

Representativeness of the LGBTQIA+ population in epidemiological research in the context of the National Policy for Comprehensive Health of Lesbians, Gays, Bisexuals, Transvestites and Transsexuals in Brazil: expanding the production of knowledge within the SUS for social justice

Daniel Canavese de Oliveira¹ 

¹Universidade Federal do Rio Grande do Sul, Departamento de Saúde Coletiva, Porto Alegre, RS, Brazil

In this reflection, I argue that, throughout the implementation of the Brazilian National Health System (SUS) and just over a decade since the policies to promote equity in health¹ were implemented, the production of information on gender issues and sexual orientation still needs to be expanded. Regarding the central idea, I affirm that advances in these themes are necessary in the planning of epidemiological research, information systems and actions in health, health insurance, protocols and dissemination of technical documents. Therefore, a complex analysis of the integrality in health care for lesbians, gays, bisexuals, transvestites, transsexuals, queers, intersex people, non-binary people and others, whose acronym is LGBTQIA+, has come across gaps and the persistence of structural homophobia, a concept employed here, including all LGBTQIA+ people.

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It is important to present the long and continuous trajectory of action of social movements and LGBTQIA+ collective subjects, with irreversible achievements in different sectors of Brazilian society.^{2,3} Together, it has been possible to demand State action. The same State that should guarantee the right to health, should also be responsible for the promotion and protection of other human rights.

Thus, it is worth mentioning that despite the recognition of the importance of producing information about this population group, there is still a lack of consensus among the technical and scientific community. It is worth highlighting that the right to health as a duty of the State, a conquest ensured in the 1988 Federal Constitution, needs to support sexual and reproductive health as an inalienable guarantee of human rights. This necessarily includes the recognition of sexual orientation and gender identity as categories in order to understand subjects and populations.⁴

As such, in 2011, the implementation of the National Policy for Comprehensive Health of LGBT (PNSILGBT) in the SUS, was considered an important step.⁵ This equity policy has recorded, among one of its objectives, collecting, processing and analyzing specific data, including ethnic-racial profiling. In 2013, the first National LGBT Health Conference report,⁶ emphasized the need to produce information on the health of this population.

At the present moment, it can be seen, on the one hand, a large number of scientific productions and analyses using stratifications by sex, showing the importance of being aware of gender disparities, although characterized by conceptual insufficiency and focused on the binary perspective (male or female). On the other hand, there is a collection of research papers aimed at gender identity and sexual orientation, although much less frequent. According to a survey in the main public health journals, between 2004 and 2018, 27 articles on LGBTQIA+ people and public health policies were published, four of them in the field of epidemiology.⁷

It has been a long time since the demand for the representativeness of LGBTQIA+ people and their participation in research and knowledge production started, given the national health conference reports.^{8,9} Other countries with universal health care collect data by means of surveys and generate bulletins on specific demands.^{10,11} It is worth mentioning that in Brazil, the lack of information has an intersectoral characteristic and affects agencies such as the Instituto Brasileiro de Geografia e Estatística, whose population censuses and sample surveys, do not include questions related to sexual diversity, except for information on marital union (2010), and the most recent National Health Survey, the 2019 PNS, for the first time, asked questions about sexual orientation, in the sexual activity module, although the data were unavailable until the time of completion of this research.

The possibility of overcoming the aforementioned gaps is related to the necessity to incorporate more actions into the PNSILGBT, especially the production of indicators and their monitoring. A recent study, conducted in the partnership with the Pan American Health Organization, on national health plans in countries of the Americas, with the objective of characterizing the approach in health equity, pointed to weaknesses in the evaluation of Brazil, with regard to aspects such as the development of intersectoral actions, availability and use of disaggregated data, and the ability to respond.¹² A report on state health plans for the period 2016-2019 showed deficiency regarding the use of indicators and definition of parameters in situational analysis of LGBTQIA+ people in the country.¹³

Actually, one of these actions should undoubtedly be the improvement of health information systems. In 2008, the Ministry of Health identified the need to include configurations on LGBTQIA+ people in these systems.¹⁴ Unlike the item 'race/skin color' that since 2017 has been given a specific ordinance¹⁵ for its proper completion, the same measure has not been extended to gender identity and sexual orientation. When these variables are collected, their quality and availability for analysis remain restricted, and open access is not provided.

With regard to domestic, sexual and/or other types of violence notification form, available on the Notifiable Diseases Information System (SINAN), the completion of the fields related to sexual orientation and gender identity is mandatory, since the user is 10 years and older.¹⁶ This violence monitoring records cases of homophobic violence against people of all ages. The analysis of notifications of interpersonal and self-harm violence is an example of health surveillance actions that includes LGBTQIA+. An investigation developed between 2015 and 2017 on the profile of cases described the panorama of vulnerability caused by homophobia in the country.¹⁷ The study showed the potential of scientific and technological production process for the SUS, evident in health centers, such as: health care for the victims of violence; qualification in collecting and recording data - self-declared - in the notification form; availability of these data for analysis; and dissemination of information.

A study conducted in the United States, published in 2020, revealed the invisibility of transgender and transvestite people in clinical research, in addition to the severity of deficiency in data collection.¹⁸ Another study in the same country highlighted that gender identity and sexual orientation are not systematically recorded, limiting the understanding of different causes of death, in addition to affecting

specific intervention strategies.¹⁹ These situations are reiterated in Brazil. In addition to the gap in research, it is common knowledge that the violence experienced by transgender and transvestite people persists even after death, as their social name and gender identity are not respected in the Death Certificate.²⁰ The non-inclusion of these variables, in other Sinan forms and health information systems, compromises the knowledge of morbidity and mortality in the country.

The World Health Organization report on the inequities and vulnerability experienced, showed evidence of the worst health outcomes for LGBTQIA+ people related to different diseases, such as mental health, HIV/AIDS, hepatitis and types of cancer. However, the report reinforced the need to deepen the understanding of this panorama, based on quantitative and qualitative data.²¹ Important matters were included in the aforementioned document, such as: sexual health and reproductive rights; the non-pathological perspectives of body approach, especially related to transvestites, transsexuals and non-binary; the 'transsexualizer process'; coping with violence; HIV prevention; the impact of the COVID-19 pandemic; the greatest insertion of the theme in research; and intersectoral assistance involving the Unified Social Assistance System. It is necessary to expand knowledge on the specific demands of such a diverse and heterogeneous group, whose acronym is LGBTQIA+.

In 2021, the Supreme Federal Court (STF) granted a precautionary measure, allowing appointments and health examinations regardless of biological sex, inquiring about gender self-declaration in the SUS and requesting adaptations for the Certificate of Live Birth for gender identity inclusion.²² Thus, the Supreme Federal Court's order corroborates the need for change in the approach to the issue by health services.

The Supreme Court's intervention, which was a recent event, serves as a provocation for greater involvement, especially of people working in the SUS and sanitarians, in the subject, aiming to increase the representativeness and inclusion of the LGBTQIA+ population. Disinformation, stigma and exclusion of these population will persist if there is no interruption of heteronormative logic and structural homophobia.²³ Therefore, it is understood that, through the lens of complexity and sensitive science, the challenges to be faced call upon the whole society.

I conclude this article with two brief points. The first is related to the need to present this reflection in this moment of infodemic. Disinformation, fake news and misinformation have an impact on the topics discussed here. Based on ignorance, pathologizing and criminalizing discourses against LGBTQIA+ have been intensified, stigmas stimulated, discrimination spread, violence promoted and achievements suppressed.

The second point concerns the celebration of resistance through which the Brazilian Sanitary Reform movement took place, with collective engagement of subjects in the promotion of human rights. It is important to cite and show reverence for countless people, who were not mentioned in this article, their life trajectories as lesbian, gay, bisexual, transvestite, transgender and intersex people who shared their knowledge, other epistemological possibilities and mobilization for the proposition and implementation of public policies for recognition and redistribution. It has been over 40 years since the HIV/AIDS epidemic started in Brazil, being LGBTQIA+ people and their collective subjects the protagonists of the challenge of coping with this disease, enabling robust records that has showed that it is possible to advance in democratic spaces, strengthen the SUS, increase the understanding of determinants of health, improve the production of scientific information and produce solidarity and dialogical knowledge.

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Correspondence: Daniel Canavese de Oliveira | daniel.canavese@gmail.com

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