios, que potencian las asimetrías de poder, y la discriminación derivada de estigmas y preconceptos. La mayoría de las reacciones de los pacientes a la situación de violencia institucional busca una solución individual que, en muchos casos, refuerza las condiciones que generan el contraderecho. Pocas reacciones cuestionan las condiciones sistémicas que determinan la persistencia de la discriminación.
PALABRAS CLAVES Desigualdades en Atención de la Salud; Discriminación Social; Relaciones Profesional-Paciente; Derechos del Paciente; Brasil.

INTRODUCTION

> Where there is power, there is resistance.
>
> Michel Foucault (1)

Ever since the 1988 Federal Constitution in Brazil, social rights form an essential part of the condition of citizenship, and therefore it is the duty of the State to guarantee these rights universally. The Brazilian Unified Health Care System (SUS) [*Sistema Único de Saúde*], which is a public, universal, decentralized, and participatory system, was born as a response to a strong social movement that associated the struggle for democracy with the banners of universal rights and health as a public issue. The originality of this project of the Brazilian Social Welfare State lies in the creation of mechanisms of both joint management with and control by civil society, and coordinated inter-institutional relations among the three levels of government. Furthermore, the intention was to organize social protection in a comprehensive social security model, with programs and policies aimed at the promotion and inclusion of the most vulnerable social groups.

Guaranteeing the right to integral health care came to depend on the institutionalization of the SUS, in legal and regulatory terms, and on the establishment of local health systems. Therefore, the right to health is conditioned by the system capacity to meet the demand providing fulfillment of user needs and care. In that respect, it is important to point out that since its creation, the SUS has been highly dependent on contracting private hospital services, thus creating a mixed (public-private) provision.

Despite the enormous progress that this innovative constitutional design represents, throughout its 25 years of existence, these policies and services have experienced countless setbacks. The institutionalization of universal systems and policies aimed at social inclusion confronted a macroeconomic environment of fiscal adjustments and monetary stabilization. This process involved a restriction of the financial resources assigned to social policies, especially those related to universal policies of health and education. Such financial restrictions, in a social rights expansion period, meant the deterioration of the human and material resources existing in the public network. Moreover, it represented the lack of new investment required to guarantee the enforcement of those rights and to promote social inclusion. This situation had a negative impact on both the material base and the institutional culture of public entities.

The self-exclusion of the middle classes from the universal public systems of health and education weaken them politically, as their users are identified as solely the poor population who lack resources to express their demands in the political sphere. This situation has served to perpetuate the traditional values engrained in the Brazilian political culture of disregarding the poor, which impedes the development of the egalitarian conditions supposedly pre-established in the statute of citizenship (2).

Today, Brazilian society has an advanced legal structure that guarantees the population's welfare by means of universal and inclusive policies; however, it also has a precarious institutionality that does not guarantee access to or utilization of quality services to the extent required by citizenship (3). On the other hand, the increasingly urbanized and informed population gradually assimilates social rights as part of their condition as citizens, thus increasing their discontent with the government, partly as a result of the process of decentralization and participation in the universal systems of social policies (4).

During the development of the SUS over the past decades, there has been a great progress (5,6) in terms of the exponential increase in coverage and access (a). The successful programs designed to fight AIDS (8) and tobacco use (9), and the increase in primary health care through the Family Health Program (10) have been internationally recognized. Success is attributed to the universalization of the right to health as a consequence of the pressure of social movements.

However, experts and politicians affirm that the real SUS is moving further away from its constitutional design (11). Even though egalitarian access to comprehensive health care is a state duty, it has not been achieved because of tensions related to the adoption of target policies and private management strategies, in addition to chronic financial deficit (12-14).

For this reason, emergency services and scheduled surgeries are not satisfactorily

guaranteed in the public services, given the lack of professionals, equipment and medicine, the precariousness in both the working conditions and the facilities, the limited budget assigned to units, and the inability to satisfy the demand, as expressed in the long wait lines in the system.

The differing conditions of access to and use of public services, resulting from the persistent socioeconomic stratification in the Brazilian society, also reproduce unjust inequalities in the health field, that is to say, differences that do not have their origins in individual biological or behavioral conditions. The indicators of inequality in the access and utilization of healthcare services, such as the realization of exams to prevent breast and cervical cancer and prenatal visits, have a strong correlation with differences in education, income, and age, as confirmed by the National Commission of Social Determinants of Health in Brazil (15).

The determinants of health conditions include biological, behavioral, and social factors linked to stratification: income distribution and preconceptions based on gender, ethnic groups or disabilities. Additionally, political and governmental structures foster inequalities in economic power (16).

The most vulnerable groups, such as women, the black population, the elderly, the impoverished, or those with so-called socially deviant behavior are victims of stigmas and preconceptions that foster the reproduction of inequalities in the access to and utilization of public healthcare services (17-19). In this way, the values of equality, solidarity and social justice, fundamental to the concept of social security, were replaced by different types of stratification and/or denial of rights. The result was a kind of institutional hybridism or incomplete social security model (20-22). Even though the legal structure upholds egalitarian principles, this process manifests itself in diverse ways within the institutions, the formal space where the right must be implemented.

The legal and regulatory framework is necessary to make universal the right to health, but social policies depend on the set of institutions and organizations where practices and values are produced and reproduced. It is important to highlight that the implementation of social policies requires a personal relationship between a professional and a user. This singular interaction, which takes place in a specific context, is marked by social asymmetries, values and preconceptions existing among its participants, as well as by the material conditions that influence the relationship and make up the scenario in which it takes place. Therefore, violence appears in different dimensions: it is material, but also symbolic, as it is institutionalized objectively in social structures and subjectively in mental structures (23). The care provided in institutions is above all a social relationship that occurs within a class structure which imposes its effects.

If we accept Lourau's affirmation that "the material substrate, the organizational infrastructure of the institution and its materiality speak louder than its articulated words [...] that seek to disguise and rationalize values, decision-making systems and cultural models" (24 p.280), the analytic task is therefore to find ways of unveiling this power structure, revealed through deviant situations that are used as analyzers.

Ideally, the function of the institutional and regulatory context should be to limit those asymmetries in order to reduce them to a socially and legally accepted model. However, in many cases just the opposite occurs: structural patterns turn the local interaction into an expression of "the assemblage of all the other local interactions distributed elsewhere in time and space, which have been brought to bear on the scene through the relays of various non-human actors," in which inter-subjectivity must be combined with inter-objectivity (25 p.281).

In other words, the conditions of healthcare represent an interpellation, whether discursive or non-discursive, legal or material, through which relationships of exclusion and subordination are reproduced or become emancipatory possibilities for citizenship (26).

In healthcare, the social determinants of inequalities include objective and material aspects based on the socioeconomic structure, which create health conditions differentiated by social groups as well as difficulties in access and distribution of poor quality services. Sociological studies underline the symbolic aspects involved in hierarchical and discriminatory relations that are produced and reproduced within health institutions.

The term *institutional violence* (27) has been used to refer to any type of violence that occurs in institutions, especially in public services, characterized by actions or omissions of both material and symbolic conditions that impede access and generate poor quality services. Its expressions range from abuses due to unequal power relations between users and professionals to a more limited concept of intentional harm: racism, sexism, moralism and other stigmas (28). Diverse personal attributes can be the object of institutional violence as well as of disrespectful or conformist attitudes by healthcare professionals and users as long as a stigmatization exists within one of the two parties.

If a stigma is a special relationship between an attribute and a stereotype, the ideology underlying it not only includes the explanation of difference in terms of inferiority, but also defines a code of conduct in relation to others and appropriate attitudes in relation to "the self" (29).

Studies on institutional violence put into evidence its occurrence, typology and explanatory factors (30-32). However, few focus on the reactions of the harmed subjects, a central question in the ideological reproduction of violence in institutional relations and practices.

There is an asymmetry between the healthcare professional and the patient since it is the former who establishes the rules of the game unilaterally and without prior negotiation. This asymmetry is increased by social distances: the professional holds a superior position in the hierarchy of symbolic capital. Violence is produced when "a difference and an asymmetry is converted into an unequal hierarchical relationship oriented towards domination, exploitation and oppression" (33 p.35). The denial of rights are expressed in public healthcare services in different ways that show the absence of receptiveness and respect. On one hand, situations of considerable inequality in the access and utilization of services: delays in receiving care, precarious infrastructure, wait lines, and the *pilgrimages* of users to different health units in search of care for their specific pathology. On the other hand, preconceptions and discrimination towards specific segments of the population, due to generational factors, social conditions, race, and sexual orientation as well as the user's pathology, may be present in the service delivered daily.

We will use Foucault's concept of *counter-law* in order to analyze different situations of institutional violence. Through systems of micropowers, essentially unequal and asymmetric, the disciplines bring into effect counter-law:

> The disciplines characterize, classify, specialize; they distribute along a scale, around a norm, hierarchize individuals in relation to one another and, if necessary, disqualify and invalidate. In any case, in the space and during the time in which they exercise their control and bring into play the asymmetries of their power, they effect a suspension of the law that is never total, but is never annulled either. (34 p.210).

The legal existence of a right and its practice in institutional spaces do not guarantee its enforcement and implementation. The field in which the objectivity of the material actors and the intersubjectivity of institutional practices come together is where counter-law operates, in order to reproduce the relations of power and submission and the strategies of hegemony and domination (34,35).

Taking as a basis Sartre's concept of seriality, as quoted by Young (36), our assumption is that inequalities, in both their structural and ideological-symbolic aspects (institutional practices), occur in a sequential way, mutually conditioning one another and defining the possibilities social agents have in exercising their right to health. Furthermore, these inequalities are also present in the reproduction of institutional violence in healthcare services, expressed in the objective precariousness of the services and in discriminatory practices associated with social preconceptions regarding gender, race, and social class, among others.

The reactions of the individuals affected by this process are also influenced by these same conditioning factors, including denial, passive acceptance, and/or naturalization, violent resistance, politicization and court action. Many of these reactions contribute to the reification of injustice in the healthcare system, although some serve to solve individual situations. Only a few of them try to transform this reality.

Our study was based on the information obtained from a qualitative study carried out

in public hospitals in Rio de Janeiro aiming to identify evidence of inequalities, preconceptions and discrimination in the access to and utilization of the public healthcare services. We also sought to identify patterns in the repertoire of reactions of victims of institutional violence.

METHOD

The study was carried out in five public hospitals in the city of Rio de Janeiro (b), chosen because they are general hospitals with great user demand and are located in different geographic areas of the city, thus diversifying the study population. Initially, the method of participant observation was applied in all the emergency services, and it was possible to register the material and relational conditions of receptiveness and user access of the professionals responsible for the first contact with the user, including security and auxiliary staff.

In this first stage of participant observation, field notes were generated that were used to improve the interview tools. After approval by the Hospital Ethics Committee (c), the selection of interviewees was based on accessibility while preserving the sample diversification criteria, and was finally composed of 285 interviews with three types of actors: 190 users and/or their companions, 90 professionals directly involved in providing health care and 5 hospital administrators.

Grasping a complex object such as the denial of rights due to discrimination and preconceptions is a difficult task, as the phenomenon is negated culturally and prohibited legally. For this reason, we applied different research techniques in order to approach what some authors have called the *mute zone* (37), referring to that which is difficult to translate into rational language. To this effect, participant observation was combined with semistructured interviews and focus group techniques with black women who act as community leaders in healthcare, and we carried out a dramatization workshop with the participation of a diversified group of resident professionals of public hospitals. The use of the technique of dramatization, under the supervision of a professional from the school of Theater of the Oppressed (38), allowed us an

approximation to the most primitive emotional experiences of discrimination, many of which are censored in rational discourse.

We created a system of hypotheses, considered essential for the implementation of the right to healthcare or its denial, centered on perspectives taken from the literature: *professional training, institutional culture, management* and *characteristics of the users*. For each of these dimensions, we elaborated a set of hypotheses previously validated through a workshop conducted with specialists that were selected as qualified informants in the hospital and public health field.

The identification of access inequalities and situations of discrimination and preconceptions during health care utilization allow us to formulate the following hypotheses:

- The invisibility of discriminatory practices favors their reproduction in the organizational structure, especially in situations in which the prevailing institutional culture is authoritarian, with a hierarchical management that offers little opportunity for participation.
- The lack of the material and human conditions required to meet the demand increases the discretionary power of professionals, thus increasing the possibility for discrimination in the practices carried out and the choices made.
- The presence of stigmatizing characteristics in patients or professionals increases the chances of mutual discrimination.
- Organization, awareness of rights and knowledge of the healthcare system intervene in user reactions in a wide range of ways that go from denial and self-exclusion to resistance to the discrimination, including different ways of defining the issue.

RESULTS

TThe main findings show that institutional violence is grounded in macrostructural operators of socioeconomic inequalities and precarious conditions that affect both access to and utilization of services. They also affect social relations that are reproduced within institutions, operating in a strongly hierarchical class society. It is in this

everyday relational context of singular health practices that users and healthcare providers interact and unveil the knowledge/power relationships that produce multiple profiles of discrimination.

Therefore, we highlight the importance of considering the ideological-symbolic and relational dimensions of institutional violence as a complement to the structural dimension. It is important not only to try to fully understand institutional violence, but also to go beyond the mere description of this power exercise to point out its internal contraindications and shed light on the reactions of the victims of institutional violence.

Regarding our set of hypotheses, we found the hospital institution to be highly hierarchical, with the physician placed at the top of the hierarchy. Attributes such as years of service or age contribute to this higher placement, thus professionals that have less contact with patients tend to be given an even more favorable position. Although it was not possible to prove the hypothesis that a higher position increases the chances of discriminatory behavior, we did find that certain professionals were clearly closer to patients. This process of hierarchical organization allows discriminated cases to be transferred to professionals that hold inferior positions in the professional scale, a fact which appeared in both the interviews and the dramatization workshop. This proximity between the perception of professionals and that of patients was interesting in that it differed from the discourse of administrators, which was more technical and less sensitive to unmet needs.

Concerning the institutional culture and management, despite the awareness that prevails regarding the right to health, there is a trivialization of the injustices and rationalization of the inadequate conditions and precariousness present in the public healthcare services. The phrase "*that's the way the public service is*" can be found in the discourses of all the actors involved, whether patients, professionals, or administrators.

The awareness of the right to health is mitigated by the perception that the professionals have of their work as a beneficent mission encompassing more the notion of compassion than that of rights. Furthermore, the lack of effective channels for filing grievances and punishing mistreatment and discrimination is made worse by a predominant attitude that perceives any complaint

as disrespectful on the part of patients. The practice of *jeitinho*, or a solution obtained through the intervention of a person with influence in order to access public services, is accepted as part of the national and institutional culture, and is itself aggravated by a lack of participation and transparency in hospital management. The absence of clear rules, procedures and norms related to the referral of patients and the selection of those that will be assisted increases the discretionary power of professionals that are not trained for these tasks. It was impossible to show differences resulting from more participatory forms of management regarding this aspect.

The inability of hospitals to fully satisfy user demand has, as a consequence, the attribution of great discretionary power to reception and security staff, the first to meet patients. As can be seen in the following stories, they carry out a sort of "classification," both by selecting some users at the expense of others, thus granting them access to the hospital, and by accelerating procedures within the hospital by means of the informal mechanism of the "*jeitinho*" (39). Such actions are contrary to the notions of equal access and comprehensive care as guiding principles in the organization of the health care system.

> …*he's the one "who indicates it" – the "wit" – when a person is the relative of an employee…* (d) (Activist of the Black Movement)

> …*There are 20 numbers, out of which probably fifteen, fourteen, fifteen will be given out. The person who is worst off gets one, but the person who's first in line, I don't know…and some are saved, we know that if the uncle or cousin or I don't know what of the hospital employee comes they'll always have a number waiting for them.* (Female user)

> *Of course there is* [an informal mechanism]*, there's one everywhere. If my brother is having a rough time, I won't have him wait in line. I've been working here for a long time, I have the right to be seen first.* (Professional)

The findings related to the structural aspect of inequality showed the precariousness of the

public healthcare services, which is expressed in lack of materials and poor quality facilities, as well as in overpopulation and lack of effective care, thus generating a pilgrimage in users to different health units in search of care:

> Because not all places you go have available appointments, you have to go to others. You rush from one place to another with kids or sometimes even with adults in tow. Sometimes patients arrive nearly dead, and they have to depend on the hospital. (Female user)

> I went to Rochinha, and the woman looked at me and said: "Oh! You have to go to Rocha Faria." When I went to Rocha Faria they told me, "No, you have to go to Rochinha." (Activist of the black movement)

Such situations affect access to and utilization of the public healthcare services daily (17,40,41), becoming obstacles to care and favoring the occurrence of institutional violence. Given this context, the utilization of private services to carry out tests, purchase medicine, and so on, often becomes a solution for the continuity or acceleration of treatment, reinforcing socio-economic discrimination:

> The doctor explained everything to us, we have nothing to complain about… The x-ray and ultrasound machines are broken, and they don't know when they will be working again. I'm going now to the Matoso clinic to try to get an appointment; if I can't get one, I'll go to Santa Casa, because there you have to pay but at a much cheaper price, and at least we can get the studies done. If you pay, it goes fast. Besides, there is never any medicine available at the pharmacy. (Female user)

The institutional violence in health services is expressed in its structural and ideological/symbolic aspects in the *pilgrimages* of patients in search of care, which is the main analyzer of *counter-law* in health, as it reveals the lack of guaranteed protection. The notion of citizen rights refers to the expectation and certainty of such protection. However, the pilgrimages reveal not only patient suffering in the search for access to health services, but also the humiliation caused by the denial of the right and the public irresponsibility of the different health operators that delimit the problem to a search for an individual solution, outside of the collective contract of citizenship. Therefore, as opposed to the rationalization of the different actors that attribute deficiencies in care to the precarious conditions in which the hospitals work, we see the pilgrimages as a fundamental factor in the consolidation of the counter-law in health (3), in the interactions among the discriminatory interobjectivities and intersubjectivities of practices.

The perception of users is that the health care is negligent, involving disrespectful treatment and lack of communication and information between the user and the professional. All this reflects the strong demand of users for a more humane, receptive system of higher quality, capable of providing solutions (42,43), as described in the following statement:

> …the right word is carelessness; the same care is not given to every person, people are mistreated and misinformed. I can't think of a person that won't touch me or examine me properly as a doctor…I am a human being and I need someone to see me. (Female user)

The institutional violence finds its symbolic expression in a gradient that goes from disrespectful to discriminatory treatment based on preconceptions. Generally, the users perceive discrimination as a way to *"get rid of people,"* *"insult,"* *"offend,"* *"abuse,"* *"harm,"* or *"mistreat,"*; or they identify it by means of more subjective and enigmatic interpretations, such as *"their look or tone of voice during a conversation"* or in having been denied equality and made to feel their otherness while receiving care: *"The doctor didn't look at me right, didn't listen to my complaint, didn't pay attention to me, didn't touch me, it was as if the doctor were disgusted by me."*

The existence of stigmatizing characteristics increases the likelihood of the user being discriminated against, and this possibility grows if the person possesses more than one of these attributes. Administrators perceive socioeconomic conditions to be the main source of preconceptions, but race, gender and religion can also lead

professionals and patients to experience discriminatory situations. Furthermore, female and/or black physicians describe situations in which they are discriminated against by patients that identify them as nurses and sometimes refuse to be treated by them.

This type of violence can have an impact on the individual's physical and social integrity, honor and dignity. Being denied recognition and experiencing disrespectful treatment are a sort of negative equivalent to the relations of recognition (44) and can be classified as violation, deprivation of rights and humiliation. If physical abuse destroys one's self-confidence, the denial of the rights is a humiliating experience that affects one's moral self-esteem, while the denial of social respect and honor affect one's dignity. The following statement by a female user shows the degrading situations that abortion patients have to undergo:

...in the maternity ward [women who had] *an induced abortion* [...] *were the most discriminated against, by other users and even by the employees* [...] *Sometimes also by the medical staff* [...] *who are more dedicated to patients in labor. And the poor girl who is having an abortion is crying* [...] *no one gets too close* [...] *"You didn't see this through, now you have to suffer"* [...] *I heard someone, an employee of the nursing unit, say.* (Female user)

Within the hospital dynamics, discrimination and preconceptions stand out as forms of institutional violence and tend to touch specific sectors of the population, such as those with less favorable socioeconomic conditions, users who are inebriated or on drugs, and patients with certain pathologies such as cancer or infections. These experiences are also studied as institutional racism (28,45), in that they operate implicitly or explicitly in the policies, procedures, operations and culture of the institutions, reinforcing and being reinforced by individual preconceptions.

Furthermore, the combination of stigmatizing characteristics, defined as intersectionality (46) (for example: a poor black woman who is the victim of violence; or a poor black male user who is homosexual or is a transvestite, who is

homeless, and who is a carrier of AIDS or other stigmatized pathology) increase the chances the users have of receiving discriminatory and lower quality treatment:

Skin color is very important, as is the place where the person lives, whether the person comes in with muddy feet because they live in a place without paved streets, all this comes into play in a consult with a doctor. There are situations in which the doctor doesn't even want to touch the person...and doesn't touch them. (Activist of the black movement)

In the hospital environment these practices end up being reproduced and legitimized. Factors which permeate the daily reality of public hospitals, such as the difficulty of accessing services, the delay in receiving care, and the urgency of care, serve as obstacles to perceiving preconceptions and discrimination as well as a way of denying rights and citizenship.

It was observed, for example, that the hospitals had chapels and bibles next to the beds and received visits from priests and pastors, all of which were seen as normal ways of helping patients. However, the practice of African religions is not permitted. The *mãe-de-santo* [Candomblé priestesses] who participated in the focus group with activists from the black movement denounced that followers of African religions were forced to take off bracelets or other objects considered sacred, even if their carriers were not undergoing surgery, with disrespectful attitudes*: "'Take off that dirty thing,' the professional says to the patient."*

Institutional violence is rooted in the fact that every society produces its own outsiders. Human rejection, as an inevitable product of modernization and modernity (47,48), produces cognitive, esthetic and moral maps that justify the social order. The trivialization of meanness and its naturalization via institutional processes founded in knowledge and power are put in opposition to molecular reactions that break with and resist relationships of domination, in which individuals are constructed as political subjects and create their individual and/or collective alternatives.

Reactions to institutional violence: from submission/naturalization to individual and/or collective resistance

Institutional violence in the access to and utilization of healthcare services, which occurs in a context of precarious care and disrespectful and discriminatory treatment based on preconceptions, unleashed different types of reactions in the affected individuals. Such reactions included: denial, submission, naturalization, forms of individual resistance (from "transgression" of institutional rules to legal action) and forms of collective resistance.

Fleury (50) gives the name of "subjectivation" to the process of becoming political subjects, which implies the construction of individual and collective identities that break with subordinated and alienated identities through a process of singularization and the construction of a strategy for social transformation and rupture with relationships perceived as oppressive.

Therefore, we analyzed the following: in the presence of relations of oppression, domination, subordination, disrespect and injustice, how are political subjects constituted in confronting situations where rights are being denied? What is the nature of that subject and what reactions hold real potential of bringing forth an emancipating project to face institutional violence in healthcare services? What is the likelihood of the individual's own experience of discrimination, disrespect and violence being transformed into motivation for political resistance?

The first aspect to be studied refers to the process of consciousness mentioned by Gramsci in *The prison notebooks*, as quoted by Said (51), considered to be the starting point for any critical elaboration: becoming aware of ourselves as the product of a concrete historical process. Such critical consciousness of the self is what enables subjects to construct themselves as autonomous, as they become liberated from the description attributed to them within the relationships of domination. However, the constitution of political subjects is complex, since awareness is a phenomenon in motion, which develops according to a person's environment, his or her specific relations, and the interaction with nature.

The first type of consciousness manifests itself as alienation, primordially because it naturalizes

reality and disconnects it from its context and history (52). If the etymological origin of alienation refers to that which is external and belongs to others, in philosophical terms, the Hegelian-Marxist tradition translates this concept to refer "fundamentally to a kind of activity in which the essence of the agent is posited as something external or alien, assuming the form of hostile domination over the agent" (53 p.5).

The findings obtained in the research showed the predominance of a certain type of consciousness in the users of the services that tends to naturalize the disrespectful and oppressive treatment: *"Discrimination exists everywhere,"* affirms one user, while another demonstrates an attitude of conformity with the structural issue of precariousness: *"Lots of people came to the health center; there aren't any more numbers [...] They turn around and go home…"*.

The trivialization and naturalization of discriminatory relations were present in the discourse of the mother of an adolescent with a risky pregnancy in a precarious context of access to and use of services. She neutralizes the suffering which her daughter was put through after being called out to by professionals repeatedly in public in the following way:

> …"Who's the 12-year-old girl that's pregnant?" [...] *Several times…she was called out to that way by employees, nurses, doctors, everyone…* (Guardian)

Despite her daughter's complaint of such treatment, the mother shows gratitude for the fact that her daughter received care:

> …I don't like it when they call me like that… (Female user)
> …They [the doctors] *were very good* [...] *They did it* [...] *They saved my daughter's life and that was the most important thing.* (Guardian)

However, the great majority does not even identify situations of discrimination or dissatisfaction apart from the material difficulties in the access to and utilization of healthcare services. This invisibility or denial is only broken when the interviewee places the discriminatory situation on another person: an acquaintance, a

friend, but never on him or herself. Within this logic, recognizing discrimination is like reliving the experience of humiliation; therefore the suffering is attenuated by negating the experience. Many of the users interviewed declared that they had not witnessed any discriminatory situation, although their stories were marked by the presence of preconceptions and disrespect, thus reaffirming the studies that indicate that discrimination is frequently imperceptible to the victim (54).

Nevertheless, faced with the necessity, this position of tolerated coexistence with injustice can give way to the introjection of new values that in turn generate a sort of contradiction in which the individual confronts a subjective conflict. A new stage of consciousness is formed as a state of rebellion, but without having yet transcended alienation. Relationships are no longer idealized, but experienced as injustices, which reflects a disposition towards non-submission (52). We can understand this process as daring to singularize oneself, in which the way of experiencing one's subjectivity may oscillate between alienation and oppression or a relation of expression and creation (55).

Rebellion and non-submission can be understood as counter-hegemonic strategies that operate on the micropolitical level in order to try to break with subordination, according the meaning Foucault gives to resistance (1).

We identified some forms of individual resistance that the users of the healthcare services developed when faced with precarious care, such as mocking the rules, turning the situation into a show, filing complaints, looking for a relational solution or taking the conflict to court.

Breaking the institutional rules or "making a mockery of the rules" appears as a form of non-submission to the relationships of subordination, as reflected in the following testimony:

> I've developed this strategy [...]: *"Oh, the patient's inside, and the doctor is asking for the medical record." It's not true, because sometimes I'm that patient...but it's the strategy to be able to get inside [...] You need to fool them, we don't like to have to do those things, but...* (Female user)

Confronting the current unjust and oppressive system – whether through exerting violence on the oppressor (56) or through making a spectacle of institutional violence by using violence, "making noise" and "causing a scandal" – was shown to be another way of expressing individual resistance with a considerable level of efficiency:

> The girl almost grabbed hold of the doctor right over there...when she came out, she was grabbing at her [...]. But that's the way it works, I get seen because when I arrive I make a scandal. Because this is my right, you know? [...] Many people [...] do the same as her, she's known for being scandalous [...] but when she arrives, she always gets a number. (Activist from the black movement)

However, the most common way of finding an individual solution is through the traditional *"jeitinho."* This strategy implies employing a network of personal relations, in general involving professionals from the healthcare services, that enables the person to be seen and to overcome the obstacles initially imposed by the institution. This situation is accepted as natural and in a hierarchical and relational culture like that of Brazil tends to be the most effective mechanism, even when it serves as a reification of discrimination. The lower the position in the hierarchical society, the fewer the resources the person will have to put into action this network of relational power and to stand up for what should be an equal right of all citizens. In other words, the right to the access and utilization of services is achieved in a way that simultaneously negates the essence of the right, which is equality. Not only patients describe their relational strategies; professionals and even administrators consider this a natural practice, thus becoming subsumed by this relational and hierarchical logic from which they cannot escape.

Another form of resistance is resorting to the mechanism of denouncement, which demonstrates a certain level of consciousness and access to certain resources of power, such as the media or higher institutional structures. Whether used as a threat or actually carried out, this mechanism is often effective because the professional has no way of knowing whether the person does or does

not have access to this resource. Often the community leaders are those who use this strategy, as experience has taught them how to make use of such mechanisms:

> I'll call the media because it is the only thing that works for the people of our community, in the case of the health centers. [...] "You are paid by the SUS to provide services for us users [...] you'll have to take those X-rays for her right now; if not [...] I will call the Secretary of Health." I think she was also black, that's also why she was [...] there waiting for the X-rays without being seen. (Activist from the black movement)

Increasingly, taking legal action has been a strategy used in the health field. This is perhaps a consequence of the introjection of the notion of rights, whether stimulated by corporate interests or at the advice of professionals who show solidarity with the situation of patients to whom access, medicine and complementary studies are denied. The legal route itself has been highly criticized as an additional mechanism of inequity, as access to the judicial system is highly elitist and its functioning is guided by the principles of subjective law, of an individual nature. This differential access restricts the legal system's universality and impedes the rationalization of administrative practices (57-60). Most recently, a new trend has emerged to seek "agreed upon enforceability," characterized by a joint search for the defense of rights between the government powers, in which the population and health specialists are also heard. These new trends show the possibility of reducing unfair inequalities (59).

The forms of resistance that we detected are quite varied, and only in some cases adopt a political nature and become a struggle aimed at putting an end to the relationships of subordination. Mostly they seek a solution to individual demands, even at the expense of preserving structural asymmetries and relationships of domination existing in the institutional practices.

An emancipative position seeks, by means of political consciousness and collective action, the transformation of the structural relationships of subordination, which can only be achieved by changing the conditions that give rise to and reproduce injustices in accessing public services. Following Laclau and Mouffe (62), the conditions under which the relationship of subordination becomes a relationship of oppression must be identified; this is the site of antagonism. Thus, antagonism is the midwife of the subject, as it can only emerge by subverting the subordinated position of the subject (50).

An essential condition for recognizing a situation of subordination as oppression is creating a group and materializing its "consciousness of demands" (52). When people experience an injustice alone, they tend to rebel, but in certain circumstances they can see in others a reflection of that same contradiction, making collective action possible. Collective action becomes a way to move past the stage of rebellion against the established relations so as to overcome them. The supposed naturalness of these relations is questioned and so is the idea that they are inevitable.

We encountered more collective forms of political resistance against discrimination and different forms of oppression in the healthcare system in a sector composed by black women who were community leaders organized around the issue of discrimination and health into a social network called Criola. Other collective actions originated in groups of patients with specific pathologies. The first group brings its history of activism and collective organization to the health arena, while the second group organizes to guarantee patients' rights based on their shared experiences and difficulties.

We could notice, therefore, that only under special conditions, such as groups composed of patients with multiple sclerosis or renal patients, and the participation of activists in Health Councils, were we able see consciousness in relation to both the rights denied and the discriminatory practices in the healthcare service. In these cases, it is clear that the consciousness process, group organization and knowledge of the system function as forms of resistance with which to confront relationships of subordination:

> When I arrive at the council, I fight for the center to work as it should. If it doesn't, I go to the council meeting and make it work. (Activist from the black movement)

It is important not only to participate in spaces of power, but also to recognize that doing so in itself implies an exercise of power.

CONCLUSION

The SUS created participatory mechanisms in public spaces such as Health Conferences and Councils but, since they are positioned at a macro level, they do not reach everyday issues such as institutional violence, which is reflected in the precariousness of the service provision and disrespectful and discriminatory treatment. These issues are not labeled as forms of oppression, but rather are largely experienced as individual problems. In the micropolitical experience, rights become counter-law in health, and individual problems are not problematized within the public sphere of rights.

In this study, we applied different methodologies – observation, interviews, dramatization and a focus group – in order to study the forms of discrimination that exist in the access to and utilization of public hospitals located in Rio de Janeiro. Despite the existence of the SUS, whose main principle is the guarantee of the universal right to health granted by the State, it is necessary to study the factors that condition the persistent injustices. Another objective was to observe the repertoire of responses demonstrated by users in the face of discriminatory situations and inequalities in care, as well as to evaluate their potential to transform or to reproduce unfair inequalities.

We discovered that the pilgrimage is the greatest expression of unfair inequalities, sustained by structural factors such as the precarious conditions of health services which reinforce power asymmetries and the presence of discrimination arising from stigmas and preconceptions. The denial of rights most often leads to responses that, while varied, seek out an individual solution to the suffering and faults, even if the solution reproduces that same injustice. However, in some cases, the political actors organized around the issue of health are able to denounce the relationships of domination as forms of oppression, seeking a structural transformation of the system through collective action, albeit in a molecular and sectorial way.

FINAL NOTES

a. The access to healthcare services in Brazil improved considerably after the implementation of the SUS. Before its creation, the *Pesquisa Nacional por Amostra de Domicílio* (PNAD) [National Survey of Sampled Households] for the year 1981 showed that 8% of the population (9.2 million people) confirmed having used healthcare services in the past thirty days while, in 2008, 14.2% of the population (26,866,869 people) confirmed having used healthcare services in the past fifteen days. This means that the use of healthcare services increased by 174%. The number of people seeking out basic care increased by approximately 450% between 1981 and 2008 (7).

b. Hospital Federal da Lagoa, Hospital Federal do Andaraí, Hospital Geral de Bonsucesso, Hospital Municipal Miguel Couto, Hospital Federal dos Servidores do Estado.

c. In order to be able to enter into the hospitals, we obtained the approval of their respective Research Ethics Committees and we complied with all the procedures established in Resolution 196/96 of the National Health Council regarding research involving human beings.

d. "Wit" or "who indicates it" is the translation team's English adaptation of the name given to the people who choose which users are to be seen. In Portuguese the expression is "QI" or *quem indica*

and it coincides with the acronym for "Intelligence Quotient." Thus it is ironically used to highlight the informal relation of favoritism in health services in detriment to the formal access criteria.

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