Difficulties experienced by trans people in accessing the Unified Health System

Abstract  The objective of this study was to discuss the difficulties of trans people living in the metropolitan region of Greater Vitória, Espírito Santo, Brazil, in accessing the health services of the Unified Health System (Sistema Único de Saúde - SUS). We used a qualitative approach through semi-structured interviews with 15 trans people. The results point to disrespect toward the adopted name, discrimination, and the diagnosis required for the gender reassignment process as major limitations to accessing the healthcare system. The diagnosis helps hide the responsibility of heteronormativity and gender binarism in the social marginalization of trans people. It is concluded that it is necessary to review the issue of diagnosis, given that the existence of a prior pathology is not required to access the SUS. It is important to develop educational programmes and permanent campaigns concerning the right to access the healthcare system free from discrimination and to use the adopted name.

Key words  Body, Health, Gender identity, Transgendered people

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Introduction

The transformation of the body is a constructive sphere in the life of individuals. However, in the case of trans people, this sphere takes on an intense magnitude. The methods of body modification undertaken by trans people are varied; they include the use of hormones, the application of industrial silicone, hair removal, plastic surgery, and gender reassignment and vary according to factors such as desire, financial resources, and sex work-related needs.\(^1\) Trans people counter the most difficulties when seeking care. These difficulties are due to the intersection of the available gender and sexuality categories.

Recognising the multitude of body transformation procedures and gender self-identifications, in this article, the term trans person is used in accordance with what Benedetti\(^6\) termed the trans universe, according to which “the trans universe is a social domain with regard to the question of (self-)identifications.”\(^5\) However, within and beyond a policy of identification and based on this policy, body transformation and the invention of lifestyles are situated as composition processes of trans people. Thus, the term trans people corresponds to an effort not to draw boundaries between the gender identities of the study participants, respecting not only self-identification but also the intersections of the available gender and sexuality categories.

Studies\(^1\) have shown countless difficulties in the access to and permanence of the services offered by the Brazilian Unified Health System (Sistema Único de Saúde - SUS) by trans people, indicating disrespect toward the adopted name and trans/travestiphobia as obstacles in the search for healthcare services and as causes for the abandonment of treatments in progress. These studies also discuss the pathologisation of travesti and transsexual gender identities in the gender reassignment process of the SUS as a promoter of selectivity in healthcare services, hindering access for many trans people.

According to Mello et al.,\(^3\) among the LGBT population, travesti and transsexual people encounter the most difficulties when seeking care in public health services – not only when they demand specialised services, such as gender reassignment, but also at various other times when they seek care. These difficulties are due to the intense trans/travestiphobia experienced, in addition to discrimination toward other social markers such as poverty, race/skin colour, and physical appearance, and due to the scarcity of specific healthcare services.

This article discusses the main difficulties encountered by trans people residing in the municipalities in Greater Vitória, Espírito Santo, Brazil, in accessing public healthcare services.

Methods

The study adopted a qualitative approach. It was conducted (a) at the headquarters of the Espírito Santo Association of Injury Reduction (Associação Capixaba de Redução de Danos - ACARD), which conducts harm reduction work with sex workers, including trans people, in Vitória; (b) on the campus of the Federal University of Espírito Santo (Universidade Federal do Espírito Santo - UFES) with transsexual students; (c) in the Urology Clinic of the Cassiano Antônio de Moraes University Hospital (Hospital Universitário Cassiano Antônio de Moraes - HUCAM), where gender reassignment surgeries and the clinical follow-up of patients are performed; and (d) in the home of some trans people served by ACARD.

Data were collected using semi-structured interviews digitally audio-recorded with the permission of the participants. The interviews were guided by a questionnaire addressing socio-economic aspects, such as age, gender identity, sexual orientation, profession, income, educational level, having a private healthcare plan, and the neighbourhood and municipality of residence; the frequency in seeking SUS healthcare services; the primary difficulties in accessing the services sought; and body modification strategies and their impact on health.

Some participants who felt uncomfortable with recording the interview consented to completing the questionnaire. According to our guidelines, many participants provided information in excess of that requested by the questions, which may have contributed to reducing the limitations of the instrument. A field diary in which the authors’ impressions were recorded was also used. Content analysis was performed from the transcribed interviews. The material was organised into 3 axes of analysis: access to healthcare services; body modification methods; and perceptions of the influence of these methods on health.

A total of 15 trans people (10 transsexual women, 1 transsexual man, 2 travestis, and 1 homosexual [who used hormones and adopted a female name]) residing in the municipalities of the metropolitan region of Greater Vitória composed the study group. There was no prior selection of research participants. The sample
was obtained randomly – by referral, proximity, or relationship to each new participant – such that trans workers and users of ACARD services, UFES students, and HUCAM patients were part of the study.

The participation of the interviewees was subject to the signing of an informed consent form. This study was approved by the Ethics in Research Committee of the Federal University of Espírito Santo, Goiabeiras Campus. To ensure the confidentiality of the participants, the names used in the text are fictitious.

Results and Discussion

Adopted name and discrimination as dilemmas in healthcare access

The self-attribution of a new name accompanies body transformation processes. Together with the body, the name bears the multiple meanings of femininity and masculinity that operate as gender elements. The name and the body mutually affect each other. The name, as a non-physical transformation or sign designating a change that goes beyond and radicalises the physical transformation, does not dispense with the latter. The name change incites and is incited by body changes, without, however, confounding them or necessarily requiring them.

According to Teixeira, in the process of constructing a new body, trans people “are led to a significant investment in identity – a new name, a changed body – that gives meaning to the “nonsense” of a body that seems to be mistaken”. Benedetti, in turn, states that the body of trans people “is, above all, a language”. In these approaches, the name, as well as all the signs involved in the process of transformation, is taken as meaningful, a label that establishes limits amidst the chaos of a changing body. Certainly, the name may assume this identificatory function of establishing a stable being amidst experimentations, but this function is not its paramount function. The name or sign is, before anything else, another type of – non-physical – transformation that takes the body into another world order, another set of rules, another gender.

The production of trans bodies seems to be permeated by the production of signs, and their shapes and contours are produced amidst language games. Nonetheless, according to Preciado in her critique of Butler’s devaluation of the materiality of the body with regard to the productivity of language, the irreducibility of the body to language is affirmed. Hence, the change of name and the change of gender become elements that are interwoven in the material transformation of the body.

On 13 August 2009, the Brazilian Ministry of Health, through administrative rule no. 1820, released the Charter of Rights of SUS Users. The charter made it obligatory to have a field in user identification documents, such as medical records, to be filled with the name by which the user wants to be called. This should not be done disrespectfully or prejudicially, given that the charter states that “every citizen has the right to humane, welcoming treatment, free from any discrimination”. In 2011, the Brazilian Ministry of Health released the National Policy on the Comprehensive Health of Lesbians, Gays, Bisexuals, Travestis, and Transsexuals through administrative rule no. 2836, standardising the right to the “use of the adopted name of travestis and transsexuals, in accordance with the Charter of Rights of SUS Users”.

However, these regulations still have not been entirely integrated into the daily work routine of healthcare professionals, impeding the guarantee of universal access to healthcare by trans patients. Disrespect toward the name adopted by the participants of this study in public health services, in addition to other episodes of discrimination by healthcare professionals, has been relevant to the ineffectiveness of access to healthcare. The interviewee given the pseudonym Aphrodite (transsexual woman, 24 years of age) reported: It was at the Medical Examiner’s Office (MEO) that I experienced discrimination from the doctor. I asked him to call me by my adopted name. [...] He called me by my given name, and he screamed through the MEO. He screamed because he knew that I was becoming a transsexual. [...] He did not want to call me by my adopted name because according to him, he should call me by the name on my identity card. Aphrodite sought out the MEO for a forensic medical examination after having been a victim of rape while working. The interviewee compared the care at the MEO to that received when she seeks public healthcare services: I avoid it often. If I have a headache, something. I stay at home, I take a home remedy because if you go, you get even angrier, and there, it is worse. So, like I said in the case of the MEO, when I needed to look for a public service, what happened? I endured discrimination at the MEO. But at the hospital, I didn’t endure any discrimination. But at the MEO, I endured it. So, what do I prefer? Staying home.
Despite reporting not having endured discrimination in obtaining access to the post-exposure prophylaxis service offered at the University Hospital, she was emphatic in stating: That’s why a transsexual or a travesti doesn’t look for a referral centre to do tests, they don’t look for it; they don’t look for a doctor. Why? Because they know that if they go there, they will be treated poorly. So, they stay home.

There were other reports that indicated discrimination and disrespect toward the adopted name. Pandora (travesti, 43 years of age) reported enduring discrimination in an Urgent Care Centre when seeking emergency services for having a punctured foot: The women who worked in the centre’s reception saw that I was a travesti and I still said: Look, I want you to call me Pandora. When they went to call me, they didn’t call me Pandora. I freaked out. A friend of mine, who works there, let them have it. I was full of pain from having punctured my foot, the steel went through the boot, and this happened. In addition to having to cope with the pain from the injury, Pandora needed to manage the unease of being publically discriminated against by the professionals. In her questionnaire, Iphigenia (transsexual woman, 28 years of age) stated having abandoned treatments and failing to seek healthcare services to not have to endure discrimination. She wrote: There are doctors who treat one well, and there are doctors who don’t respect one’s sexual orientation and gender identity, there are doctors who don’t accept the adopted name, who call one by the given name. I have seen discrimination against friends of mine, and even I have endured homophobia and embarrassment. On the matter of whether she has already endured discrimination, Isis (transsexual woman, 53 years of age) answers: Yes! But it is up to us to tell them beforehand what we want to be called. If they mess with us, we make a scene. The need to “make a scene” appears as a strategy of trans people to fight for the right to healthcare services.

There are numerous reports of indignation and sadness due to the difficulties in seeking or frequenting a healthcare service. Similar results can be found in other studies.1-3,8,10 Through the experience as a doctor in the Family Health Programme (Programa Saúde da Família - PSF) in Lapa, Rio de Janeiro, Romano4 reports the frequent abandonment of or withdrawal from treatment in progress, even in cases of chronic or serious diseases such as AIDS, typically as a result of the discrimination that trans people endure in seeking care in the clinic. The author reports success in reducing this absenteeism through humanisation and welcoming work conducted with the patients and the team of PSF-Lapa.

Muller and Knauth10 reported the refusal of the healthcare facility to care for the trans patient, disrespect toward gender identity in cases of hospital admission, the resistance of trans people in seeking healthcare services as a result of discrimination, and “making a scene” as a form of ensuring care. According to the authors: “The low educational levels of a large segment of travestis is an impediment to their understanding day-to-day issues – such as the use of condoms, even in the case of HIV seropositivity, the efficacy of the medications used for HIV treatment, the consequences of the interruption of the use of these medications, and the use of drugs. As we can observe in the study, many travestis […] do not use condoms in their sexual relations with johns. From this picture emerge 3 public health problems: 1. reinfection by different strains of the HIV virus and the resulting resistance to medications; 2. the risk of contaminating johns who, in some situations, offer more money not to use condoms in sexual acts; and 3. the possible transmission of the HIV virus to a spouse because the majority of johns maintain a stable marital relationship.”

Caution is suggested in conclusions such as those of Muller and Knauth10 so as not to moralise the involvement of trans people in the networks of contamination by HIV and other sexually transmitted diseases (STDs), designating them as the risk group responsible for this public health problem. It should be considered that oftentimes, the low educational levels of trans people result from difficulties in staying in school because of discrimination; however, stating that the low level of education is responsible for a lack of understanding concerning the effects of HIV treatment medication and the use of condoms may be refutable and suggests the inability or unwillingness of healthcare services to communicate with the diversity of subjects about health education.

It cannot be ignored that interventions with sex workers, including trans people, through health educational programmes involving the information brought forth by Muller and Knauth10 may be an important intervention strategy in networks of HIV and STD infection. Nevertheless, there is a series of problems experienced by these individuals, reported in this study and others1-3,8,9 concerning discrimination, social marginalisation, poverty, etc., that need to be
I think to stay closer to my desire. I like to be seen as a bombshell. And I like those very large, very beautiful, very hot women. Bombshells get more attention, and I like that. In Helen, the ideal of beauty is associated with the ideal of gender. This idealisation is shaped personally and socially by the desire to receive more attention. The figure of the bombshell operates as an objective that guides body modification by means of silicone, a sign that guides the body during the transformation processes. Based on this perspective, the reasons for body modification are diverse, as can be observed in other studies.² The shaping of the body to please oneself, one’s companions, or one’s johns is not specific to trans and travesti women; countless cisgender women may modify their bodies for the same reasons. Advertisements and commercials and the labour market, among other things, are incentives for individuals, especially women, to invest in the transformation of their bodies.

To not overlook and ignore questions unique to trans people, it is important to pay attention to aspects such as poverty, homo/trans/travestiphobia, social marginalisation, violence, dropping out of school, unemployment, and the loss of family ties, among many others, which comprise the lives of the study participants. The difficulties that travesti, trans men, and trans women face in accessing the resources for body modifications – difficulties that go beyond those of cisgender men and women – are thus observed. Pelúcio, for example, finds that financial difficulties define the limits of and possibilities for body investments among travestis in São Paulo.

The difficulties in obtaining effective support from the SUS for the various body transformation motivations and needs, intersected by various social determinants, led many interviewees to run the risk of illness and death by resorting to the use of hormones unattended by healthcare professionals and to the application of industrial silicone. Desire, dream, need, and survival are combined in the endeavour to shape the body under risks. Some interviewees reported health problems resulting from these methods. According to Cassandra (travesti, 31 years of age), situations have occurred where people died at the hands of the bombadeira (a travesti who injects industrial silicone into other travestis) […] I had several friends who took hormones and got cancer. Isis reported: You may die on the spot. It really hurts. You may die afterward. I have seen many queers dying. It can go to the foot. […] I have regrets. I could… you know what? Have gotten an implant.
I couldn’t afford it [...]. It gives me a fever, I rest, don’t eat anything fatty [...] because my silicone gives me boils on my butt. In her questionnaire, Aphrodite reported that because of the use of hormones, she developed abscesses in various parts of her body. Pandora reports the intention to replace the industrial silicone in her breasts with a breast implant: At times, the silicone goes to the “cock” [penis], it goes to the sack [scrotum, testicles]. I have a friend that has a “large ball”. [...] Now, I want to remove the silicone in my chest and get an implant [...] It is hurting me [...], and this is not good. I only did this because I needed to make money. But, if it were today, I would not put it on. Helen reported being relieved that her applications of industrial silicone did not cause her health problems. Nevertheless, she spoke of her friends’ problems: I have no regrets. I just don’t recommend that anybody else do it. I was in recovery for the right amount of time, but there are people who don’t do this. [...]. The interviewees referenced a necessary recovery time after the application of industrial silicone of at least 15 days for deformities not to develop. However, the need to work for the silicone and its application, pimping, etc. do not allow many individuals to take the necessary recovery time, which can lead to deformities.

Romano⁷ reported the use, considered abusive, of hormones among trans and travesti women as a cause of liver disorders and the applications of industrial silicone as an important cause of infections and thrombosis of the lower limbs. However, the need for a change of perspective concerning the causes of the problems related to trans health is suggested. It is necessary to examine the individual blame assigned to trans people for illnesses and to consider the problem as a collective issue, which also implicates the ways in which health services function. As Almeida and Murta¹⁸ suggest, the lives of trans people should be analysed from the perspective of historical totality, in which individuals and groups have their lives intersected by cultural, economic, political, and subjective determinations. These lives experience repercussions related to social class, race/colour, sexual orientation, gender, dropping out of school, difficulties in accessing healthcare, etc. As a result, the use of hormones and industrial silicone may not signify an inconsequential and isolated action because it consists of a real dynamic of a society in which trans people construct means of resistance and survival¹⁸.

Gender reassignment surgeries and procedures were authorised in Brazil in 1997 by the Federal Council of Medicine (Conselho Federal de Medicina - CFM) through resolution no. 1482²⁰. Over the course of more than a decade of legalisation in the country, the CFM has updated the resolution twice. The more current resolution is no. 1955/2010, according to which transsexual patients are carriers “of a permanent psychological sexual identity disorder, with the rejection of phenotype and a tendency toward self-mutilation and self-extermination”²⁰. In this interpretation, the resolution defines the following as criteria for access to gender reassignment procedures: the medical diagnosis of transsexualism, an age of over 21 years, and the absence of physical characteristics inappropriate for surgery²⁰. These criteria guide the work of the multi-professional healthcare team composed of a “psychiatrist, surgeon, psychologist, social worker, and endocrinologist”²⁰ and are involved in the selection and care of patients, seeking to find in patients “discomfort with the natural gender; the express desire to eliminate the genitals, lose the primary and secondary gender characteristics, and achieve the opposite sex; the permanence of this disorder in a continual and consistent fashion for at least 2 years; and the absence of mental disorders”²⁰.

In 2008 the Brazilian Ministry of Health launched the SUS’s gender reassignment process through Ordinance 1707/2008²¹. Only transsexual women were provided access to hormone therapy services, clinical, psychological, and social care, and gender reassignment surgeries. Via ordinance 2803 of 2013²², the gender reassignment process was reformulated and came to meet the demands of transsexual men and travestis for hysterectomy, mastectomy, neovaginoplasty, hormone therapy, etc. The ordinance restricted access to procedures by means of a nosological diagnosis, reiterating the criteria defined in Resolution no. 1955/2010.

The incorporation of trans people’s demands for bodily transformation by the SUS is a victory arising from intense months of negotiation between the government and organised civil society¹¹, which led to the recognition of these healthcare demands by the Brazilian State. However, the SUS’s gender reassignment process is still not standardised across all of the country’s states and regions, and there are hospitals, such as the HUCAM-UFES, which – despite performing gender reassignment surgeries and clinical, psychological, and social welfare consultations – is not yet integrated in the SUS’s gender reassignment process, which has created difficulties in accessing
these services. Citing these difficulties and relating them to the waiting time for the performance of her gender reassignment surgery, Helen states: *Today, I am 28 years old, but I learned to have patience, to get used to my shape. But, I have never accepted it. So, for me, this surgery will be [great], I will feel free. It is as if I am in a body that does not belong to me.* Hercules (transsexual man, 26 years of age), in reporting roadblocks to obtaining care in the gender reassignment process, noted the diagnosis as a limitation to accessing these types of services: *So, it is wanting to put a transsexual in the hands of doctors, cis people, for them to judge if you can be operated on or not, with you not having control over your own body. The multi-professional team exists for you to give up on the operation, not for it to be performed. For example, a person removes breasts, puts on breasts, puts on a cock. Now, we transsexuals have to go through a process of only being operated on when having medical authorisation, psychological authorisation. The doctor's hegemony in the gender reassignment process is therefore noted, with the multi-professional team subjected to and subjecting itself to the arrangement of the process framed by the diagnosis and by the medical procedures. Aphrodite also cited waiting in line and left the issue of the diagnosis implicit in her speech: *I know. My friend, too. She is in line. I know all the difficulties [...] The tricks, too! Maybe by already being so feminine, I think that maybe I won't have much of an issue with this... In theory, at least, right? I am saying this because that's what I hear.*

The studies of Bento indicate the diagnosis as the catalysts for selectivity in accessing these programmes, such that they are guided by stereotypes of masculinity and femininity referred to in binary gender – which produces the idea that gender is a reflection of genitalia and genetics, that nature distributes the body dichotomously, penis-masculine-man versus vagina-feminine-woman – and in heteronormativity – which is the “ability of heterosexuality to present itself as normal, the law that regulates and determines the impossibility of life outside these markers”.

Thus, the work of the multi-professional team operates as a device of transsexuality, seeking to identify among patients those who are true transsexuals, those who best reproduce truths culturally – conceived around behaviours, clothing, preferences, etc. and based on homogenising and standardising the ideas of masculinity and femininity desired in “true” men and women – and those who exhibit what the CFM calls the express desire for self-extirpation and self-multilation. Therefore, the work of the teams has been to perform gender asepsis, refitting the body of those who best reproduce the gender binary. Isis fumbles over the certainty about the existence of a true transsexual: *I always felt pleasure. I had a nice transsexual. I always felt pleasure from the front [with this penis]. I am not like those crazies, who say they don’t feel pleasure [...] Simply, if I were to choose to do the surgery, I wouldn’t do it. I did it because I had a health problem that accelerated my surgery. [...] But I’m loving it. [...] I forget that I had the surgery. When I do remember, I get really happy because now I can use the women’s bathroom with my head held high, there is no way to say that I’m a queer [...] Isis had the surgery because of the displacement of industrial silicone in her body. However, she did not report a history of repulsion toward her genitalia or any post-surgery dissatisfaction, which reinforces the need to defend the autonomous participation of trans people in their body transformations in the gender reassignment process.

Hercules questions the medical authority, through the diagnosis, over trans bodies, denouncing the loss of autonomy endured in not being considered as subjects of their body change processes but being treated as abject bodies subject to the intervention of a power/knowledge. He denounces the operation of the device of transsexuality that disallows trans people from making decisions on the interventions in their bodies, as cisgender people do. Aphrodite, in turn, believes that because of her ability to reproduce the stereotypes of the “true woman” and being “feminine enough”, she will not face difficulties, as her friends did, in accessing gender reassignment services. She also cited “tricks”, also reported in Bento as, as strategies to ensure access to the gender reassignment process.

Diagnosis in the gender reassignment process has been widely debated in the social movement and academic environments. There are arguments for the maintenance of the diagnosis treating the pathologisation of trans identities as a political strategy to ensure the maintenance of public health services and studies that point to the diagnosis as a cause of marginalisation and exclusion from healthcare services and as an evasion of the interrogation of gender binarism. Almeida and Murta argue that it is necessary to understand that “the possible hardships experienced by transsexuals, travestis, and even by homosexuals do not result from some pathology inherent in such individuals but from trajectories of social exclusion.” It is necessary to question the
contribution of the diagnosis of trans identities in masking and strengthening social marginalisation, trans/travestiphobia, violence, poverty, and so many other ills experienced by trans people by placing the origin of their problems on the individual.

It is important to note that understanding concerning health and disease are produced by historically established social norms\textsuperscript{25,26}. Thus, the diagnoses not only evaluate anatomical/physical/psychological/pathological structures but are also intersected “by the common representation of the norm in a social environment at any given time”\textsuperscript{26}. Therefore, the experience of health and disease transcends the biomedical perspective by combining “norms, values, and expectations, both individual and collective, and is expressed in specific ways of thinking and acting”\textsuperscript{25}. In a society whose predominant norms for the intelligibility of bodies reside in the gender binary and in heteronormativity, all bodies that do not fit this standard might be considered ill, as is the case with trans bodies.

**Trans health requires a universal, comprehensive, egalitarian SUS**

Disrespect toward the adopted name, trans/travestiphobia in healthcare services, and the pathologising diagnosis in the gender reassignment process were found to be primary impediments to universal, comprehensive, and egalitarian access to the SUS by the participants of this study.

Together with healthcare professionals, it is necessary to question the consequences of the gender binary and heteronormativity for the health of trans people by means of continuing education programmes and interventions, such as those described by Romano\textsuperscript{8}, in addition to permanent campaigns publicising the right to care free of discrimination and the right to the use of the adopted name.

Selectivity in accessing the SUS’s gender reassignment process fostered by the diagnosis must continue to be discussed. Although pathologisation is a strategic concession\textsuperscript{24}, the Federal Constitution of 1988 does not condition access to healthcare in the SUS by the existence of a prior pathology\textsuperscript{22}, and this focus on health by the negation of disease has hindered trans people from accessing public healthcare services for assistance and professional care in the modification of their bodies.

The SUS may become an important tool for the citizenship promotion of trans people with regard to implementing the universality of access – seeking to overcome the impediments in accessing the SUS – the comprehensiveness of care – offering, in a coordinated and continual manner, services that make it possible to confront the determinants and conditionants of health and illness – and equality – considering the issues unique to trans people’s health.

**Collaborations**

PC Rocon, A Rodrigues, J Zamboni, and MD Pedrini participated in the study’s conception, data analysis, writing, and final revision of the manuscript.
References
