ESTUDOS DE PSICOLOGIA
Psychological Studies

RESEARCH REPORT
RELATO DE PESQUISA

Health Psychology
Psicologia da Saúde

Editor
Raquel Souza Lobo Guzzo

Conflict of interest
The authors declare they have no conflict of interests.

Received
July 30, 2021

Final version
December 1, 2022

Approved
February 3, 2023

Experiences with breast cancer: A study between Brazilian and German women

Experiências com o câncer de mama: um estudo entre brasileiras e alemãs

Maristela Júlia Fernandes[1], Luciana Kind[2]

[1] Pontifícia Universidade Católica de Minas Gerais, Programa de Pós-Graduação em Psicologia, Grupo de Pesquisa Narrativas, Gênero e Saúde. Belo Horizonte, MG, Brasil. Correspondece to: M. J. FERNANDES. E-mail: <maristela.fernandes.psi@gmail.com>.
[2] Pontifícia Universidade Católica de Minas Gerais, Faculdade de Psicologia, Programa de Pós-Graduação em Psicologia. Belo Horizonte, MG, Brasil.

How to cite this article: Fernandes, M. J., & Kind, L. (2023). Experiences with breast cancer: A study between Brazilian and German women. *Estudos de Psicologia* (Campinas), *40*, e210113. https://doi.org/10.1590/1982-0275202340e210113

Abstract

Objective
This study aimed to identify the experiences of women from two different countries, through the discovery and treatments of breast neoplasms, highlighting the phenomenon based on relationships with socio-cultural aspects.

Method
The Grounded Theory was the theoretical and methodological tool for data collection and analysis, in this qualitative research of which 15 Brazilian women (35-65 years old) and 12 German women (50-81 years old) participated, all in treatment for breast cancer.

Results
The results revealed differences in obtaining the diagnosis – in Brazil mostly sought from self-examination, and in Germany, for complying with the invitation letter for mammography. The disease's disclosure pointed out that cancer's stigmas are more significant among German women than Brazilian women.

Conclusion
Differences between prescribed treatments reveal that Brazilian women receive more chemotherapies, and German women, radiotherapies. Finally, it is considered that some women's attitudes bring gains and decrease suffering, while others, losses, and stigmatization.

Keywords: Breast neoplasms; Grounded theory; Self; Psychology social.

Resumo

Objetivo
Buscou-se por meio deste estudo, identificar as experiências de mulheres de dois países distintos, mediante a descoberta e os tratamentos das neoplasias de mama, evidenciando-se o fenômeno a partir das relações com os aspectos socioculturais.

Método
A Teoria Fundamentada foi a ferramenta teórico-metodológica para coleta e análise dos dados, nesta pesquisa qualitativa, da qual participaram 15 mulheres brasileiras (35-65 anos) e 12 alemãs (50-81), todas em tratamentos contra o câncer de mama.

Resultados
Os resultados trazem as diferenças para obtenção do diagnóstico – no Brasil majoritariamente buscado a partir do autoexame; e na Alemanha, pelo atendimento à carta convite do Seguro de Saúde, para fazer a mamografia. A revelação da doença apontou que os estigmas do câncer são maiores dentre as alemãs do que dentre as brasileiras.

Conclusão
As diferenças dentre os tratamentos prescritos sugerem que no Brasil as mulheres recebem mais quimioterapias e na Alemanha, mais radioterapias. Considera-se que alguns posicionamentos trazem ganhos e diminuição do sofrimento, outros trazem prejuízos e estigmatização.

Palavras-chave*: Neoplasias da Mama; Teoria fundamentada; Self; Psicologia social.*

Breast cancer is a worldwide public health problem affecting almost every country globally. Bray et al. (2018), through a study based on the results of Global Cancer 2018 – International Agency for Research on Cancer, analyzed the incidence and mortality of 36 different types of cancer in 185 countries around the world. According to the authors, breast cancer, which most affects women, had about 2.1 million new cases registered in the world's population in 2018. They also clarify that the incidence and mortality from cancer are growing rapidly in the world, and although the reasons for explaining the phenomenon are complex, they are associated with aging and population growth. In the year 2018, breast cancer caused about 627,000 women deaths worldwide.

Germany belongs to the group of countries with the highest Human Development Index (HDI) on the planet, while Brazil has a high HDI (Bray et al., 2018). Recent data from the United Nations Development Programme (2021) show that, between 1990 and 2021, Germany's HDI increased from 0.829 to 0.942, which places the country among the most developed countries in the world. In the same period, Brazil's HDI varied from 0.610 to 0.754, putting it as a country in a high category for the indicator. However, both countries have, among their populations, high incidence rates of breast cancer. For German women, according to the Robert Koch-Institut ([RKI], 2017a; 2020), the largest institution in Germany responsible for monitoring different types of diseases, breast cancer is the pathology with the most elevated incidence, with 69,220 records of new annual cases, excluding non-melanoma skin cancer. For Brazilian women, the situation is similar; according to the National Cancer Institute José Alencar Gomes da Silva, breast cancer appears as the disease with the highest incidence among the female public, with a total of 59,700 new cases of the disease in 2016 (Instituto Nacional de Câncer José Alencar Gomes da Silva, 2017). In more recent data from Instituto Nacional de Câncer (2020), breast cancer remains the highest incidence among women, with 73,610 new cases.

More than 17,000 women die annually in Brazil due to breast cancer (Instituto Nacional de Câncer, 2020), a number equivalent to the annual deaths from the disease in Germany, revealing that there is still a high mortality rate from breast cancer in the country (RKI 2017a; 2017b). The RKI (2017b) relates high mortality to late diagnoses, despite early detection efforts, such as the invitation letter sent by Health Insurance, so that all women between 50 and 69 years old get a mammography every two years. Early detection measures aim not only to identify breast cancer as early as possible but also to treat the disease in a less invasive way, which increases the quality of life of patients and their chances of recovery.

In Germany, health services are mostly offered by state-owned Health Insurance companies, managed by the State, and citizens' adherence to one of them is mandatory, differing from what

happens in Brazil (Das Gesundheitssystem kennen lernen, 2015; Giovanella & Stegmüller, 2014). According to the document Das Gesundheitssystem kennen lernen (2015), about 90% of the country's citizens are associated with State Health Insurance, 5% have Private Health Insurance, 2% have other operators, and about 3% of Germans are not insured. In practice, Health Insurance companies collect employee contributions (employee/employer; pensioners/pension), fixed rates on the worker's gross salary, and manage these resources in Mandatory Health Insurance. As a result, those covered by the health plan have access to all treatments and medications, with the appropriate medical prescriptions, without other direct costs, in addition to the monthly fees already paid to the Health Insurance.

In Brazil, citizens can choose whether or not to adhere to private health insurance, since the country has the *Sistema Único de Saúde* (SUS, Health Unic System), which guarantees access for all, entirely, without direct costs for users. Duarte et al. (2018) draw attention to the "30 years of the Health Unic System", completed in 2018, and the importance of SUS in the lives of Brazilian citizens, highlighting the principles of universality, equity, and integrality. The authors point out that 80% of Brazilians depend exclusively on the SUS in the country, not being insured by private health plans and not having the financial conditions to pay for consultations, exams, and complex or prolonged treatments. Instituto Nacional de Câncer José Alencar Gomes da Silva (2019) clarifies that treatments for breast cancer in Brazil are offered by the SUS, part of the care line strategies ranging from Basic Health Care to high-complexity care. In addition to the SUS having its own hospital network, it also relies on the infrastructure, and the private network service, by contracting the provision of services.

Despite advances in screening techniques and treatments against the disease, breast cancer still carries a strong social stigma, causing various difficulties for those who receive and must deal with the diagnosis. According to Sontag (1978/2002), an author who also had cancer, the disease is seen as synonymous with death, something incurable. The diagnosis affects not only physically the sick but also their daily life, permeated by routine treatments. It also impacts the family and close people, as there is a fear of challenges appearing in the course of the disease, especially in the most severe cases, accompanied by radical surgeries and chemotherapy.

Scorsolini-Comin et al. (2009) pointed out, in a qualitative study, that stigma was the theme of many discussion topics among women participating in research and intervention groups developed by a public University in São Paulo. Faced with the need to deal with the uncertainties arising from the diagnosis and treatments, the participants sought out these groups. They found themselves in paradoxical situations, afraid of death, rejection, and even doubting the effectiveness of treatments. The researchers concluded that the stigma surrounding the disease hinders healing processes, and the professionals who deal with these sick women should not neglect it.

Ernst et al. (2017) developed a quantitative study with 858 cancer patients in Germany, of which 43% were women, and among them, 47% with breast cancer. The researchers sought to assess the stigma linked to the work context using a Likert-type Scale. According to them, stigmatization manifests itself in two ways in the work environment, surpassing the aspirations of the employee, as well as the role and posture of the employer. First, due to the diagnosis, because, in the working environment, they value people's health and their working ability. Second, due to physical and/or psychological aspects – when disfigurement occurs after treatments, with consequent rejection by colleagues in the work environment; and when the sick person becomes emotionally fragile and does not deal with the pressure at work in the same way as before.

According to Ernst et al. (2017), in the workplace, women are more exposed to stigmatization due to cancer than men. The authors also consider that someone employed, sick with prostate or breast cancer, suffers less stigma than someone unemployed. According to the authors, this is because unemployment is stigmatizing in itself. Therefore, the challenges breast cancer brings to women's lives pervade the search for a diagnosis, the management of treatments, the new routine, and fears, among them fear of death; and the social stigma that the disease brings.

As a starting point for thinking about the experiences of women survivors of breast cancer in both countries, we consider the reflection of Charmaz (1995), a reference researcher in the field of Grounded Theory, on serious illnesses. The author maintains that body, identity, and self are intertwined during a prolonged illness or in the life of someone with a chronic disease. Says the author "Bodily limits and social circumstances often force adaptation to loss. Adaptation sets the tone for acceptance. Thus, sick people adapt when they try to accommodate and flow with the experience of illness" (Charmaz, 1995, p. 657).

In this study, we sought to understand the experiences of women in Brazil and Germany, from different socioeconomic backgrounds, regarding the diagnosis and treatments for breast cancer. For this, the processes of discovery of the disease were systematized and compared, the types of treatments, as well as the stigmas most present in their reports. Finally, we made an inflection on the main challenges faced and their relationship with their culture.

Method

Participants

The main research question, of a qualitative nature, was: What are the main challenges faced by Brazilian and German women through the discovery and treatments of breast cancer? To answer it, a study was carried out in Brazil with women undergoing treatment for breast cancer, linked to CETUS Oncologia, a Day Hospital that assists private patients, health insurance plans, and the SUS, located in the metropolitan region of Belo Horizonte, Minas Gerais. In Germany, women receiving breast cancer treatments at Kliniken Ostallgäu-Kaufbeuren, a Regional Hospital located in Bavaria, in the south of the country, participated in the research.

The study met the criteria required for conducting research involving human beings in Brazil, per the resolution of the National Health Council, Ministry of Health, nº 466 of 2012 - CNS 466/12 (Conselho Nacional da Saúde, 2012), and approved by the Research Ethics Committee of PUC Minas, registration nº 1,906,726.

Fifteen Brazilian women with breast cancer, aged between 35-65 years, chosen randomly, and indicated for the study by CETUS Oncologia, participated in the research. Twelve German women participated in the study, indicated by the Regional Hospital of Kaufbeuren, aged between 50-81 years, also randomly chosen.

Instruments

Semi-structured interviews were conducted with all 27 participants. Each participant was interviewed according to a semi-structured interview guide in a single meeting. During the interview, other questions arose and were included. Each interview lasted an average of 50 minutes. The researcher also resorted to the records made in her field diary to understand the studied phenomena

better, as pointed out by Laperrière (2010). A form with treatment data such as diagnosis time, cancer stage, and therapies applied served as a recording instrument.

Procedures

The Brazilian participants signed the Informed Consent Form. This stage took place between April and August 2017 in Brazil. Exclusion criteria for participation in the research in both countries were: cancer detected at a stage considered non-curable, that is, receiving only palliative care; pregnancy; the presence of clinically detected neurological problems. The criteria for inclusion in the study was diagnosis time between six and twenty-four months to address women still undergoing treatment. The methodological approach sought a group of participants who were not directly dealing with death or other psychological distresses that could harm them due to their inclusion in the study.

Following the ethical guidelines promulgated by the Declaration of Helsinki, the German participants also signed a consent form (General Assembly of the World Medical Association, 2014). The research phase in Germany took place between April and November 2019.

Data analysis was performed using Grounded Theory, in line with the synthesis proposed by Charmaz (2009), incorporating line-by-line reading and coding, constant comparison, axial coding, and theoretical coding. Memos were also prepared throughout the work with the empirical material, the approximation and distancing of the data to capture the process of the narrated experiences. The continuous comparative process began by grouping the participants according to their socioeconomic conditions, creating fictitious names for each one of them, and linking them to their grouping (by the initial letter of the given name, for example, A: Ana, Aline; B: Beatriz, Bianca, and so on). Subsequently, a detailed analysis of the phenomena was carried out. At this stage, the "(...) six Cs: Causes, Contexts, Contingencies, Consequences, Covariances, and Conditions" (Glaser *apud* Charmaz, 2009, p. 94) linked the studies to certain theoretical codes that emerged from the research data. In sequence, these codes were grouped by categories, which were also compared, reorganized, and reanalyzed, until the studied experience could be presented in theoretical statements. As Charmaz (2009) recommended, the gerund's use in the construction of the analysis process intends to demonstrate the intermediary codification process and the construction of memos that allow the ordering of the material.

Results

Comparing the discovery of the diagnosis to the socioeconomic condition, most Brazilian women noticed the presence of a lump or other alteration in the breast (self-examination), which led them to search for the diagnosis, while among the German women, mostly, it was attending the claim (a letter from the Health Insurance) for mammography, that led them to the discovery of the disease. Table 1 organizes information about the Brazilian participants divided into three subgroups (A, B, and C), concerning family income at the time of the interviews.

Concerning obtaining the diagnosis, three distinct situations point to a relationship between the discovery of the disease and the social condition of Brazilian women: eight women identified an alteration in the breast by themselves and sought immediate medical help to investigate the possibility of a diagnosis (3 of them from group A, three from group B and two from group C).

Table 1
Socioeconomic Data of the Women Participating in the Research in Brazil

Social Actor	Age	Marital Status	Children	Education	Profession	Family Income in Minimum Wages*
Ana	35	Divorced	2	Technical High School	Attendant	5 or more
Aline	42	Married	1	Postgraduate	Dentist	5 or more
Aurora	56	Married	2	Postgraduate	Social Assistant	5 or more
Antônia	52	Married	3	Technical High School	Housewife	5 or more
Beatriz	47	Married	2	Elementary School	Attendant	3-4
Bianca	37	Married	2	Undergraduate student	Secretary	3-4
Bruna	51	Married	3	High School	Sales Worker	3-4
Brigitte	60	Single	-	Elementary School	Babysitter	3-4
Carolina	44	Civil partnership	-	Elementary School	Production Worker	1-2
Cássia	37	Civil partnership	2	Technical High School	Housemaid	1-2
Cláudia	65	Widow	3	First four years of the Elementary School	Pensioner - Housewife	1-2
Camila	44	Divorced	4	First four years of the Elementary School	Cleaning Assistant	1-2
Cristina	38	Married	2	High School	Housewife	1-2
Carla	55	Single	1	Technical High School	Nursing Assistant	1-2
Clarisse	59	Married	3	First two years of the Elementary School	Retired- Housemaide	1-2

Note: *The minimum wage in 2017 was R$ 937,00 (nine hundred and thirty-seven reais). The average per capita family income was R$ 1,271 per month in 2017, and around 50% of workers in the country were earning less than the minimum wage. The data are from the *Pesquisa Nacional por Amostra de Domicílios Contínua* (PNAD Contínua, Continuous National Residence Sample Research) – which measured the income of Brazilian families in 2017 and released the results through the *Instituto Brasileiro de Geografia e Estatística* (IBGE, Brazilian Institute of Geography and Statistics) (Lencione, 2018).

Four women did not notice anything in their breasts and only glimpsed the possibility of a diagnosis from a routine medical consultation with the gynecologist, who located the tumor and requested the mammography (1 in group A, 1 in group B, and 2 in group C); and 3, three women noticed something different in their breasts, but did not immediately seek specialized medical help, only having done it later, following the advice of people around them (all of them in group C, the poorest in the study). Therefore, it is noteworthy that the highest number of self-discoveries of the disease occurred for the richest Brazilian women, in contrast to the more significant difficulty in finding out the disease, which occurred among the poorest Brazilian women.

In Table 2, a similar ordering was created for the German participants, also divided into three groups (K, L, M).

Table 2
Socioeconomic Data of the Women Participating in the Research in Germany

Social Actor	Age	Marital Status	Children	Education	Profession	Monthly Family Income
Karen	81	Widow/ civil partnership	-	Technical High School (Ausbildung)	Retired -Cosmetics/Beautician	4000 Euros or more
Larissa	67	Married	3	Technical High School (Ausbildung)	Retired -Commerce/Buyer	2000-3000 Euros
Layla	67	Married	-	Technical High School (Ausbildung)	Retired -Cosmetics/Beautician	2000-3000 Euros
Liane	63	Married	3	Technical High School (Ausbildung)	Cosmetics/Beautician	2000-3000 Euros
Lisa	59	Married	3	Technical High School (Ausbildung)	Hospitality/Cook	2000-3000 Euros
Loren	50	Married	2	High School	Production Worker	2000-3000 Euros
Louise	53	Married	2	High School	Service Worker	2000-3000 Euros
Ludmilla	54	Married	2	High School	Machine Operator	2000-3000 Euros
Marlene	61	Married	2	High School	Production Worker	1000-2000 Euros
Matilda	70	Married	2	Elementary School	Pensioner- Housewife	1000-2000 Euros
Melinda	69	Married	2	Elementary School	Retired Seamstress	1000-2000 Euros
Mia	74	Married	-	Technical High School (Ausbildung)	Retired Trade/Buyer	1000-2000 Euros

Among the German women, also divided into three groups according to socioeconomic conditions, six women discovered the disease through periodic mammography at the call from the Health Insurance (5 of them participants in group L and one in group M). Two women discovered the disease through tests they had done to check for other health problems. Finally, four Germans detected the disease from self-examination and sought immediate medical help. These data reveal the importance of screening programs for early diagnosis of breast cancer, a technique adopted in many European countries for over 20 years, corroborating the propositions of Bray et al. (2018). This data suggests that a lower socioeconomic condition for German women does not make them vulnerable to the late discovery of the disease.

Discussing the disclosure of the disease and the construction of the support network, the most frequent finding among Brazilian and German women was that the disease's disclosure happened first to the spouses, demarcating that most of them were married. Three Brazilian women did not have spouses, and they disclosed the illness to adult children/grandchildren or another close relative. All German women were married and lived with their respective spouses. However, two of them, both from group M, had elderly and convalescent spouses dependent on their care. It is remarkable that they did not have a support network other than the professional during the illness.

A Brazilian woman in group C was married to a woman, from whom she received full support, contrary to what happened with a participant in group A and another in group B, whose illnesses triggered divorce proceedings, since their husbands, men, began to hit them ever since. As for these cases, it is worth reaffirming the high rate of domestic violence in Brazil, especially against women. M. C. Guimarães and Pedroza (2015) link domestic violence to the gender perspective, stating that the Brazilian sexist and patriarchal culture legitimizes various types of violence practiced by men against women. And, despite the Maria da Penha Law, in force in the country since 2006, there is still a lot to be overcome to change the everyday scenes of violence against women in Brazilian homes.

Regarding still the support network, the children, when adults, appeared in sequence to the spouses as pillars of trust for women in both countries. However, among older women in Germany, some were childless. Even some aged women who had children, such as the two in group M whose husbands were bedridden, could not count on their help coping with cancer. Younger German women were able to rely on their children for support. An exception happened to a woman in group L, who complained about her children, saying that the fact that they were all men justified their lack of interest in their sick mother. This indicates that the participant accepts and incorporates the separation of gender roles into her speech.

The results suggest that cultural differences between countries also lead to differences in coping with the disease, significantly changing the characteristics of support networks. Among the German women, the disclosure of diagnosis remained predominantly within the nuclear families, not having been done spontaneously to the other relatives or acquaintances. Most Germans reported trying not to let people know about their illness, as a way of preserving themselves from the social judgment of being "at death's door" – an expression that appeared in several reports. This reveals the strength of the disease's stigma among the participants in the European country.

Finally, and as a strong contrast between women in both countries, support networks were identified among Brazilian women that extend beyond family and friends, called in the study in the code *Strengthening yourself, strengthening others*. Such networks were composed of women undergoing treatments or who had already undergone them, who met in person to discuss various aspects of the illness. The Brazilian women participating in this study discovered that they could strengthen each other through the exchange of experiences, as reported by Ana and Bianca:

> We promote meetings at least every 15 days, not via WhatsApp, but in person, so we can talk, exchange ideas, and find out what each one is going through. With that, as you strengthen others, you strengthen yourself. (Ana)

> You look inside yourself, and you look at your family around you, and you can't tell them [family members] many things. And you get anguished. (...) So you tell your colleague, she will have something to tell you, she will help you. (Bianca)

Speaking about the treatments and their implications, in Brazil, most women in groups B and C depended exclusively on the SUS to carry out their treatments. In Germany, all interviewees were covered by health insurance, regardless of their socioeconomic status.

Among the Brazilian women, three underwent a radical mastectomy, complete breast removal, and only one had already undergone reconstruction (user of the private health plan), while the others were waiting for the procedure on the SUS waiting list. Seven women underwent partial surgeries, predominantly quadrantectomy, three others were receiving neoadjuvant chemotherapy, but had their surgeries already scheduled. Three women were receiving chemotherapy at the time of the interview but did not yet have any surgical prescriptions. Stand out that all Brazilian women underwent chemotherapy. They received two stages of this treatment, one named by them "the red one" which lasts, in most cases, four sessions, and another called "the white one" with an average of 12 prescribed sessions. Only two women also received radiotherapy after the completion of chemo. Among all the Brazilian interviewees, seven were also receiving hormone therapy.

The German participants received different medical prescriptions compared with the Brazilian ones for the treatment of breast cancer discovered in the same stages, which in the research were II and III, according to medical records. Unlike what happened to the Brazilian women, the twelve interviewees underwent radiotherapy as adjuvant or neoadjuvant, and their surgeries were performed promptly after the cancer confirmation; highlighting that, in some cases, more than one surgery was performed. Only three of them received chemotherapy treatments, one from group L and two from group M. Another woman from group L also received a prescription for chemotherapy. However, she refused to undergo the treatment, revealing that she was more afraid of dying from that than dying from cancer.

The Brazilian women experienced chemotherapy as very invasive, "Chemotherapy was a tsunami for me," said one of them. The woman associated her experience with being hit by a tsunami, as other women, who also reported feeling devastated by the side effects of the treatment. However, in this public, no one gave up chemotherapy. One participant questioned the prescription with the physicians but did not abandon the treatment. For most women, chemotherapy brought significant changes in the organism, which ranged from physical to psychological and/or emotional, which required them to wage real battles to survive the fight against the disease. Aline clarified that if she kept thinking about the side effects of chemotherapy, she would have gone crazy:

> When I looked in the mirror and saw that figure, which did not represent me in any way, I was terrified. So I chose to take my time, and avoid thinking about all the side effects of chemo because I didn't want to go crazy. (Aline)

When the German women narrate the chemotherapy subject, the code Sighing relieved appears: the "*getting rid" of chemotherapy*. Nine participants did not undergo this treatment, considering it a relief from the suffering of the diagnosis. The eight women who did not receive a medical prescription for chemotherapy included reports associated with medical statements that this was a good sign, as Melinda stated:

> He [the physician] came through the hall and said, 'Mrs. [Generic name], you can open a bottle of wine or sparkling wine today! Because for you, it's like winning the lottery. You don't need chemo.' That was really cool; I got excited too. (Melinda)

The discovery of cancer shocked all respondents from both study groups. Initially, the women sought to assimilate and think about how they could manage what was happening to them. In a single case of an elderly German woman from group M, whose husband depended on her for everything, a limitation was observed talking about what she experienced. Additionally, she seemed to neglect her physical suffering, maintaining an unaltered routine, even in the face of illness.

Surviving the illness is the process that allows monitoring coping strategies between Brazilian and German women. Some Brazilian women in groups A and B adopted an educational attitude towards themselves and others. This attitude occurred in terms of adaptation experiences through side effects and also in the fight against stigmas, such as the fear of death. They not only coped better with suffering, for example, when they lost their hair or gained weight but also tried to convey their ideas to other treatment colleagues by acting as protagonists in the face of the disease. Among the German women, a similar attitude was observed in three women, one from each group, revealing fewer differences regarding sociocultural issues, despite socioeconomic differences. Here are some examples of what was considered Transcendence to suffering, an experience summarized by Aline:

> What are people most afraid of in this life? (...) People are certainly afraid of death! Many women die, but I don't necessarily have to die because I have cancer! I didn't get attached to that idea and explained to the others that they shouldn't do that (...). (Aline)

Like other women interviewed, the participant did not succumb to the stigma of death related to the disease. Likewise, Bianca reports her affinity with her hair, which loss is feared among Brazilian women:

> My hair was waist-length here [showing the old length with her hands]. It was straight with a Brazilian progressive straightening brush and black dyed because it grows white. (...) I was initially scared when I saw myself bald, but then I put on makeup and went out without a turban, showing everyone that I was also beautiful without hair; and now I feel like a diva. (Bianca)

Karen, an 81-year-old German woman, explained that she had overcome the initial shame of being sick and started to tell other women her age that cancer could also appear in their lives: "I was ashamed, but I fought. I went back to socializing with friends, and I always said to them: 'Age does not protect against breast cancer, women and health insurance should know that'. (...)" The participant's statement, also revealing that she had transcended suffering, was understood as a criticism of the call for mammography for the 50-69 age group in Germany, thus excluding older women from this opportunity.

Other participants, who form most of the interviewees, adopted different postures. For a total of eleven women from both countries, their attitudes oscillated between overcoming suffering through religiosity or their children, and, rarely, through their own personal perspectives of a better future. In the study, the phenomenon is named *Adaptation*, a term proposed by Charmaz (1995, 1997), who evaluated the characteristics and attitudes of people when facing different chronic diseases. Adaptation was considered the recognition of losses caused by the disease and its treatments; but, simultaneously, a positive view about the possibility of overcoming daily life, as well as the idea of overcoming the disease.

For a minority, however, there were no expectations of breaking out with suffering, even if momentary or conditioned to a cause, such as children or faith. This last group identified women

prone to *Succumbing to the disease*. Five women were immersed in pain and sadness due to hair loss or changes in their physical form – one from group B and four from group C, among the Brazilian women. They had many complaints, cried a lot, and got attached to some stigmas such as: " You cannot survive cancer"; " A woman without hair is not a woman"; "The metastasis can appear, and I will die"; "I will never have a beautiful body again." Five German women also remained shipwrecked in losses (groups L and M), without much conviction that they would be able to overcome the adversities present in the diagnosis (stigmata) and in the treatments (losses and side effects).

Discussion

Concerning the discovery of cancer, it was evident that there is a significant discrepancy in Brazil regarding the socioeconomic classes of the interviewees and access to the diagnosis. Women with higher incomes found out faster that they were sick, while the poorest took longer to obtain the diagnosis. In Germany there was no such difference, indicating that financial power does not limit women's knowledge about their health, not leaving them at the mercy of external circumstances. It was evident that the screening program, as already mentioned, was responsible for most of the diagnostic discoveries – revealing the importance of this technique in the fight against the disease.

In this sense, the findings of the study corroborate what Lombardo & Popim (2020) say, as well as Arruda (2019), whose analyzes bring the inequality of access of users to health services in Brazil, mainly associated with low socioeconomic and educational levels, as factors that hinder access to diagnosis. The authors also cite SUS's structure as co-responsible for the delay in diagnoses.

As for disclosing the disease, the fact that most German women have hidden the diagnosis from many relatives, friends, and neighbors can be explained by two reasons: A) Sociocultural differences, since they appreciate privacy and a more secluded life within the intimate family; B) The strength of the disease's stigma – associated with death and disability for this group of interviewees. Although isolating cultural characteristics is not a simple task, the interest of some German and Australian researchers in mapping qualitative studies demonstrates that the degree of information to which cancer survivors have access (Blödt et al., 2018) or the possibility of developing post-traumatic effects from diagnosis and treatment (Rosemberg et al., 2022) are relevant experiences for developed countries.

Brazilian women were not free from the stigma of death, but this did not occur as strongly as reported. In addition, the stigma of disability linked to cancer for these women was not identified. Therefore, it can be suggested that the difference in cultural values of each society shapes the characteristics of coping. In Brazil, the female body is highly valued, emphasizing certain aesthetic standards as definitions of being a woman: such as long and painted nails, long and straightened hair, thin and shapely body (Dourado et al., 2018; Goldenberg, 2010). In Germany, a country that recovered from a catastrophic post-war period, relying massively on female labor for that purpose, concepts linked to the valuation of the female universe are financial autonomy, studies, and career, as well as social insertion mediated by work (A. Q. Guimarães et al., 2014; Deutscher Bundestag, 1949/2019; Goldenberg, 2010).

Regarding attitudes towards illness, we sought to understand the phenomenon through symbolic interactionism, as proposed by Charmaz (1995, 1997), who takes the concept of authors such as Mead, describing that personal identity is how the individual defines, locates, and differentiates the self from others. Mead (1984), one of the pioneers of Social Psychology, suggested that this perspective considers the self in a subjective matrix that defines it, as it is shaped in an intersubjective

process, ensured by symbolic communication. This happens insofar as the person differentiates themself from the others with whom they interact; at the same time they assimilate and internalize ideas extracted from their own social environment. Thus, when revealing their behaviors, choices, resignations, fears, expectations, and others, from their sickness, the women in the study also did it assured themselves. These analyzes helped identify ways of coping with the disease: succumbing to the illness and its circumstances, adapting to or transcending the disease.

For Lopes et al. (2020), the disfiguring consequences of breast cancer are the main problems that affect women's identity, which is associated with hair and breasts, social symbols of femininity. Brazilian women had more significant suffering associated with physical losses, especially those prone to succumbing to the disease. It is considered an assumption that there is a social construction about what means to be a woman. Therefore, their identity is shaped according to physical characteristics shared by the sociocultural group to which they belong. Since the disease's treatment wrecks some physical aspects, suffering devastates the woman, who no longer recognizes herself as she used to be.

Among the German women, the phenomenon of succumbing to the disease was also observed, as some evaded losing themselves through silence and not sharing the diagnosis with other people. However, at the time of the interview, through the researcher's listening, sadness and desolation appeared. The lack of hope emerged, putting at stake all the protections they used in the social environment, especially those regarding their health. Their main problems turned out to be related to the stigma of having a severe illness, considered terminal and debilitating/disabling, which corroborates the research by Ernst et al. (2017). The self-definitions of German women were more linked to the roles they played: wife, mother, grandmother, employee, self-employed, and religious, among others. Besides, although convalescing, they tried to maintain their activities.

Finally, it was observed that most participants from both countries had complaints and assessed their physical, emotional, and psychic losses; even so, they had positive perceptions about their conduct and coping with the situation as well as the future. Sometimes the factors that motivated them to move on were not their own purposes, but faith, religiosity, children, and grandchildren. Such women were considered as people who experienced adaptation to the disease.

Resuming Charmaz (1997), when the disease does not fulfill or inundate the self, even if it can fulfill and inundate the sick person's experience, self-acceptance, and adaptation to circumstances occur. Transcendence implies a reassessment of one's life goals and renewal from that. Transposing Charmaz's conjectures to the study results, the transcendence phenomenon was observed as more stable in two participants, one Brazilian woman and one German woman, both of high social status. This outcome reveals again that the most socially favored Brazilian women are also the ones who most question and confront labels and stigmas, having more possibilities of successfully coping with breast cancer.

Other relevant aspects were found in the research, such as the rehabilitation program offered in Germany – as one of the guidelines of public policies against breast cancer (Deutsches Krebsforschungszentrum, 2018). This program goes from immediate assistance to women's demands, from physiotherapy to psychotherapy, to later issues, such as returning to work or even instructing how to claim rights through training and group activities. If, on the one hand, in Brazil, women associate with each other to overcome particular challenges, in Germany, there is a formality, revealing an interventionist State, regarding the creation of groups, within rehabilitation programs (Deutsches Krebsforschungszentrum, 2018).

Comparing Brazilian with German treatments, they were significantly different; since medical prescriptions to treat breast cancer were distinct. The data the researcher had access to were not enough to elucidate the gap between the medical prescriptions to treat cancer in the two countries – since the diagnoses had similarities regarding the staging of the disease.

Initially, it was envisaged that the differences between the medical prescriptions could be associated with the age differences among the women since the German group in the sample is older (simple average of 64 years old) than the Brazilian group (simple average of 48.18 years old). However, a review of the medical literature did not confirm this hypothesis but refuted it, as found in Maluf et al. (2014) and Souza et al. (2015). The authors state that therapeutic prescriptions depend directly on the stage and type of cancer, not the patient's age. This error can lead to elderly people receiving undertreatment instead of effective treatment.

Conclusion

Finally, it is considered that some positions taken by women in both countries brought them gains – and a certain reduction in suffering, especially when they achieved a transcendence of the self, whose assimilation overlapped the disease. In addition, when they managed to break out of the stereotypes of what it means to be a woman in the society of which they are part, they reduced their expectations for themselves, whether concerning their physical body (appearance) or regarding productivity, and social roles to be played. On the other hand, certain attitudes brought them losses, some with consistent entailment to suffering, especially when the self did not adapt to the new reality of physical and/or psychological losses, revealing a certain passivity in the face of circumstances, as well as a limitation to question and break out with the labels and expectations of the social.

It is suggested that scientists from other areas of knowledge expand the research so that the decisions and options for treatments can be better verified – since they were quite discrepant in the study when comparing the two countries.

References

Arruda, L. C. (2019). *Acesso à atenção especializada*: *câncer de mama como condição traçadora* [Master's dissertation, Universidade de São Paulo]. Biblioteca Digital USP – Teses e Dissertações. https://doi.org/10.11606/D.6.2019.tde-26082019-130442

Blödt, S., Kaiser, M., Adan, Y., Adami, S., Schultze, M., Müller-Nordhorn, J., & Holmberg, C. (2018). Understanding the role of health information in patients' experiences: secondary analysis of qualitative narrative interviews with people diagnosed with cancer in Germany. *BMJ Open, 8*, e019576. https://doi.org/10.1136/bmjopen-2017-019576

Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A. (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *Cancer Journal for Clinicians, 68*(6), 394-424. https://doi.org/10.3322/caac.21492

Charmaz, K. (1995). The body, identity and self: Adapting to impairment. *The Sociological Quarterly, 36*(4), 657-680. https://www.researchgate.net/publication/227723579_The_Body_Identity_and_Self

Charmaz, K. (1997). *Good Days, bad days*: *the self in chronic illness and time*. 2nd ed. Rutgers University Press.

Charmaz, K. (2009). *A Construção da Teoria Fundamentada*: *Guia Prático para Análise Qualitativa*. Artmed.

Conselho Nacional da Saúde. (Brasil). (2012). Resolução n. 466, de 12 de dezembro de 2012. *Diário Oficial da União*. https://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf

Das Gesundheitssystem Kennen Lernen. (2015). *Kompetent als Patient*: *TK-Kursreihe.* Techniker Krankenkasse. https://docplayer.org/21703160-Das-gesundheitssystem-kennen-lernen-tk-kursreihe-kompetent-als-patient.html

Deutscher Bundestag (Germany). (2019). *A Lei Fundamental da República Federal da Alemanha* (A. Mendonça Trans.). Deutscher Bundestag. (Original work published 1949). https://www.btg-bestellservice.de/pdf/80208000.pdf

Deutsches Krebsforschungszentrum. (2018, April 23). *Rehabilitation für Frauen mit Brustkrebs*. Cancer Information Service. DKFZ. www.krebsinformationsdienst.de/tumorarten/brustkrebs/rehabilitation.php

Dourado, C. S., Fustinoni, S. M., Schirmer, J., & Brandão-Souza, C. (2018). Body, culture and meaning. *Journal of Human Growth and Development, 28*(2), 206-212. http://dx.doi.org/10.7322/jhgd.147240

Duarte, E., Eble, L. J., & Garcia, L. P. (2018). 30 anos do Sistema Único de Saúde. *Epidemiologia e Serviços de Saúde, 27*(1), e00100018. https://dx.doi.org/10.5123/s1679-49742018000100018

Ernst, J., Mehnert, A., Taubenheim, S., Rentsch, A., Hornemann, B., & Esser, P. (2017). Stigmatisierung von erwerbstätigen Patienten mit Brust-, Darm-, Prostata- und Lungenkrebs. *Psychotherapie Psychosomatik Medizinische, 67*(7), 304-311. https://doi.org/10.1055/s-0043-110138

General Assembly of the World Medical Association (2014). World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects. *Journal of the American College of Dentists, 81*(3), 14-8.

Giovanella, L., & Stegmüller, K. (2014). The financial crisis and health care systems in Europe: universal care under threat? Trends in health sector reforms in Germany, the United Kingdom, and Spain. *Cadernos de Saúde Pública, 30*(11), 2263-2281. https://doi.org/10.1590/0102-311X00021314

Goldenberg, M. (2010). *O corpo como capital*: *gênero, sexualidade e moda na cultura brasileira*. 2nd ed. Estação das Cores e Letras.

Guimarães, A. Q., Barbosa, F. C., Costa, G. O., Natalino, E., & Oliveira Neto, P. (2014). Alemanha: o modelo de capitalismo social e os desafios no limiar do século XXI. *Revista de Sociologia e Política, 22*(51), 55-75. https://dx.doi.org/10.1590/1678-987314225104

Guimarães, M. C., & Pedroza, R. L. S. (2015). Violência contra a mulher: problematizando definições teóricas, filosóficas e jurídicas. *Psicologia & Sociedade, 27*(2), 256-266.

Instituto Nacional de Câncer José Alencar Gomes da Silva. (2017). *Estimativa 2018*: *incidência de câncer no Brasil*. INCA.

Instituto Nacional de Câncer José Alencar Gomes da Silva. (2019). A situação do câncer de mama no Brasil: síntese de dados dos sistemas de informação. INCA. https://www.inca.gov.br/sites/ufu.sti.inca.local/files/media/document/a_situacao_ca_mama_brasil_2019.pdf

Instituto Nacional de Câncer. (2020, June 23). *Estatísticas de câncer. Ações de Vigilância do Câncer, componente estratégico para o planejamento eficiente e efetivo dos programas de prevenção e controle de câncer no país*. Ministério da Saúde. https://www.gov.br/inca/pt-br/assuntos/cancer/numeros

Laperrière, A. (2010). Os critérios de cientificidade dos métodos qualitativos. In J. Poupart, J.-P. Deslauriers, L.-H. Groulx, & A. Laperrière (Orgs.), *A pesquisa qualitativa*: *enfoque epistemológicos e metodológico* (2nd ed., pp. 410-435). Vozes.

Lencione, C. (2018, April 12). *Brasil*: *50% dos trabalhadores ganham menos de um salário-mínimo. Dado é da PNAD Contínua 2017, divulgada agora em abril pelo IBGE*. Observatório do Terceiro Setor. https://observatorio3setor.org.br/carrossel/brasil-50-dos-trabalhadores-ganham-menos-de-um-salario-minimo

Lombardo, M. S., & Popim, R. C. (2020). Acesso do paciente à rede oncológica na vigência da "Lei dos Sessenta Dias": Revisão Integrativa. *Revista Brasileira de Enfermagem, 73*(5), e20190406. https://doi.org/10.1590/0034-7167-2019-0406

Lopes, A. P., Camargo, C. A. C. M., & Maia, M. A. C. (2020). Sofrimento psíquico vivenciado por mulheres diante do diagnóstico de câncer de mama: uma revisão bibliográfica reflexiva. *Revista Eletrônica Acervo Saúde, 52*, e3556. https://doi.org/10.25248/reas.e3556.2020

Maluf, F. C., Buzaid, A. C., & Varella, D. (2014). *Vencer o Câncer*. Dendrix.

Mead, G. H. (1984). *On social psychology*. The University of Chicago Press.

Robert Koch-Institut. (2017b). Früherkennung von Brustkrebs: Inanspruchnahme der Mammografie in Deutschland. *Journal of Health Monitoring, 2*(4), p. 74-80. https://doi.org/10.17886/RKI-GBE-2017-114

Robert Koch-Institut. (2020). *Aktuelle Daten und Informationen zu Infektionenskrankheiten und Public Health: Epidemiologisches Bulletin*. RKI. https://www.rki.de/DE/Content/Infekt/EpidBull/Archiv/2020/Ausgaben/06_20.pdf?__blob=publicationFile

Robert Koch-Institut.(2017a). *Krebs in Deutschland für 2013/2014*. RKI. https://www.krebsdaten.de/Krebs/DE/Content/Publikationen/Krebs_in_Deutschland/kid_2017/krebs_in_deutschland_2017.pdf?__blob=publicationFile

Rosenberg, J., Butow, P. N., & Shaw, J. M. (2022). The untold story of late effects: a qualitative analysis of breast cancer survivors' emotional responses to late effects. *Support Care Cancer, 30*, 177-185. https://doi-org.ez93.periodicos.capes.gov.br/10.1007/s00520-021-06402-7

Scorsolini-Comin, F., Santos, M. A., & Souza, L. V. (2009). Vivências e discursos de mulheres mastectomizadas: negociações e desafios do câncer de mama. *Estudos de Psicologia* (Natal), *14*(1), 41-50. https://dx.doi.org/10.1590/S1413-294X2009000100006

Sontag, S. (2002). *A Doença como Metáfora* (3th ed). Graal. (Original work published 1978)

Souza, C. B., Fustinoni, S. M., Amorim, M. H. C., Zandonade, E., Matos, J. C., & Schirmer, J. (2015). Estudo do tempo entre o diagnóstico e início do tratamento do câncer de mama em idosas de um hospital de referência em São Paulo, Brasil. *Ciência & Saúde Coletiva, 20*(12), 3805-3816. https://dx.doi.org/10.1590/1413-812320152012.00422015

United Nations Development Programme. (2021). *Human Development Index (HDI): Explore HDI*. UNDP. https://hdr.undp.org/data-center/human-development-index#/indicies/HDI

Acknowledgments

The development of the work in Germany was made possible by funding obtained from the Deutscher Akademischer Austauschdienst (DAAD) – scholarship program in the country, which financed, through a monthly doctoral scholarship, the main author of the text for 18 months. Our thankfulness to DAAD.

Contributors

M. J. FERNANDES participated in all stages of the text, from its conception and configuration to the final approval of the article. L. KIND participated in the research's conception and design, and the text's revision, contributing to the final version of the article.