

## "I DIDN'T CHOOSE TO HAVE MY BREAST REMOVED": BRAZILIAN LESBIAN/BISEXUAL WOMEN'S JOURNEY THROUGH BREAST CANCER\*

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### Abstract

Gender and sexuality are social determinants of health. Recognizing and guaranteeing the rights of women and LGBTQIA+ people is a necessary condition for them to access better living and health conditions. The literature on breast cancer and female homosexuality explores how the disease and treatment have a different impact on the quality of life of lesbian and bisexual women. Considering these assumptions, this study aims to investigate the experiences of lesbian/bisexual women who have had breast cancer and how these experiences are elaborated during cancer treatment. This is a qualitative, interpretative, cross-sectional study that has as its theoretical reference the gender studies. Three lesbian women and one bisexual woman who were diagnosed with breast cancer participated in the research. To build the corpus of analysis, individual interviews were conducted in a face-to-face situation. The interviews were digitally recorded with the participants' consent, and the audio-recorded content was transcribed verbatim and in full. Subsequently, the data were analyzed and discussed based on reflexive thematic analysis. The categories identified from the participants' interviews were discovering the diagnosis, tumor removal surgery, breast reconstruction, adjuvant therapies and hair and body hair loss. Even today, the diagnosis of cancer and the mastectomy take patients to stigmatizing places in society, which are related to the treatment of the disease itself, which, being very aggressive, causes various adverse reactions to occur in these women's bodies, such as pain, loss of movement in the arms, loss of hair and body hair, nausea, fatigue, among others. All four participants mentioned these aspects in their interviews, feeling each of the consequences of cancer treatment with greater or lesser intensity. The participants also mentioned that breast removal was a difficult aspect for them and that the chemotherapy sessions were worse than the radiotherapy sessions. None of the participants related their experiences during cancer treatment with their sexual orientation, which indicates similarities between the experiences of heterosexual and lesbian women regarding the oncological treatment. However, bearing in mind that the ideal of public policies is to offer comprehensive and humanized health care to all people, it is understood that giving a voice to sexual minorities to express themselves in the field of health is to give consistency to an organizing and structuring principle of humanization in care. This, in turn, broadens the opportunities for integrating sexual diversity into the context of cancer care.

**Keywords:** *Breast neoplasms, lesbianities, bisexuality, women's health.*

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### 1. Introduction

The population's adherence to care actions is related to the way in which health services welcome and build meaningful bonds with its users. Considering that gender and sexuality are social determinants of health, recognizing and guaranteeing the rights of women and LGBTQIA+ people is a necessary condition for these people to access better living and health conditions. However, what is observed in the health itineraries of LGBTQIA+ people are barriers that make it difficult for professionals to relate to these users. Therefore, many advances are still needed for policies aimed at the well-being of this population to be perceived and put into practice, in order to reduce inequalities and health disparities experienced by LGBTQIA+ people (Belém et al., 2018; Gomes, Murta, Facchini, & Meneghel, 2018).

Ethical attitudes, positive social representations, availability of health workers to do their best, understanding that non-heteronormative people face specific barriers in health and experience situations

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\* Funding: São Paulo Research Foundation (FAPESP), process 2020/09464-3 and 2023/09356-4

of prejudice in exclusionary social contexts, can contribute to raising awareness and improving care in health, especially in breast cancer. It is important that health services take responsibility for transforming practices and that health professionals develop permanent self-criticism and reflection on their work, so that discriminatory attitudes do not go unnoticed, and that they can be a topic of confrontation in their everyday life (Belém et al., 2018; Silva, Finkler, & Moretti-Pires, 2019).

Brazilian scientific production that addresses the topic of health and female homosexuality/bisexuality is scarce (Rodrigues, 2013; Rufino, Madeiro, Trinidad, Santos, & Freitas, 2018). Health policies aimed at tackling the difficulties and needs experienced by these women are still incipient and their implementation precarious, since they are unknown to most professionals (Rodrigues, 2013; Souza & Santos, 2022). The literature on breast cancer and female homosexuality explores how the disease and treatment have a different impact on the quality of life of lesbian and bisexual women, but there is still little knowledge produced about this topic and an almost complete absence of adequate health care technologies for lesbians and bisexuals (Souza & Santos, 2021, 2022).

Furthermore, breast cancer is experienced in different ways by patients, as each woman constructs meanings for their emotions and feelings that are influenced by the context in which they are inserted, making care for these patients a challenge for health professionals (Taylor, Harley, Absolom, Brown, & Velikova, 2016). That way, this study aims to investigate the experiences of lesbian/bisexual women who have had breast cancer and how these experiences are elaborated during cancer treatment.

## 2. Methods

### 2.1. Research design

This is a qualitative, interpretative, cross-sectional study applied to the health field (Turato, 2005).

### 2.2. Participants

Three lesbian women and one bisexual woman participated in the research. The participants were selected based on the following criteria: being 18 years old or older; self-identification as lesbian or bisexual; having had breast cancer; and consenting to participate. Women with comprehension and communication difficulties which could hinder their interviews were excluded. Table 1 presents the sociodemographic data of the participants. Names have been changed to protect women's identities.

Table 1. Sociodemographic characteristics of the participants.

Name (fictitious)	Age (years)	Color	Sexual orientation	Occupational status	Education*	Family income
Beatriz	33	Black	Lesbian	Psychologist	Postgraduate	R\$ 2500
Dalva	28	White	Bisexual	Educator	HE Complete	R\$ 5700
Amanda	56	White	Lesbian	Civil servant	HE Complete	R\$ 13000
Malu	36	Black	Lesbian	Advertising professional	Postgraduate	R\$ 11000

Source: prepared by the researcher.

\*HE: Higher Education.

### 2.3. Research instruments

**2.3.1. Sociodemographic form.** A form containing sociodemographic and clinical data.

**2.3.2. Brazilian Economic Classification Criteria (CCEB).** This instrument aims to characterize the participants in terms of purchasing power and their position in the social hierarchy (Brazil, 2021).

**2.3.3. Semi-structured interview script.** A tool to access speech and used to find an effective access and investigation of the research theme (Dockhorn & Macedo, 2015).

### 2.4. Research process

**2.4.1. Data collection.** The researcher contacted participants through invitations issued to lesbian/bisexual activist groups and through researchers/professionals who work in healthcare. Then, participants were recruited through a snowball sampling process. Preliminarily, the researcher contacted the eligible women and, if they agreed, the researcher scheduled a meeting according to the participant's availability. Due to the COVID-19 pandemic, all interviews took place through a digital platform (Google

Meet). The interviews were audio and video recorded, with consent from participants. All interviews were conducted in Portuguese, from September 2021 to February 2023.

**2.4.2. Data analysis.** The interviews lasted between 48 and 152 minutes and were subsequently transcribed and analyzed following the reflexive thematic analysis approach (Braun & Clarke, 2019; Clarke, Braun, & Hayfield, 2015). The six recommended methodological steps were followed: 1) Familiarization with the data; 2) Generating initial codes; 3) Searching for themes; 4) Revising the themes; 5) Defining and naming the themes; 6) Producing the report. The coding was done with the help of MAXQDA 2022 program. After the data analysis, the results were systematized into thematic categories and interpreted based on the literature about breast cancer.

### 2.5. Ethical considerations

The study was approved by the Research Ethics Committee of the faculty where the research was conducted, CAAE No. 36146920.0.0000.5407, following the ethical procedures according to Resolution No. 466/12 (2012).

## 3. Results and discussion

The thematic analysis allowed the construction of the following thematic categories: **discovering the diagnosis, tumor removal surgery, breast reconstruction, adjuvant therapies and hair and body hair loss**. Regarding the **diagnosis discovery**, Bia reported that she felt helpless, “ungrounded”, upon learning of the cancer diagnosis and Amanda explained that she was worried when they asked her to redo the mammogram, already suspecting that the exam had indicated some change. Dalva expressed a reaction of disbelief upon learning of the diagnosis and questioned why this was happening to her: “[...] I thought, 'Man, it's not possible that this is happening to me, like, right now', and you're like [...], 'Why? Why me? Why now...?' [...]”. In fact, cancer treatment, and the moment of diagnosis itself, involves a long journey into the unknown, which brings countless fears and increases the uncertainties of affected women (Al-Azri et al., 2014; Inocenti, Santos, Loyola, Magalhães, & Panobianco, 2016). Malu, on the other hand, said that her first concern when she found out about the cancer was losing her breast. This preoccupation is widespread in the literature on breast cancer (Lima et al., 2018; Taylor et al., 2016; Vrinten et al., 2017).

Women are guided throughout their lives to realize that the female body is different from the male body, with the breasts being one of the markers that most highlight this difference. Therefore, when a serious disease such as cancer affects this organ, women see **surgery to remove the tumor** as an aggressive and mutilating process, in addition to being an attack on self-esteem and body aesthetics. All of this makes the patient feel their body in a strange way after surgery (Lima et al., 2018; Peres & Santos, 2012). Bia commented that only recently has she felt the loss of her breast as an issue that influences her relationships, her self-esteem, and her body image: “[...] I cry today for my breast. At the time [of surgery] I wasn't aware of the extent of this [loss]”. Amanda reported that she cried a lot when she saw that her breasts were different sizes after the quadrantectomy and said that she usually wears looser blouses or padded bras when she is at work to disguise this difference in size: “When I went to the room [after mastectomy], I [...] looked down, I saw one tiny breast and the other normal, right? I just cried [...]”. On the other hand, and contrary to the literature on the field, Malu stated that she did not feel any pain and that her healing was good.

About **reconstruction surgery**, Bia tried to undergo reconstruction twice, but both times there was rejection, as well as a lot of pain after the surgeries. Thus, due to the pain and understanding that the reconstruction would be something purely aesthetic and would not bring the sensitivity of the breast back, Bia understood that this surgery no longer made sense to her: “[...] I tried to do reconstruction twice, both times it went wrong [...]. I went through so much pain both times, that I abandoned the idea [...]. The breast is purely aesthetic, because it has no sensitivity, it is completely different from the other”. Amanda says she is very eager to undergo reconstruction, as she would like her breasts to return to a similar size and would like to “see everything back in place”. Malu did her reconstruction immediately after the mastectomy and she is satisfied with the result. The reconstruction surgery can often give women back their self-esteem, the feeling of being complete again and their self-image, in addition to helping to overcome the consequences of the disease (Inocenti et al., 2016; Márquez, Gil-Olarte, Molinero, & Bozal, 2022). However, it is important to remember that the way a woman sees her body before and after the changes caused by cancer can influence the way she sees herself after surgery. Thus, breast reconstruction can also be seen as another mutilation that leaves marks on women and maintains the stigma they previously felt (Inocenti et al., 2016). The participants felt the reconstruction in different ways, one as a painful process and others as a positive surgery for their self-esteem.

Regarding the **adjuvant therapies**, the literature states that chemotherapy and radiotherapy can bring different side effects: the first can cause muscle fatigue, febrile neutropenia, depression, weight gain, dyspnea, pain, nausea and vomiting (Ferreira & Franco, 2017) and the second can cause mucositis, radiodermatitis, trismus, xerostomia and osteoradionecrosis (Leite, Ferreira, Cruz, Lima, & Primo, 2013). Bia and Malu mentioned that the chemotherapy left them both weakened, with the first reporting feeling pain and nausea and the second that her immunity was lower. Dalva said that chemotherapy made her feel “dizzy”. About radiotherapy, the three participants brought skin sensitivity as a side effect, as exemplified by Dalva: “The radio was calm, the only thing that was really bad for me was an absurd burn”. Bia and Malu explained some side effects of hormone therapy. Bia described that she had hot flashes, which is consistent with the literature. Half of the participants (38 women) in the research by Lin, Chao, Bickell and Wisnivesky (2017) reported that they also experienced hot flashes as one of the side effects of hormone therapy. Malu talked about a rare side effect: she had a liver thrombosis caused by tamoxifen. Despite this rarity, there are articles linking the use of tamoxifen with liver complications (Hsu, Belkin, Han, & Pellish, 2015; Yang et al., 2016).

About the **loss of hair and body hair**, it is understood that hair is one of the symbols related to the feminine and it appears that coping with its loss by women who have had breast cancer varies according to the situation and personality of each one of them. That is why this coping has positive and negative points. Many women claim that hair loss did not affect their femininity, and for them the most important thing was to be alive. However, hair is seen as one of the greatest symbols of femininity in Western culture and its loss can be felt as a very traumatic experience that influences the self-image of breast cancer patients (Reis & Gradim, 2018; Souza et al., 2017). Malu talked about the positive aspects of hair loss and explained that she felt that being bald was important for her: “[...] Going bald was important for me as a black woman with curly hair. I was going through a hair transition [...] and I faced going bald in a very positive way [...]”. Moreover, the loss of eyelashes and eyebrows is also experienced with great discomfort (Santos, Ford, Santos, & Vieira, 2014), as stated by Bia and Dalva. For both, losing eyebrows was more worrying than losing hair, as they related their eyebrows to the expressiveness of the face. Bia explained that “Without eyebrows and eyelashes for me, that was [...] very strange [...]”.

#### 4. Conclusions

It is important to notice that none of the participants related their experiences during cancer treatment with their sexual orientation, which indicates similarities between the experiences of heterosexual and lesbian women regarding the oncological treatment. However, bearing in mind the ideal of public policies is to offer comprehensive and humanized health care to all people, it is understood that giving a voice to sexual minorities to express themselves in the field of health is to give consistency to an organizing and structuring principle of humanization in care. This, in turn, broadens the opportunities for integrating sexual diversity into the context of cancer care. The goal is for cancer treatment to be inclusive and not segregate patients. Moreover, there is an anticipation that it will heighten the awareness of health professionals regarding the significance of incorporating gender perspectives into cancer care.

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