

## Itineraries of transvestites and transsexuals accessing hormonal treatment at the AMIG (RJ) and characterization of service users

*Itinerários de travestis e transexuais no acesso ao tratamento hormonal no Amig (RJ) e caracterização dos usuários do serviço*

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**ABSTRACT** This article aimed to obtain a profile of and understand how transsexual and transvestite people gained access to the health system up until referral to the reference unit for hormonal monitoring at the Multidisciplinary Gender Identity Outpatient Clinic in Rio de Janeiro state (AMIG). Data were collected from 458 medical records to characterize the clinic's patients. Bertaux Life Narrative method was employed for the interviews, with the participation of 16 people, namely, six transsexual women, two transvestites, and eight transsexual men. The results indicate that most medical records (61%) are from trans women; most clients served are Black (Black and brown) and do not have chronic diseases. The analyzed interviews revealed that the problematic access was associated with the perceived lack of health professionals' qualifications, the lack of a standardized protocol for regulation, and centralized care in the reference unit. It is necessary to develop a protocol for equity in regulation, the continuing education of PHC professionals to clarify the transition process and its needs, and the decentralization of the transsexualization process in order to promote equitable access.

**KEYWORDS** Effective access to health services. Transsexualism. Transvestism. Comprehensive health care.

**RESUMO** O artigo objetivou levantar o perfil das pessoas transexuais e travestis atendidas no Ambulatório Multidisciplinar de Identidade de Gênero (Amig) do estado do Rio de Janeiro, bem como compreender como se deu o acesso ao tratamento hormonal nessa unidade de saúde. Quanto à metodologia, para atender ao primeiro objetivo, foram estudados 458 prontuários. Em relação ao segundo objetivo, foram realizadas entrevistas com 16 pessoas, sendo 6 mulheres transexuais, 2 travestis e 8 homens transexuais; o método utilizado foi o de Narrativas de Vida de Bertaux. Os resultados da pesquisa nos prontuários apontam que 61% são mulheres trans; a maioria dos usuários atendidos são negros (pretos e pardos) e não possuem doenças crônicas. Os resultados obtidos pela análise das entrevistas revelam que a dificuldade no acesso esteve associada à percepção de falta de qualificação dos profissionais de saúde, à inexistência de um protocolo padronizado para regulação e à centralização do atendimento na unidade de referência. Conclui-se que é necessário elaborar um protocolo para que seja praticada a equidade no encaminhamento e na regulação, a educação permanente dos profissionais da atenção primária visando ao esclarecimento em torno do processo de transição e suas necessidades, bem como a descentralização do processo transsexualizador.

**PALAVRAS-CHAVE** Acesso efetivo aos serviços de saúde. Transexualidade. Travestilidade. Assistência integral à saúde.

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## Introduction

The United Nations Universal Declaration of Human Rights (UDHR)<sup>1</sup> in 1948 was a milestone in international law, with repercussions for medicine and the social sciences, as it guided how all human beings should be treated and what their rights should be. The human rights set out in the Declaration alluded to protecting all people without ethnic, religious, or gender/sex discrimination. As a result, some Constitutions were inspired by these precepts and incorporated these rights as fundamental, underpinning local struggles to guarantee rights and ensure the principles of freedom and equality among citizens<sup>2</sup>.

The so-called 'Yogyakarta Principles' reaffirm the application of these human rights standards to people with diverse sexual orientations and gender identities, prohibiting any discrimination, sanctions, or limitations for expressing sexuality or gender other than that defined genetically. Thus, the Yogyakarta Principles<sup>3(7)</sup> state that "all human beings are born free and equal in dignity and rights [...]" and that the freedom to choose one's "sexual orientation and gender identity are integral to every person's dignity and humanity and must not be the basis for discrimination or abuse".

Although the UDHR has existed for several decades, Brazil still fails to apply it to guarantee the best quality of life for minorities. In this sense, the report 'Situation of Human Rights in Brazil' shows that the country has advanced in some respects. However, we must consider the history of systematic violations of rights during the military dictatorship and the persistent violations of minority rights today. The research is based on the recognition of the need to improve several aspects in the defense and promotion of the rights of the Lesbian, Gay, Bisexual, Transvestite, Transsexual and Transgender, Queer, Intersex, and Asexual population (LGBTQIA+)<sup>4</sup>.

Although progress has been made in the formulation of health policies, homophobia and transphobia hinder the promotion of

citizenship and respect for the human rights of LGBTQIA+ people. There has been no effective achievement of equity and equality in access to health provided by the Unified Health System (SUS), which violates the principles advocated by the Brazilian Health Reform<sup>5</sup>.

Related to this, in 2015, the World Health Organization found that it was hard for transgender people to have equal access to health services worldwide and that obstacles and deficiencies in access significantly affected their mental health<sup>6</sup>. In the state of Rio de Janeiro, the policies that implement the transsexualizing process include a reference institution in the field of endocrinology and diabetes called the Luiz Capriglione State Institute of Diabetes and Endocrinology (IEDE), which was accredited in 2016 by the Ministry of Health to provide hormonal monitoring to transsexuals and transvestites who are seeking to change their secondary sexual characteristics, through multidisciplinary care at the Multidisciplinary Gender Identity Outpatient Clinic (AMIG) in comprehensive and humanized fashion. This service had been provided since 1999 before the first legal provision on the transsexualizing process was made official.

The specific objectives of the research were: i) to characterize the people treated at the outpatient clinic of this unit and ii) to understand how transsexual and transvestite people accessed and traveled through the SUS until they were admitted to the reference unit for hormone monitoring at the AMIG in the state of Rio de Janeiro. Opinions N° 5.320.867 (IEDE) and N° 5.220.717 (Sergio Arouca National School of Public Health) attest to the approval of the Research Ethics Committees of both institutions.

## Methods

The research was conducted in two stages: the first was to characterize the sociodemographic profile of the 458 transsexuals and

transvestites treated at AMIG, based on the collection of information available on the Social Service form attached to the medical records of the research participants in which we aimed to identify personal data, such as gender, place of birth, age group, skin color/ethnicity, schooling, functional situation (employment and social security), health situation, sexual violence history. The second stage involved interviews with 16 transsexuals and transvestites being monitored at AMIG, who were willing to tell us about their experiences – six transsexual women, two transvestites, and eight transsexual men, one of whom was intersex.

We collected sociodemographic data of the respondents from the 458 medical records studied in the first stage. The participants' anonymity was preserved at all times. Regarding sociodemographic data, we used all the medical records of transsexuals and transvestites who were seen by AMIG Social Services from 2015 to 2021.

The interviews were conducted and analyzed using Daniel Bertaux Life Narratives method<sup>7</sup>. Noteworthy is that the research schedule influenced the number of respondents, the availability of the participants (many refused to participate), and the method adopted, which had a qualitative bias. The interviews were held from April to October 2022. When structuring the interview, the theoretical reference was Daniel Bertaux Life Narratives method<sup>7</sup>, which aims to obtain information about the experiences of the research participants in order to understand the infinite situations that determine, affect, or influence their trajectories and provide knowledge of their operating setting. The interview method asks someone to talk about their specific experiences, focusing on aspects of their biography related to the work's subject.

The research's guiding question was: 'Tell me about your experience of accessing the health service up to the specialist center'. In order to bring the respondents' narratives closer to the research objective, the filters or aspects of most significant interest were

presented before the interview: reception in Primary Health Care (PHC), waiting time until arrival at the specialized unit, follow-up in PHC, and institutional violence. By the method's guidelines, the interviews were not interrupted, giving freedom to the flow and order of the respondents' thoughts and narratives<sup>7</sup>.

We employed comparative analysis after collecting the data, a form of analysis that seeks to find recurrent events and logical similarities to look for the same process in the narratives of several individuals. We can understand the experiences of difficulties in access through the narratives of the biographical journeys, reinforcing the research hypothesis to contribute to the proposal and development of actions to improve the process.

Analyzing the interviews, we aimed to discover the clues and the different paths taken by the respondents to interpret and understand the facts narrated. To this end, the logical sequence of the narrative must be recognized, valuing the sequence of events presented. The people interviewed were identified by the letter E, with a numerical sequence from 1 to 16.

The audios were transcribed after the interviews, which is a fundamental step when analyzing the content in detail and retrieving the story's diachronic structure, considering the distance between the moment when the experience occurred and when it was told to the researcher. The comparative analysis of the Life Narratives method requires the researcher to transcribe the narratives, which helps to trigger elements of his memory and can be essential for a more robust analysis. The transcribed narratives were separated by whether or not the subjects reported difficulties accessing health services up to the specialized center, which were considered negative or positive cases. Some participants took the same route, with or without obstacles to access, with less or greater success.

The research was approved by the Research Ethics Committee of the Luiz Capriglione

State Institute of Diabetes and Endocrinology under N° 5.320.867. It followed all the requirements imposed by Resolution N° 466/2012 of the National Health Council<sup>8</sup>, which contains human research guidelines, and the Informed Consent Form was applied.

## Results and discussion

Client care and attention mechanisms focused on conducting the transsexualizing process and prioritized PHC as the client's gateway to the Health Care Network<sup>9</sup>. Secondly, primary and specialized care complement each other and are hierarchized into care points requiring different technologies, including emergency, specialized outpatient care, and hospital services.

Consulting the medical records enabled us to learn about the reality of 458 people who self-declared transgender, with approximately 61% transsexual women, 35% transsexual men, and 4% transvestites, besides the main aspects related to their situation of social vulnerability. Transsexual women and transvestites are identified in this study as trans women.

The Southeast has a predominance of trans women, with approximately 80% of them in Rio de Janeiro. The Northeast has approximately 9% of the trans women treated by IEDE. Clients benefit from Ordinance N° 55/1999<sup>10</sup> of the Health Care Secretariat that regulates Treatment Away from Home. Transmen account for around 90% of the population in Rio de Janeiro state. Those born in other states or countries account for around 9%.

Trans women are aged 30-39, totaling 102 clients (almost 34%), and 95 clients are aged 40-49, or almost 32%. Interestingly, clients aged 18 and 19 are not registered with the service. There is a decline in the number of women aged 20-29, and it is assumed that economic barriers, such as family dependency and unemployment, lead to delays in accessing the referral unit because there is no decentralized service. Similarly, trans men have a higher

percentage in the 30-39 age range (almost 62%) and 40-49 age range (almost 27%).

Approximately 43% of the clients self-declared white, around 36% brown, and 16% Black. Two clients self-declared Indigenous. Twelve medical records lacked information on ethnicity/skin color. Regarding trans men, 65 (40.6%) self-declared white, 66 (41.3%) brown, 26 Black, and one Indigenous.

Approximately 40% of the trans women had completed high school; 14.4% had incomplete high school; 4.4% had completed elementary school; and 11.7% had incomplete elementary school. Around 11% had completed higher education; 16.4% reported having incomplete higher education; and 2.3% had postgraduate degrees. Two were illiterate, and one had unidentified schooling. Regarding trans men, approximately 46% had completed high school, and 11.3% had incomplete primary education. Approximately 11% had higher education (2% have a postgraduate degree), and 28.8% had not completed higher education.

Noteworthy is that many of those who did not finish school attribute this to transphobia. According to Foucault<sup>11</sup>, school is one of the 'disciplinary power' devices and controls the behavior of bodies and normalizes them through micro-violence manifestations, indicating and valuing the standards to be followed. It is often a 'non-place' for transsexuals, who often feel watched and marginalized. Dropping out of school, repetition, and discouragement with studies are frequently seen in this population<sup>12</sup>.

Regarding formal employment, governed by the Consolidated Labor Laws, almost 29% of trans women are employed with social security contributions; 1.7% of them are already retired. The majority, almost 45%, have no employment relationship or social security; 8.4% contribute independently to social security. Almost 29% of trans men have a formal job, while the majority, approximately 57%, are unemployed. Informal activity is part of the universe of 14.3% of these trans men. Of this figure, only 2.5% contribute to social security.

The difficulty of entering the job market is more significant for social minorities and those in vulnerable situations. Moreover, the COVID-19 pandemic has aggravated the unemployment situation of this population, especially those who declared themselves brown and Black, which seems to be attributable to racism combined with transphobia.

As for their health situation, 68% of the 298 trans women included in the study did not have any disease. However, when they did, the most common were HIV (55.9%), hypertension (12.9%), syphilis (5.4%), diabetes mellitus (4.3%), bronchial asthma (3.2%), and hypothyroidism (3.2%). Concerning trans men, 78% of a total of 160 did not have any disease. When reported, the diseases were hypertension (15.2%), bronchial asthma (12.1%), hypothyroidism (9.1%), obesity (9.1%), and diabetes mellitus (6.1%).

Concerning HIV+, it is interesting to note that in the 1980s, the effort to combat the AIDS epidemic was led by social movements that defended the rights of sexual and gender diversity. In the wake of the defense of rights, transsexual people care policies also emerged, such as Ordinance GM/MS N° 1.707/2008<sup>13</sup>, revoked by Ordinance GM/MS N° 2.803/2013<sup>14</sup>, which redefines and expands the transsexualizing process in the SUS. The rights also advanced significantly under the National Comprehensive Health Policy for Lesbians, Gays, Bisexuals, Transvestites, and Transsexuals<sup>15</sup>.

Hormonization without medical supervision is common among this population. The desire to change their physical appearance, combined with the difficulty of finding available professionals – and reliable – to prescribe medication and provide follow-up, means that people often self-medicate. However, self-medication is harmful to health, even more so if the person already has an underlying disease or comorbidities<sup>16</sup>. Thus, the health risk would be reduced if equitable access to services were a reality throughout Brazil.

Violence against trans people occurs in a variety of spaces, whether in the daily social

environment or in spaces that would theoretically be a protection against daily violence, such as the home or family environments. Among the trans women and men studied, 12% reported having suffered sexual violence and pointed to someone in their family as the perpetrator. However, violence can also be perpetrated by strangers, which reflects the patriarchal, sexist, and transphobic culture, using this violence to correct ‘deviant’ bodies<sup>17</sup>. One example is ‘corrective’ rape, something often experienced by trans men<sup>18</sup>. Prejudice and violence result from the stigma experienced by these people in a society in which homosexuality and transsexuality are targets of criticism and discriminatory acts since heterosexuality is the standard<sup>19</sup>.

## Life Narratives

In the health services, nine people reported that they had been well received; seven pointed to PHC’s poor reception; five participants identified that the service at the specialized center was better than at the PHC; one participant related the good PHC reception because he arrived ‘very quickly’ at IEDE.

Eight of the 16 people interviewed had a waiting time of less than six months, and the other eight had more than six months. The intervals in regulation time ranged from two days to five years. Regarding health care for transsexuals and transvestites, only five people reported being followed up at the Family Clinic, and of these five, only three were followed up for hormone therapy.

Noteworthy is that the gateway to outpatient care for hormone monitoring in Rio de Janeiro state occurs by entry in the regulation platform called the State Regulation System (SER)<sup>20</sup>, performed by Family Clinics or PHC Units (UBS). Once entered, clients wait in the queue to be referred to the outpatient referral unit.

*It took me around five years to finally enter the system, be called here [IEDE], and start*

*being seen and regulated here... I was referred to a doctor for some periods, and that doctor would examine me. She would tell me, 'Not at the general clinic. I do not know. Look, there is no way to refer you, and there is no way to treat you here. Until once she said: 'Look, you go to the Mesquita Polyclinic, which serves the whole city'. When I went there, they did not recommend access to IEDE again. Even though I always commented on the SER and IEDE to be referred, she said it was impossible; there was no way. They explicitly said that there was no way I could be referred to IEDE. (E13).*

*I go to the clinic for follow-up because they provide what we do not have: the first reception, specific tests we need, differentiated tests, and more in-depth tests. They were willing to understand our needs more, so they tried to go deeper into endocrinology to see what they could do to prescribe hormones. Everything was done right for our bodies to adapt. (E9).*

Nine respondents (trans women and men) noted that there was professional knowledge about regulation and transsexuality; seven felt that the professional regulator lacked knowledge; three pointed out that there was guidance on IEDE. Five respondents reported professional non-commitment; professional commitment was essential to four participants, as it was a differential in care due to their inclusion in the system.

*I went to find this person in São João de Meriti, and when I got there, this person was already a friend of mine and had access to the SISREG system. (E10).*

*My first contact with healthcare for this purpose was at the Family Clinic in March 2018. I made my appointment in March 2018 and was seen by Dr. Eunice. I explained to her that I wanted to start my transition. This is when she said she did not know what to do; she did not know where to refer me or did not even know that SUS offered this type of treatment. (E11).*

Seven clients said they had not suffered institutional violence, and nine reported experiencing such violence. Disrespect for the use of the social name was also pointed out by three participants in the survey as one of the most common forms of violence experienced by transgender people.

*Two years after my transition, a female doctor still opened the office door where I was being seen by two doctors for orthopedic and rheumatology issues, and she came in just to say that my face used to look like a doll's and that I had changed a lot. I thought that kind of comment was utterly unnecessary. I do not even know why she came in while I was being attended to, precisely to cause this discomfort, just as she did on the first day of my appointment when she asked me whether I had a uterus, saying, 'How are you a man if you have a uterus?'. (E2).*

*When I went to the clinic for the first time, I managed to demand that they call me by the social name I already had on my SUS card. It was difficult, as it took them a while to accept that I could already have my social name inserted into the system and be called by it. I was often not called by my social name, even though I was being attended to. (E13).*

Other aspects identified in the narratives were the feelings related to the transition process, with categories identified such as gratitude, dreams come true, happiness, upset, sadness, resilience, frustration, embarrassment, indignation, psychological shock, and desire for respect. The desire to take care of one's health appears in 13 statements, such as:

*No, I did not have the guidance for IEDE. I heard about it through my friend, you know? However, nobody told me, 'There is an outpatient clinic there where you can get hormone treatment', or nothing like that. They just threw me in. They thought, 'They will handle him there'. That is how I felt: just thrown in. (E2).*



*My process was very long and painful for me. The time from the family clinic to IEDE was tough for me because I felt despondent as I wanted something, and I did not have my rights veiled, you know? (E5).*

Cisheteronormative conceptions<sup>21</sup> perpetuated by society impose a lack of empathy and a failure to be receptive to those who fall outside sociocultural norms on how health professionals act<sup>22</sup>. These concepts show that repressive control acts to standardize behavior tend to create a ‘disciplinary’ society in which some manifestations of sexuality are pathologized<sup>23</sup>. Furthermore, health professionals’ lack of sensitivity can lead to trans and transvestite people being unwelcomed and uncommitted to the need for gender transition.

For risk classification, doctors are likely to be more committed to healthcare when they show empathy for LGBTQIA+ causes and struggles. So, subjectivity in risk assessment and classification for regulation is more evident. However, subjective criteria can lead to inequalities due to different risk classification criteria.

## Final considerations

The difference in access to the health system is understood by the possibility of the influence of risk classification on the system and care subjectivity. Someone classified as an ‘emergency’ can affect how quickly they arrive at the unit. The demographic data routinely used to plan health actions and services contextualized and gave visibility to the transsexuals and transvestites who require hormonal monitoring at IEDE – and, by highlighting factors that interfere with access, contributed to proposing strategies to facilitate it. As a result, the narratives presented possibilities for identifying barriers to accessing health services, especially those that are hormone therapy references for transsexuals and transvestites.

Regulation and access to health services involve several factors: ensuring adequate access to services; ensuring that SUS and the Federal Constitution principles are applied; disseminating and implementing regulation protocols; guiding and adapting care flows, with aspects related to training, standardization of the regulator’s conduct, communication and management as supporting elements<sup>24</sup>. Therefore, the professional regulator’s lack of knowledge of how to enter clients in the system has negative consequences, such as hormonal monitoring, generating a lack of care for the client and, thus, the search for self-medication, as they do not find support in the health network.

Regarding healthcare, although the transsexualizing process ordinance has accredited IEDE as an outpatient reference unit, the difficulty in finding access to care remains since it is centralized in just one unit. For many, it is far from their home and represents an expense in terms of travel people cannot afford, which demonstrates the geographical and economic barriers they routinely face.

One alternative is decentralized care, with the option of offering hormone monitoring at Family Clinics. To do this, the standardizing instruments must be activated, and each federative entity must be verified that it is autonomous and sovereign in its decisions and activities, constituting instruments that define the healthcare model and direct public policies in the field of health<sup>25</sup>.

The feeling of not being received reported by the respondents may be related to the lack of awareness of health professionals, who still have a preconceived and heteronormative idea<sup>21</sup> about gender relationships, which adversely affects the understanding of the need for and importance of gender transition for transsexuals and transvestites. Furthermore, professional lack of commitment to the client, more than a background based on prejudiced precepts, is also related to the team’s lack of training, i.e., it is not only because of prejudice

that someone can be poorly served but also because the professional is unaware of the gender, sexuality, and health issues that permeate this service.

Although the right to a social name has been provided for since 2009 in the Charter of Rights of Health Clients<sup>26</sup>, this regulation has not yet been effectively incorporated into the routine of health professionals, which compromises effective healthcare and clients' perception of the health system and its professionals<sup>27</sup>.

We can conclude that health professionals need continuing education on gender issues, with a paradigm shift to improve care and reaffirm SUS principles. According to Foucault<sup>28</sup>, the medical association, with its disease-centered view and guided by a biologicist model, without looking at individuals and their social context, modifies the way transsexuals and transvestites are seen, restricting their autonomy in the

decision-making process related to the medical approach to their bodies.

Given this evidence, actions are recommended in the SER software, which, when fed with information from the UBS and Family Clinics, will automatically distinguish between the following factors: time of entry in the system, age groups, and people with disabilities, the last two of which are provided for by law, rescheduling all those registered in a new queue. Thus, equal access can be guaranteed from now on – the system's *reset* date, which must be communicated to all those entered.

## Collaborators

Moquedace PS (0000-0003-4556-1293)\* and Maciel EMGS (0000-0002-9095-3141)\* contributed to the manuscript's elaboration. ■

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